CHAPTER 6: EMPIRICAL FINDINGS FROM THE QUANTITATIVE AND QUALITATIVE PHASES OF THE STUDY: THE BIOPSYCHOSOCIAL FACTORS INFLUENCING HIV/AIDS PATIENT ADHERENCE TO ANTIRETROVIRAL THERAPY (ART): A SOCIAL WORK STUDY

6.1 Introduction

The general purpose of this research is to explore and gain insight into the biopsychosocial factors related to adherence as regards antiretroviral therapy for HIV/AIDS patients, within the South African context, since little is known about this field.

This chapter consists of a discussion of the research methodology and the research findings, which are presented according to the subsections in the questionnaire used for the quantitative part of the study, in terms of the biographical, medical and psychosocial data. The qualitative part of the study is presented throughout the discussion wherever applicable, including the narrative quotes from interviews and the themes and sub-themes.

6.2 Research Methodology

6.2.1 Type of research, and research approach and design

Applied research, was employed in this study since the general purpose of this study was to stimulate thought and action concerning the challenges faced by patients on ART. The knowledge generated from the findings will be aimed at improving adherence and sets out to solve practical problems (Grinnell, 1993:15; Fouche, 2002:108; Neuman, 2003:21). The aim of the research is to provide improved service delivery. “Applied research … is aimed at solving specific policy problems or at helping practitioners accomplish tasks. It is focused on solving problems in practice” (Fouche, 2002:109; Rubin & Babbie, 1993:79).

The researcher sought various types of sources that could provide insight into the research question. She is of the opinion that the combination of the two approaches, qualitative and quantitative, led to more reliable results. According to Creswell's dominant-less-dominant model Fouche, (2002:365) confirms that the above two approaches are often employed in the same study with one approach being used more than the other, according to the demands of the study.

For the quantitative phase the quantitative descriptive design was used and for the qualitative phase collective case studies were used. In addition to this the quantitative approach was primarily utilized, employing a questionnaire as a method of data collection. In the qualitative part of the study a collective case study was utilized as the less dominant part. The intention was to unearth the knowledge, perceptions, feelings and attitudes of the participants in the research regarding factors that influence adherence. The specific aim of the qualitative phase of the study was to explore the views of the multidisciplinary team members with regards to biopsychosocial aspects that could influence adherence of HIV/AIDS patients on ART.

6.2.2 Research questions and hypothesis

The researcher aimed to obtain answers to the following research questions:

- What are the biopsychosocial factors that influence adherence to ART, as perceived by multidisciplinary team members involved in the service delivery to HIV/AIDS patients on ART?
- What are the existing biopsychosocial circumstances influencing adherence of HIV/AIDS patients already on ART?
- How can these identified biopsychosocial factors be utilised in service-rendering to enhance adherence to ART by HIV/AIDS patients thereby minimising the development of resistance?

A hypothesis is defined by Kerlinger (1986:17) in De Vos (2002:36) 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.

6.2.3 Goal and objectives

The specific goal of the 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.

The researcher has identified the following objectives for the study:

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

6.2.4 Methods of data collection

Data collection methods for both paradigms were employed; i.e. semi-structured interviews with an interview schedule for the qualitative data collection methods. The interview was tape recorded and transcribed. A structured questionnaire and documents (CD4 laboratory results of patients) were used for the quantitative data collection (Bless & Higson-Smith 1995:113; Delport 2002:172; Greeff 2000:302 & 306-317; Rubin & Rubin in Mouton, 2003:196; Strydom, 2002:292.)

Various sampling techniques were employed for the two research groups. A sample of two hundred and one (201) respondents was selected by means of the probability simple random sampling technique, for the quantitative research from patients attending the ARV clinic at Tshwane District Hospital.

The respondents to the quantitative study were asked to complete the structured questionnaire after providing their informed consent. The questionnaire is attached in Appendix 5 of this thesis. The research was conducted during October and November 2005. The questionnaire was self administered but the researcher had individual and personal contact with each respondent and assisted with the filling in of the questionnaire.

6.2.5 Sampling method and sample

The total population consisted of participants, male and female, older than 18 years, of all races and socio-economic groups, who are HIV-positive and have been referred for ART to the ART Clinic at the Pretoria Academic Hospital, which became Tshwane District Hospital during 2006. The clinic is in the Tshwane/Metsweding Region of the Gauteng Department of Health and forms part of the Comprehensive HIV/AIDS Treatment Clinic of the Gauteng Provincial Government. With regards to the quantitative-descriptive (survey) design, random sampling methods were employed for the selection of respondents. According to Strydom, (2002c:197) maintains the following regarding drawing 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.

In addition to this, the collective case study strategy was utilised for the qualitative approach of the research, which aims to understand and interpret the meaning that the subjects give to their everyday lives (Creswell, 1998 in Fouche, 2002:273 & Neuman, 2003:142 & 148).

The non-probability sampling method was implemented in the qualitative research utilizing the purposive sampling technique (Neuman, 2003:211 & 223), in order to select 20 multidisciplinary team members. A collective case study was employed for the qualitative study (Fouche, 2002:275). The aim was to ensure that rich information on the subject was obtained.

The multidisciplinary team members are knowledgeable and possess experience in the area of the current study. The researcher wanted to understand a certain issue (i.e. factors influencing adherence) and according to Fouche, (2002:277), "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". (Strydom & Venter, 2002:201) The researcher purposively selected multidisciplinary team members, experts who are practising in the field of ART, or possess knowledge, regarding ART, to participate in the study. The said researcher interviewed respondents from the multidisciplinary team in various ART settings.

The criteria for the selection of this sample required that the respondents must be:

- Multidisciplinary team members, male or female, any race and age; and
- Professional as well as non-professional individuals (medical doctors, professional nurses, social workers, dieticians, pharmacists, lay counsellors).
- The individuals must be actively involved in the rendering of service to HIV/AIDS patients, particularly those on ART, for at least one year or are perceived to be 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. The selection of experts is illustrated in Table 2 in Chapter 1.

6.2.6 Methods of data analysis

In conducting data analysis during data collection, the researcher made use of triangulation, and sought different sources that could provide insight regarding the data. Triangulation denotes the mingling of qualitative and quantitative styles of research in data collection and the recording of data in order to keep it intact, complete, organized and accessible.

As De Vos (1998:48) observes, data analysis follows data collection. Mabutho (2004:28) defines data analysis as a search for a pattern in recurrent behaviours or objects of a body of knowledge. Once a pattern is identified, it is interpreted in terms of social theory or the setting in which it occurred.

Data analysis is, therefore, a process of bringing order, structure and interpretation to the mass of data collected and should include examining, categorizing, tabulating or otherwise recombining the evidence in order to address the research problem. The researcher agrees with the aforementioned definition and applies it in her study. The quantitative data analysis in this research was performed with the use of computer software for quantification (De Vos, Fouche & Venter, 2002:224).

The quantitative data will be presented in percentages and frequencies and by means of tables and graphs according to the various sub-sections in the questionnaire. The researcher presented quantitative 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.

Qualitative data analysis and interpretation was therefore carried out by means of the identification of themes, recurring ideas and patterns or beliefs, and was interpreted in order to perceive patterns and increase credibility.

The qualitative data analysis and interpretation was carried out by means of the data recorded from the transcribed interviews, classified into themes, recurring ideas and patterns or beliefs, and presented as direct quotes (De Vos,

2002:354). The grounded theory analysis of the data was conducted in the following manner: She clustered the categories that emerged most prominently; various themes emerged from these clusters. She then searched for commonalities in or contradictions to the findings and, thereby forming sub-themes.

The research findings of the qualitative part of the research will be presented as verbatim quotes from the interviews according to the different themes and sub-themes. These themes are discussed in the light of relevant literature or supporting narratives.

According to Strauss and Carbin (1998:10-11), a qualitative research approach is an approach that elicits participant accounts of meaning, experience or perceptions. They add that it also produces descriptive data in the participant's own written or spoken words (Bailey, 1994:62-63, Grinnell, 1997:12, Neuman, 1997:14, and Fouchѐ, 2002:271-272).

The steps in qualitative data analysis are not as linear as they may appear, but are outlined as such for the purpose of the current study. The researcher employed her powers of reasoning in order to reach conclusions based on evidence collected (De Vos, 2002c:341; Neuman, 2003:430).

The researcher followed the process of analyzing data qualitatively as described by Creswell and presented by De Vos (2002c:340). The data analysis comprised the following aspects: Collecting and recording data, managing the information, reading, writing memos, describing, classifying and interpreting, presenting and visualizing the data.

6.2.7 Collecting and recording data

Collection and recording of data was carried out through interviewing. The researcher used an interview schedule to produce findings. Interviews were based on the biopsychosocial model. This data consist of field notes and tape

recordings. As data were gathered they were managed and analysed by the following methods:

6.2.7.1 Managing the data

The data obtained from the interview schedule were dealt with as follows: the tape recordings of the interviews were transcribed, organized, taking notes and also making use of computer programmes so that the information was easily retrievable.

The researcher evaluated the merits of the transcribed interviews and determined whether the data was authentic, valid, true, worthy, manageable, and of value for the research.

She converted the files into sentences or an entire story for the purposes of analysis. During this phase she kept the literature review, the previous data and earlier analytic memos in mind.

6.2.7.2 Reading, writing memos

After the collection of the transcribed data, they were studied to enable the researcher to become familiar with the content as a whole.

The researcher read the transcripts in their entirety several times in order to describe, classify and interpret the data, prior to categorizing it in order to identify similarities that might exist in the various categories. She kept memos of the different themes uncovered.

6.2.7.3 Describing, classifying and interpreting

The data were subsequently sorted and interpreted to bring order and structure and to give meaning. 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 also sought to identify the salient themes, noting regularities or patterns of meanings held by the participants that would then be reduced to small, manageable sets of themes and sub-themes to be written into the final report.

She sought explanations and identified similarities from the views of the various multidisciplinary team members and compared them before describing these, employing descriptive statistical analyses for the purposes of summarizing, describing and analyzing the major characteristics of the collected data.

In particular, she interpreted and reviewed data, about factors influencing adherence, piecing together patterns in order to accord meaning to them before conclusions were drawn.

Mark (1996:211) states that findings may be presented in the form of categories or statements about the nature of persons, groups or events under study. Hence the researcher defined specific categories, to represent the research findings. The categories defined are:

- Bio- or medico-physical factors affecting adherence;
- Psychological factors influencing adherence;
- Social circumstances impacting on adherence;

Discrete themes and sub-themes were further derived from the above categories to:

- answer the research questions;
- supplement the quantitative analyses;
- present solid descriptive data, leading to a better understanding of the phenomenon of biopsychosocial factors possibly affecting adherence.

6.2.7.4 Representing, visualizing

The researcher presented data in qualitative findings by means of narratives, themes, sub-themes, and quotes from interviews supported by the literature. A presentation and visualization of data and reporting of the findings follows:

Table 10: The themes and sub themes, derived from the interviews for the qualitative part of the study:

CATEGORY: BIOGRAPHICAL	
THEME	**SUBTHEMES**
Gender plays a role in adherence to ART	• Women comprise the majority of patients attending ART clinics. • Females are perceived by respondents as more adherent than males.
Age plays a role in adherence to ART	• Younger people show more insight, are motivated to live longer and tend to be more adherent. • Young adults have further issues (psychological changes and psychosocial challenges) to deal with, other than adherence to ART. • Older people are more reliable and responsible, but they do not evidence much insight and are often supported by younger family members.
Language, culture and traditions influence adherence to ART	• Different ethnic groups hold to different traditions, values and believes that influence adherence • Certain cultures do influence adherence through myths and certain traditional beliefs and values. • Certain traditional healing methods can jeopardize adherence to ART.
CATEGORY: BIOLOGICAL OR MEDICAL	
THEMES	**SUB-THEMES**
The period a patient has been on ART influences adherence	• The period on ART does not indicate non-adherence, but patients tend to stop ART once they feel better. • After a lengthy period on ART some patients tend to get tired of pill taking (pill fatigue). • Patients are not always aware that ARV medication is for life. • Monitoring of adherence throughout ART treatment is indicated.
Knowledge of the CD 4 count could influence adherence to	• The CD4 count is a reflection of the improvement of the immune system and tends to serve as a

ART	motivation. • The CD4 count can also influence adherence negatively in some circumstances, e.g. the CD 4 count might not improve and patients may tend to become disillusioned. • If the CD 4 count increases, some patients do not adhere for fear of losing their disability grant, which requires the patient to be in stage IV or CD 4 count under 200. • The CD4 count is a difficult concept to try and explain in counselling.
Performance status (Karnofsky) of patients influences adherence to ART indirectly	• This status is not used directly in counselling patients at clinics. • It is a difficult concept to try and explain to patients. • The performance status is a confirmation of the improvement of the physical functioning and could serve as a motivation to adhere to ART.
WHO staging does not influence adherence to ART directly	• WHO staging is only used by clinicians prior to initiation in clinics and is not used by counsellors. • It is also a difficult concept to try and explain to patients. • WHO staging is an indication of the improvement of the medical condition and could likewise serve as a motivation. • WHO staging does not influence adherence, since patients just see an improvement of their functions and the regaining of lost roles.
Patients experience various difficulties regarding adherence to ART	• Patients do experience side-effects and complications of ART. • These side-effects and complications are contra-indicated for adherence. • Financial difficulties and material needs do influence adherence to ART. • Patients are not educated regarding various grants that they qualify for.
Patients do require various or holistic counselling throughout	• Common standards are required in counselling, specifically regarding adherence counselling.

ART treatment	• Patients need holistic help. • Patients need trained counsellors to support them.
SOCIAL CATEGORY	
THEMES	**SUB-THEMES**
Marital status influences adherence to ART	• Marriage, specifically supportive relationships, influence adherence to ART positively. • Disclosure of HIV status to the partner is indicated for adherence to ART. • Marriage, if not a supportive relationship, coupled with non-disclosure to the partner, influences adherence to ART negatively.
Education influences adherence to ART	• Better educated people demonstrate greater insight regarding adherence to ART. • Better educated people are more open to training. • Formal education should not play a role in adherence issues. • People can be educated by means of counselling and training to help improve adherence.
Residential area influences adherence to ART	• Rural people prefer to travel to urban clinics; they perceive the clinics to offer better treatment. Urban clinics are thus valued more by patients than rural clinics. • Patients still fear discrimination and prefer to attend clinics far away from home. • Easy access to a clinic influences adherence positively, due to transport costs.
Living conditions influence adherence to ART	• Overcrowded living conditions influence adherence negatively. (Urban –flats) • Chaotic living conditions are contraindicated for adherence. • The type of house (shack or house) does not influence adherence. • Homeless people have difficulty in adhering.
Social support is very important in adherence Support from a comprehensive ARV clinic is important	• Family support appears to be the most common form of support to patients. • A comprehensive ARV clinic can offer good support.

Support groups are essential and this form of assistance needs attention Employers are not seen as supporting adherence	• Support from all team members involved in a comprehensive ART clinic is recommended • Common standards should be adhered to by all team members regarding adherence issues. • The health team is an important form of support. • The private and public sectors should maintain common standards regarding ART matters. • Support groups are not valued by patients • Support groups should comply with common standards to promote credibility. • Patients experience anxiety due to their non-disclosure to employers and their need for absenteeism from work to attend medical appointments.
Patients experience various psychosocial needs Various forms of support and aids are necessary to enhance, adherence to ART The social worker with her specialize skills is very important in supporting patients	• Material needs feature strongly in adherence. • Financial assistance and disability grants are major needs. • Nutritional assistance is needed by many patients. • The need for psychosocial support regarding adherence is reported. • Family support, especially mothers appear to be the most common form of support to patients. • Patients use mainly cell phones as reminders. Some patients plan pill-taking around TV or radio programs. • Patients do not use aids, like pillboxes, to support adherence. • Patients do use diary charts if supplied by clinic. • Pill counts done at clinics are a good form of supporting adherence and detecting adherence problems. • Social worker can assess needs and refer to appropriate resources. • Social worker can network. • Social workers can co-ordinate services.
Drug abuse not reported to be prominent at ART clinics	• Drug abuse is not reported by patients. • Patients are too poor to afford drugs

	• People do not easily disclose drug abuse. • Drug abuse is more prominent amongst white or financially stronger patients.
Alcohol dependency not reported at ART clinics	• Alcohol dependency or abuse does not feature strongly at ART clinics. • Alcohol abuse is not often or willingly disclosed.
Criminal involvement Minimum influence on adherence to ART	• Criminal involvement does not feature in adherence to ART. • Prisoners should receive treatment in prison and not visit local clinics as is the present practice in local clinics in S.A.
Psychosocial needs of patients featured strongly Psychosocial needs of counsellors featured strongly	• Patients need support structures that are supportive and standardized. • Patients have a need for maintenance of confidentiality. • All patients need a thorough assessment of personal circumstances and needs • Lay counsellors concerning adherence matters need formal training. • Lay counsellors in general need better working conditions and expect formal employment with benefits. • The standards governing lay counsellors need to be standardized and uplifted.
Disclosure influences adherence to ART	• Disclosure of HIV status features as a major issue in adherence to ART. • Disclosure or non-disclosure of HIV status causes anxiety and influences adherence to ART. • Patients tend to disclose mainly to immediate family for support. • Patients try to avoid disclosing to employers and strangers. • To demand disclosure of status to at least one person prior to initiation not always possible and cause anxiety.
Sexual relationships do influence adherence to ART	• Sexual matters are not specifically discussed in counselling. • Disclosure of HIV status influences sexual

People do not practice safe sex Sexual matters are reported to be associated with ART People do not practice safe sex Sexual matter are reported to be associated with ART	relationships as well as adherence to ART. • Non-disclosure of status to sexual partners influences adherence to ART negatively, specifically if patients must visit clinics for follow-up appointments and take medication in secrecy. Patients also experience problems when developing side-effects from ART. • Female patients increasingly report being pregnant on ART. • Patients moreover report STI's at clinics. • Patients (both sexes) report an increase of libido on ART. • Sexual dysfunction is reported by males, specifically erectile dysfunction while on ART.
Traditional healing influences adherence to ART in S.A.	• Certain traditional beliefs and rituals are contraindicated for adherence to ART. Like cleaning of the body. • Traditional healing does interfere with ART.
Accommodation needs do not play a role in adherence	• Most people are content with their accommodation.
Economic factors influence adherence to ART	• Lack of money influences adherence to ART. • Poverty should not prevent adherence. • People need financial support to adhere to ART and to attend clinics. • Unemployed patients, dependent on disability grants, fear discontinuing of grant, when adhering and the subsequent improvement of CD 4 count.
Financial difficulties are reported by respondents influencing adherence to ART	• Supporting patients financially is important for adherence • Unemployed patients need disability grants to support adherence. • Patients rely mainly on financial support from families.
Religion can influence adherence to ART	• If patients are religious, the church and spirituality will convey hope and motivate them to adhere. • Some churches issue special instructions regarding treatment (faith-healing, cleaning of body and other rituals) which could be

	contraindicated for adherence. • The concept of faith healing and patients believing that they are cured can result in non-adherence to ART.
The quality of life of most patients had improved on ART	• A dramatic improvement if on ART is shown, if patients are adherent with no complications. • The quality of life has improved and most patients can assume lost roles.
PSYCHOLOGICAL MATTERS	
The need of patients to stay alive (survival) features as their strongest motivation to adhere to ART	• Patients are mostly motivated to adhere in order to improve their health in general and to be symptom-free. • Patients are motivated to adhere so as to be able to care for their families. • Patients are frequently urged by external pressure to adhere to ART.
Patients reported in general positive feelings and feelings of optimism, hope and gratitude	• Feelings of anxiety were reported regarding disclosure of status. • Complications, treatment failure and side-effects lead to feelings of despondency and depression.
Depression not reported to be prominent at ART clinics	• Depression is more often reported in white patients. • Depression did not feature frequently in patients attending the clinics where research was conducted.

6.3 Research Findings

As mentioned above, the quantitative data, which were collected by means of questionnaires, will be presented and interpreted by means of percentages and frequencies. The more significant data will also be represented by means of tables and graphs. The questionnaire consists of questions that explore the biographical, medical, as well as the psychosocial circumstances of respondents.

The qualitative data will be presented using verbatim quotes from the interviews, which were transcribed and classified, scientifically, into themes and

sub themes, and will then be supported with the literature. The data from the qualitative element of the study will be provided throughout, where applicable, in conjunction with the quantitative findings.

6.3.1 Biographical Data

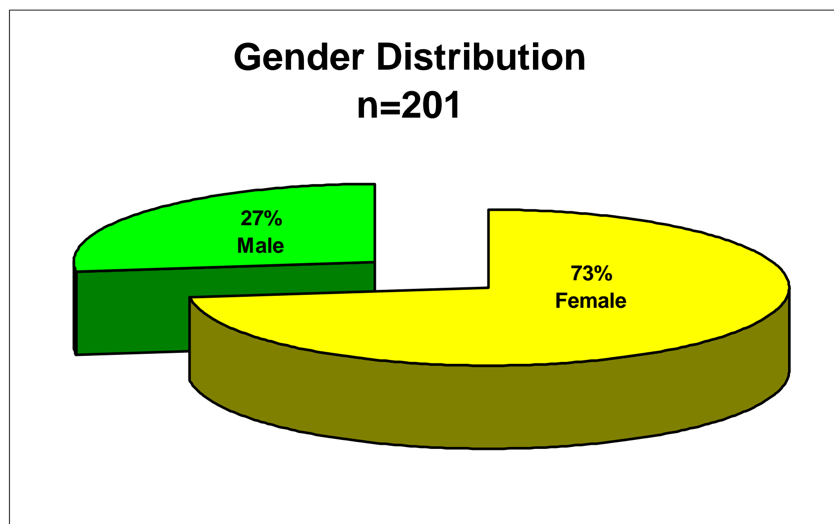
In this subsection, personal information was collected from the respondents, in order to gain a better understanding of their circumstances.

Biographical data were gathered with regards to gender, age, marital status and educational level. An intensive literature search revealed that marital status, level of education, race and living conditions of respondents do influence adherence to ART, and that certain groups are more adherent than others (Friedland, 2002:35-40). The researcher wished to ascertain whether these results could be verified by means of the current study.

6.3.1.1 Gender of Respondents

This question formed part of the biographical data in order to establish the gender distribution of the respondents, since gender has always been a prominent issue in HIV/AIDS discussion.

Figure 5: Gender Distribution



The above graph illustrated the following:

54 (27%) of the respondents were male

147 (73%) of the respondents were female

It is evident from the above research results, that the majority of respondents were women: 147 (73%) and only 54 (27%) were males. This correlates with the National HIV and Department of Health's Syphilis Antenatal Sero-Prevalence survey in South Africa (2005:1), which reported that, globally, 40.3 million people worldwide are living with HIV, of which an estimated 25.4 million live on the African continent. Of these, 17.6 million were women. The above survey further estimated the number of infected women in South Africa to be 3.12 million and, 2.19 million infected males from a total population of 5.30 million.

The data from the qualitative part of the study correlates with the findings from the quantitative part of the study.

Theme:

- Gender plays a role in adherence to ART.

Sub-themes:

- Women comprise the majority of patients attending ART clinics.
- Females are perceived by respondents as more adherent than males.

Table 9: Theme: Gender plays a role in adherence to ART

Respondent	Verbatim interview quotes from the research interview.
Social Worker	"Yes, gender plays a role in adherence. Women are better at adhering because they have better coping skills".
Pharmacist	"Women are better adherents they seem to be more responsible".
Medical doctor	"Gender plays no role in adherence".
Counsellor	'Woman wants medication because they want to care for their children. The males are in denial".

The above research findings are supported by the following literature:

Abdool Karim & Abdool Karim (2005:276) state the following with respect to gender: “The importance of gender as a dominant force in young people’s relationships has been shown through research in a number of settings. Women represent the majority of those living with HIV/AIDS in sub-Saharan Africa.”

Regarding the gender issue Venter (2005:23) observes that men are grossly underrepresented in all the large ARV clinics that have reported data, with women accounting for over two-thirds of the numbers. This probably reflects the social behaviour of men who tend to seek healthcare services less often and at a later stage of the disease. VCT attendees are predominantly women and active discovery of cases among women occurs by means of pregnant-mother-to-child-transmission (PMTCT) programmes. Factors contributing to this situation could be the high incidence of HIV in women in general, or it could be speculated that women seek medical treatment more often than men. Thus, gender seems to play a role in adherence and it was found that women are thought to be more adherent and evidence more determination to do so because they feel responsible for their children.

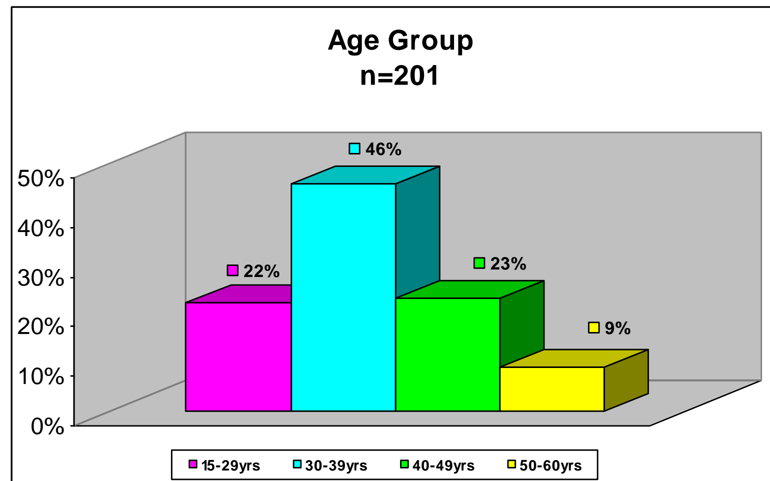
The above research data also correlate with the high response rate of female respondents, 143 (73%), in the quantitative part of the present study. The present researcher is of the opinion that these findings indicate a need for active programmes that specifically focus on men, such as workplace programmes, or male wellness clinics. Such a clinic could possibly be attached to an antenatal clinic, since, for every pregnant woman there must be a sexually active man who could be actively involved in HIV awareness, education and/or testing at such a clinic.

If men are actively focused on it could lead to an increase in VCT and awareness. Wilson and Fairall, in Abdool Karim & Abdool Karim (2005:489) state the following regarding gender:” This is explained by HIV/AIDS programmes which to date have prioritised access to antiretroviral for PMTCT and PEP. Until this imbalance is addressed, and men distanced from blame for the spread of the disease, intervention to encourage safe sex practices can be expected to be of limited effectiveness.”

6.3.1.2 Age Group

The purpose of this question is to establish the age of respondents who receive ART.

Figure 6: Age Distribution



<u>The above graph illustrates the following:</u>

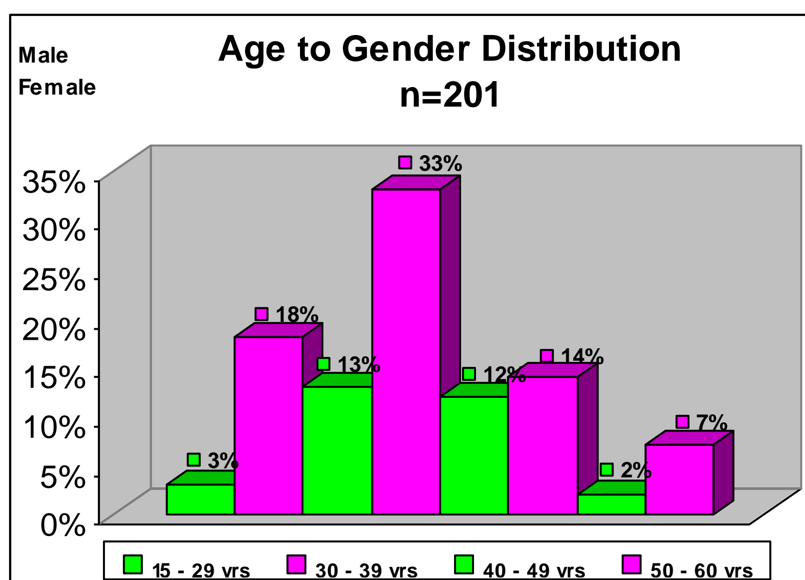
44 (22%) of the respondents were between 15-29 years

93 (46%) of the respondents were between 30-39

46 (23%) of the respondents were between 40-49

18 (9%) of the respondents were between 50-60

Figure 7: Age to gender distribution



<u>The above graph illustrated the following:</u>

(3%) of the male respondents were between 15-29
(18%) of the female respondents were between 15-29
(13%) of the male respondents were between 30-39
(33%) of the female respondents were between 30-39
(12%) of the male respondents were between 40- 49
(14%) of the female respondents were between 40-49
(2%) of the male respondents were between 50-60
(7%) of the female respondents were between 50-60

It is evident from this research that the majority of respondents, 137 (68%), fall in the age group of under 40 years. Of these, 137 (69%) respondents were single women. This research has further revealed that 44 (22%) of respondents were under the age of 30.

The data collected from the qualitative part of the study with regards to age: correlates with the findings from the quantitative part of the study. Thus the theme of age and adherence was prevalent under the category of biographical data, with interesting contradictory findings.

One main theme emerged from the responses to the semi-structured interview schedule: Age plays a role in adherence; with the following extremes: the youth are more adherent due to better insight and the elderly are more responsible and thus more adherent.

Theme:

- Age plays a role in adherence to ART.

Sub-themes:

- Younger people, show more insight, and are motivated to live longer and tend to be more adherent.
- Young adults have further other issues (psychological changes and psychosocial challenges) to deal with, other than adherence to ART.

- Older people are more reliable and responsible, but they do not show a lot evidence much of insight and is often supported by younger family members.

Table 10: Theme: Age plays a role in adherence to ART.

Respondent	Verbatim interview quote from the research interview
Medical doctor	"Age plays no role in adherence."
Counsellor 1	"The young are better adherent, they understand better and they want to live longer."
Counsellor 2	"The older are not so educated and they don't understand, but older people can be reliable. Older people ask their children and grandchildren to help them."

The above research findings are supported by the following literature:

These findings correlate with the National HIV and Syphilis antenatal sero-prevalence survey in South Africa (2004:1), where the number of women with HIV infection attending the antenatal clinics is greater among women in their late twenties and early thirties and lower among teenagers (22%) being between 15 and 29). The risk of HIV infection increases with age, indicating a higher risk among the older teenagers and women in their early twenties. This age group (25 to 34) is also associated with higher fertility and sexual activity.

Regarding adherence and age, Friedland (2003:35-40) comments: "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 and people with low literacy levels are associated with poorer adherence." Whether this finding will hold in Africa remains undetermined.

The researcher is of the opinion that younger people will most probably be more adherent, since they are usually better informed. She set out to establish whether this allegation holds true in South Africa, in contrast to Friedland's

(2003:35-40) statement that older adults are likely to be more adherent in USA studies.

The above research findings also correlate with those of Venter (2005:23) where limited data indicates the average age of ARV access to be in the late 30s, while epidemiological data suggests a high death rate in the late 20s. He suggests that attempts should be made to make clinics more accessible and youth-friendly.

Furthermore, the present research also indicates that the majority of people are infected during late adolescence and their early twenties. It is only when they start developing AIDS-related symptoms and are confronted with the reality, severe symptoms and death, that they are forced to seek medical treatment.

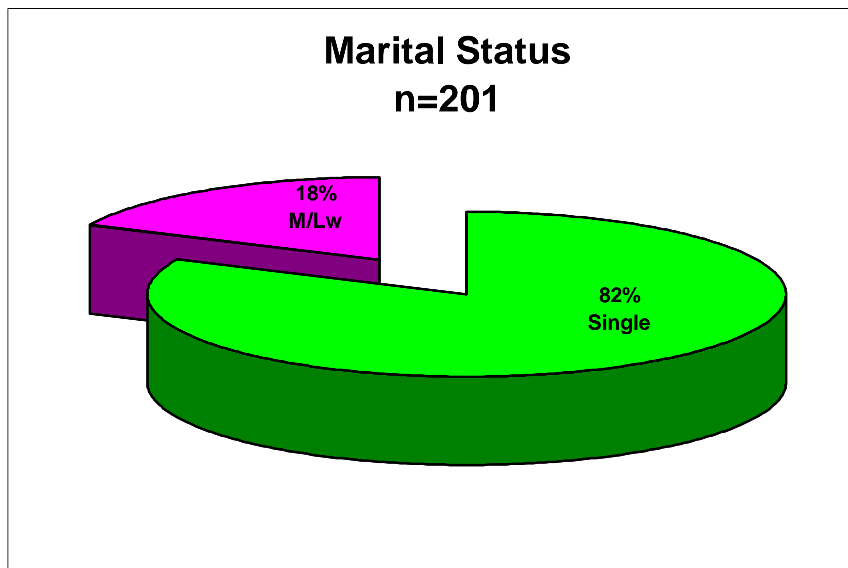
The researcher is further of the opinion that adolescents and young adults, who are generally associated with psychological changes and psychosocial challenges, are currently also confronted with the specific challenges of HIV/AIDS and issues regarding illness and death. It is here that the specific role of the social worker in the HIV/AIDS field is indicated regarding earlier education and training and access to VCT. Quicker and better access to ART and counselling is also indicated, especially in the late adolescent and early twenties age group.

The researcher confirms Venter's (2005:23) view that there have been several reports of the high expectations with regards to adherence "overkill" for example, the demands for multiple visits, "buddy" support, inexperienced and inflexible staff, and exposure of the patient to unnecessary morbidity and mortality risks. The said researcher supports Venter in that patients should be targeted earlier for ART. Most patients visiting the clinics are already very weak. Long waiting lists, multiple visits, and the need for a "buddy", discourage patients who often do not have the strength to return for follow-up visits.

6.3.1.3 Marital Status of Respondents

The researcher intended to establish the marital status of respondents since it is generally accepted that social support is associated with better adherence.

Figure 8: Marital status



<u>The above graph illustrates the following:</u>
165 (82%) of the respondents were single
36 (18%) of the respondents were in a relationship, (including those married by civil rights (m), customarily married (lw) and living in cohabitation.)

This research indicates that most of the respondents, 165 (82%) were single. Of these respondents, more than half, 147(73%), were women. These results explain the dilemma of why patients are reluctant to disclose their HIV status, since people who are not in stable relationships will have difficulties disclosing their status.

The data collected from the qualitative part of the study with regards to the influence of marital status on adherence to ART, correlate with the findings of the quantitative part of the study and literature. The data reveal the following:

Theme:

- Marital status influence adherence to ART.

Sub-themes:

- Marriage, specifically supportive relationships, influence adherence to ART positively.
- Disclosure of HIV status to the partner is indicated for adherence to ART.
- Marriage, if not a supportive relationship, coupled with non-disclosure to the partner, influences adherences to ART negatively.

Table 11: Theme: Marital status influence adherence to ART

Respondent	Verbatim quotes from the research interview
Social Worker	"If they have not disclosed their status to their partner, taking medication in secrecy could influence adherence negatively."
Counsellor	"Marriage could influence adherence both ways: if people disclosed their status to their partner, it has a positive influence on adherence, if they didn't, it could influence adherence negatively."
Medical doctor	"Supportive relationships influence adherence positively."

The above research findings are supported by the following literature:

Friedland (2003:37) postulates that social isolation predicts poor adherence levels and encourages patients to bring supportive family members with them to clinic visits. Literature further indicates better adherence among patients with families, including children, than among young, unmarried patients, as stated by O'Brien (1990:209) with reference to adherence by dialysis patients.

As indicated in the quantitative part of the study, most of the respondents 137(69%) are single women and this could further indicate that they are solely responsible for the upbringing of the children and that this motivates them to seek treatment. One main theme emerged from the responses to the semi-structured interview schedule. In the sub-theme that emerged it was reported that marital status as such, does not influence adherence, but rather, whether

the patient discloses his/her status to the partner. The issue of disclosure, and subsequently, receiving support emerged strongly.

The researcher considers that these findings, confirm the relationship between marital status, support and disclosure of the HIV/AIDS status of the patient. This is of particular significance, since a correlation between age, gender and marital status is indicated, considering that the majority of respondents were women, 147 (73%), less than 40 years of age 137(68%) and in no stable relationship 165 (82%).

This further indicates why patients are reluctant to disclose and/or find it difficult to adhere to The National Antiretroviral Treatment Guidelines (2003:4) which recommends that patients should be encouraged to disclose their HIV status to at least one friend or family member (buddy), or join a support group before ARV medication can be initiated.

The researcher is of the opinion that it is not always possible for patients to disclose their status, since the present research indicates that many patients are not in a supportive relationship.

The social worker, with her specialized skills in counselling, can assist patients with respect to disclosure and network regarding support structures. The researcher is further of the opinion that this situation is one where the skills of the social work profession can be utilized in motivating patients to disclose their status and also to explore alternative support systems by means of networking.

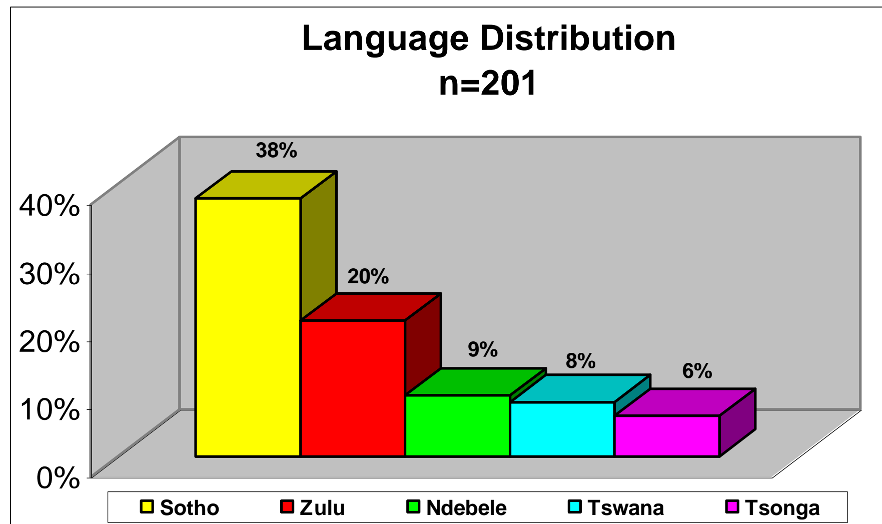
6.3.1.4 Home Language

The researcher did not ask any direct questions regarding race but included this question regarding home language since this could provide an indication of the language spoken, and thus, the ethnic groups represented by the respondents.

In South Africa specifically there is sensitivity when probing into racial matters due to the history of apartheid that is why the researcher asks specifically this

question related to language as each language is an indication of a racial group, and this is certainly influenced by a specific culture and traditions.

Figure 9: Home language



<u>The above graph illustrates the following:</u>

76 (38%) of the respondents spoke Northern Sotho

40 (20%) of the respondents spoke Zulu

18 (9%) of the respondents spoke Ndebele

17 (8%) of the respondents spoke Tswana

13 (6%) of the respondents spoke Tsonga

In the table above respondents indicated that they spoke Sotho 76 (38%), the most predominant language. The languages spoken by the respondents indicate that they belong to various African ethnic groups. The ART clinic is situated in Gauteng and the above findings correlate with the language of prevalence, Northern Sotho, spoken in this area. This could also be an indication that the majority of patients are from the Gauteng area, since this is the local clinic and language.

From the data collected for the qualitative part of the study with regards to the influence of language on adherence to ART one main theme emerged.

Theme:

- Language, culture and traditions influence adherence to ART.

Sub-Themes:

- Different ethnic groups have hold to different traditions, values and believes that influence adherence.
- Certain cultures do influence adherence through myths and certain traditional beliefs and values.
- Certain traditional healing methods and certain cultures (language) can jeopardize adherence to ART.

Table 12: Theme: Language, culture and traditions influence adherence to ART.

Respondent	**Verbatim quotes from the research interview**
Nursing sister	"Traditional healers want to clean the body from evil through vomit/enemas; this is a problem when taken with ART medicine."
Dietician	"Certain cultural groups are more susceptible to influence."
Medical doctor	"Certain cultural groups are more traditional."
Counsellor	"Culture definitely influences adherence like visiting traditional healers. Some cultures have certain beliefs and rules regarding medicine. Family pressure on patients to adhere to their beliefs influence adherence."
Counsellor	"Some cultures can be difficult especially, Zulus - it is their tradition."
Counsellor	"Yes, it depends on the background of the patient. For example people from Kwazulu Natal must discuss medication, treatment first with elderly."
Counsellor	"Ikilele", is a Setswane tradition, where a woman whose husband passed away must stay at home except for work or funerals. They drink "muti" that the family gets from "inyanga"/ traditional healers for 6 months to 1 year to clean themselves."

The above research findings are supported by the following literature:

From the above data regarding the theme of language, the following sub-themes emerged – that culture, myths, and ethnic groups influence adherence. The researcher holds the view that this again strongly indicates that the influence of culture should not be underestimated where ART is concerned.

She concurs with Cockerham (2001:54) in that the time is rapidly approaching when racial/ethnical HIV/AIDS differences will no longer be based primarily on comparisons between whites and blacks, but will, rather, be determined by socio-economic status and, specifically, poverty, knowledge, education, culture and the access to medical treatment, since the living conditions associated with poverty influence the onset and cause of most health problems.

The above research results show that it is important to note that the majority of respondents are black and stem from various ethnic groups who experience varying cultural influences. These influences should not be underestimated since they can have a major impact on ART and adherence. The researcher opines that this also indicates the language that should be employed for educational and adherence material.

Furthermore, the said researcher believes that traditional beliefs and values should be taken into account regarding adherence since culture has been identified by various sources as one of the primary barriers to preventing the spread of HIV/AIDS. Culture and specific cultural beliefs, values and traditions could also influence treatment and adherence to therapy (Friedland, 2002:35-40). Ross and Deverell (2004:16) are of the opinion that cultural considerations definitely affect whether members of a population choose to participate in prevention campaigns and whether they choose to believe, internalise and accept the messages propagated by such campaigns, such as adhering to ART.

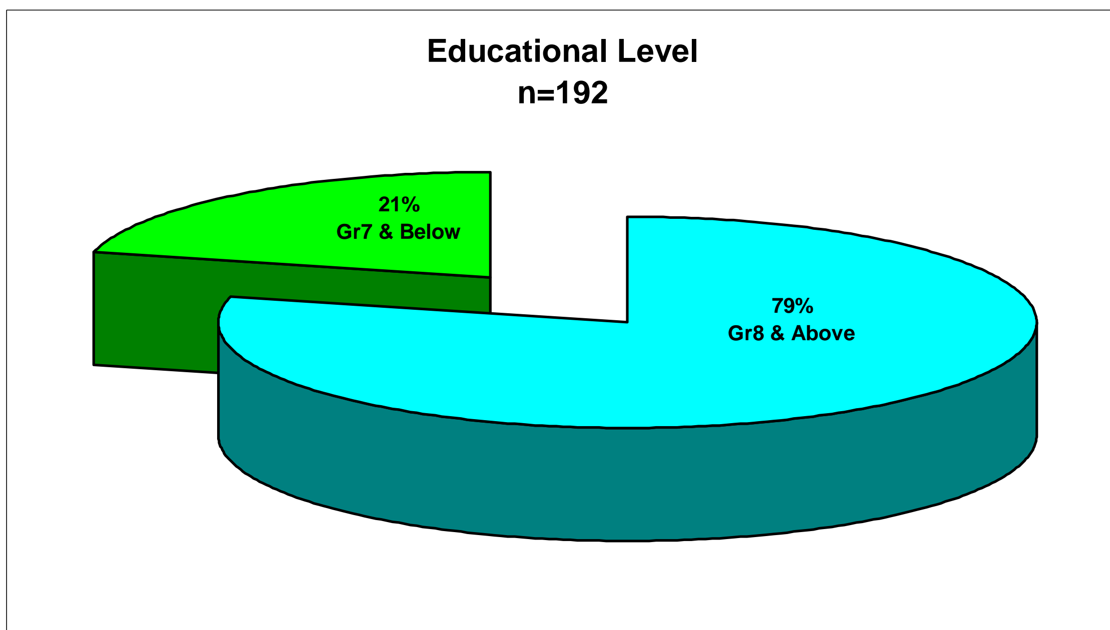
If Friedland's (2002:35-40) remark that USA studies have found that the African American are associated with poorer adherence holds true, the results with regards to adherence would be significant, since the present research indicates that the majority of respondents belong to the African ethnic groups (Northern. Sotho, 76 (38%) and Zulu 40 (19%). It is further noted that 6% of the respondents are Afrikaans speaking. This could be an indication that they belong to the White or coloured racial groups. The research was conducted at a state clinic, where the majority of patients belong to various black ethnic groups.

They are dependent on state hospitals and clinics, since they are not members of a private medical aid, owing to their socio-economic status.

6.3.1.5 Educational level of respondents

Education and knowledge, or rather the lack thereof, have been identified as important factors in HIV/AIDS education. The researcher has also identified educational level as an important factor for adherence to ARV medication. Thus the intention was to establish the educational level of the respondents, because insight into this complicated disease and treatment regimen is the key to adherence. Since South Africa is a developing country, the assumption exists that the profile of people with HIV/AIDS is linked to low education or lack of literacy.

Figure 10: Educational level of respondents



<u>The above graph illustrated the following:</u>

71(37%) of the respondents have completed Gr. 12

46 (24%) of the respondents have completed Gr. 8 – Gr. 10

39 (20%) of the respondents have completed Gr. 1 – Gr. 7

30 (16%) of the respondents have completed Gr. 11

4 (2%) of the respondents have received tertiary education

2 (1%) of the respondents have had no schooling

The above research results reveal that the majority of patients in the sample could be regarded as educated and literate, since 119 (79%) of respondents reported an educational level of Gr. 8 (secondary school level) and higher.

The data collected for the qualitative part of the study with regards to the influence of education on adherence to ART, reveal interesting contradictory findings. One main theme emerged.

Theme:

- Education influences adherence to ART.

The sub-themes:

- Better educated people demonstrate better greater insight regarding adherence to ART.
- Better educated people are more open to training.
- Formal education should not play a role in adherence issues.
- People can be educated by means of counselling and training to help improve adherence.

Table 13: Education influences adherence to ART

Respondent	Verbatim quotes from the research interview
Social Worker	"Education seems to play a role in adherence: people show more insight if they are better informed which comes from education."
Medical doctor	"Education should not play a role if people are adequately counselled."
Counsellor	"People know how to drink tablets, even if they can't read."
Medical doctor	"Definitely, educated people understand better – especially if they can read."

The above research findings are supported by the following literature:

The above findings from the qualitative and quantitative research indicate that respondents were subjected to HIV/AIDS education and training, especially since this forms part of the curriculum of the Department of Education in all

South African schools. Abdool Karim & Abdool Karim (2005:268) corroborate this view on HIV/AIDS and education: “Widespread education and associated high levels of knowledge have done little so far to contribute to a decline in HIV prevalence.” The general assumption that illiterate people are ignorant and more susceptible to HIV infection thus does not hold true since, in this study 119 (79%) of respondents reported an educational level of Gr. 8 (secondary school level) and higher.

The WHO (2004:39) states that good adherence in settings with few resources can be achieved if the programme combines patient-centred education with individual, peer and practical support. A study done by O’Brien (1990:212) with regards to dialysis patients shows that people tend to cope with health and illness-related problems according to the knowledge they possess in the area.

The view of the present researcher is that it is not the level of literacy, but rather, the lack of HIV education, training, and counselling by experienced counsellors, as well as the attitudes and motivation of the patient, that, are the predicting factors in adherence.

The present researcher adds that the respondents were already receiving ART and is of the opinion that the research results could further indicate that education and literacy specific play a role in motivating patients to seek medical treatment. It is easier to provide information and education and to develop insight into cultural beliefs and norms when people are well informed and literate.

As noted above, Friedland (2002:370) claims that in the USA, studies have found that low literacy levels are associated with poorer adherence. The researcher is of the opinion that literacy should not be a factor excluding the assessment of patients for adherence to ART, but that education and knowledge regarding HIV/AIDS and ART should rather receive priority. Abigail Harrison in Abdool Karim and Abdool Karim, (2005:277) has observed that there is a link between education and improved sexual health outcomes, such as a reduced incidence of teen pregnancy in South Africa and globally.”

6.3.1.6 Areas where respondents were staying.

The intention of the researcher was to establish whether respondents were living in rural or urban areas. As already mentioned, the clinic, where the research was conducted, forms part of the Comprehensive HIV/AIDS Treatment Clinic of the Gauteng Provincial Government at the Pretoria Academic Hospital. This clinic is in the Tshwane/Metsweding Region, of the Gauteng Department of Health. Geographically, this is an urban treatment centre attached to an academic hospital.

Table 14: Distribution regarding urban and rural area

Rural	Urban
15(8%)	186(92%)

n=201

The above table indicates that the majority of respondents reside in an urban area, 186 (92%). These results could be explained by the fact that the clinic where the study was conducted, serves patients mainly from the urban area, as stated above. The researcher is of the opinion that a factor contributing to good adherence could be the fact that the respondents were residing in an urban area, close to the facility, and that this limited their travelling costs.

From the data collected from the qualitative part of the study with regards to the influence of living conditions on adherence to ART emerged the following theme.

Theme:

- Residential area influences adherence to ART.

Sub-themes:

- Rural people prefer to travel to urban clinics; they perceive the clinics to offer better treatment.
- Urban clinics are valued more by patients than rural clinics.
- Patients still fear discrimination and prefer to attend clinics far away from home.

- Easy access to a clinics influences adherence positively, due to transport costs.

The above research findings are supported by the following literature:

A matter of concern, as indicated by the above sub-themes that emerged from the findings, is that patients show an unwillingness to attend rural local clinics in their own area, because they are afraid of being identified in their communities. These patients use a local address in urban areas to be able to attend clinics in urban areas. Some patients also assume that urban clinics attached to a provincial/tertiary hospital, offer better services than the local, rural clinics.

The researcher concurs with Frohlich in Abdool Karim (2005:351) that HIV/AIDS, coupled with urbanization, has a major impact on individuals and community structures, such as the family. Traditionally, the family has been the fundamental unit of any society, but as the epidemic progresses, this structure is steadily being eroded. One of the most obvious changes has been the increase in single-parent households. The present researcher has experienced, within her working environment that HIV infection presents a medical and psychosocial crisis of unparalleled proportions for the majority of infected and affected.

If the number of unemployed respondents (72%), as shown in this research is taken into account and compared to the number of respondents 186 (92%) living in an urban area, it can be assumed that most people in the urban area are seeking employment or medical treatment. In addition to this, judging by the 151 (79%) respondents who reported an educational level of Gr. 8 and higher, a further assumption can be made that respondents live in the urban area, and are seeking better opportunities.

Table 15: Theme: The influence of living area on adherence

Respondent	Interview quote
Social Worker	"Patients prefer to attend urban clinics, as they perceive the urban clinics to be better and they fear discrimination at their local clinics."
Counsellor	"Urban versus rural can have an influence: if people have to travel far to attend a clinic it is too costly."
Medical doctor	"The area where people live could influence the level of understanding – but depends on education and resources."

6.3.1.7 Living conditions of respondents (Type of accommodation)

The aim of this question was to establish the living conditions of the respondents. The clinic where the study was conducted, as indicated in the previous section, serves patients from the urban area. Urban living conditions tend to comprise more formal structures, and are further characterized by over-sharing due to financial, recreational, educational, employment and medical constraints.

Table 16: Living conditions of respondents

Type of living	Percentage	Frequency
House	62%	125
Shack	20%	41
Flat	16%	8
Room	16%	8
Hut	1%	3

n= 201

<u>The above table illustrates the following:</u>

125 (62%) of the respondents were residing in a house

41(20%) of the respondents were residing in an iron/tin shack

16 (8%) of the respondents were residing in a flat

16 (8%) of the respondents were residing in a room

3 (1%) of the respondents were residing in a hut

As indicated in the above table, the majority of patients, 157 (78%), reported that they were staying in what can be described as proper well-constructed accommodation, e.g. either a house, 125 (62%), flat, 16 (8%), or room 16(8%).

From the data collected for qualitative element of the study regarding the influence of living conditions the following themes and sub-themes emerge:

Theme:

- Living conditions influence adherence to ART. .

Sub-themes:

- Overcrowded living conditions influence adherence negatively.
- Chaotic living conditions are contraindicated for adherence.
- The type of house (shack or house) does not influence adherence.
- Homeless people have difficulty in adhering.

Table 17: Theme: Living conditions influence adherence to ART.

Respondents	Verbatim quotes from the research interview
Social Worker	"If their living conditions are overcrowded people could miss medication because their environment is chaotic and they do not have any routine, medication does get lost."
Counsellor	"Type of housing does not play a role."
Medical doctor	"Crowded living conditions in urban areas/or lack of sanitary or clean water in rural areas plays a role."

The above research findings are supported by the following literature:

The researcher suggests a link between the accommodation or living conditions of patients, urban living 186 (92%) and high educational levels that were reported. The myth that lower-educated, homeless people are more likely to suffer from HIV/AIDS, does not hold true.

The researcher supports the National Antiretroviral Treatment Guidelines (2003:4) in that taking ART medication in secrecy in crowded and chaotic living conditions could be a factor contributing to non-adherence for the following reasons.

- Patients who have not disclosed their status might experience problems with storing and or transporting medication;
- It will be difficult to use reminders to remember to take medication at specific times;
- Side-effects and adverse reactions to medication cannot be reported or monitored by family members; and
- Family members could not take medication to the patient in the case of hospitalisation or family responsibilities such as funerals.

The sub-themes that emerge from the above findings indicate that overcrowded, chaotic living conditions influence adherence more negatively than the type of housing

6.3.2 Clinical factors and adherence detail

The next phase of the questionnaire was aimed at exploring the biological, medical or clinical factors that could possibly influence adherence (negatively and positively), to ART as experienced by HIV/AIDS patients receiving it.

The biopsychosocial model as constructed by Engel (1980:535) is in the researcher’s view a scientific model, which takes into account the missing dimensions of the biomedical model. Assessing the patient as a whole is relevant, particularly with regards to the delivery of service to the HIV/AIDS patient, and thus, to the present study.

According to Kaplan, *et al.,* (1994:1), this model stresses an integrated systems approach to human behaviour and disease; because of the continuous interaction between the individual’s body, mind and social context. Karoly (1985:434) argues further that the biopsychosocial orientation involves an

interdisciplinary systems-orientation towards healthcare. This orientation enables the service providers to consider the biological, psychological and environmental information concerning a patient, in order to make an appropriate diagnosis and develop a treatment programme that encompasses all three of these areas. Green and Shellenberger (1991:19) postulate that, the biopsychosocial approach to health and wellness, views these states as the result of the interaction of biological, psychological and social factors. The psychosocial aspects will be discussed in the next phase of the questionnaire.

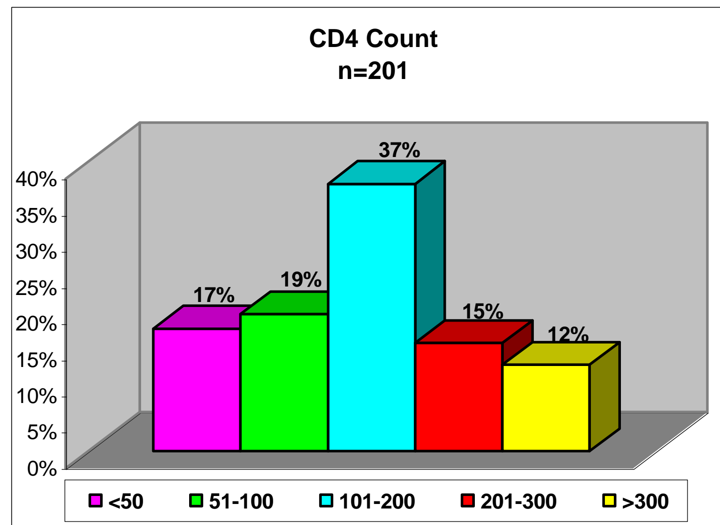
As indicated earlier on, the biopsychosocial model is based on the systems approach, which stresses an integrated systems approach to human behaviour and disease. The assessment of the biopsychosocial factors, in the view of the present researcher, will enable the health team to provide a treatment programme that is responsive to the needs of individuals. Without this holistic approach, the patient will be provided with an incomplete assessment when all the aspects, specifically the psychosocial, are not attended to, which could lead to non-adherence and treatment failure. The researcher strongly believes that the biopsychosocial model is the relevant model to be used at the ARV Clinic.

The questions in this section of the research, give consideration to the CD4 count of the respondents, the WHO stage and performance status, and also concentrate on ART matters. The researcher further explores the period for which the respondents have been on ART, the factors enhancing the adherence of the respondents to ART, and the difficulties respondents have experienced since commencing ART. The person (if any) who assists the respondents with their ART, as well as alternative healing, were also explored.

6.3.2.1 CD4 counts of respondents

Using this question the researcher intended to explore the CD4 cell counts of respondents, because it is an important method employed in assessing the effectiveness of ART.

Figure 11: CD4 Counts



<u>The above graph illustrates the following:</u>

35 (17%) of the respondents reported a CD4 count of <50

39 (19%) of the respondents reported a CD4 count of 51 - 100

75 (37%) of the respondents reported a CD4 count of 101 - 200

30 (15%) of the respondents reported a CD4 count of 201 - 300

22 (12%) of the respondents reported a CD4 count > 300

The above research findings indicated that the CD4 count of most respondents 149 (73%), was below 200. The majority of patients 75(37%), reported a CD4 count of between 101 - 200. In this respect, the criterion for initiating patients to receive ART, according to the National Antiretroviral Treatment Guidelines of South Africa's (2003:4), is a CD4 count of <200 or an AIDS-defining disease as discussed in the above phase.

The data collected from the qualitative element of the study regarding the influence of knowledge of the CD 4 count on influencing adherence to ART reveals the following:

Theme:

- Knowledge of the CD 4 count, could influence adherence to ART.

Sub-themes:

- The CD4 count is a reflection of the improvement of the immune system and tends to serves as a motivation.
- The CD4 count can also influence adherence negatively in some circumstances, e.g. the CD 4 count might not improve and patients may tend to get become disillusioned.
- If the CD 4 count increases, some patients do not adhere for fear of losing their disability grant. W, which requires the patient to be in stage IV or CD 4 count under 200.
- The CD4 count is a difficult concept to try and explain in counselling.

Table 18: Knowledge of the CD 4 count could influence adherence to ART

Respondent	Interview quote
Social Worker	"The CD4 count has a definite influence on adherence; it seems to motivate patients once they understand it. The results are shown and explained to them."
Pharmacist	"CD4 count can also influence adherence negatively, as patients tend to not understand why they have to still take antiretroviral when their CD4 is high."
Medical doctor	"CD4 count does not influence adherence, but pill fatigue does influence adherence."
Counsellor	"CD4 count does not make sense to most people, you can try and explain but they do not understand it. If they understand it, it motivates them when it goes up."

The above research findings are supported by the following literature:

From the above findings, the sub-theme, CD4 count and its link to motivation, has emerged. It is indicated that the CD4 count can be utilized to indicate to patients the restoration of their immune system and thus motivate them to continue with ARV medication.

The R.S.A. Comprehensive Care and Treatment of HIV/AIDS and TB: Rollout plan for Antiretroviral Treatment (2003:4) criteria for ARV initiation is the following:

- CD4 <200 or
- AIDS defining diseases regardless of CD4 count.

In other words, only patients who are diagnosed with AIDS can be initiated. For example a patient whose CD4 count is >200 but suffers from cancer and possibly needs chemo- or radiation therapy, also qualifies for ART.

The respondents participating in this research had received ART for less than a year, which could explain the above findings if it is taken into account that the CD4 response is generally a mirror image of the HIV/RNA decay curve, with increases that average 50-60 cells/mm³ in the first 4 months, with subsequent increases at a rate of 8-10 cells mm³/month or 100-150 cells/mm³/ per year with good viral suppression. It is reported in Bartlett, Gallant & Joel (2005:3) that a CD4 count should increase by 50% after 8 months of treatment.

One of the goals of ART is that the CD4 count of the patient should rise and remain above the baseline count. The CD4 count of a patient is highly variable and dependent on the individual immune system, the general state of health and the presence of concurrent diseases (S.A., 2004:2). According to the selection criteria of the National Antiretroviral Treatment Guidelines (2003:4), patients must have a CD4 count <200 cell/mm³, irrespective of the WHO stage or WHO stage IV disease, and irrespective of the CD4 count, in order to be initiated on ART.

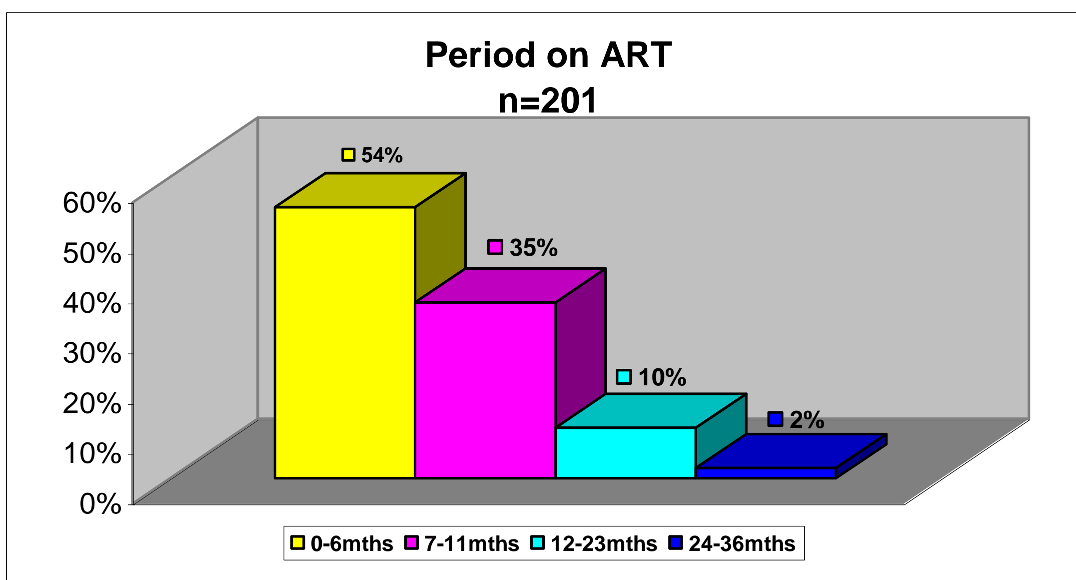
Furthermore, therapeutic decisions are usually based on viral load data. Virological failure is ascribed either to resistance or failure of the drugs to reach the virus, owing to inadequate adherence, altered metabolism or drug interaction (Bartlett, Gallant & Joel, 2005.4).

6.3.2.2 Period on ART

The present researcher included this question regarding the respondent's period on ART, to explore issues such as pill fatigue and monitoring of treatment.

The research was conducted at the Tshwane District Hospital, one of the Government's sites for Comprehensive Care and Treatment of HIV/AIDS and TB between October and November 2005. This ART site only initiated treatment of its first patients during June 2004. The respondents participating in the present research would thus have been on ART for approximately 1 year.

Figure 12: Period on ART



From the above graph the following information was captured:

109 (54%) of the respondents were on ART for 0 - 6 months,

71 (35%) of the respondents were on ART for 7 – 11 months,

2 (10%) of the respondents were on ART for 12-24 months, and

1 respondent was on ART for >24 months.

The majority of respondents, 180 (90%) reported to have been on ART for less than a year. This correlates with the period mentioned above that they were on ART, reflecting a reliable response as expected.

The data collected from the qualitative element of the study regarding adherence and the length of the period on ART reflects the comments of the team members.

Theme:

- The period a patient has been on ART influences adherence.

Sub-themes:

- The period on ART does not indicate non-adherence, but patients tend to stop ART once they feel better.
- After a lengthy period on ART some patients tend to get tired of pill taking (pill fatigue).
- Patients are not always aware that ARV medication is for life.
- Monitoring and motivating adherence throughout ART treatment is indicated

Table 19: Theme: The period a patient has been on ART influences adherence

Respondents	Verbatim quotes from the research interview
Social Worker	"Patients tend to stop medication once they are feeling better."
Medical doctor	"Pill fatigue, which is coupled to period on ART influences adherence. The late Peter Bussie, an AIDS activist reported publicly, shortly before his death in 2003, at an adherence seminar, that he is suffering from pill fatigue and that he is taking a break from it".
Counsellor	"Patients must be made aware that AIDS is a chronic disease, like high blood pressure."

The above research findings are supported by the following literature:

The above findings, regarding the influence of period on ART on adherence, the multidisciplinary team acknowledged the correlation between the period on ART and pill fatigue, emerged strongly. The researcher considers that this is an indication of the need to educate patients regarding chronic illness and their responsibility for taking life-long medication in order to maintain their health. The following theme and sub-theme emerged.

A strong correlation exists between virological response and adherence and the need for >95% adherence is reported (John G. Bartlett, 2005:68). Regarding adherence in general, Kaplan & Sadock (1994:11) postulate that, in general, about one third of all patients comply with treatment, one third sometimes comply with certain aspects of treatment and one third never comply with treatment.

The researcher is of the opinion that if patients are assessed trained, counselled and supported, it will make a dramatic difference to adherence.

6.3.2.3 Current performance status of respondents according to the Karnofsky Scale

With this question, the intention was to establish the physical wellness or performance status of respondents. For this, the researcher has found the Karnofsky's Scale, which is widely accepted as a measuring tool for performance, to be the most appropriate, as previously discussed in chapter 3: http://www.cancerbacup.org.uk/Qas/AboutcancerQAs/AllQAs/related_faqs/Qas/993:28.02.2006

Respondents reported the following performance status, according to the Karnofsky scale (N 201).

72 (36%) of the respondents reported normal health
84 (42%) of the respondents reported minor symptoms
25 (12%) of the respondents reported normal activity but with some effort
20 (10%). of the respondents reported less than 80% performance status

The research findings regarding the performance status of the respondents indicate that most of the respondents 156 (78%) reported normal health or suffering from minor symptoms.

The data collected from the qualitative element of the study regarding the influence of patients performance status, reveals that the team members do not seem to make use of the Karnofsky scale in practice. The following themes and sub-theme emerged.

Theme:

- Performance status (Karnofsky) of patients influences adherence to ART indirectly.

Sub-themes:

- The performance is status is not used directly in counselling patients at clinics.

- It is a difficult concept to try and explain to patients.
- The performance status is a confirmation, of the improvement of the physical functioning and could serves as a motivation to adhere to ART.

Table 20: Performance status (Karnofsky) of patients influences adherence to ART indirectly

Respondent	Verbatim quotes from the research interview
Medical doctor	"The performance status is not utilized at the clinics by counsellors."
Counsellor	"The performance status is not something we use a lot in explaining to patients. It plays no role in adherence."

The above research findings are supported by the following literature:

The findings regarding the performance status of patients revealed that the performance scale is not utilized in clinics, the reason being that counsellors are not specifically trained regarding the Karnofsky Scale. The use of an increasing CD4 count or viral load is preferred in motivating patients regarding ART.

The above results can be explained by the fact that, according to the R.S.A. Comprehensive Care and Treatment of HIV/AIDS and TB: Rollout plan for Antiretroviral Treatment (2003:4), and in terms of the clinical selection criteria, the symptoms of the patient must be treated prior to initiating ART, and active TB must be excluded. One of the goals of ART is that patients should experience fewer HIV-related illnesses (S.A., 2004:2).

In conclusion, it is evident that respondents reported high scores according to the Karnofsky scale, since the majority reported normal functioning. This could be an indication of good adherence and the subsequent success of ART.

6.3.2.4 The WHO staging before initiation of treatment

The immunodeficiency that develops during HIV infection is a continuum, but several discrete clinical phases can be identified. The researcher included this

question because the CDC staging of AIDS Surveillance Case Definition for Adolescents and Adults (Centers for Disease Control and Prevention, 1993) includes all HIV-infected individuals with either a CD4 count <200cell/mm³ or an AIDS indicator condition.

The quantitative part of the study indicates the following regarding staging:

n=201

(27)13 % of the respondents reported WHO stage 1
(27)13 % of the respondents reported being in the WHO stage 2,
(104) 52 % of the respondents reported being in the WHO stage 3
(43) 21% of the respondents reported being in the WHO stage 4.

The majority of respondents 147(73%) reported to be in between stage 3 and 4. One hundred and four (52%) reported to be in stage 3, and 43 (21%) reported to be in stage 4. These research results should be seen in the light of the R.S.A. Comprehensive Care and Treatment of HIV/AIDS Antiretroviral Treatment guidelines (2003:4). Once a patient has been "staged", he/she remains in that stage with or without symptoms (HIV/AIDS management for Professional Nurses Manual, FPD: 2004:90).

Similarly to the above question regarding the Karnofsky scale, the qualitative aspect of the study reported the following regarding the WHO staging:

The following themes and sub-theme were revealed:

Theme:

- WHO staging does not influence adherence to ART directly.

Sub-themes:

- WHO staging is only used by clinicians prior to initiation in clinics and is not used by counsellors.
- It is also a difficult concept to try and explain to patients.

- WHO staging is an indication of the improvement of the medical condition and could likewise serves as a motivation.
- WHO staging does not influence adherence, since patients just see an improvement physically and the regaining of lost roles.

Table 21: Theme: WHO staging does not influence adherence to ART directly

Respondent	Verbatim quotes from the research
Medical doctor	"The WHO staging is only used in clinical diagnoses, not in adherence issues as a person once staged does not go back to."
Counsellor	"The WHO status is not used in counselling as is just too difficult to explain."

The above research findings are supported by the following literature:

The World Health Organization (WHO) utilizes standardised criteria to clinically stage HIV infection. This staging accommodates facilities where CD4 testing is not freely available and thus only uses patient clinical determinants (Botes and Levay 2004:13).

The above findings indicated that the WHO staging is not utilized by counsellors in adherence issues. WHO staging could be linked to quality of life issues, for example, a person with WHO stage 4, would suffer from severe AIDS-related symptoms, which will impair his/her, quality of life severely.

After initiation of ARVs, a person's WHO staging might improve to stage 1 or 2, with a concurrent improvement in her/his quality of life. This, according to the present researcher, is the most important goal of ARV therapy. These clinical facts could be used to motivate people regarding adherence to ART.

6.3.2.5 Factors that enhance adherence to ART

This question has been included because, as indicated by most of the literature, adherence is a very important aspect in ART. Adherence was defined and discussed in chapter one.

Table 22: Adherence enhancement to ART by respondents as indicated across the nine individual aspects measured

Adherence enhancement to ART	Frequency	Percent
No support	123	17
Diary chart	139	19
Family / "buddy"	168	23
Pill-count	143	19
Electronic device	1	0.13
Pillbox	10	1
Support group	21	3
Cell phone	93	12
Clock/watch	47	6

The above table illustrates the following:

The above data were obtained from a multi-answer questionnaire, where the respondent could indicate more than one method of support concerning adherence. The respondents could indicate more than one method used to enhance their adherence. With the assistance of the Department of Statistics, University of Pretoria, the data was processed and programmed using the SAS, version 8.2, statistical software. It is illustrated in one graph for practical and comparative reasons.

The data collected from the qualitative element of the study regarding methods use to support and enhance adherence reveals the following:

Theme 1:

- Various forms of support and aids are necessary to enhance, adherence to ART.

Sub-themes:

- Family support, especially mothers appear to be the most common form of support to patients.
- Patients use mainly cell phones as reminders.
- Some patients plan pill-taking around TV or radio programs.

- Patients do not use aids, like pillboxes, to support adherence.
- Some patients can adhere and are responsible on their own.
- Patients do use diary charts if supplied by clinic.
- Pill counts done at clinics are a good form of supporting adherence and detecting up problems.

Theme 2:

- The social worker with her specialized skills is very imported in supporting patients.

Sub-themes:

- Social worker can assess needs and refer to appropriate resources.

Theme 3:

- Support groups are not valued at present.

Table 23: Theme: Various forms of support and aids are necessary to enhance, adherence to ART.

Respondent	Verbatim quotes from the research interview
Medical doctor	"The patients rely a lot on all forms of support, at the ART clinic. Specially the social worker, it seems the only easy access they have to specialized services."
Social Worker	"The patients to not use aids in supporting adherence. If they are supplied with adherence aids they will use it."
Social Worker	"In my experience, family shows to be the major form of support to ART patients- especially mothers."
Counsellor	"Patients do not have confidence in support groups unless they get something out of it." "ART is a complex issue if support groups are not educated and trained in ART they might do more harm than good."
Counsellor	"If a support group is well organized by a company, or sponsored, it works, but most people in the community do not have the resources to start and maintain support groups."
Counsellor	"Patients use mainly cell phones as reminders. Other aids not popular." they do not want to focus attention on medication."
Counsellor	"Patients do not use pillboxes. Reminders use are mainly cell phones, TV or radio programmes and clocks are also used by specially older people."

Medical doctor	“Pill counts and diary charts are good forms of monitoring adherence especially for the older and less literate patients.”

The above research findings are supported by the following literature:

In the qualitative part of the study, most of the respondents, multidisciplinary team members, especially the counsellors, who were involved in ART, indicated a need for common standards for support.

Thus, the sub-themes that emerged from the above qualitative findings show the need for support groups that comply with common standards in order to promote credibility. Patients generally do not trust support groups. The support offered by a comprehensive ARV clinic is very important in facilitating the social needs of patients. Often, family support proves to be the only form of support.

From the above data, 68(84%) respondents reported their family as being their major source of support. The family included children, parents and extended families. The present researcher has experienced that the family support usually comprises the elderly. As conveyed by Marais, (2005:82). “The ’reverse orphans’ who, in the twilight of their lives and in grossly disadvantageous circumstances are transforming themselves again into mothers and fathers”. The pattern of burden-shifting onto the elderly is also clearly evident in the current study and clinic. The present researcher would like to add that the burden of care is also shifting to young and teenage children who care for and support ill parents.

A matter of great concern for the researcher is the fact that 123 (61%) respondents reported no significant support. This can be linked to the 165 (82%) respondents who reported that they are single and not in a significant relationship, bringing the importance of the issue of support structures for patients to the fore.

One hundred and forty three (71%) respondents reported that they make use of daily medication, diary charts or pill-counts at the clinic. The researcher

considers that this indicates that the ARV clinic is a major form of support for most patients, which, again, indicates the importance and comprehensive role of an ARV clinic, where patients on ART are monitored during their routine clinic visits.

The physical decline of patients often forces them to seek medical support. Difficult socio-economic circumstances coupled with physical symptoms aggravate the patient's need for support at a one-stop service centre.

The researcher asserts that people are not naturally adherent and that patients should utilize some kind of reminder or support system to support their adherence. The researcher further confirms the view of Friedlands (2002:45) that behaviour skills, with regards to taking medication, should be developed, not only for HIV/AIDS patients, but that the general public should also be educated regarding the importance of adherence and the development of good medication habits.

Disclosure appears to be viewed as a form of punishment rather than a mechanism in order to provide adherence support (Venter 2005:22). This research further indicates that devices, like pillboxes or electronic devices are not popular aids to support adherence. Regarding this, one could speculate that patients still prefer to keep their status confidential, which will influence their medication routine: using devices (for example pill boxes), could attract attention.

The above findings stemming from both the qualitative and quantitative parts of the study indicate that support groups are not popular. The majority of respondents reported not having access to support groups or not being interested in support groups. The researcher is of the opinion that HIV/AIDS is still a sensitive and traumatic experience for patients, who fear discrimination. Issues regarding HIV/AIDS almost always have a sexual connotation, a sensitive issue in all cultures. Patients perceive their status as confidential and do not want to share it with strangers or the community in general. Confidentiality cannot always be guaranteed in support groups. Furthermore,

support groups are not always easily accessible, which places an extra financial burden on patients. The facilitators of support groups are not always trained in adherence to ART. The researcher is not suggesting that support groups are not an important form of support, but, rather, that patients need professional, non-discriminating support, without an added financial burden, where credibility and confidentiality can be guaranteed.

The researcher further argues that there is no workforce regulatory framework to protect patients and promote high standards of practice or build professional credibility for support groups in general. Support groups and counsellors without professional training should be subjected to some sort of registration or license to practice. The poor public image of some support groups in the HIV/AIDS and ART field has done little to support the majority of patients, as indicated in the study.

The Government's Comprehensive Care and Treatment of HIV/AIDS and TB: Rollout plan for Antiretroviral Treatment, accepted during November 2003 (2003:4), makes provision for such support systems. It has acknowledged the need for psychosocial support to the patients and makes provision for social workers, dieticians and lay counsellors at each ART site.

Factors promoting adherence include affordability, disclosure of status to partners and family, and regimens with limited numbers of pills. Poor clinical management and side-effects can adversely affect adherence.

6.3.2.6 Difficulties that respondents experience as a result of ART

The researcher is aware of the fact that adherence to chronic medication is a complex issue and is influenced by various factors. The advent of ART, specifically HAART has revolutionised the treatment of HIV, with improvements in both quality and quantity of life.

Table 24: Difficulties experienced with ART as reported by respondents across the ten individual aspects measured

Difficulties experienced regarding ART	Frequency	Percentage
Side Effects	114	57
Clinic Visits	71	36
Nutrition	59	30
Medication	58	29
Financial	52	26
Employment	46	23
Support Group	23	12
Housing	19	8
Red Tape	11	5
Resistance	8	4

The above data was obtained from a multi-answer questionnaire, where the respondent could indicate more than one problem in response to this question The above table illustrates that the majority 114 (57%) of respondents experienced difficulties with adherence to ART owing to side-effects, while 71 (36%) found that it was difficult to maintain regular clinic visits. Other difficulties that the respondents experienced in this regard were related to nutrition: 59 (30%), financial 52 (26%), medication 58 (29%), employment 46 (23%), support groups 23 (12%), housing 19 (8%), "red-tape" 11 (5%), and resistance 8(4%).

The research findings of the qualitative part of the research indicate, the difficulties experienced with regards to ART. In this qualitative section of the research, the participants also reported adverse reactions and side-effects as a major reason for non-adherence. The data collected from the qualitative element of the study reveals the following:

Theme:

- Patients experience various difficulties regarding adherence to ART.

Sub-themes:

- Patients do experience side-effects and complications of ART.

- These side-effects and complications of ART are contra-indicated for adherence.
- Financial difficulties and material needs do influence adherence to ART.
- Patients are not educated regarding various grants that they qualify for.

Table 25: Patients experience various difficulties regarding adherence to ART

Respondent	Verbatim quotes from the research interview
Pharmacist	"Patients suffer from severe side-effects; they sometimes decide themselves which of the combination pills is the cause of it and then stop taking medicine."
Medical doctor	"Side-effects are a major problem in ART."
Counsellor	"Patients are not aware of all the grants they qualify for."
Social worker	"Material needs feature strongly."
Medical doctor	"Difficulty to adhere to specific time to take pills." "Side-effects and complications of treatment." "Patients do not like routine blood-taking."

The above research findings are supported by the following literature:

Sub-themes that emerge from the findings of this section of the study are side-effects, indicated to be a major problem in adherence issues, financial problems, and material needs, which suggest socio-economic status also seriously influence adherence.

A wide variety of ART drugs are now available, but antiretroviral drugs, like most chronic medication, do not come without their negative aspects such as drug interactions, pill burden, drug toxicity, adverse events, concomitant illnesses, side effects and contra-indications. All of the above adverse events, coupled with adherence issues and individual factors such as pill fatigue, transport and disclosure, contribute to ART being a very complex issue. The research findings of the qualitative part of the research indicate, the difficulties experienced with regards to ART. In the qualitative section of the research, the

participants also reported adverse reactions and side-effects as a major reason for non-adherence.

Thirty percent of respondents reported nutritional needs. The researcher is of the opinion that this might be due to financial insecurity since 145(72%) of respondents reported unemployment as stated above. Nutrition is a primary need and if not addressed, it will severely affect their adherence and quality of life.

Other problems reported by 71 (36%) of respondents were clinic visits. This is primarily perceived as a financial difficulty and could be seen in the light of the reported unemployment and the socio-economic status of the respondents.

Patients who are employed also perceive clinic visits to be a problem since they are required to take a day's leave or sick leave in order to visit the clinic. Although respondents perceive the clinic as a support, nevertheless, it constitutes an additional burden (transport costs).

Although Government's Comprehensive Care and Treatment of HIV/AIDS and TB: Rollout plan for Antiretroviral Treatment (2003:4) has made provision for nutritional needs by means of supplements, food parcel projects and, PMTCT programmes, as well as social security and disability grants, a matter of concern is that the food parcels, food supplements and other aids are not easily accessible or always available. The researcher has experienced since the treatment rollout in June 2004, that these programmes are generally not well-administered.

6.3.2.7 Respondents' motivation for ART

The researcher's intention in this question was to establish the motivation of respondents for ART since it is well-known that motivation is a strong determinant of behaviour. She identifies with the view of Bandura (Meyer, Moore and Viljoen, 2003:296) in this respect: "Instead of attributing motivation to specific motives or drives, the social cognitive learning theorist regards

motivation as they do any other aspect of human functioning - as the result of two processes, namely interaction and learning." The basic idea here is that individuals are not motivated only by specific intrapersonal drives, nor are they motivated only by external stimuli. They are motivated by the interaction between the individual and the situation.

Table 26: Motivation for adherence to ART as indicated by Respondents across the eight individual aspects measured

Respondent's motivation for ART	Frequency	Percent
Survival	197	99
Strength	193	97
Children	175	88
Model	174	87
Doctor	158	79
Family Support	155	78
MPTC	125	63
Encouragement	105	53

The following findings are evident from the above table:

The above data was obtained from a multi-answer question, where the respondent could indicate more than one motivation for ART.

The majority of patients, 197 (99%), reported that their primary motivation for ART is to stay alive and to be physically stronger 193 (97%), without symptoms. The Southern African HIV Clinicians Society (2005:31) postulates, regarding the above motivations, that "patients are frightened by the prospect of losing control and the prospect of disabling symptoms of advanced AIDS".

The present researcher wishes to explain the motivations of the patients to stay alive, be physically strong and be without pain, according to the basic human needs as identified by Maslow.

Furthermore, 175 (88%) of respondents reported that they want to see their children grow up and need to support their families 155 (79%). Since 165 (89%) respondents of the total sample size are single women, it explains why this is a major motivation (for women) to seek ART. The multidisciplinary team in the qualitative research also reported motivation as a strong force for adherence through the interviews:

The data collected from the qualitative element of the study regarding the motivation for adherence ART indicated the following themes and sub-themes:

Theme:

- The need of patients to stay alive (survival) is featuring features as their strongest motivation to adhere to ART.

Sub-themes:

- Patients are mostly motivated to adhere in order to improve their health in general and to be symptom-free.
- Patients are motivated to adhere so as to be able to care for their families.
- Patients are frequently urged by external pressure to adhere to ART.

Table 27: The need of patients to stay alive (survival) are featuring features as their strongest motivation to adhere to ART

Respondent	Verbatim quotes from the research interview
Social Worker	"Getting better to see progress because they are single parents."
Counsellor	"The motivation of patients for ART is usually to be healthy and live longer because they want to and care for their families."
Medical Doctor	"Patients want to be symptom free." "Patients want to feel healthy, strong and gain weight." To look after their children if they are primary caregivers.
Medical Doctor	Outside pressure from family or employers.

The above research findings are supported by the following literature:

The sub-theme that emerged strongly from the above findings is that people want to be symptom-free and healthy so as to be able to take up their responsibilities to care for their families.

As stated before, adherence is a complex clinical behaviour with a wide array of determinants. The researcher is of the opinion that motivation is probably the strongest determinant of adherence and therefore, this question regarding motivation for ART was included. In the treatment of an HIV/AIDS patient receiving ART, which requires lifelong behavioural change, motivation plays a very important role, which might include attitude and beliefs, social support, trust in the physician, the psychological status of the patient, and competing priorities.

The present researcher avers that the characteristics or personality of the patient, and his/her readiness to begin and maintain treatment are of the utmost importance in adherence issues. Adherence to therapies has been shown to be influenced by behavioural difficulties such as depression and social isolation (Friedland, 2002:38).

Friedland (2002:35) further broadly defined motivation to include all variables that encourage or discourage adherence. These might include attitudes and beliefs about HIV treatment and a specific medication, social support, trust in the physician, the patient's psychological status, and the presence of competing priorities in the life of the patient. Adherence to therapies has been shown to be influenced by behavioural difficulties such as depression and substance abuse (e.g. alcohol and mood-altering drugs) and social isolation.

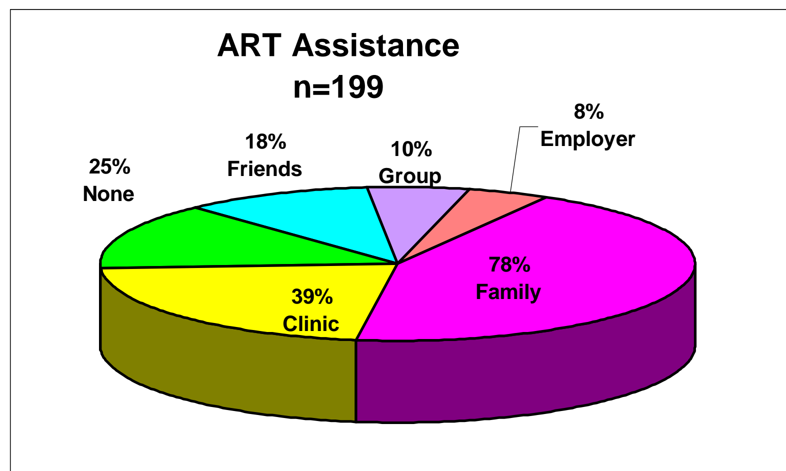
In summary, the researcher supports the socio-cognitive learning view of motivation: "To a great extent individuals, in interaction with the situation, determine their own motivation and that human behaviour is therefore determined by a large variety of different, individual motives." (Meyer, Moore, and Viljoen, 2003:298).

The social worker's role regarding motivation and adherence would be: to assess the patient's circumstances, to develop insight and determine the patient's reason (motivation) for ART.

6.3.2.8 Assisting Respondents with adherence to ART

The intention of this question was to explore the support systems of the respondents. It is generally accepted that HIV/AIDS patients who are isolated and without support do not cope well with ART. The Gauteng Department of Health's Comprehensive HIV/AIDS Guidelines (2004), strongly recommends support structures, including disclosure, before initiating patients for ART.

Figure 13: Assisting with adherence to ART



<u>The above graph illustrates the following:</u>

155 (78%)) of the respondents report family as a support

77 (39%) of the respondents report the clinic staff as their support

49 (25%) of the respondents report no assistance with ART

36 (18%) of the respondents reported their friends as their support

19 (10%) of the respondents reported a support group

15 (8%) of the respondents reported their employers as their support

The above research results have indicated, yet again, that patients (155 (78%)) rely heavily on family structures to support them with ART. This pattern of burden-shifting onto the elderly is clearly evident in most highly HIV-prevalent countries (Marais, 2005:82). The pattern of burden-shifting is also clearly

evident in the ARV clinic. The researcher has seen the responsibility of caring being shifted from adult children to, not only the elderly, but also children who support ill parents, men caring for small babies and employers supporting weak employees.

Family support was reported by 168 (84%) respondents as their major source of support. The question was compiled to include children, parents and extended families with reference to family support. This family support, as previously reported usually refers to the elderly (Alpaslan & Mabutho, 2005:276). A further 77 (39%) respondents indicated clinic staff to be their support in ART issues. These findings correlate with the Gauteng Department of Health's Comprehensive HIV/AIDS Guidelines (2004), where support structures at an ART site were implemented in order to assist patients with ART. These results indicate that, besides the family, the clinic is the patient's primary form of support. This further indicates the importance of the role of the comprehensive ART clinic in adherence matters. Routine clinic visits and consultation with professional and trained staff comprise a major means of supporting and monitoring ART. This was also indicated in section 6.3.2.5.

Friends, employers and support groups are not indicated as their major means of support, which could be explained in the light of stigmatisation and fear. Patients do not disclose their status to their friends and employers. They are also reluctant to attend support groups. This correlates with 6.3.2.5 where patients did not indicate the need for support groups.

The data collected for the qualitative element reveals the following from the multidisciplinary team with regards to assistance with ART. The following theme and sub-themes emerged:

Theme:

- Assistance and support regarding adherence of patients on ART is very important for adherence.

Sub-themes:

- Family support features strongly
- Employers play no role in adherence issues
- Medical team is an important form of support

Table 28: Assistance and support regarding adherence of patients on ART is very important for adherence

Respondent	Verbatim quotes from the research interview
Medical doctor	"Employers play a role, usually to complain."
Counsellor	"Medical team plays a big role."
Social Worker	"The most significant assistance with ART is family, particularly mothers. Spouses few. Children supporting parents a few. A lot of support from siblings. Boyfriends do not assist a lot, they tend to disappear."
Medical doctor	"The medical doctor should also take responsibility for counselling and not leave it to counsellors."
Social Worker	"I do not know what counsellors cover in their counselling. I am not sure of their level of understanding and training."
Medical doctor	Counselling services are not always comprehensive
Professional nurse	"General practitioners, in private practice are still testing and prescribing ART without sufficient counselling, specifically adherence."
Professional nurse	"There are a lot of problems at support groups."
Medical doctor	"Continuing care. Counselling from all team members. Family support.

The above research findings are supported by the following literature:

Thus, the sub-themes that were found again indicate family support to be very important, while support from the medical or clinic teams was also mentioned. Employers do not feature strongly with respect to supporting patients receiving ART.

Support groups are also not perceived to be a good form of support as indicated by the qualitative and quantitative part of the study. In order to increase

confidence in support groups, the researcher believes that a national body, on government level, is required, to monitor credibility and the overall standards.

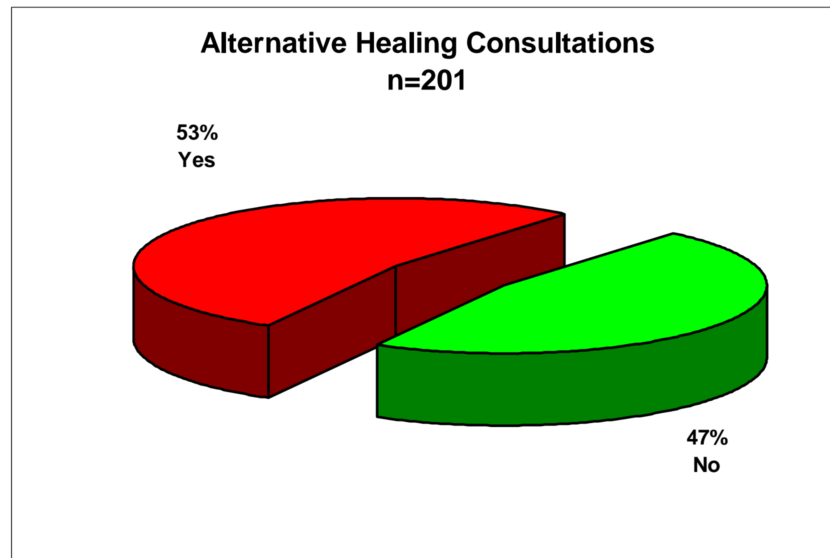
A factor contributing to the difficulties with counsellors is that there are no general or minimum standards. The researcher maintained that people in such a position of responsibility regarding the most intimate circumstances of the patients, should adhere to common standards. No register for either counsellors or support groups is kept where their credibility can be monitored. The standardizing of counselling services would increase confidence in such a service. This would further demonstrate to the general public a commitment to high standards and abilities.

Counsellors have complained that the community does not understand their function, and this, in turn, means that the latter do not sufficiently value counselling. This image has affected morale and recruitment. The Department of Health places a high priority on counselling, but no controlling body specifically monitors, trains and supports counsellors. The public service should start turning this around by being both a guardian of standards and supporter of the committed support structure (General Social Care Council United Kingdom, 2002).

6.3.2.9 Alternative healing methods

This question has been included, since it is a well-known fact that people suffering from chronic, especially life-threatening diseases, will investigate different means of healing. Some alternative healing methods could be a contraindication for ART, but no scientific research has been undertaken in this regard.

Figure 14: Alternative healers consulted



The above graph illustrates that 84 (47%) of the respondents reported not using alternative healing methods, while 117 (53%) reported having used these methods. This includes traditional healers, "sangomas", witchdoctors, herbalists and faith healers.

In the qualitative part of the study, the following was reported with regards to traditional healing:_ Similarly to the results of the qabove question regarding the qualitative aspect of the study reported the following. Themes and sub-themes derived from the data:

Theme:

- Traditional healing influences adherence to ART in SA.

Sub-themes:

- Certain traditional beliefs and rituals are contraindicated for adherence to ART.
- Traditional healing does interfere with ART.

Table 29: Traditional healing influences adherence to ART in SA

Respondent	Interview quote
Social Worker	"Traditional healing still plays a big role in healing and we must always remember that."

Counsellor	"I believe that if somebody is on ART they should not take traditional medicine. The 'muti' that causes diarrhoea and vomiting to clean the body interferes with the absorption of ART."
Medical doctor	"Traditional healing influences adherence."

The above research findings are supported by the following literature:

Both indicate that traditional healing is an important factor concerning adherence issues. Rossouw (2006:18) postulates that the issue of traditional healers and traditional medicine has become one of the most complex to deal with, concerning ART. The WHO estimates that 80% of African populations consult traditional healers.

Anecdotal and early scientific evidence issues a warning of significant interactions between traditional and Western medicine. This has raised the question of whether patients using traditional medicine should be excluded from the ARV programme. Regarding traditional healers, the present researcher is of the opinion that patients will not willingly disclose their participation in traditional medicine, since they know that proponents of western medicine tend to hold negative views towards traditional medicine.

Certain traditional beliefs, such as "makgome" are practiced amongst most South African cultures. "Makgome" is a condition one might contract from having close contact with a person whose partner has died if he/she has been through the expected cleansing process. The surviving partner is compelled to visit a traditional healer ("Inyanga" or "Nyaka") after the death of the spouse. This cleansing method requires traditional medicine (muti) to be taken for a certain period (3-6 months).

Patients are not eager to take ARV medicine while they are taking traditional medicine, which could also be a contraindication for ART. The family usually insists that the person participate in the above traditions so as not to infect others with "makgome". The researcher is of the opinion that if a patient were to

take ART against the wishes of their family and the requirements of their traditions and culture, it would complicate adherence. Thus, a consciousness regarding different cultures and traditions is necessary in adherence matters.

The researcher believes that the incidence could be even greater, since most patients could be afraid to report that they also consult traditional healers. She further believes that in Africa, and specifically South Africa, a country rich with cultures, western medicine should meet with traditional medicine. The team at an ARV clinic should be aware of the different beliefs of patients. The role of the social worker could include the development of insight into the different cultures by facilitating / taking part in networking.

6.3.3 Psychosocial needs of respondents

Engel (1980:538) argues that when collecting data regarding the biological aspects of the patient, it is crucial also to explore her/his psychological being, because the course of the illness and the care of the patient may be importantly influenced by processes at the psychological level. Engel (1980:543) further illustrates that by using the biopsychosocial model, the medical practitioner is able to identify and evaluate the stabilising and destabilising potential of events and relationships in the social environment of the patient, while not neglecting the way in which the destabilising effects of the patient's illness on others may feed back as a further destabilising influence on the patient. This argument emphasises the important influence of the patient's social environment on his/her health and illness.

According to Kaplan, *et al*. (1994:1), the psychological dimension emphasises the effects of psychodynamic factors, motivation and personality on the experience of illness and the reaction of the patient. This dimension forms an important component of the biopsychosocial model, in the sense that it helps the medical practitioner to understand the patient's perceptions of his/her condition and the extent to which he/she is motivated towards obtaining help.

In this section of the questionnaire, the psychological needs and circumstances of the respondents are explored. Questions included in this section focus on the psychosocial support – the needs and problems of the respondents, alcohol consumption, drug abuse and criminal records, as well as counselling needs. Questions regarding financial circumstances, religious matters and accommodation issues were also included. Furthermore, the emotions of the respondents, disclosure issues and sexual matters were explored. The last question posed, concerned the quality of life of the respondents.

6.3.3.1 Psychosocial needs/problems that respondents experienced since receiving ART: psychological dimension

It is a well-known fact that the social and psychological issues confronting HIV/AIDS patients are enormous. Patients diagnosed with most life-threatening diseases such as cancer are usually smothered with sympathy and support. The diagnosis of HIV/AIDS is often characterised by stigmatisation, and subsequent social rejection and emotional isolation. The social stigmatisation reminds us of the rejection with which a person suffering from leprosy met in the biblical period. (Holy Bible: Luke 17:11 and Leviticus 13)

Table 30: Psychosocial needs of Respondents as indicated across the eight individual aspects measured

Psychosocial needs of Respondents	Frequency	Percent
Disability Grant	96	48
Counselling	48	24
Emotional Problems	48	24
Sexual Problems	34	17
Relationship Problems	24	12
Alcohol Problems	11	5
Stigmatization	9	4
Terminal Care	4	2

The following findings are emphasised in the above table:

The above data was obtained from a multi-answer questionnaire, where the respondent could indicate more than one psychosocial need.

The above research findings indicated that a need for disability grants (96 (48%)) is the greatest psychosocial need reported by respondents while 48 (24%) indicated needs with respect to emotionally related problems and only 34(17%), sexual matters.

The findings from the qualitative aspect of the study revealed the following regarding psychosocial needs: Similarly to the above question regarding the Karnofsky scale, the qualitative aspect of the study reported the following regarding the WHO staging:

Theme 1:

- Psychosocial needs of patients featured strongly.
- Patients need support structures that are supportive and standardized.
- Patients have a need for maintenance of confidentiality.
- Patients need ongoing motivation and support.
- All patients need a thorough assessment of personal circumstances and needs.
- Financial assistance featured strongly.

Theme 2:

- Psychosocial needs of counsellors featured strongly.
- Lay counsellors in concerning adherence matters need formal training.
- Lay counsellors in general need better working conditions and expect formal employment with benefits.
- Lay counsellors
- The standards governing lay counsellors need to be standardized and uplifted.

Table 31: Psychosocial needs of patients featured strongly

Respondent	Interview quote
Social Worker	"Patients needs presented to me, are always material needs. Need for a disability grant or food. But when I assess the patient I always find more complex issues to attend to."
Social Worker	'A thorough assessment is necessary of each patient's needs."
Counsellor	"The government is seeing us as the last resort. We are the doormats of the government."
Counsellor	"Why can't counsellors be officially employed?"
Counselling	"Motivate counsellors by bursaries and educational and learning programmes to uplift their standards."
Counsellor	"Nobody represents counsellors and there are no support structures and there are no standard services."
Medical Doctor	"Support and motivations is one of the major needs."

The above research findings are supported by the following literature:

The researcher is of the opinion that the hierarchy of needs developed by Maslow, a pioneer in the field of psychology, is very applicable to HIV/AIDS patients. If the basic needs such as hunger, thirst, sex and the maintenance of the internal state of the body are not fulfilled, respondents will not indicate higher psychological needs, such as emotional needs (Maslow, 1954). This paradigm is an indication of the need to belong in a social and familial sense and to be accepted and affiliated to others and could include the need to reach self-fulfilment.

An interesting aspect that emerged during this study in the interviews with lay counsellors, was the needs of these counsellors. The sub-themes that emerged, were focussed on the needs of counsellors and not on the needs of patients. The researcher is of the opinion that the latter's self-interest and concern with their own personal needs and welfare, rather than those of the patients, features strongly in the above findings, and is contra-indicated for counsellors. These lay counsellors, their skills, training and recruitment should

thus be addressed. The qualitative part of the study, has thus revealed a need for common standards being applied to counselling services in ART.

It seems that “a can of worms” was opened regarding various aspects of lay counselling. Self-interest, often equated with egoism, an exclusive concern with one’s own personal needs and welfare rather than those of others, as discussed by Baran, Byrne & Branscombe (2002:88), featured strongly in the above findings. Baran *et al.* (2002:88) further proclaimed that if lay counsellors are motivated by self-centred needs, such as gaining self-understanding, and self-esteem enhancement, these tend to be stronger predictors of prolonged volunteerism.

The researcher is further of the opinion that in the recruitment of lay counsellors, the motivations for their involvement, specifically in HIV/AIDS matters, should be explored. Baron *et al.* (2002:412) discusses the different theories attempting to explain the reasons for pro-social behaviour as follows:

- Negative-state relief model; proposes that people help other people in order to relieve and make less negative their own emotional discomfort.

The above findings are again an indication of the comprehensive service that is needed at an ART site. Social workers and counsellors should be skilled and trained in the thorough assessment of clients. Some of the roles that are indicated for a social worker in the ART clinic are indicated as being an advocate for the rights of patients, educator, and supervisor for standards in counselling.

6.3.3.2 Alcohol Consumption

This question explores the presence of alcohol use/abuse in respondents, since it is perceived as a contra-indication for adherence.

Only 9 (4%) respondents reported moderate alcohol consumption on Fridays, 16 (8%) on Saturdays, and 11 (5%) on Sundays. The research results indicated that only 35 (17%) respondents reported mild alcohol use over weekends.
In the qualitative part of the study, the multidisciplinary team members reported the following regarding alcohol use:

Theme:

- Alcohol dependency not reported often at ART clinics.

Sub theme:

- Alcohol dependency or abuse does not feature strongly at ART clinics.
- Alcohol abuse is too often or willingly disclosed.

Table 32: Alcohol dependency not reported often at ART clinics

Respondent	Interview quote
Counsellor	"Patients counselled are drinking but they are scared to tell. Patients commonly drink ijuba (zulu beer) as it is cheap."
Counsellor	"If you ask, they say they drink because of stress." "If you drink you forget to take the pills."
Counsellor	"Men drink more because of traditional beliefs and they have more money than women."
Social worker	"Alcohol does not feature strongly – most people are just too poor or sick to drink."
Medical Doctor	"Alcohol - cases are isolated."

The above research findings are supported by the following literature:

The theme that emerged is that alcohol does not feature very strongly in ART matters. The notion of the present researcher is that the above results can be attributed to the fact that the economical and/or physical status of most patients does not allow for alcohol abuse or even its use. Most respondents reported that they were unemployed and dependent on family members for their basic human needs, which certainly does not include alcohol. If a patient should have an alcohol problem this would influence adherence. According to Kaiser (2002:10) many predictors of poor adherence to ART have been identified and

include active drug use and alcohol abuse, active mental illness, in particular, depression.

Furthermore, the reported low consumption of alcohol or its abuse could also be attributed to the fact that the respondents participating in this research have already been initiated on ART. According to the Government's Comprehensive Care and Treatment of HIV/AIDS and TB: Rollout Plan for Antiretroviral Treatment (2003:4), alcohol abuse should be excluded before initiating ART and this could explain the reported low consumption of alcohol.

6.3.3.3 Drug Abuse

Regarding drug abuse, the following was reported in the qualitative part of the study:

Similarly to the above question regarding the alcohol, the qualitative aspect of the study reported the following regarding the WHO staging:

Theme:

- Drug abuse not reported to be prominent at ART clinics.

Sub-themes:

- Drug abuse is not reported by patients. Patients are too poor to afford drugs.
- People do not easily disclose drug abuse.
- Drug abuse is more prominent amongst white or financially stronger patients.

Table 33: Theme: Drug abuse and adherence

Respondent	Interview quote
Counsellor	"I have never seen somebody that takes drugs - maybe they are not telling."
Social worker	"Drug abuse is not a problem. If there is drug abuse - it is usually the white patients."
Medical Doctor	"Isolated cases."

The above research findings are supported by the following literature:

No significant sub-themes emerged from the above question, except the possibility that drug abuse is found more often among white, rather than black patients.

As with alcohol, the abuse of recreational drugs is contraindicated for adherence. The National Antiretroviral Treatment Guidelines (2003) consider drug abuse as an excluding factor before initiation of ART.

Respondents in this research reported no drug abuse, because, the present researcher believes, that since the respondents were already receiving ART, they would have been screened for, drug abuse, an exclusion factor for initiating patients for ART.

The researcher is also of the opinion that another reason why drug abuse is not reported, as discussed in section 6.3.3.2 regarding alcohol, is that the patient's financial circumstances also cannot support the use of recreational drugs. If this research had been conducted in a private facility where the financial circumstances of patients were different, drug abuse might have been mentioned.

6.3.3.4 Criminal Record

By including this question, any criminal record/history of the respondents is investigated, since criminal activity could be an indication of irresponsibility. Prisoners, receiving treatment at the ART clinic, were not included in the research for practical reasons. Less than a third of the respondents 44 (22%) reported some kind of criminal record.

Similarly to the above in the qualitative element of the study, criminal activity was also not reported as an issue in HIV/AIDS and ART. The data collected from the qualitative element of the study reveals the following:

Theme:

- Criminal involvement. Minimum influence on adherence to ART.

Sub-theme:

- Criminal involvement does not feature in adherence to ART.
- Prisoners should receive treatment in prison and not visit local clinics as is the present practice in local clinics.

Thus, the sub-theme that emerges from the above questions regarding criminal involvement indicates that, in general, patients do not break the law. The sub-theme that emerged strongly was that prisoners should be treated in prison and not at ART clinics in the community, for various reasons.

Table 34: Theme: Criminal record and adherence

Respondent	Interview quotes
Counsellor	"Most patients have not been involved with crime."
Professional Nurse	"Some patients feel uncomfortable with the prisoners and their guards armed."
Medical doctor	"Prisoners sometimes waste time by faking symptoms to spend time outside. It is a waste of government human resources personnel and transport."
Medical doctor	"No role."

6.3.3.5 Need for Counselling

HIV counselling is defined as a confidential dialogue between a client (patient) and a care-provider, aimed at enabling the client to cope with stress and be assisted in taking personal decisions related to HIV/AIDS (WHO Global Programme on AIDS, 2006).

<u>The quantitative research results indicated the following regarding counselling:</u>

123 (61%) of the respondents reported a need for more adherence counselling,
37 (18%) of the respondents reported a need for more post-test counselling,
33 (16%) of the respondent reported a need for counselling regarding death and dying,

20 (10%) of the respondents reported a need for counselling of important others/family, and 16 (8%) of the respondent reported a need for disclosure counselling.

The above research results indicated that the majority of respondents reported the need for adherence counselling 123(61%). This is significant but could also be biased since adherence counselling is indicated as part of the Gauteng Department of Health's Comprehensive HIV/AIDS Guidelines (2004) before initiating ART. Furthermore, respondents could have felt obliged to indicate adherence counselling, since they are aware of the fact that adherence is important in ART.

In the qualitative part of the study, the following was reported with regards to counselling needs of patients. The data collected from the qualitative element of the study regarding the counselling needs of patients, reveals the following:

Theme:

- Patients do require various or holistic counselling throughout ART treatment.
- Common standards are required in counselling, specifically regarding adherence counselling.
- Patients need holistic help.
- Patients need trained counsellors to support them

Sub-theme:

- Common counselling standards.
- Standards for counselling and adherence specific.
- Holistic help.

Table 35: Theme: Counselling needs

Respondent	Interview quotes
Social Worker	"I do not know what counsellors do cover in their counselling. I am not sure of their level of understanding and training of counsellors."

Counsellor	"General practitioners, in private practice are still testing and prescribing ART without sufficient counselling, specifically adherence."
Medical doctor	"Patients do not need specific counselling they need holistic help."

The above research findings are supported by the following literature:

Much emphasis is placed on counselling in HIV/AIDS. Terms like VCT, PMTCT; pre-test; post-test and adherence counselling are now well known in terms of HIV/AIDS matters. The Department of Health makes special provision for counselling and counsellors (South Africa, 2003). The researcher is of the opinion that counselling should not be labelled and fragmented, for example, adherence counsellors or VCT counsellors. Counsellors should be able to render a holistic and comprehensive service in assessing patients.

The social-work profession, with its specialized skills, could play an important role in assessing the patient and rendering the necessary therapeutic interventions if required. The social worker has knowledge of community resources and will be able to network with organizations. The present researcher, as confirmed in the qualitative study, has experienced, that most often, patients need more than just pre-test and post-test counselling. A comprehensive assessment by an experienced counsellor and knowledge of resources is often required since patients do experience various biopsychosocial needs that should be addressed by a qualified professional.

6.3.3.6 Issues relating to accommodation

By including this question, the normal circumstances of respondents were explored in order to establish the need for alternative care, such as community home-based care, or institutionalisation, such as hospitalisation or care in a hospice.

The research findings indicate that 18 (9%) of the respondents reported a need for alternative accommodation, 15 (3%) for home-based care, none needed hospitalisation, while only one required hospice care, owing to lack of support.

The researcher holds the view that the above figures could be an indication that the patients do adhere to their treatment because a lesser need for hospitalisation or home based care is indicated. This could further be an indication that this goal (reduced hospitalisation) of ART has been met. No terminally-ill patients were included in the study since this would not have been ethically responsible.

Regarding accommodation, the following was reported in the qualitative part of the study: - The data collected from the qualitative element of the study regarding accommodation needs reveals the following:

Theme:

- Accommodation needs is not prominent in adherence matters.

Sub-theme:

- Most people are content with their accommodation.

Table 36: Accommodation needs is not prominent in adherence matters

Respondents	Interview quotes
Counsellor	“Patients are happy where they are – it is home.”
Counsellor	“I do not see a lot of homeless people they are few."

The above research findings are supported by the following literature:

One of the secondary aims of ART is to minimize hospitalisation. The researcher also intended to establish the need for community-based care, which is the care provided to individuals in their own homes where they are supported by their families, a multidisciplinary team, and complementary caregivers (Van Dyk, 2006:14). No significant sub-themes emerged from this question regarding accommodation and adherence issues, except that the patients have a place of abode and are relatively happy where they reside.

6.3.3.7 Financially-Related Problems

The researcher considered that the relationship between HIV/AIDS and poverty, which thus far, has been merely alluded to, would also indicate a correlation between adherence to ART and poverty / socio-economic status. By including this question, the researcher intended to establish the respondent's financial circumstances.

Poverty is a key factor contributing to the AIDS epidemic, according to the First full-scale report of the WHO Global Programme on AIDS (GPA, 2002). The researcher believes that financial hardship will be the key factor contributing to non-adherence; people will default and discontinue ART owing to financial issues such as transport and therefore only visit the clinic for treatment when they can afford it or are admitted to hospital owing to AIDS-related symptoms.

According to the research results, the majority of the families in the present study are unemployed and live on child-support grants as a means of coping with their desperate financial situation. This places a huge responsibility on the few who are employed and the self-employed family members who have to shoulder the basic necessities for the entire family.

The researcher also confirms Janet Frolich's opinion in (Abdool, 2005:365), who states that there is still widespread ignorance of the financial support available to communities, families and individuals affected by HIV/AIDS, and that education programmes are urgently needed to make people aware of the grants for which they are legally eligible.

Table 37: Financially-related problems reported by respondents

Financial related problems	n	Percent
Unemployed	145	72
Disability Grant	103	51
Employed	55	27
Productivity	15	7

The above research findings are supported by the following literature:

The above data was obtained from a multi-answer questionnaire, where the respondent could indicate more than one financially-related problem.

The findings, highlighted from the above table, indicate that 72% of respondents reported unemployment and a further 103 (51%) reported the need for a disability grant. This correlates with section 6.3.3.1 where 96 (48%) respondents reported a need for a disability grant with respect to psychosocial needs. The above minor discrepancy can be attributed to the fact that some patients 83 (41%) were already receiving a disability grant, or are in the process of applying for one and thus did not perceive it as a need.

A matter of great concern for the present researcher is that the majority of patients only receive the disability grant for a temporary period of 6 months, where after they need to re-apply for a further period, as the criteria for the grant in SA is a CD4 count of below 200. The researcher has experienced in her work that patients with a CD4 count that rises above 200, fear the discontinuation of their grants, which is their only means of financial support. This could contribute to non-adherence, in an attempt to keep their CD4 cell count at below 200.

The findings of the qualitative element of the study were reported with regards to financial issues. The data collected from the qualitative element of the study regarding the financial needs of respondents. The theme and sub-themes are as following:

Theme:

- Economic factors influence adherence to ART.

Sub-theme:

- Lack of money influences adherence to ART.
- Poverty does not really prevent adherence.
- People need financial support to adhere to ART and to attend clinics.

- Unemployed patients, dependent on disability grants, fear discontinuing of grant, when adhering and the subsequent improvement of CD 4 count.

Table 38: Economic factors influence adherence to ART

Respondents	Interview quote
Counsellor	"People need grants to come to the clinic."
Counsellor	"If people are really motivated financial issues do not stop them from taking ARV's."
Medical Doctors	"They find money to come."
Social Worker	"Patients are poor and need financial support."
Medical doctor	"No money for basic needs does influence adherence and pre-planned defaulting to keep CD4 count < 200 to keep disability grant."

The above research findings are supported by the following literature:

The sub-themes that emerge from the above discussion are that most people need some form of financial support or grants. It has also emerged that people who are really motivated can adhere, in spite of poverty.

The social elaboration of HIV/AIDS and poverty is endorsed by Mashologu-Kuse (2005:378), as well as Strydom, Cronje, Roux, Strydom, and Wessels (2005:68), who confirm that poverty and the high level of unemployment, coupled with families headed by females, and who receive no support from their partners, and are almost totally dependent on child-support grants, are an indication of the plight of disadvantaged families. The researcher asserts that the issue of disability grants for HIV/AIDS patients should receive special attention. Frohlich, as quoted in Abdool Karim & Abdool Karim (2005:351), asserts that legal mechanisms such as wills, foster care and social grants are foreign concepts for many communities, particularly those in rural areas.

6.3.3.8 Financial Support

The intention of this question was to explore the respondents' socio-economic status.

As discussed above in section 6.3.3.7, most HIV/AIDS patients do experience financial difficulties owing to lack of productivity, caused by the AIDS-related symptoms.

Table 39: Financial support of respondents as indicated across seven individual aspects measured

Financial support	Frequency	Percent
Self	109	54
Family	84	42
Disability Grant	83	42
Spouse	31	15
Child	19	10
Friend	13	7
Colleagues	2	1

The following findings are evident from the above table:

The data was obtained from a multi-answer question, where the respondent could indicate more than one form of financial support.

These findings are interesting, since more than half of the respondents 109 (54%) indicated that they support themselves. These findings could include some form of grant or assistance, but are perceived by the respondents as self-support. Forty-two percent 84 (42%) of the respondents reported family financial support and a further 83 (42%), reported a disability grant as their form of financial support.

The researcher believes that section 6.3.3.7, where 145 (72%) of respondents reported unemployment and financially-related problems, correlates with section

6.3.3.8, where 149 (75%) respondents reported that they are financially dependent on someone. The 134 (67%) respondents, who reported financial support from their families, include: extended family 84 (42%), spouses 31 (15%), spouses and children 19 (10%). It is important to note that 83 (42%) respondents reported that they already receive a disability grant. The data indicates that almost all the respondents experience some form of financial need.

Regarding financial issues and adherence, the respondents reported the following in the qualitative part of the study: - The findings of the qualitative element of the study are: Regarding accommodation, the following was reported in the qualitative part of the study:

Theme:

- Financial difficulties are reported by respondents as to influence adherence to ART.

Sub-themes:

- Supporting patients financially is important for adherence.
- Unemployed patients need disability grants to support adherence.
- Patients rely mainly on financial support from families.

Table 40: Financial difficulties are reported by respondents as to influence adherence to ART

Respondents	Interview quote
Medical doctor 1	“Patients are sick and want to come for follow-ups but due to non-disclosure to employers they cannot keep medical appointments.”
Medical doctor 2	“Transport fees v/s basic human needs are a problem specially patients outside the service areas.”
Counsellor 1	“Patients are supported mainly by mothers.”
Counsellor 2	“Patients need grants the most.”
Social Worker 1	“Patients needs presented to me, are always material needs.”
Social Worker 2	“Need for a disability grant or food.”

The above research findings are supported by the following literature:

The most notable sub-theme that emerges from these data is that patients do need financial support in order to sustain adherence. Often the needs being presented are material in nature, but once they have been assessed, further problems emerge.

HIV usually affects more than one in the household (husband and wife or mother and child). The financial burden is usually borne by the household, e.g. a grandmother who only receives an old-age pension or child-support grant. Whilst a general relationship exists between poverty and poor health, this is particularly so between HIV and poverty (Abdool Karim & Abdool Karim, 2005:381).

The researcher asserts that the above research results confirm, yet again, the need for financial assistance for HIV/AIDS patients who receive ART. The role of the social worker is to assess the patient biopsychosocially. The criteria for disability grants cannot not only rely on the medical report if adherence issues regarding ART are taken into account. The social worker has a role to play in bringing cases with special needs to the forefront.

6.3.3.9 Emotions

By exploring the emotions of respondents, the intention was to establish the feelings of the respondent with regards to their experience of illness and their reaction to it.

According to Kaplan, *et al.* (1994:1), the psychological dimension of the biopsychosocial model, emphasises the effects of psychodynamic factors. This dimension forms an important component of the biopsychosocial model. It assists the medical practitioner to understand the patient's perceptions of his/her condition and the extent to which he/she is motivated to obtaining help. When using the biomedical model on its own, these aspects are neglected, resulting in a negative impact on the patient.

Kerns and Curley (1985:150) add that the individual's cognitive, affective and behavioural functioning greatly influences the extent and meaning of perceived psychological and social losses, as well as their coping with or adapting to these.

Table 41: Emotions as indicated by Respondents across the five individual aspects measured

Emotional	Frequency	Percent
Acceptance	192	96
Positive	187	93
Gratefulness	172	86
Mixed Feelings	72	36
Depression	49	24

The following findings are illustrated in the above table:

The above data was obtained from a multi-answer questionnaire, where the respondent could indicate more than one form of emotional need.

Most respondents reported positive feelings. Regarding this, the researcher confirms that the majority of patients on ART are positive and grateful. These positive feelings can be contributed to the fact that they do experience a sense of control. The patients have accepted their status and are willing to take responsibility in controlling the disease. It has been reported that if a patient experienced greater control, he/she would show stronger feelings of being contented and positive.

In the qualitative part of the study the following was reported regarding emotions: The data collected from the qualitative element of the study regarding the emotions presented by patients, reveals the following:

Theme:

- Patients reported in general positive feelings and feelings of optimism, hope and to be grateful gratitude.

Sub-themes

- Feelings of anxiety were reported regarding disclosure of status.
- Complications, treatment failure and side-effects lead to feelings of despondency and depression.

Table 42: Patients reported in general positive feelings and feelings of optimism, hope and to be grateful gratitude.

Respondents	Interview quotes
Social Worker	"Patients tend to be positive in general."
Social Worker	"Matters regarding disclosure and confidential issues still cause the most anxiety in patients."
Counsellor	"We do not see a lot of seriously depressed patients."
Medical doctor	"When a patient is initiated on ART and experience complications they do tend to be depressed and default." "Emotional immaturity or lack of insight – they do not understand the importance of adherence."

The above research findings are supported by the following literature:

From the above data regarding the theme of emotional needs and adherence, the sub-theme that emerged is that people on ART demonstrate positive feelings.

The present researcher has experienced that when a person is diagnosed with a life-threatening or chronic illness, like HIV/AIDS, they tend to go through certain of the stages identified by Kubler-Ross (Taylor; 2003:400). In general, the HIV/AIDS patients also experience feelings of fear, anger, anxiety and guilt. The said researcher has experienced that most patients express feelings of guilt, often feeling ashamed and afraid of being questioned concerning infidelity or homosexuality. The stages do not occur in a predetermined order. Most patients experience some of the stages more than once: for example they might experience depression each time they develop new symptoms, or their CD4 count drops.

The present researcher proposes that the emotional phases that patients with HIV/AIDS experience are: anger, shock, denial, anxiety, guilt, fear, bargaining, depression and acceptance. In previous research carried out by the said researcher (Spies, 1999:88) the respondents reported shock, depression and fear as their primary emotions. After initiation on ART patients do tend to express anxiety, excitement, anticipation, bargaining, and happiness.

6.3.3.10 Treatment for depression

In including this question, the intention was to explore the feelings of respondents, particularly depression.

Only one respondent reported depression. The researcher explains this, in that the respondents already receive ART and generally feel very optimistic. The respondent is also aware that untreated depression is an exclusion criterion for initiating ART. These results correlate with the results in subsection 6.3.2.9 where patients reported their feelings as being happy, grateful and positive.

Regarding this question on depression, the qualitative part of the study reveals the following: - The data collected from the qualitative element of the study regarding depression specific, reveals the following:

Theme:

- Depression is often contraindicated for adherence to ART.

Sub-themes:

- Depression is more often reported in white patients.
- Depression did not feature frequently in patients attending the clinics where research was conducted.

Table 43: Theme: Depression is often contraindicated for adherence to ART

Respondents	Interview quotes
Counsellor	"Patients on antidepressants are usually the white patients; they have a lot of issues."
Counsellor	"We do not see too many depressed patients."

Medical doctor	"Depression goes hand in hand with feelings of futility - If a patient experiences this they might decide to give up treatment – they lost hope."

The above research findings are supported by the following literature:

The most important sub-theme which emerged from this question regarding depression is that the members of the multidisciplinary team involved in ART do not perceive depression to play an important role in HIV/AIDS patients on ART. Depression is also reported to be more prevalent in white patients.
Co-morbid depression, or alcoholism and drug dependency, negatively impacts on adherence, whereas disclosure and social support may impact positively (Abdool, 2005:514).

6.3.3.11 Religions

As values and beliefs are integrated with sexual behaviour, the researcher wanted to establish the influence of religion.

Respondents reported the following about the Christian denominations they belong to:

38 (20%) Apostolic
31 (17%) ZCC
22 (12%) Roman Catholic
10 (5%) Lutheran
8 (4%) Methodist

The above research results indicated that respondents represent Christians from different denominations, the highest percentage being Apostolic 38 (20 %), and Zionist Christian Church (ZCC) 31 (17%). Most respondents indicated that they participated in religious activities. This could be another indication for churches to become actively involved in HIV/AIDS/ART training, education and prevention programmes.

The data collected from the qualitative element of the study regarding religion revealed the following:

Theme:

- Religion can influence adherence to ART.

Sub-themes

- If patients are religious, the church and spirituality will convey hope and motivate patients to adhere.
- Some churches have special rituals or prescriptions regarding treatment (faith-healing, cleaning of body and other rituals) which could contra-indicate adherence.
- The concept of faith healing and patients believing that they are cured can result in non-adherence to ART.

Table 44: Theme: Religion and adherence

Respondent	Interview quotes
Social Worker	"Certain churches have special instructions regarding illness and or medication and this can influence adherence."
Counsellors	"Religions play a role in adherence. Special instructions from certain churches might cause non-adherence."
Medical doctor	"If patients belong to a religion they feel that there is a purpose to life and tend to be adherent." "Religious leaders might influence patients to believe in faith-healing – which can cause them to default."

The above research findings are supported by the following literature:

The sub-theme which emerged from the research regarding religion is that religion and spiritual issues play a role in adherence matters. All individuals possess some kind of belief and some set of values about other people, groups, objects or ideologies. Religion may be described broadly as a system of beliefs and practices which are usually considered to be directed towards the "ultimate concern" of a particular society (Jones, 1991:355).

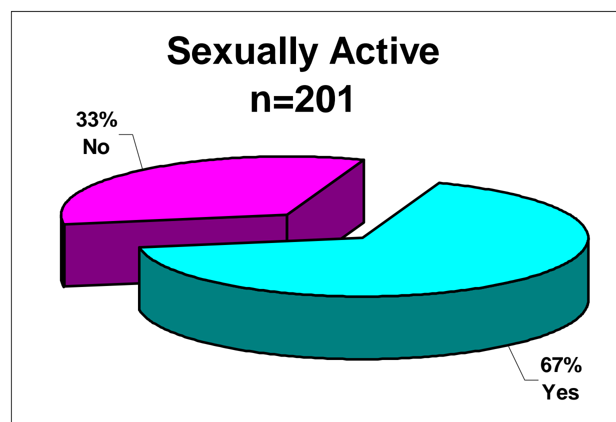
The present researcher is of the opinion that the role of religion should not be underestimated in the treatment of HIV/AIDS patients. Often patients hold quite specific beliefs about the nature of disease (witchcraft) which might be in direct conflict with those held by medical professionals.

6.3.3.12 Sexual activity of the respondent

The present researcher is of the opinion that the co-existence of sexual behaviour and HIV, coupled with the conspiracy of silence and shame surrounding these, are at the core of the pandemic. The results of the questions regarding sexual activity, practicing safe sex and methods of safe sex or contraception are presented together. These questions are all linked, which provides a good indication of the sexual behaviour and circumstances of the respondents.

Figure 15: Sexually Active

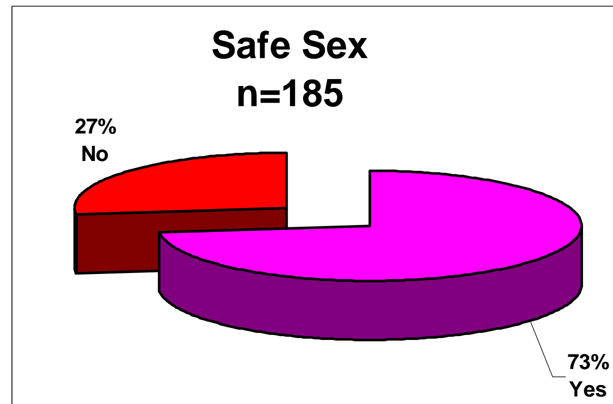
The intention was to establish whether patients are sexually active.



The above graph illustrates that more that half of the respondents, 135 (67%), were sexually active. If these results are compared to the 165 (82%) respondents who reported being single in Figure 8, this could indicate that patients are still sexually active, even without being in a supportive relationship.

Figure 16: Practising safe sex

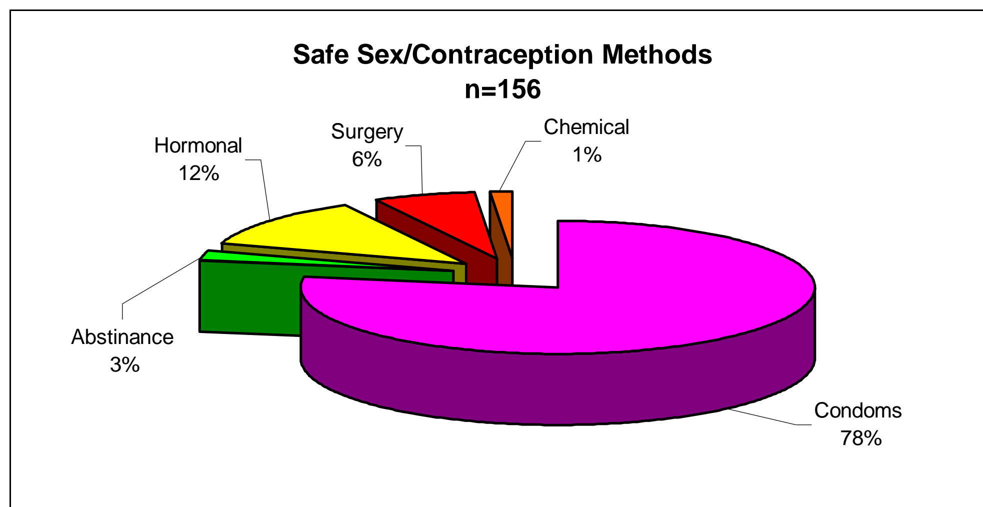
In this question, the intention was to establish whether the patients who are sexually active practise safe sex.



The above graph illustrates: that the large majority, 135 (73%), of respondents reported that they practise safe sex, while 50 (27%) responded negatively.

Figure 17: Safe Sex/Contraception Methods

The views of the respondents with regards to safe sex were explored. In this question the respondents were asked to indicate what they perceive safe sex to be. Contraception was included, because there is a belief that being on contraception such as the pill, is practising safe sex.



The following findings are illustrated in the above table:

The above data was obtained from a multi-answer question, where the respondent could indicate more than one form of safe sex and to explore what they understand under "safe sex."

121 (78%) of the respondents reported the use of condoms (male and female)

19 (12%) reported hormonal methods

10 (6%) reported surgery (hysterectomy/vasectomy)

5 (3%) reported abstinence and

2 (1 %) reported the use of chemicals.

More than half of respondents 125 (67%) reported that they were sexually active, compared to 135 (73%) of respondents who indicated that they practise safe sex and a further 121 (78%) of respondents who indicated the use of condoms as the primary method of safe sex. These results indicated an alarming number of patients who still do not use condoms 36 (22%), which presently is the only safe method except for abstinence (2.56%). Hormonal contraception was included as an option in order to establish whether patients perceive contraception methods to be safe sex: a total of 19 (12%) of respondents responded affirmatively. This is an indication that education should focus on the difference between contraception and HIV positive safe-sex methods.

The data collected from the qualitative element of the study regarding the influence of patients performance status, reveals the following living conditions, and the sub-themes reveal the following:

Theme:

- Sexual activities do influence adherence to ART.

Sub-themes

- Disclosure in sexual matters influence adherence to ART
- Non disclosure in sexual relationships, negatively influence adherence to ART.

Theme:

- People do not practise safe sex.

Sub-themes

- Patients on ART fall pregnant.
- Patients report a lot of STD's at clinics.

Table 45: Sexual activities do influence adherence to ART

Respondent	Interview quotes

Medical doctor	“I see a lot of STI and pregnancies on ART – which can only be caused by unprotected sex.” “Reason nondisclosure, unwillingness of partners and need of partner for children.”
Pharmacist	"Sexual relationships will influence adherence especially if they did not disclose to partner.”
Professional nurse	“A lot of patients on ART fall pregnant while on ART. They start feeling better. Their blood is warming.”
Counsellor	“It seems that the patients do not use condoms.”
Counsellor	“People do not use condoms especially if they did not disclose.”
Medical doctor	“Patients who have not disclosed to partners will have to take treatment in secrecy and this might lead to non-adherence.”
Social Work	“A lot of patients are falling pregnant – this shows that they do not practice safe sex.”

The above research findings are supported by the following literature:

The sub-theme that emerges from the research regarding sexual matters is that people do not practise safe sex.

In South Africa, gender role norms contribute to the pronounced gap between HIV awareness and practices and the social processes that influence the disproportionate risk for contracting HIV among young women. There is an increasing recognition that public health approaches which promote abstinence, fidelity and the use of condoms in the absence of wider societal changes are not effective. Unequal power in relationships prevents the negotiation of safe sexual practices in order to reduce the impact of HIV infection and re-infection. Young women have difficulty overcoming existing gender inequalities. A distinct gap exists between cognitive knowledge (knowledge of safe sex and risky sexual behaviour) and behavioural outcome (actual refraining from risky behaviour) (Kasiram; Dano; & Partab, 2006:54-55). As previously mentioned the present researcher is of the opinion that there is little correlation between knowledge and refraining from unprotected sexual encounters, since knowledge

is cognitive and sexual behaviour is usually an emotional act as well as a basic human need.

Whiteside & Sunter (2002:71) postulate that the nature of a person's sexual behaviour is determined by the number and type of sexual encounters he will have. Since sexual behaviour is one of the basic human needs, it renders serious challenges to the health care professions. Sexual behaviour describes the set of behaviours and practices that define sexual activities, and is, in turn, determined by economical, social and cultural factors.

With regards to the risk for HIV, cross-national studies of sexual behaviour across age groups, marital status, gender and age are the strongest determinants of sexual networking patterns (Abdool Karim & Abdool Karim 2005:268). The present researcher believes that sexual behaviour is part of human nature and is very strongly related to cultural beliefs.

Until alternative methods become available, male and female condoms will remain the principal technology for preventing the sexual transmission of HIV in South Africa. A large efficacy trial is planned in South Africa in order to assess the effectiveness of the vaginal diaphragm or gel in preventing HIV infection.

Abstinence, or refraining from sexual activity, is an often-cited prevention strategy among young people, especially women. Abstaining from sex is obviously an important prevention strategy. Secondary abstinence refers to a prolonged periods without sexual activity among those who have already been sexually active (Abdool Karim and Abdool Karim, 2005:277). The said researcher asserts that to promote abstinence is a difficult but long-term possibility, which could work, especially for the youth. This is however, against a basic human need.

6.3.3.13 Other sexual matters

The researcher is of the opinion that sexual matters and HIV/AIDS are connected and at the core of the HIV/AIDS pandemic.

The qualitative element of the study revealed the following regarding sexual matters: The data collected from the qualitative element of the study regarding the influence of patients sexual matter, reveals the following:

Theme:

- Sexual relationships do influence adherence to ART.
- Sexual matters are not specifically discussed in counselling.
- Disclosure of HIV status influences sexual relationships as well as adherence to ART.
- Non-disclosure of status to sexual partners influences adherence to ART negatively, specifically if patients must visit clinics for follow-up appointments and take medication in secrecy. Patients also experience problems when developing side-effects from ART.

Theme:

- People do not practice safe sex.
- Female patients increasingly report being pregnant on ART.
- Patients moreover report STI's at clinics.

Theme:

- Sexual matters are reported to be associated with ART.

Sub-themes

- Patients (both sexes) report an increase of libido on ART.
- Sexual dysfunction is reported by males, specifically erectile dysfunction while on ART.
- Sexual matters not specifically discussed in ART matters.

Table 46: Theme: Sexual problems and adherence

Respondent	Interview quotes
Social Worker	"Physically stronger and without symptoms patients can participate in sexual activities. One of ART side effects is an increase in sexual drive."
Professional nurse	"On ARV the libido comes back. The blood is not cold anymore. They start again with sex."
Medical doctor	"Some patients complain of sexual dysfunctions on ART, this is more white patients." And specifically erectile dysfunction problem in men

Medical doctor	“This is not a subject discussed often. We focus so much on getting patients better; sexual matters are not really discussed. Patients shrink away from discussion of sexual matters.”

The above research findings are supported by the following literature:

Thus the sub-theme that emerges in exploring sexual matters is that ART has an effect on sexual behaviour, particularly, an increase in libido.

Sexual dysfunction/disorders are frequently characteristic of HIV/AIDS relationships, and include inhibited sexual desire, sexual aversion disorder, sexual arousal disorder, male erectile disorder, male/female orgasmic disorder, sexual pain disorder, premature ejaculation and vaginismus (Kasiram, M *et al*., 2006:54).

These sexual dysfunctions are often of psychosocial origin, such as guilt and fear, which, coupled with the complicated and sensitive communication surrounding sexual activity, misconceptions and cultural issues present a challenge for the social workers who should possess the necessary experience, knowledge and skills to probe into sexual matters.

The present researcher speculates that where respondents indicated an increase in their sexual drive this could be attributed to their improvement while receiving ART, so that they are physically stronger and have more energy to indulge in sexual activities. The research also confirms this since 49 (25%) of the respondents reported an increase in their sexual drive.

The researcher is of the opinion that people begin to experience a better quality of life as a result of ARV medication, and therefore could establish new relationships owing to their renewed hope for the future. An increase in sexual drive could also be a side-effect of ART, which has not yet been researched. It is reiterated that the role of the social worker or counsellor is also to educate and develop insight into sexual matters.

Sexual behaviour is the main driver of the South African HIV epidemic. Sexual behaviour is part of the basic human need shaped by various factors: including personal, interpersonal and those related to the immediate living environment and the distal context, as well as structural and cultural issues (Eaton, Flisher and Aard as quoted by Mathews in Abdool Karim and Abdool Karim (2005:146).

6.3.3.14 Disclosure

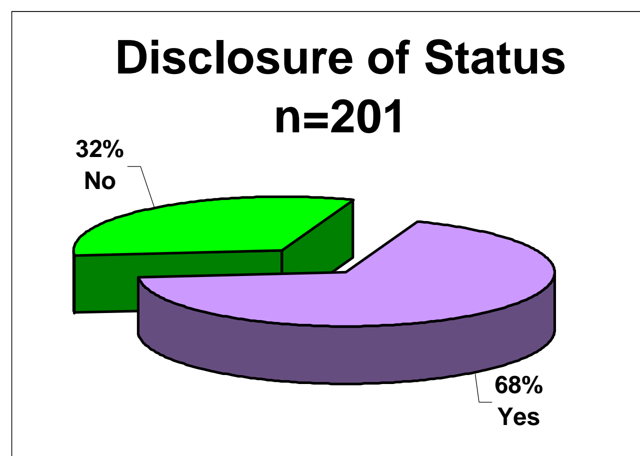
The low percentage ((25%) 50) of respondents who disclosed their HIV/AIDS status to their spouses could be explained by comparing this to the results of 6.3.1.3 where 165 (82%) respondents indicated that they are single and not in a formal relationship. This could explain why patients are reluctant to disclose their HIV status to their spouses and would rather disclose to significant others 80 (40%).

The questions 6.3.3.15 regarding disclosure and 6.3.2.16 with regards to whom they disclosed will be discussed together.

6.3.3.15 Disclosure

In this question the intention was to explore disclosure of HIV status.

Figure 18: Disclosure of Status



<u>The following findings are highlighted from the above graph:</u>

137 (68%) of the respondents disclosed their status while 64 (32%) did not do so. The results indicated that more than half of the respondents disclosed their status to at least one person.

6.3.3.16 Disclosure to whom

Table 47: Disclosure as indicated by respondents across seven individual aspects measured

Disclosed to Whom	n	Percent
Family	129	65
Parents	116	58
Significant (Buddy)	80	40
Spouse	50	25
Children	49	25
Employer	17	9
Colleagues	7	4

The above data was obtained from a multi-answer questionnaire, where the respondent could indicate one or more persons to whom they disclosed their status.

The researcher is of the opinion that these results are an indication of the important role that the family plays in supporting the HIV/AIDS patient. The respondents reported family to be their major form of support: parents 116 (58%), spouses 50 (25%) and children supporting their parents 49 (25%).

HIV/AIDS carries with it a discreditable stigma and disclosure is often avoided as a result of both felt and enacted stigmas. Historically, in South Africa, disclosure is still linked to job loss, partner abandonment, social ostracism, personal injury, refusal of medical treatment, refusal of insurance, and death. (Ross & Deverell, 2004:206). A further task of the social worker would be to identify and address these fears and network with the patient's social structure. The qualitative element of the study revealed the following regarding disclosure:

Theme:

- Disclosure influence adherence to ART.

Sub-themes:

- Disclosure of HIV status features as a major issue in adherence to ART.
- Disclosure of HIV status causes anxiety and influences adherence to ART.
- Patients tend to disclose mainly to immediate family for support.
- Patients try to avoid disclosing to employers and strangers.

Table 48: Theme*:* Disclosure influence adherence to ART

Respondent	Interview quotes
Social Worker	"Patients especially women still have a problem with disclosure to their partners. They fear the loss of financial support."
Medical Doctor	"Most of the time disclosure is to immediate family – they have problems in disclosing to partners, employers and elderly parents."
Social Worker	"Disclosing issues is causing the most anxiety in patients and could also be the reason of a lot of adherence issues."
Counsellor	"Most patients are supported by their families."
Counsellor	"In general patients will avoid disclosing to employers."

The above research findings are supported by the following literature:

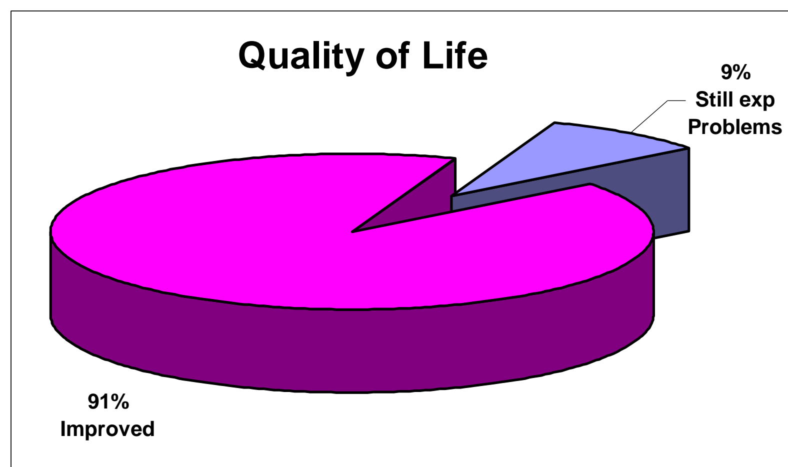
Thus the sub-theme that emerges from the above investigation is that disclosure remains a major issue in adherence matters and causes much anxiety in patients.

The present researcher is of the opinion that a question regarding disclosure is important, since this could also be an indication of the nature of the respondent's support system. Furthermore, it is difficult to take medication in secrecy, as previously discussed. Patients suffering from AIDS-related symptoms usually need the support of their family to care for them.

While the present researcher identifies with the need for disclosure, reports that patients are not being initiated on ARV's due to non-disclosure (even where this is justified) continue. Disclosure thus appears to be used as a form of punishment rather than a mechanism to provide adherence support (Venter, 2005:22).

6.3.3.17 Experience regarding quality of life

Figure 23: Quality of life



The above graph illustrates that the majority of respondents reported an improvement in quality of life.

The improvements vary between an increase in physical strength and wellbeing 196 (98%), regaining lost roles 195 (98%), and taking control 198 (99%). A small percentage reported continuing to experience problems in their daily functioning.

28 (14%) respondents report rejection or loss, 6 (3%) report physical abuse, 12 (6%) report emotional abuse, 12(6%) report stigmatisation, and 42 (21%) report that they continue to experience AIDS- related symptoms.

As indicated in the above research results, the majority of patients report a general increase in their quality of life in that they experience increased physical

strength, regained independence and lost roles, and are able to take control of their lives.

This is a major indication that ART improves the biopsychosocial functioning of patients in general.

The results of the qualitative part of the study show a very positive response from team members towards an improved quality of life on ART. The data collected from the qualitative element of the study regarding the patients quality of life reveals the following:

Theme:

- The quality of life of most patients had improved on ART.

Sub-themes

- Drastic improvement on ART if adherent and no complications.
- Patients can assume lost roles."

Table 49: Theme: The quality of life of most patients had improved on ART

Respondent	Interview quotes
Social Worker	"Patients can assume lost roles."
Medical doctor	"Patients become more functional they start feeling better about themselves and it improves self esteem. It is self motivating if you feel better and that will let them adhere better."
Counsellor	"Patients not only look much better but function better since on ART."
Medical doctor	"I see a definite improvement of quality of life, patients can assume their positions in life e.g go back to work and feel better about themselves."

The above research findings are supported by the following literature:

The most important sub-theme that emerges from this theme is that patients demonstrate an increase in their quality of life when on ART.

The researcher is of the opinion that the most important goal of ART should be to enhance quality of life. Quality of life and the psychosocial consequences of illness and treatment were not always considered a psychological issue of importance. The researcher contends that quality of life is significant among respondents in that by measuring the impact of treatment in this respect, one can assess their treatment is more harmful than the disease itself. (Taylor, 2003:356)

The present researcher suggests that, respondents reported overall positive feelings due to the fact that they believe that they can control their illness/disease by complying with treatments in that they personally have direct control over the illness by means of self-administration of the treatment regimen. According to Taylor (1993:362) evidence suggests that the experience of control and self-efficacy may prolong life. Control appears to be helpful not only in coping with acute disorders and treatments, but also with the long-term debilitation that may result from chronic illness. The said researcher believes that this is specifically relevant for HIV/AIDS.

HIV/AIDS, like many chronic diseases, affects all aspects of a patient's life. Those who live with chronic illnesses need to make intermittent or permanent changes in their physical and social activities. Chronic illness can produce drastic changes in self-concept and self-esteem, including one's body image and social functioning (Taylor 2003:356). In the case of HIV/AIDS, one's physical appearance can be very degrading.

The social worker's role is to motivate patients to adapt to the psychological and physical effects of living with a chronic illness.

6.4. Summary

The research has revealed the following tendencies with regards to the profile of AIDS patients with respect to their age and gender.

6.4.1 Biographical

The biographical section of the present study has indicated that the majority of respondents who participated in this research were women, in the age category <40 years. This correlates with literature and other research findings in that women are the more vulnerable group and men are underrepresented in ARV clinics.

The present research has also confirmed that the majority of people suffering from HIV/AIDS are single, which could complicate disclosure. The researcher is of the opinion, and this was confirmed by the qualitative phase of the study that people are still practising unprotected sex whilst not in a stable relationship.

The research further indicated that, the general assumption that mainly the lower-educated patients suffer from HIV/AIDS, does not hold the truth as respondents indicated higher educational levels and literacy. She has further found in practice that the better educated seek treatment sooner. Thus literacy seems to play a role in seeking medical treatment.

The majority of respondents, as could be expected, spoke North Sotho since the research was conducted in the ART clinic at Pretoria Academic Hospital, of the Gauteng Provincial Government. Regarding accommodation, the research has indicated that the majority of patients resided in an urban area, and lived in properly constructed accommodation.

6.4.2 Medical

Regarding medical and adherence issues, respondents reported that family support is the main factor enhancing adherence to ART. More than half of the respondents reported no support at all; this is alarming. The lack of interest in support groups requires attention. Respondents regard the assistance with ART received from the ART clinic as very important and, sometimes, the only form of support. In the light of the results that most patients are mainly single, unemployed women, this answers the query why patients are reluctant to disclose their status to their sexual partners.

The CD4 counts of the respondents were mostly < 200, which could be an indication that patients are still suffering from minor AIDS-related symptoms. It could also be an indication that they are adhering to ART, since the researcher has experience that most patients initiated on ART, reported very low CD 4 counts (<50) and even reported CD 4 counts of nil values. Most respondents had been receiving ART for a period of 6-12 months at the time of their response to the questionnaire; this could be explained in that the given ART Clinic only opened during July 2004. Respondents could thus be seen to be adherent. The current performance status of the respondents, according to Karnofsky's scale, is that of experiencing mostly normal health. Side-effects of ART are reported by more than half of the respondents as being a perceived problem.

6.4.3 Social matters

With regards to the psychosocial circumstances, this research revealed that financial needs are a priority. Most of the respondents were unemployed and thus economically dependent on either a disability grant or family support.

Difficulties relating to alcohol, drugs, and accommodation or criminal records were not significantly reported. No report of significance regarding depression arose.

Regarding sexuality, more than half of the respondents indicated that they are sexually active, but practise safe sex. Respondents reported the use of condoms as the major means of practising safe sex.

Due to the sensitive matters surrounding HIV/AIDS/ART, respondents reported disclosure to family in preference to others. Among HIV/AIDS patients, their needs comprise socio-environmental problems as being the most prevalent.
The majority of patients require assistance in applying or reapplying for disability or foster grants. Deficits in external systems, such as the bureaucratic delays in the approval of grants, are primary barriers.

Disclosure was reported as a continuing issue. This could also be attributed to the fact that respondents are single. The lack of available or intact social support systems was also reported.

The majority of respondents do not show a particular need for counselling. It is evident from the research that the emphasis placed on counselling should focus on trained, skilled and experienced counsellors who can deliver a comprehensive service. The specific counselling needs reported was for adherence counselling.

Regarding quality of life, a large number of respondents expressed satisfaction with their current quality of life, and reported positive feelings and hope.

6.4.4 Psychological matters

Motivation for ART is discussed as an important determinant for adherence. Respondents reported their motivations to be to care for their families, stay alive, be physically stronger, be symptom free, and the fear of losing control.
Alternative healing methods and the influence of culture should not be underestimated, since these were reported to be significant by more than half of the patients.

The researcher is of the opinion that these findings indicate that the social work profession could focus on education and information, particularly with respect to women concerning their responsibility for their own health regarding safe sex.

These findings further call for education and information programmes regarding ART, in particular, those that target men, since a contributing factor to this could be that there is no active case finding programmes for men, such as the PMTCT programmes for women. Since the current research indicates a need for active programmes that specifically focus on men, such as workplace programmes or, male wellness clinics, such a clinic could possibly be attached to an antenatal clinic, especially when one considers that for every pregnant

woman there must be a sexually active man that could be actively involved in or enrolled at such a clinic.

The researcher believes that with the adoption of the biopsychosocial model at the ARV Clinic, it will be possible to attend to the above findings, improve service delivery and in so doing enhance adherence to ART.

6.5 Final remark

In this chapter the findings from the quantitative, as well as the qualitative, part of the research were presented and discussed. In the following chapter the researcher will summarize the research process and the findings, draw conclusions and make recommendations.