



## CHAPTER 1: GENERAL INTRODUCTION TO RESEARCH

### 1.1 Introduction

The Human Immuno-deficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) have emerged as the most challenging health matters in modern times. The pandemic has created not only medical, but also ethical, legal, social, and political issues, together with economic and human rights implications. Although HIV/AIDS is incurable at present, with the introduction of antiretroviral therapy (ART), it is now considered a manageable life-threatening disease.

Epidemics are not new in the history of humankind, nor are the reactions such as fear, ignorance, panic and isolation that often accompany such diseases. History has not forgotten the devastation caused by epidemics such as the bubonic plague (Black Death) during the fourteenth century in Europe. For modern people, however, epidemics have lost their sting. Van Dyk (1993:10) alleged that our present generation believed that the time of devastating epidemics is long past. The last major epidemic to plague the world was polio during the 1930s and 1940s, which was soon conquered by medical science. HIV/AIDS, however, has shattered this false sense of security.

*The Joint United Nations Programme Report on the HIV/AIDS Epidemic for 2006* (UNAIDS, 2006) found that the number of people living with HIV/AIDS worldwide was estimated to be about 39.5 million during 2006 of which 37.2 million are adults, 17.7 million women, and 2.3 million children. The above estimates the AIDS deaths in 2006 to be a total of 2.9 million. An estimated 24.7 million people in Sub-Saharan Africa live with HIV. Since the discovery of AIDS during 1981, more than 60 million people worldwide have been infected with HIV and it is estimated that about 21.8 million people have died of the disease.



According to the *Department of Health's National HIV and Syphilis Antenatal Sero-Prevalence survey in the Republic of South Africa* (South Africa, 2005) South Africa has recorded one of the highest HIV prevalence rates in the world. This country, with a population of 47 million, contains an estimated 5.54 million South Africans who are HIV-positive. The findings of above survey estimated prevalence rate of 27.9% amongst South Africans.

Of these 5.54 million HIV-positive people, 500 000 are estimated to suffer from Acquired Immunodeficiency Syndrome (AIDS) and are thus in need of ART's. The researcher is of the opinion that these statistics are an indication that everything possible should be done to treat as many people as possible and promote adherence to ART.

The presence of HIV infections is currently concentrated in the developing world, and over two-thirds of all people living with HIV are situated in Sub-Saharan Africa. This region is bearing the brunt of the global HIV/AIDS epidemic. The circumstances with which immuno-suppressed individuals living in resource-poor communities have to contend are different from those who live in affluent communities. In South Africa, HIV/AIDS is as much a political as a social issue. This is apparent from the *Government's Operational Plan for Comprehensive HIV/AIDS and TB: Rollout plan for Antiretroviral Treatment*, which was accepted during November 2003 (South Africa, 2003).

The researcher is of the opinion that the above statistics imply that the AIDS epidemic continues to increase, despite the dramatic advances made in understanding the natural history of the HIV disease and the development of antiretroviral therapies. The aforementioned growth has displayed some disturbing trends. HIV/AIDS morbidity and mortality increasingly impact on the poor, the disenfranchised, and the young. The statistics, in themselves, are an indication for further study regarding the present research topic. Research in the field of HIV/AIDS is exceptionally relevant at present, since we are not only reaching the peak of the risk, but we are also facing new challenges with the availability of ART. The emphasis on adherence to ART further contributes to



the need for research, especially due to the possibility of resistance developing in non-adherent patients.

Over the last few years there has been a rapid change in the treatment strategies used for HIV infection. Numerous new therapies have been introduced since 1996 and the indications for antiretroviral therapy have undergone dramatic changes in recent years. Antiretroviral treatment has moved from mono-therapy to triple drug or combination therapy - highly active antiretroviral therapy (HAART), since it has been found that these drugs are more effective when three or more are taken at the same time (Kasper, Braunwald, Hauser, Longo, Fauci, & Jameson, 2005:1071; Van Dyk, 2004:69).

One of the foremost concerns of ART programmes is the ability of people living with HIV/AIDS to maintain near-perfect adherence in the long term. Both patients and healthcare providers face significant challenges with respect to adherence to ART. In order to achieve the goal of antiretroviral therapy (ART), i.e. undetectable levels of the virus in the blood, patients are required to maintain more than a 90-95% adherence. Once initiated, ART is a lifelong treatment that consists of multiple medications. Inadequate adherence to treatment is associated with detectable viral loads, declining CD4 counts, disease progression, episodes of opportunistic infections and poorer health outcomes (Botes & Levay, 2004:13-20; Friedland, 2003:35-40; WHO, 2003; Van Dyk, 2004: 69; South Africa, 2003a; Ross & Deverell, 2004:10).

Antiretroviral medication only controls HIV virus replication or multiplication. Even when the virus is undetectable in the blood as a result of successful ART, there are some sites in the body where drugs are unable to reach the virus. Therefore, it cannot be completely eradicated from the body and it continues to remain hidden in these sanctuary sites. The virus emerges when ART fails or is discontinued. Since the virus cannot be eradicated, antiretroviral medication has to be taken regularly for the rest of the patient's life.

HIV infection still cannot be cured, but it can be managed. The goal of ART is to achieve the maximum, longest-lasting suppression of virus replication (Botes



& Levay, 2004:13-20; Friedland, 2003:35-40; WHO, 2003; Van Dyk, 2004:65; South Africa, 2003; Horizons, 2004).

One of the multitude of problems the multidisciplinary health team encounters regarding antiretroviral treatment, is the burden of responsibility to ensure that patient adhere to therapy. The researcher has experienced that most of the patients are not aware of the protocol, are symptomatic, often terminal, and they have to use their last degree of strength to obtain ART.

The potential of a patient developing resistance to antiretroviral medication should always be remembered. Resistance is an important reason why many antiretroviral drugs have limited or short-term effects. Whenever HIV is still able to reproduce in someone taking antiretroviral drugs, it is extremely likely that resistant strain will eventually emerge and that the viral load will increase. When patients take their medication irregularly, or when providers prescribe inappropriate doses of combinations of medication, the virus is exposed to inadequate concentrations of antiretroviral medication. This, in turn, leads to ongoing viral replication and to the development of resistance to antiretroviral medication. Such resistance, accounts for a large portion of treatment failures (Friedland, 2003:35-40; WHO, 2003; Van Dyk, 2004:65; Horizons, 2004).

An additional critical problem is the issue of cross-resistance. Once the virus becomes resistant to a particular antiretroviral medication, the virus may also exhibit resistance to other medications of the same class. The second issue stemming from viral resistance is that resistant strains of the virus can be transmitted. This is a major public health problem in resource-limited situations where the choice of medication is already restricted due to high costs and limited availability (Kasper *et al.*, 2005:1071; Horizons, 2004).

The worldwide increase in the prevalence of antiretroviral resistance is of particular concern to researchers and practitioners. Resistance remains one of the most significant threats to the long-term success of any HAART regimen. The multidisciplinary team involved with ART is therefore anxious to learn from past mistakes, translate new knowledge into appropriate treatment strategies,



and develop new drugs that remain useful in the face of established resistance. Further to this, the development of resistance due to poor adherence to the therapy can accelerate, rather than retard, disease progression (Chesney, 1997:2; Friedland, 2003:35).

Many terms have been used during the past century to describe how well patients follow – or do not follow – the advice of doctors, for example defaulters, faithless, untrustworthy, unreliable, non-compliant, concordance etc. The more recent term, “adherence”, is a better alternative because it captures the increasing complexity of medical care by characterising patients as independent, intelligent and autonomous people who take a more active and voluntary role in defining and pursuing goals for their medical treatment. It can be defined as the act or quality of “sticking” with something or “adhering” to something (South Africa, 2003a:4).

The researcher is of the opinion that whatever term emerges as the most popular, the most important issue in ART is ensuring that patients take the drugs as prescribed, at the right time, in the right way, and in the right quantity, because missing a dose, taking the wrong dose, or taking a drug in such a manner that one absorbs too little, may lead to the more rapid development of resistance to the drug. Strict adherence to these multi-drug regimens is essential to obtain the full benefits of the therapy, maintaining suppression of the viral load, and preventing the development of drug resistance (Chesney, 1997:1).

Regarding the issue of compliance, Friedland (2003:39) notes that, “Added to the challenge of more widespread and equitable access to antiretroviral therapy in South Africa and elsewhere, is the issue of adherence to these therapies when they are made available. Clinicians need to develop and employ strategies to support antiretroviral adherence that are practical, relevant and appropriate to the African context.” As suggested above, research has found that adherence greater than 95% is needed to achieve virological suppression (South Africa, 2003a).



The researcher believes that patients need to be educated and screened with regards to the potential development of resistance to antiretroviral drugs, its consequences, and the implications of non-adherence. However, more information regarding the biopsychosocial factors influencing adherence to ART needs to be established by research. This knowledge may be utilised during assessment in order to establish a patient's risk for non-adherence. The service rendered to patients should be adjusted in order to assist the team and the patient in an attempt to achieve maximum adherence. The knowledge obtained from such research could therefore also serve a preventative purpose.

The researcher argues that adherence should be assessed by means of the biopsychosocial model, which recognises the interaction between the medical, behavioural, psychological and emotional dimensions of the patient. The researcher firmly believes that the biopsychosocial model, with its focus on the promotion and maintenance of health by means of socio-environmental and behavioural changes, is an appropriate model that could successfully be used in researching the HIV/AIDS pandemic.

Barker (1991:23) defines the biopsychosocial model as "...a phenomena that consists of biological, psychological and social elements". Kaplan *et al.* (1994:1) assert that the biopsychosocial model of disease, stresses an integrated systems approach to human behaviour and disease. Shannon (1989:35) also notes the importance of social, cultural and economic conditions in health. Furthermore Sherr (1995:69), stresses that the psychosocial functioning of the individual impacts on adherence to antiretroviral therapy. Practitioners are now experiencing the fact that medical treatment is often incomplete, and occasionally, impossible to render, without the accompanying social support and counselling services.

Skidmore, Thackeray & Farley (1994:146), define social work in health care as the application of social work knowledge, skills, attitudes and values in healthcare, where the social worker addresses him/herself to illness, brought about by, or related to, social and environmental stresses that result in failures in social functioning and social relationships. The researcher is of the opinion



that this is applicable to HIV/AIDS, since the disease is closely related to social circumstances and can result in social malfunction. This challenges all social workers in healthcare to establish themselves as essential members of the HIV/AIDS multidisciplinary health team.

The researcher believes that without taking all the dimensions into consideration, it would not be possible to support and treat the HIV/AIDS patient effectively. It is therefore essential to provide all patients with a comprehensive plan to support adherence. It is not possible for health care providers to reliably predict which individuals will ultimately adhere to their treatment plan, since adherence does not correlate with gender, cultural background, language, socio-economic or educational level (South Africa, 2003).

However, Friedland (2003:35-40) states the following: "With regard to patient related characteristics, the literature in the developed world indicates that age and race consistently predict adherence. Older adults are likely to be more adherent, and in the USA, studies have found that the African Americans race and low literacy levels are associated with poorer adherence." Whether this finding will hold in South Africa remains undetermined.

The researcher believes that the issue of adherence to ART is accompanied by various biopsychosocial factors that patients face, and which need to be attended to by the relevant professions. These aspects require a comprehensive service rendered by the multidisciplinary team to enable patients to successfully adhere to treatment (Botes & Levay, 2004:13-20; Friedland, 2003:35-40; WHO, 2003; Van Dyk, 2004:65; South Africa, 2003a).

Factors that have been studied regarding patients' adherence to ART include socio-demographic factors such as gender, ethnicity, age, employment, income, education and literacy; as well as psychosocial factors such as active drug or alcohol use, degree of social support, social stability, depression and other psychiatric illnesses. Patients' knowledge of their medication regimen and their understanding of the relationship between non-adherence and the building-up of resistance to medication, also predict better adherence. A patient's belief



and confidence in the therapy and his/her self-efficacy (confidence in the ability of oneself to adhere), also influences adherence to medication regimens.

Adding to this complex issue, research has also shown that monitoring and support of adherence is essential, because adherence tends to wane as time progresses, and new symptoms and diagnoses also influence compliance. Assessing the patients' biopsychosocial circumstances for adherence to ART treatment is essential to maintain long-term health and to avoid the development of drug resistance (Friedland, 2003:35; Gray, Morris & McIntyre, 2002:5; Roux, 2002:34; South Africa, 2003).

The paradigm employed by the researcher focuses on her belief that all individuals have the right to comprehensive health care and quality of health. She believes that all people must enjoy access to the best service, regardless of their financial status. Reality has shown that it is usually the poor who have no access to treatment, feel worthless and cannot help themselves. This is specifically true in a developing country like South Africa.

Regarding this matter, Cockerham (2001:28) states: "What makes AIDS a disease of society is that it is clearly grounded in the conduct of social life, and its potential for changing norms, values, sex habits and lifestyles worldwide is enormous. Thus AIDS is no ordinary epidemic; it is a lethal illness with far-reaching implications for individuals, families, communities, health care providers, delivery systems and societies around the globe".

The researcher's employer, the *Department of Health confirms, with its Comprehensive Care and Treatment of HIV/AIDS and TB rollout plan for Antiretroviral Treatment* (South Africa, 2003a) confirms that research regarding adherence would be welcomed since it could break new ground in South Africa with regards to the issue of adherence.

Several experts and multidisciplinary team members, Rossouw (2005), clinical Manager, ART clinic, Tshwane District Hospital; Ghood (2005), Medical doctor, Dept of Family Medicine, University of Pretoria; Nkhwashu (2005), Dept. of





Health, HAST unit; Stoltz (2005), Specialist Physician; Brouard (2005), Assistant Director, Centre for the Study of AIDS, University of Pretoria, were all consulted to determine the extent of the problem and thus, the need for this study. These experts all confirmed the researcher's view and are of the opinion that research in the field of adherence to ART in HIV/AIDS patients is needed, specifically with regard to the factors influencing adherence (Strydom, 1998:181).

This particular research will, in the opinion of the researcher, contribute to the *Government's Comprehensive HIV and AIDS Care, Management and Treatment plan*, (South Africa, 2003) especially since Cabinet has instructed the Department of Health to develop a detailed plan on antiretroviral treatment. *The National Government's Comprehensive HIV and AIDS Care, Management and Treatment plan*, which was approved during November 2003 (South Africa, 2003), proposed that not everyone who is HIV-positive needs ART; and the decision as to whether or not to put a patient onto ART should be based on clinical staging (WHO, 2006), CD4 counts, and psychosocial considerations.

In conclusion, the researcher holds the view that adherence to antiretroviral therapy has emerged as one of the most challenging issues in services rendered to HIV/AIDS patients, especially in South Africa. She, in exploring the biopsychosocial circumstances of HIV/AIDS patients on ART, will make recommendations for improved service delivery by means of socio-environmental and behavioural changes in order to address the HIV/AIDS pandemic.

## **1.2 Problem Formulation**

A research problem is defined as a difficulty of which we are aware, and about which something ought to be done (Grinnell, 1993:22; Grinnell & Williams, 1990:58). Fouche (2002a:102) also emphasises that the problem must be researchable and its meaning should have a clear significance and utility for practice. Fouche (2002a:96) states further, there are various sources for the



identification of research problems such as “observation of reality, theory, previous research, curiosity and supervisor”.

The researcher is of the opinion that adherence to antiretroviral therapy has emerged as one of the most important issues regarding the rendering of services to HIV/AIDS patients. “Strict adherence to ARV multi-drug regimens is essential to obtaining the full benefits of therapy, maintaining suppression of viral replication, and preventing the development of drug resistance” (Chesney 1997:1). In South Africa, in particular, screening procedures are fairly new and rely mostly on assumptions. Friedland (2003:37) adds that: “Adherence is a complex clinical behaviour with a wide array of determinants. A useful framework is to consider characteristics of the patient, the provider or clinician, the regimen, the clinical setting and the disease itself”.

Further to this, the development of resistance in patients with poor adherence to treatment can accelerate, rather than retard, the progression of disease. The biopsychosocial circumstances of people inevitably influence adherence and cannot be over-emphasised.

The researcher, within her working environment at the ART clinic at Tshwane District Hospital, is confronted with patients referred for assessment and screening for ART. She has observed the need for more information on and knowledge about the factors and circumstances that may influence patients’ adherence to ART.

With the introduction of ART and the possibility of patients developing resistance and infecting other individuals with the resistant virus, it is necessary to explore the factors and/or circumstances affecting adherence to ART. The burden of education, training and research increasingly falls on the health professionals involved with service delivery to HIV/AIDS patients referred for ART.

Adherence counselling has emerged as an approach in HIV/AIDS counselling. However, little knowledge and information is available regarding this topic,



which, therefore, results in non-effective and conflicting screening methods of patients for ART. More knowledge with regards to the factors influencing HIV/AIDS patients' adherence to ART will clarify circumstances or specific factors that should be considered in assessing patients for ART. This new knowledge could enhance service delivery by means of relevant assessment and screening procedures that are responsive to the needs of patients in order to enhance adherence, and subsequently limit the development of resistance, to ART.

This research problem has been formulated by the researcher as follows: The biopsychosocial factors influencing the HIV/AIDS patient's adherence to ART are unknown. There are insufficient guidelines for assessing and screening the biopsychosocial circumstances of HIV/AIDS patients, as regards antiretroviral therapy, that are practical, relevant and appropriate in the African context. Sufficient guidelines for assessment and screening could lead to enhanced adherence and thus minimise the development of resistance to antiretroviral drugs.

- There is consequently a need to explore the biopsychosocial factors that should be assessed when screening patients for ART.
- There is also a need for universal screening criteria and guidelines, to be employed by the multidisciplinary team specifically related to adherence in receiving ART, from the biopsychosocial perspective.

The proposed study focuses on investigating the biopsychosocial factors related to HIV/AIDS, specifically those that influence adherence to antiretroviral therapy, as experienced and perceived by both the multidisciplinary team involved with the service rendering of ART to HIV/AIDS patients, and the patients themselves. In this respect, "The complexity of factors involved in the disease process calls for comprehensive care, which integrates the patient's physical, psychological and social well-being. Since this kind of care cannot be provided by a single health profession, it brings with it the need for a multidisciplinary approach based on teamwork" (Ross & Deverell, 2004:6).



## **1.3 Purpose, Goal, and Objectives**

### **1.3.1 Purpose**

The *Concise Oxford Dictionary* (1995:1113) defines “purpose” as: “An object to be attained, a thing intended, the intention to act, resolution, determination”.

According to Neuman (2003:28) the purpose of the research can either be descriptive, exploratory, explanatory or a combination thereof. Grinnell & Williams (1990:105) assert that the idea of an exploratory research study is to explore; nothing more and nothing less. Bless & Higson-Smith (1995:20), also state that exploratory research is conducted in order to gain insight into a situation, phenomenon, community or individual. Rubin & Babbie (2001:123), see the purpose of exploratory study as examining a new interest, even if the subject of study is relatively new and unstudied.

The researcher has formulated this study to be exploratory in nature, making use of descriptive measures (Grinnell, 1993:136; Fouche, 2002a:108 and Neuman, 2003:29). The general purpose of this research was to explore and gain insight into the biopsychosocial factors related to adherence to antiretroviral therapy for HIV/AIDS patients, within the South African context, since little is known about this field of study. The said researcher has made recommendations regarding the factors to be considered during the assessment of these patients.

The researcher has thus explored and described the biopsychosocial predicting factors of HIV/AIDS patients that influence adherence to antiretroviral therapy, in order to formulate recommendations for this purpose.

### **1.3.2 Goal**

A "goal" is defined by The Concise Oxford Dictionary (1995:580) as: “The object of a person’s ambition or effort, a destination, an aim.” Fouche (2002b:108), cites Neuman’s view that the goals of research are “...exploratory, descriptive and explanatory”. The specific goal of the present study is to explore the



biopsychosocial factors that influence patient adherence to ART, in order to make recommendations for practical and relevant factors which should be considered in assessing patients for ART.

### 1.3.3 Objectives

Fouche (2002b:107,109) asserts that being “exploratory, descriptive and explanatory” can be regarded as objectives of professional research and also goes further, explaining that the “goal, purpose or aim” is the dream, while “objectives” are the steps one has to take one by one, realistically at grass-roots level, within a certain time span, in order to attain the dream. “Objective” is defined by the *Concise Oxford Dictionary* (1995:938) as “aimed at, something sought or aimed at”.

The researcher has therefore identified the following objectives for the current study:

- To explore the importance of adherence and the implications of non-adherence, and subsequently, the development of resistance to antiretroviral therapy;
- To explore, and describe the biopsychosocial factors that influence adherence to antiretroviral therapy in patients, as perceived by the multidisciplinary team members actually involved in service delivery to HIV/AIDS patients on anti-retroviral therapy;
- To explore the biopsychosocial factors that influence adherence (negative and positive) to antiretroviral therapy as experienced by HIV/AIDS patients on anti-retroviral therapy; and
- To explore and analyse circumstances to determine whether the predictive generalisation of the theory holds true, and to make recommendations regarding the biopsychosocial factors that are practical, relevant and appropriate in the South African context and that should be considered when screening HIV/AIDS patients for ART.



#### **1.4 Research Questions and hypothesis**

The researcher examined a subject (the biopsychosocial factors influencing a patient's adherence to ART) and determined the questions that the study is designed to answer. The said research seeks to answer the basic questions, as identified by Grinnell (1993:25, 45) i.e. what is the researcher trying to determine (the factors), and for what purpose (the recommendations) will the findings be used?

In the current study, the researcher aims to answer the following questions:

- What are the biopsychosocial factors that influence adherence to antiretroviral therapy, as perceived by multidisciplinary team members involved in service delivery to HIV/AIDS patients on antiretroviral therapy?
- What are the existing biopsychosocial circumstances influencing adherence of HIV/AIDS patients already on antiretroviral therapy?
- What influence do the biopsychosocial circumstances of HIV/AIDS patients on antiretroviral therapy have on their adherence and the subsequent development of resistance to antiretroviral therapy?
- How can these identified biopsychosocial factors be utilised in the rendering of services to enhance the adherence of HIV/AIDS patients to antiretroviral therapy in order to minimise the development of resistance?

Kerlinger (1986:17), defines the formulation of the hypothesis as a conjectural statement of the relationship between two variables. The researcher has formulated the following hypothesis for this research :

- The biopsychosocial circumstances of HIV/AIDS will influence adherence to ART.

#### **1.5 Research Approach (Qualitative and Quantitative)**

At present there are two well-known and recognised approaches to research, viz. the qualitative and the quantitative paradigms (Fouche & Delpont, 2002:79). In this study, a combination of qualitative and quantitative approaches,



according to Creswell's dominant-less-dominant model will be utilised (De Vos, 2002a:365). According to Fouche (2002c:365), the two approaches are often both employed in one study with one approach being used more than the other, according to the demands of the topic.

The researcher sought various types of sources that could provide insight with regards to the same events or relationships. A combination of the two approaches has led to a greater confidence in the results, because comprehensive and rich data could be gathered. According to this type of triangulation, the researcher presented the study within a single, dominant paradigm (quantitative), with one small component being drawn from the alternative paradigm (qualitative).

One might engage in qualitative observations with a limited number of informants, followed by a quantitative survey of a sample from a population. The advantage of this approach is that it presents a consistent paradigm picture in the study and still gathers limited information to probe, in detail, one aspect of the study (De Vos, 1998:118; Strydom & Delpont, 2002:334; De Vos, 2002b: 366; Grinnell, 1993:159,162; Grinnell & Williams, 1990:22,128; Neuman, 2003:213, 223; Strydom & Venter, 2002:2005).

The researcher utilized a combination of research designs for the current research. A randomised cross-sectional survey; i.e. a quantitative-descriptive one, requiring the selection of respondents by random sampling methods, utilising questionnaires for data collection, was conducted. She added to this the collective case study strategy as a qualitative research strategy, which aims to understand and interpret the meaning that the subjects give to their everyday lives (Fouche, 2002c:273 & Neuman, 2003:142,148).

Data collection methods from both paradigms were employed; i.e. semi-structured interviews with an interview schedule for the qualitative data collection methods, and the questionnaire and documents for quantitative data collection (Bless & Higson-Smith, 1995:113; Delpont, 2002a:172; Greeff, 2000:302, 306-317; Rubin & Rubin, in Mouton, 2003:196; Strydom, 2002b:292).



Various sampling methods were employed. Probability (random) sampling methods were used in the quantitative research, as well as the non-probability sampling (non-random) method, in the qualitative part of the study (Neuman, 2003:211, 223). Sampling techniques of the various sampling methods were utilized; i.e. purposive sampling techniques for the qualitative research and a simple random technique for the quantitative approach. Qualitative (less standardised) and quantitative (standardised) data analysis techniques were employed (De Vos, 2002:341; Neuman, 2003:430).

## **1.6 Type of Research**

The type of study can either be basic or applied. Basic or pure research seeks an understanding of social reality or increases the knowledge base, whereas applied researchers wish to apply and tailor knowledge to address the specific practical issues (Grinnell, 1993:14; Fouche, 2002c:108; Neuman, 2003:21). Fouche (2002c:108), further states: “We see basic and applied research as broad goals of research and exploration, description and explanation as objectives, mainly of basic or knowledge-generating research”.

De Vos, Schurink & Strydom (2001:8) define applied research as follows: “It addresses immediate problems facing the professional in practice. The goal of applied research most often is the scientific planning of induced change in a troublesome situation. Baily (1982:21), concurs with the above definition where the findings can be applied to solve social problems of immediate concern. Applied research covers a wide range of social science areas, including education.

The research questions of the present study fit the description of empirical questions, according to Mouton (2001:153) because they address real life problems. The research is intended to be applied since the aim was to provide improved service delivery. “Applied research, however, is aimed at solving specific policy problems or at helping practitioners accomplish tasks. It is focused on solving problems in practice” (Fouche, 2002c:109; Rubin & Babbie, 1993:79).





The above clearly indicates to the researcher that applied research is found to be relevant because the aim of the current study was to explore the biopsychosocial factors related to ART for AIDS patients and to make recommendations for intervention. This will benefit the comprehensive service delivery to HIV/AIDS patients on ART and promote adherence thereto.

The present study, therefore, is applied in nature, since its primary task was to stimulate thought and action about the challenges faced by patients on ART. The knowledge generated from the findings was aimed at changing adherence counselling in South Africa, since it was aimed at improving adherence and sets out to solve practical problems in social welfare (Grinnell, 1993:15; Fouche, 2002c:108; Neuman, 2003:21).

The findings of the said study realise the goal, since it was geared towards the improvement of adherence in HIV/AIDS patients to ART. By unearthing the biopsychosocial factors influencing adherence and addressing the screening criteria for ART, the research could possibly lead to enhanced adherence.

## **1.7 Research Design and Methodology**

Whereas a research design is a plan or a blueprint of how the research is to be conducted (Grinnell, 1993:45 & Mouton, 2003:45), research methodology refers to the systematic methodological and accurate execution of the design (Fouche & Delport, 2002:79). In the present study, both quantitative and qualitative research designs were used.

In line with the literature, the researcher believes that a research design is a form of planning required before a research project is undertaken. This implies that this planning will guide the process from the beginning to the end. Rubin & Babbie, as cited by Fouche & De Vos (2002:138), define design as a set of logical arrangements to be selected, and they take the stand that research design should only refer to those groups of small, worked-out formulas from which prospective (quantitatively orientated) researchers can select. In qualitative research literature the preferred term is strategy.

The researcher would like to illustrate this research process, according to Fouche & Delpont's (2002:85) proposed steps:

**Table 1: Illustrated research process**

<b>Type of research: Applied</b>		
	<b>Qualitative</b>	<b>Quantitative</b>
Approach	Creswell's: dominant-less-dominant design/Triangulation Qualitative – (Less-dominant)	Quantitative (Dominant)
Design/strategy	Case study Collective case study	Quantitative-descriptive (survey) design Randomised cross-sectional survey
Respondents	Multidisciplinary team (20)	Patients on ART (200)
Data collection	Semi-structured interview Interview Schedule Documents	Questionnaires Personal questionnaires
Sampling Type/method/	Non probability sampling	Probability random sampling
Sampling technique	Purposive	Simple random
Data analysis technique	Themes, Sub themes Meanings	Figures, tables

## 1.7.1 Research Design

### 1.7.1.1 Quantitative research design

Fouche & De Vos (2002:138), describe quantitative research designs as falling into two broad categories, viz. experiments and surveys, and provide the following examples:

- Pre-experimental/hypothesis-developing/exploratory design;
- Quantitative-descriptive (survey) designs;
- Quasi-experimental/associative designs; and
- True experimental/cause-effect/explanatory design.



The researcher found the quantitative-descriptive (survey) design relevant to the current study, because, by means of this type of research design, and by utilising a questionnaire, she was able to unearth the knowledge, perceptions, feelings and attitudes of the research participants regarding factors influencing adherence. Fouche & De Vos (2002:148) point out that the purpose of this design is typical when a researcher examines a new interest and the subject of study is relatively new and unstudied.

#### **1.7.1.2 Qualitative Research Design**

Denzin & Lincoln (1994:202-208) prefer to term methodologies such as ethnography, phenomenology and the biographical method, “strategies of enquiry or tools that can be used to design qualitative research”. A research design in a qualitative study is tentative and open to change (Fouche, 2002c:122).

Fouche (2002c:272) further identifies the strategies of inquiry that could be employed to design qualitative research as biography, phenomenology, grounded theory, ethnography and case study.

The qualitative research strategy employed in the current study is the case study. A case study, as a qualitative research strategy, aims to attain an in-depth description of a case, or cases, within its larger context, with the focus remaining on the issue being illustrated (Fouche, 2002a:275).

The researcher employed collective case studies, where multiple cases were explored and analysed. Where multiple cases are involved, the research is referred to as a collective case study (Fouche, 2002a:275). The researcher wishes to understand a certain issue (i.e. factors influencing adherence) and according to Fourie (2002a:277), “The collective case study furthers the understanding of the researcher about a social issue or population being studied. The interest in the individual case is secondary to the researcher’s interest in a group of cases”. Fouche (2002a:275), describes the case study further: “The exploration and description of the case take place through



detailed, in-depth data collection methods, involving multiple sources of information that are rich in context. These can include interviews, documents, observations or archival records. Cases are selected so that comparisons can be made between cases and concepts, and theories can be extended and validated.”

## **1.7.2 Data Collection Methods**

The researcher collected data from respondents or research subjects selected from the ART Clinics of the Tshwane/Metsweding Region of the Gauteng Department of Health.

Both quantitative and qualitative data collection methods and techniques were employed. The instruments utilised for data collection were tested for validity and reliability (De Vos, Fouche & Venter, 2002:242,361; Delpont, 2002a:166).

### **1.7.2.1 Quantitative Data Collection Methods**

The selection of data collection methods for a quantitative approach, as categorised by Delpont (2002a:171), can include questionnaires, checklists, indexes and scales. In the current study, questionnaires were utilised as the method for the collection of the quantitative data. According to Fouche & De Vos (2002:142), a survey design requires utilisation of questionnaires as a data collection method, and respondents are selected by means of the simple random sampling method.

In the present study, the questionnaires, delivered by hand in order to gather information, and administered by the present researcher, were given to 201 respondents already on ART.

### **1.7.2.2 Qualitative Data Collection Methods**

Fouche (2002b:275) defines data collection for the case study as a method used in qualitative studies as “...detailed in-depth data collection methods, involving multiple sources of information that are rich in context. These can



include interviews, documents, observations or archival records. As such the researcher needs access to, and the confidence of, the participants.”

The researcher used the semi-structured, one-on-one interview with an interview schedule in this research as a method of data collection. She interviewed a total of 20 members from the multidisciplinary team who were actively involved in service-rendering to ART patients. The participants were perceived to be experts in the field of ART and therefore, afforded maximum opportunity to provide input. The interviews were recorded and transcribed. As has been pointed out, “Semi-structured interviews are especially suitable where one is particularly interested in complexity or process, or where an issue is controversial or personal.” (Bless & Higson-Smith, 1995:113; Delpont, 2002:172; Greeff, 2002:302, 306-317; Rubin & Rubin in Mouton, 2003:196; Strydom, 2002b:292)

The interview schedule is defined by Greeff (2002:302) as: “A questionnaire written to guide interviews.” Such a schedule provided the researcher with a set of predetermined questions.

The researcher also utilised document study as a method of data collection. According to Strydom & Delpont (2002:321), document study is often neglected in research. Official documents imply that documents are compiled and maintained on a continuous basis by large organisations such as government institutions.

The said researcher reviewed documents, which indicate bio-chemical results of the patients, such as CD 4 counts and viral loads, on the initiation of ART. The records could then be compared to the CD 4 count and viral loads at follow-up visits, since this is usually a good indication of adherence, and may also indicate the effects of alcohol or drug abuse.



### **1.7.3 Methods of Data Analysis**

Data analysis refers to the manner in which data will be analysed and the statistical procedures employed (Grinnell & Williams, 1990:275). The analysis of data is intended to reduce the collection of data to simple and more understandable terms without distorting or losing too much of the valuable information collected (De Vos, 2002c:340-346; Mouton, 2001:108,110; and Neuman, 2003:430).

In this regard De Vos, Fouche & Venter (2002:222) state: “One reason is that, in a well-designed research study, the question of what to do with the data was anticipated and the analysis planned well before the data were collected.” The present researcher has adhered to this method.

#### **1.7.3.1 Quantitative Data Analysis**

Basically, data analysis (in the quantitative paradigm) requires that the analyst breaks the data down into constituent parts in order to obtain answers to research questions and test research hypotheses (De Vos, Fouche & Venter, 2002:223).

Quantitative data analysis involves the data collection process, complemented by the use of computer software, after it has been collected. Processing, with a view to quantification, is an important procedure in the data analysis (De Vos, Fouche & Venter, 2002:224). The researcher constructed the questionnaire so that it could be processed by computer in numerical form, with the help of the Department of Statistics at the University of Pretoria.

#### **1.7.3.2 Qualitative data analysis**

Data analysis is the process of bringing order, structure and meaning to the mass of collected data. Qualitative data analysis and interpretation was carried out by means of the identification of themes, recurring ideas and patterns or beliefs, and was interpreted to demonstrate credibility (De Vos, 2002c:354).



The steps in qualitative data analysis are not as linear as they appear, but are outlined as such for the purpose of the current study. The present researcher employed reasoning in order to reach conclusions based on evidence collected (De Vos, 2002c:341; Neuman, 2003:430). She followed the process of analysing data qualitatively as described by Creswell and presented by De Vos (2002c:340), which comprises the following aspects:

### **Collecting and recording Data**

In conducting data analysis during data collection, the researcher utilised triangulation, and sought different sources that could provide insight regarding the data. The triangulation method means mingling qualitative and quantitative styles of research in data collection and the recording of data in order to keep it intact, complete, organised and accessible. She kept records of interview notes and recordings of interviews according to themes, e.g. bio-themes, psycho-themes and social-themes.

### **Managing the data**

The researcher managed the data obtained from the interview schedule by organising files and notes and also making use of computer programmes so that it was easily retrievable. She evaluated the merits of the transcribed interviews and determined whether the data was authentic, valid, true, worthy, manageable, and of value for the research currently being undertaken.

### **Reading, writing memos**

After the collection of the transcribed data, the data were studied to enable the researcher to become familiar with the content as a whole, prior to categorising it in order to identify similarities that may exist in the various categories. She kept memos of the different themes uncovered.

### **Describing, classifying and interpreting**

De Vos (2002c:344) states that, in this regard, classifying means taking the text or qualitative information apart and searching for categories, themes or dimensions of information. The researcher sought explanations and identified similarities from the views of the various multidisciplinary team members and



compared them before describing the data. She also interpreted the data in order to accord meaning to it before they were analysed and conclusions were drawn.

The said researcher employed descriptive statistical analyses for the purposes of summarising, describing and analysing major characteristics of the collected data.

### **Representing, visualizing**

The researcher presented data in text, tabular and figure form, thus creating a visual image of the information, making use of the Department of Statistics, University of Pretoria.

## **1.8 Pilot Study**

The author holds to the usual definition of a pilot study as a study conducted on a small scale prior to a large piece of research, with the intention of determining whether the methodology, sampling instruments and analyses are adequate and appropriate. Such a study is performed in order to determine the feasibility of conducting the main study (Strydom, 2002c:202, 11). A pilot study is defined by the *New Dictionary of Social Work* (1995:45) as the “process whereby the research design for a prospective survey is tested”.

The pilot study commences with a literature study, which places the experiences of various experts on the table, together with an overview of the actual, practical situation where the prospective investigation will be executed, as well as an intensive study of strategic units, which will allow for feedback from the respondents. Strydom (2002c:210-214) adds that the pilot study is one way in which the prospective researcher can orientate him/herself to the project in mind.

### **1.8.1 Feasibility of the Study**

One of the major reasons for sampling is to sustain feasibility, as stated by Strydom & Venter (2002:199). The researcher is of the opinion that the current





research is feasible, taking into account that she has conducted previous research in this field and thus knows the nature and extent of the problem. Since the said researcher is employed by The Department of Health, ART clinic at Tshwane District Hospital, the current study is within the scope of her work.

Furthermore, the said researcher holds the view that the following contributed to the feasibility of the study:

- Consultation with experts and the pilot project provided her with an indication as to whether or not the study was feasible.
- She obtained support from the following key role players: South African Council for Social Services Professions (SACSSP), National Health, Gauteng Province (HIV/AIDS STD & TB Program), the Centre for the study of AIDS, University of Pretoria and the CEO's of the various hospitals involved in the research.

The said author conducted an in-depth literature review regarding this topic, and has consulted good introductory textbooks, studied journals and research reports, conducted literature searches, consulted various resources on the internet, and attended the 2005 AIDS Conference in Durban.

### **1.8.2 Testing the Data Collection Instruments**

Bless & Higson-Smith (1995:50) maintain that pilot testing of the data collection instrument enables the researcher "to identify any difficulty with the method or materials and to investigate the accuracy and appropriateness of any instruments that has been developed". Strydom & Delpont (2002:216) support this, by asserting that thoroughly pilot-tested questionnaires ensure that errors are rectified immediately at little cost and that necessary modifications are made before the questionnaire is presented to the full sample.

- For the purpose of the present quantitative study, questionnaires were administered to the respondents. In the pilot phase, these were administered



to two respondents who were not part of the main study. Modifications were made for the main investigation.

- Since the researcher conducted semi-structured interviews guided by an interview schedule as a data gathering method for the qualitative part of the current study, the interview schedule was also administered during the semi-structured interview to two respondents of the multidisciplinary team at the comprehensive ART clinic of the Pretoria Academic Hospital prior to the actual study. This was performed in order to test whether the constructed interview schedule yielded the expected information.
- This was executed very carefully exactly according to the plan for the main investigation in order to identify possible deficiencies. Feedback was requested from the respondents and they were asked to evaluate the interview schedule so that the author could effect the required changes prior to the full-scale study (Bless & Higson-Smith, 1995:43).

None of the participants who participated in the pilot project were included in the main study. Their views and opinions on the methods used were obtained and changes were made (Strydom, 2002c:215). The present researcher acknowledges that the testing of the interview schedule and questionnaire is important.

## **1.9 Research Populations, Sample and Sampling Methods**

### **1.9.1 Research Population**

Seaberg in Strydom & Venter (2002:199) describes a population as the total set from which the individuals or units of the study are selected. The population sets boundaries on the study units. The population in the present study comprises the multidisciplinary team, who are viewed as experts regarding ART, are practising and have experience regarding adherence and/or non-adherence to ART. These are the specific characteristics on which the researcher focused for the qualitative part of the current study. Further to this, the population consisted of HIV/AIDS patients older than 18 years, referred to Tshwane District Hospital for ART. All the HIV/AIDS patients in South Africa on



ART constitute the universe of the current study. In this context, "universe" refers to all potential subjects who possess the attributes in which the researcher is interested (Strydom & De Vos, 2002:198).

### **1.9.2 Delimitation of Sample**

This study was conducted in Pretoria, in the Tshwane/Metsweding regional ART sites of the Gauteng Provincial Government, during October and November 2005. The focus of the research fell on the ART clinic of the Tshwane District Hospital, which forms part of the Comprehensive HIV/AIDS Treatment Clinic of the Gauteng Provincial Government.

The respondents had all been referred to the Clinic for antiretroviral therapy and were therefore already in the AIDS phase, mostly with a CD 4 count of <200 and in Stage 3 or 4 (WHO, 2004) of the disease. Most patients were already severely immuno-suppressed. The researcher also interviewed respondents from the multidisciplinary team, who are viewed as experts in ART, and purposively selected according to their involvement in ART.

### **1.9.3 Research Sample, Sampling Method and Procedures**

The researcher believes that a complete coverage of the total population is seldom possible since all the members of a population of interest cannot possibly be reached. Sampling may, therefore, result in more accurate information than might have been obtained if one had studied the entire population. It is usually not possible to study the entire population, or the universe, for that matter (Arkava & Lane, 1983:157 in Strydom & Venter, 2002:199). This fact, therefore, compels the researcher to consider the use of a sample as a means of studying only units (a portion of the population) that represent the entire set from which a sample is drawn, and also, to understand that particular set (Grinnell, 1993:154; Strydom & Venter, 2002:199).

Various authors describe probability and non-probability as the two major groups of the sampling procedures. The researcher was aware that the concept of sampling is one of the most important considerations in the total



research endeavour; since it possesses elements of the actual population considered for inclusion in the study. A combination of both sampling procedures was followed in the current study. The researcher divided the population into two main sectors, i.e. patients on ART and the multidisciplinary team members.

### **1.9.3.1 Quantitative Sampling**

Selection of participants (patients refer for ART) to complete the questionnaire. The present researcher employed probability sampling to select a total of 201 participants to complete the questionnaire, and particularly, the simple random sampling technique. Random sampling refers to drawing a sample of a population so that each member of the population has an equal chance of being selected. (Strydom & Venter, 2002:197).

The list of the file numbers of patients attending the ARV clinic represented approximately 2000 patients. The present researcher decided on a sample size of 201. Strydom, (2002c:197) maintains the following regarding drawing of a random sample: "As mentioned above some methodologists suggest that drawing a 10% sample of a known population has become convention which serves as a handy rule of some". The researcher decided on 201 (10%) of the total population of 2 000 registered ART patients at the time of the research.

She selected participants at the ART clinic where she is employed. Each participant was numbered. She then selected every tenth person on the list to participate in the study, until the desired sample size was reached; these participants completed the questionnaire.

### **1.9.3.2 Qualitative Sampling**

For inclusion of respondents in the qualitative part of the current study, the present researcher utilised the non-probability sampling technique (Strydom & Venter, 2002:201).



A sample of 20 multidisciplinary team members was drawn from the population using the purposive sampling technique. This technique is defined by Strydom & Venter (2002:207) as “a sample composed of elements that contain the most characteristic, representative or typical attributes of the population”.

The criteria for the selection of this sample were:

- Multidisciplinary team members, male or female, any race;
- Professional as well as non-professional individuals (medical doctors, professional nurses, social workers, dieticians, pharmacists, lay counsellors); and
- Individuals actively involved in rendering services to HIV/AIDS patients, particularly for ART, for at least one year or are perceived as experts due to their contribution to this field of study (i.e. published authors, academics, policy writers). The team members could include individuals from the private sector, as well as the public sector.

According to Creswell in Strydom & Delpont (2002:334); Grinnell (1993:162); Grinnell & Williams (1990:128), as well as Neuman (2003:213), the above refers to the purposive selection of participants where the researcher determines a clear rationale for her decision and seeks to obtain rich information from the participants. This approach will ensure that in-depth information on the subject is obtained, since the multidisciplinary team members are knowledgeable and have experience in the area of study.

The selection of experts is illustrated in table 2.

**Table 2: Multidisciplinary team members purposively selected for interview**

National Department of Health- HAST Directorate	1
Gauteng Health- HAST program	1
Gauteng Health- HAST programme ART sites:	
Social Worker:	
Kalafong Hospital	1
Laudium Clinic	1
Soshanguve Clinic	1
George Mukari Hospital (SW)	1
Mamelodi Hospital	1
Pharmacist	2
Dietician Pretoria Academic Hospital	1
Professional nurse	1
Medical doctors	2
Adherence lay counselors	4
NGO's	1
Academic Institution: University of Pretoria	1
Foundation for Professional Development	1
Total	20

### 1.10 Ethical Aspects

The ethical guidelines for research have been designed in order to help protect the interests of participants. Extensive literature reviews discuss ethical considerations in research (Grinnell, 1993:304; Grinnell & Williams, 1990:304; Mouton, 2003:245-246; Neuman, 2003:120-127; Strydom, 2002a:63-64).

The researcher is aware of her responsibility to ensure that this study meets all the ethical requirements, and is of the opinion that ethical issues are of the utmost importance in research. She is further aware of the fact that, in researching HIV/AIDS issues, where human behaviour, stigmatisation and disclosure of certain behaviours play a role (specifically sexual behaviour), the respondents can easily feel threatened.



The screening of patients for antiretroviral treatment is itself an ethical issue because, if a patient is denied ART, this person will inevitably die of AIDS. On the other hand, prescribing ART irresponsibly can contribute to the development of a resistant virus (a threat to the community at large), and this is also an ethical aspect to be taken into consideration.

The researcher found the following ethical issues to be relevant to this study:

#### **1.10.1 Consequences for Human Beings. Harm to Experimental Subjects and/or Respondents**

The researcher is aware of the fact that she has an ethical obligation to protect respondents against any form of discomfort in extracting sensitive and personal information from subjects, unless such information is crucial for the purposes of the present research. The researcher was further aware of the fact that circumstances linked to their possible HIV transmission may be recalled to memory by respondents during the investigation and that it could be the beginning of renewed emotional harm. Bailey (1994:472) assert: "in some cases negative effects of a more negative nature than the anticipated harm of the research project exist in respondents' everyday, natural situation. In these cases it is surely justified that respondents suffer a certain degree of discomfort in order to eventually better circumstances" (Grinnell, 1993:304; Mouton, 2003:245-246; Neuman, 2003:120-123; Strydom, 2002a:63-64).

The researcher concurs with Strydom (2002a:63-64), who states the following regarding this matter: "We take the firm stance in this book that a researcher is ethically obliged to change the nature of his research rather than expose his respondents to the faintest possibility of physical and/or emotional harm of which he may be aware". The writer was aware of the fact that negative behaviour in the past, e.g. stigmatisation, promiscuity, rape, abuse and infidelity, might be recalled during this specific investigation and could initiate renewed personal trauma or embarrassment in the respondents. The researcher did not include sensitive matters, such as probing into who and how respondents contracted HIV. Only questions crucial to answer the research



questions were included in the questionnaires. Potential respondents, who were vulnerable, such as terminally ill patients, were eliminated from the study beforehand.

The researcher explained the anticipated consequences of her research to the participants by means of the letter of informed consent. Possible risks or harm that could emanate from participation in the research were disclosed by her; for example, renewed emotions. This was handled with great sensitivity. If counselling was needed, the participants were referred to an appropriate team member to address his/her needs.

### **1.10.2 Informed Consent Voluntary Participation**

The researcher obtained written, informed consent from each respondent. The content was also discussed personally with each respondent, particularly, illiterate respondents. At every ART site, lay counsellors, specifically trained in ART matters and who are members of the multidisciplinary adherence team were called upon by the researcher, to interpret when necessary. This implied that the respondents had adequate information with regards to the goal of the investigation and the subsequent procedures. The possible advantages and disadvantages of the current study were discussed with the respondents.

The respondents were thoroughly informed regarding the potential impact of the investigation, beforehand. Each respondent received an information leaflet together with an informed consent form. A signed copy was handed to the patient and a copy was kept by the researcher. The researcher was aware of all the above ethical issues. In particular, the fact that respondents might have felt obliged to participate in this research, since they need antiretroviral therapy, was discussed and handled with the necessary honesty and sensitivity. Participants were likewise informed of their right to refuse to participate in this research study and also that they could withdraw at any time, as their participation was entirely voluntary (Grinnell, 1993:82-84; Mouton, 2003:245-243; Neuman, 2003:124; Strydom, 2002a:65-66).





### **1.10.3 Deception of Subjects and/or Respondents**

The researcher was aware of the danger of deliberately misrepresenting facts such as withholding information, or offering incorrect information in order to ensure participation of subjects, when they would otherwise, possibly, have refused participation. Strydom's (2002a:67) view regarding deception of subjects is that: "...no form of deception should ever be inflicted on respondents. If this happens inadvertently, it must be rectified immediately after or during the debriefing interview". The said researcher is the social worker at the clinic and is thus part of a multidisciplinary team that monitors the patients. No deception of any form was inflicted on any respondents.

### **1.10.4 Confidentiality and Violation of Privacy**

The researcher has not disclosed any information concerning the respondents, since she was aware of the importance of safeguarding their privacy and identity. Furthermore, she firmly believes in the individual's right to self-determination, regardless of age, cultural or economic status. According to Strydom (2002a:67), privacy implies the element of personal privacy, while confidentiality indicates the handling of information in a confidential manner. Singleton, as quoted by Strydom (2002a:67), argues that sexual behaviour and illegal activities are two areas, which almost everyone will consider private.

Stigmatisation and the issues of confidentiality have always characterised HIV/AIDS issues, and this was taken into account with regards to the family life, relationships, and employment situations of the respondents. Doing research in the field of HIV/AIDS almost always implies questions concerning the sexual behaviour of patients. Questionnaires were therefore anonymously completed by respondents and were personally distributed by the said researcher. A copy of the signed consent forms were given to each respondent and the original was kept by researcher in a file, with the other confidential information of the patients. The completed questionnaires were numbered and stored in sealed boxes at the residence of the researcher for analysing purpose. The data will be stored for 10 years as prescribed by the University of Pretoria. (Grinnell, 1993:82-87; Mouton, 2003:245-243; Neuman, 2003:127; Strydom, 2002a:68).



#### **1.10.5 Action and Competence of Researcher**

The researcher is of the opinion that she is competent and adequately skilled to undertake this sensitive research. She has 20 years of experience dealing with confidentiality issues regarding HIV/AIDS, is knowledgeable regarding the subject of research and has completed a similar research study for her Master's degree.

#### **1.10.6 Cooperation with contribution credit for endeavors**

The said researcher has not involved any sponsors for the current research. She has received a bursary from the University of Pretoria and is only bound by the standards of the University of Pretoria's Ethical Committee, as well as the standards of Tshwane District Hospital and the Department of Health, her employer, with regards to the current research.

The necessary protocols were followed and acknowledgement has been given for the contribution of each participant (Strydom, 2002:71; Grinnell, 1993:88).

#### **1.10.7 Release or Publication of the Findings. Reporting and Analysis of Data**

A further ethical issue, as discussed by Strydom (2002a:69), and one that the researcher took into account, concerns the correct reporting of the analysis of data and the results of the present study. "Apart from the normal situation in qualitative research, the onus is also on the researcher to deal ethically not only with the research results, but also with the therapy" (Strydom, 2002a:69).

Since the current research was also conducted across cultural boundaries, the researcher respected the cultural values, norms and customs of the respondents. Regarding the above, Strydom (2002a:70) also contributes the following: "No value judgments are to be made, under any circumstances whatsoever, on the cultural aspects of communities".

The said researcher has, as far as possible, formulated the information accurately and objectively in the present research report, which includes the



shortcomings of this research. She is aware of the necessity of avoiding plagiarism and acknowledgement is given to all sources consulted as well as to the people with whom she had collaborated. Regarding this ethical issue, Strydom quotes Babbie (1988:73), who states that "...closely related to altering the results are the incorporation of someone else's work into your own without proper acknowledgement".

The present researcher has also been granted ethical clearance by the Ethical Committees of the Faculty of Health Sciences and the Faculty of Humanities, University of Pretoria.

#### **1.10.8 Debriefing of Subjects or Respondents**

The respondents continue to be supported and monitored following the study. The respondents will be debriefed by the researcher if needed. If further counselling is indicated the researcher will refer the respondents for counselling.

#### **1.11 Limitations of the Study**

The elaborate bureaucracy, with which the present researcher had to deal prior to commencing the current research, was very time consuming. This included obtaining permission from the Department of Health, clearance from two different ethics committees, one from the University of Pretoria, Faculty of Health Sciences and the other, from the Faculty of Humanities, regarding ethical matters; they each had different expectations.

Various expectations stemming from the Department of Social Work and Criminology prior to even beginning the research, such as: oral exams regarding the research methodology, a research forum and a doctoral seminar, made the period of study very lengthy.

The submission of a lengthy research report, when the submission of the research findings, by means of an article published in a scientific journal, seems to be more appropriate.



The fact that the Department of Statistics, University of Pretoria, which processed and analysed data, had different expectations to those of the Department of Social Work and Criminology, was also time-consuming and thus, required discussions between the role players.

All electronic devices, a personal computer and a dictaphone were lost during a theft at Tshwane District hospital. The researcher lost almost all the literature study data gathered and had to start from scratch again with the literature study. No confidential data were stored on the computer that was stolen only literatures study. Thus patient confidentiality and privacy was not compromised.

Further limitations that the said researcher experienced were related to the fact that HIV/AIDS issues, and particularly, antiretroviral matters, are so dynamic and controversial, with daily changes and constant reports of new research, that data needed to be updated regularly.

Conducting the present research, specifically the qualitative part, was very time-consuming. In retrospect, the said researcher should have utilized focus groups in order to gather information for this part of the study.

## **1.12 Definition of Key Concepts**

The following key concepts are defined for better understanding of the text:

### **1.12.1 Adherence**

“Adherence, the quality of yielding to pressure or force without disruption. An expression of the ability to yield to pressure without disruption” (*Dorland’s Illustrated Medical Dictionary*, 1994:388).

Adherence is also defined as the act or quality of sticking to something, or to adhere to something. Adhere - to behave according to, follow in detail, faithfully observing a rule (*The Concise Oxford Dictionary*, 1995:272).



The researcher is of the opinion that both compliance and adherence refer to the act of “sticking to” a treatment regimen since it captures the increasing complexity of medical care by characterising patients as independent, intelligent, and autonomous people who take more active and voluntary roles in the decisions regarding their treatment.

### **1.12.2 Anti Retroviral Therapy (ART)/Highly Affective Antiretroviral Therapy (HAART)**

Combination antiretroviral therapy (Kasper, *et.al.*, 2005:1124) is defined as “or HAART, is the cornerstone of management of patients with HIV infections” (Kasper, *et.al.*, 2001:1899). The present researcher defines antiretroviral therapy and HAART as the use of several antiretroviral drugs (combination of drugs) for the treatment of HIV/AIDS.

### **1.12.3 Antiretroviral (ARV)**

“An agent with the quality of being effective against retroviruses” (Mosby Pocket Dictionary of Medicine, Nursing & Health Professions, 2006, 97).

### **1.12.4 Biopsychosocial**

“A phenomenon that consists of biological, psychological and social elements, a term applied to phenomena that consist of biological, psychological and social elements”. (Barker, 1991:23) “The bio-psychosocial model of disease stresses an integrated systems approach to human behaviour and disease”. (Kaplan, *et al.*, 1994:1)

The current researcher believes in a holistic approach to healthcare management, which the term “biopsychosocial” encompasses, that is the patient’s medical-, psychological- emotional-, and social (behaviour, relationships, support systems and environment) functioning, in order to provide a comprehensive service.



#### **1.12.4 Compliance**

“Compliance is the act of conforming. Compliance, the act or an instance of complying, obedience to a request, command” (*Dorland’s Illustrated Medical Dictionary*, 1994:388).

The term "adherence" is preferable to "compliance", since compliance implies that some prompting is necessary to ensure that the medication is taken, whereas adherence is voluntarily driven by the individual.

#### **1.12.5 Concordance**

Concordance is based on the notion that the work of prescriber and patient in the consultation is a negotiation between equals and that therefore the aim is a therapeutic alliance between them. Its strength lies in a new assumption of respect for the patient’s agenda and the creation of openness in the relationship, so that both doctor and patient together can proceed on the basis of reality and not of misunderstanding, distrust or concealment. It is promoting power sharing between provider and patient and in respecting the patients’ perspective (Rier & Indyk, 2006:137).

#### **1.12.6 Counselling**

Counselling is defined in the *New Dictionary of Social Work* (1995:15) as comprising “interviewing procedures aimed at guiding the client towards insight, with a view of promoting his social functioning”.

In the *Dictionary of Counselling* (1994:63), counselling is similarly defined as a “helping process in which one person, a helper, facilitates exploration, understanding and actions about developmental opportunities and problem conditions presented by a helper or client”.



## **1.12.7 Counsellors**

### **1.12.7.1 Registered professional or trained counsellors**

Registered counsellors are psychological workers who perform psychological screening and basic assessment and technically limited psychological interventions with a range of people, aiming at enhancing personal functioning in a variety of contexts including school, work sport and community. Registration as a Registered Counsellor is contingent on completion of: An accredited 4 year B Psych or Honours degree in Psychology accredited by the Board as equivalent to the B Psych degree and an approved 6 month's practicum in the designated practice area. The required practicum included in the B Psych must be done under supervision of a registered Psychologist according to criteria set by the Professional Board. (*Health Professions Council of South Africa (HPCSA): Professional Board for Psychology: Framework for Education, Training and Registration as a Registered Counsellor*)

### **1.12.7.2 Lay counsellors**

Lay counsellors in ARV are defined as voluntary workers who do basic assessments and limited interventions with a range of people aiming at enhancing their bio-psychosocial functioning in a variety of contexts including the realm of HIV/AIDS: VCT, PMTCT, HIV pre-test, HIV post-test and adherence to ARV counselling. Such counsellors receive in-service training to conduct such services (Dept of Health, South Africa: 2003).

## **1.12.8 HIV/AIDS**

"Human immunodeficiency virus". (*Dorland's Illustrated Medical Dictionary*, 1994:826) AIDS: any HIV-infected individual with a CD4+T cell count of <200/ $\mu$ L has AIDS by definition, regardless of the presence of symptoms or opportunistic disease" (Kaplan, *et al.*, 2001:1852).



### **1.12.9 Multidisciplinary Team**

“A multidisciplinary health team can be defined as a team whose members represent the widest possible spectrum of individuals and organisations concerned with, or involved in, any aspect that has a bearing on the health and welfare of the community, in an attempt to provide effective, comprehensive health care that will assist in the achievement of optimal health for all people” (Dennill et al., 1995:111).

The WHO (2005) defines the multidisciplinary health team as: “A group of people who share a common health goal and common objectives, determined by community needs, to the achievement of which each member of the team contributes, in accordance with his or her competence and skills, and in coordination with the functions of others.”

The researcher is of the opinion that multidisciplinary teamwork in healthcare is the delivery of critical, comprehensive interventions, to the individuals, families, groups and/or communities, who are related or affected by illness. The aim of the team intervention is to provide a holistic approach that could ultimately improve social functioning and quality-of-life in general, including prevention of illness and promotion of health by means of education. By acknowledging the physical, mental, emotional, social, economical, cultural and spiritual dimensions of human life, the members of the multidisciplinary team in healthcare are all role players, who, according to their knowledge, contribute to a patient’s holistic medical care.

### **1.12.10 Screening**

“A system of checking for the presence or absence of a disease, ability, attribute; check on (a person) for the presence or absence of a quality, esp. reliability or loyalty” (*The Concise Oxford Dictionary*, 9th Edition.1995, 1995:1241)  
Social Work profession.





### 1.13. Contents of the Research Report following this Chapter

**Table 3: Contents of research report**

<b>Chapter</b>	<b>Contents</b>
Chapter 2	Medical aspects of HIV/AIDS
Chapter 3	Antiretroviral therapy
Chapter 4	Resistance and the role of adherence to antiretroviral therapy
Chapter 5	The social workers role in assessing the HIV/AIDS patient for anti-retroviral therapy utilising the biopsychosocial model
Chapter 6	Empirical findings (qualitative) Empirical findings (quantitative)
Chapter 7	Summary, conclusions and recommendations