ADHERENCE AND NON-ADHERENCE TO ANTIRETROVIRAL TREATMENT IN HIV POSITIVE PEOPLE IN PORT ELIZABETH

Kgomotso Quentinne Masokoane

Treatise submitted in partial fulfillment of the requirements for the degree of Magister Artium in Counselling Psychology in the

Faculty of Health Sciences at the Nelson Mandela Metropolitan University

December 2009

Supervisor: Dr Diane Elkonin
Declaration

I, the undersigned, hereby declare that the research hereby submitted by me for the Magister Artium Degree in Counselling Psychology at the Nelson Mandela Metropolitan University, is my own independent work and has not previously been submitted by me at another university/faculty. I furthermore, cede copyright of the research to the Nelson Mandela Metropolitan University.

________________________
Kgomotso Masokoane

________________________
Date
Dedication

This research is dedicated to the memory of my grandmother,

**Makabi Quentinne Masokoane**

*I miss you, Nkgono*

*May your soul rest in peace.*
ACKNOWLEDGEMENTS

I would like to extend my sincerest gratitude to the following people who helped me with this research:

- **My friends** Gaone Magogwe and Bonolo Ramphomane, for their assistance and understanding—especially during my antisocial moments when I had my nose in a book. I love you guys.

- **Ms Ottillia Brown** for her input and research material. It helped a great deal.

- **My supervisor**, Dr Diane Elkonin for her guidance, understanding and above all patience and care were greatly appreciated. She was the wind beneath my wings during this journey.

- **My family** for their continued support, love and unwavering confidence in my abilities and you are still a great source of inspiration and motivation for me. I love you.

- All those who took out the time to complete the questionnaires—none of this would be possible without you.

- The Somtsewu family. Thank you for accommodating me when I needed somewhere to lay my head. You welcomed me into your family and I see you as my second family. Your assistance with this study is very much appreciated.

- Cynthia Busakwe. Sisi, thank you very much for all your assistance and letting me invade your office when I desperately needed assistance.

- **The Almighty**, without whom none of this would have been possible. Thank you for the daily blessings, continued health and strength that helped me through the trying and tiring moments.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>DECLARATION</td>
<td>ii</td>
</tr>
<tr>
<td>DEDICATION</td>
<td>iii</td>
</tr>
<tr>
<td>ACKNOWLEDGEMENT</td>
<td>iv</td>
</tr>
<tr>
<td>LIST OF FIGURES</td>
<td>ix</td>
</tr>
<tr>
<td>LIST OF TABLES</td>
<td>x</td>
</tr>
<tr>
<td>ABSTRACT</td>
<td>xi</td>
</tr>
</tbody>
</table>

## CHAPTER 1: INTRODUCTION AND PROBLEM STATEMENT

1.1. Introduction 1
1.2. Theoretical overview 1
1.2.1. The Health Belief Model 2
1.2.2. The Theory of Reasoned Action 3
1.2.3. The Theory of Planned Behaviour 4
1.3. Problem statement 5
1.4. Aim of the study 5
1.5. Chapter overview of the study 6
1.6. Conclusion 6

## CHAPTER 2: HIV/AIDS, ANTIRETROVIRAL TREATMENT AND ADHERENCE

2.1. Introduction 7
2.2. HIV/AIDS in Sub-Saharan Africa 8
2.3. HIV/AIDS in South Africa 9
2.4. Antiretroviral treatment and Adherence 11
2.4.1. Antiretroviral agents 11
2.4.2. Adherence in HIV/AIDS 14
2.4.3. Adherence and ARVs 16
2.5. Methods for assessing adherence 17
2.5.1. Asking the clinician 17
2.5.2. Patient self-reports 18
2.5.3. Incidences of missing or forgetting to take pills 18
2.5.4. Assays of drug levels 19
2.5.5. Electronic Monitoring Systems 19
2.6. Conclusion 20

CHAPTER 3: THE HEALTH BELIEF MODEL
3.1. Introduction 21
3.2. Theoretical framework: The Health Belief Model 21
  3.2.1. Development of the Health Belief Model 21
  3.2.2. Variables of the Health Belief Model 23
3.3. Health Belief Model Constructs 25
  3.3.1. Perceived Susceptibility 25
  3.3.2. Perceived Seriousness 26
  3.3.3. Perceived benefits of and barriers to taking action
      3.3.3.1. Benefits 26
      3.3.3.2. Barriers 26
  3.3.4. Self-efficacy 27
  3.3.5. Cues to Action 28
3.4. Application of the Health Belief Mode in adherence research 29
3.5. Advantages and Limitations of the Health Belief Model 29
3.6. Conclusion 30

CHAPTER 4: RESEARCH DESIGN AND METHODOLOGY
4.1. Introduction 31
4.2. Primary Aim of the Study 31
4.3. Research Design and Methodology 31
  4.3.1. Quantitative Research 31
  4.3.2. Exploratory-Descriptive Research 32
  4.3.3. Questionnaires as a Survey Method 33
4.4. Participants and Sampling Procedure 34
4.5. Measures 35
  4.5.1 Biographical Section 35
### 4.5.2. Health Beliefs and Adherence Section

### 4.6. Procedure

### 4.7. Data Analysis

### 4.8. Ethical Considerations

- 4.8.1. Informed Consent
- 4.8.2. Coercion
- 4.8.3. Privacy and Confidentiality

### 4.9. Conclusion

---

### CHAPTER 5: RESULTS AND DISCUSSION

5.1. Introduction

5.2. Biographical description of the sample

- 5.2.1. Gender
- 5.2.2. Age
- 5.2.3. Ethnicity
- 5.2.4. Home Language
- 5.2.5. Marital Status
- 5.2.6. Employment
- 5.2.7. Salary/ per month

5.3. Results of the measures

- 5.3.1. Section B: Health
- 5.3.2. Section C: Treatment
- 5.3.3. Section D: Support System

5.4. The Health Belief Model applied to the results

5.5. Conclusion

---

### CHAPTER 6: RECOMMENDATIONS, LIMITATIONS AND CONCLUSION

6.1. Introduction

6.2. Aims of the study revisited

- 6.2.1. The factors influencing adherence treatment
  - 6.2.1.1. Unemployment/Poverty
  - 6.2.1.2. Substance abuse
6.2.1.3. Support  62
6.3. Value of the research  62
6.4. Limitations of the research  63
6.5. Recommendations  64
6.6. Conclusion  65

REFERENCES  66

APPENDICES  79
    APPENDIX A: Cover letter for permission to conduct research
    APPENDIX B: Cover letter for participants
    APPENDIX C: Consent form
    APPENDIX D: Biographical and Health Beliefs Questionnaire
List of Figures

Figure 1: Provincial distribution of new HIV infections and AIDS related deaths for 2008 10
Figure 2: Number of people on antiretroviral treatment in low- and middle-income countries 13
Figure 3: Conceptual Model of the Health Belief Model 24
Figure 4: Alcohol consumption of participants 49
Figure 5: CD4 count at start of ARV treatment 50
Figure 6: Number of years on treatment 52
List of Tables

Table 1: Estimates for adults and children affected by HIV/AIDS in Sub-Saharan Africa 9
Table 2: Eastern Cape AIDS and AIDS statistics 11
Table 3: Gender distribution of participants 43
Table 4: Age distribution of participants 43
Table 5: Ethnic distribution of participants 44
Table 6: Home Language distribution of participants 44
Table 7: Marital status distribution of participants 45
Table 8: Employment distribution of participants 46
Table 9: Income distribution of participants 46
Table 10: Mean and Standard deviation of Health section 47
Table 11: Percentage of Health responses 48
Table 12: Mean and Standard deviation of Treatment section 51
Table 13: Percentage of Treatment responses 53
Table 14: Mean and Standard deviation of Support section 55
Table 15: Percentage of Support responses 56
Abstract

The introduction of antiretroviral drugs (ARVs) in 1996 transformed the treatment of HIV and AIDS, improving the quality and greatly prolonging the lives of many infected people. HIV (Human Immunodeficiency Virus) is the virus that is believed to cause AIDS. AIDS (Acquired Immune Deficiency Syndrome) is the collection of illnesses or symptoms that ultimately results in death. Antiretroviral (ARVs) drugs or Highly Active Antiretroviral Therapy (HAART) is the treatment that has been applied to combat the HI virus in a bid to slow down the progression of AIDS and ultimately prolong the life of the infected individual.

The study aimed to explore and describe the factors contributing to adherence and non-adherence to ARVs in individuals on treatment. A sample of 81 individuals who have been on ARV and HAART treatment for six months or more was used. The methodology used was exploratory-descriptive and the data obtained was quantitative in nature. A biographical questionnaire and questionnaire with questions aimed at ascertaining the possible factors that contribute to individuals either adhering to or defaulting on their treatment, such as side effects and cost of treatment, was administered. The data obtained was analysed by means of descriptive statistics and frequency counts.

The results of the study showed that the sample had a fairly high level of adherence. The factors that could undermine adherence were identified as lack of support, as familial and health provider support acts as a motivator to adhere; substance abuse as it can lead to forgetting to take treatment; unemployment and poverty, as these can lead to an inability to return for follow up clinic visits or failure to have food to take with the pills; and the type of treatment regimen whereby the more complex the treatment is the more likely it is that adherence will be difficult to maintain. Suggestions were made as to future research involving antiretroviral therapy (ART). Finally the limitations as well as the value of the research were outlined.

Key words: Human Immunodeficiency Virus (HIV), Acquired Immune Deficiency Syndrome (AIDS), Antiretroviral (ARV), Highly Active Antiretroviral Treatment (HAART), adherence, non-adherence, antiretroviral therapy (ART)
CHAPTER 1

Introduction and Problem Statement

1.1. Introduction

In this chapter, an overview of the theory underlying the research is provided. The motivation for the study is outlined and a literature review against which the study will be viewed is presented. The aims of the study are discussed and the chapter ends with an outline of the chapters that are to follow. It should be noted that only a macro theoretical outline is covered in this chapter to provide a context for understanding of the broader theoretical framework on which the study is based. A more comprehensive theoretical review follows in chapter 3.

1.2. Theoretical Overview

When attempting to identify and understand the factors influencing drug adherence or non-adherence, health psychology is the discipline that has theories and models that contextualise them. Health psychology was formally recognised in 1979 when the American Psychological Association approved the formation of the division of health psychology (Division 38) (Sheridan & Radmacher, 1992) and is a branch of psychology that is concerned with an individual’s behaviours and lifestyle as well as the effect that these have on his/her physical health. The field of health psychology emerged as a result of the growing movement away from the conceptualisation of health as simply the absence of disease. The World Health Organisation (2007) has defined health as not only the absence of disease but has also embraced the concept of quality of life and a state of complete physical, mental and social well-being.

Health psychology therefore incorporates psychology’s contributions to the improvement of health, the treatment and prevention of disease, identification of health
risk factors, the enhancement of the health care system and the shaping of public opinion regarding health (Brannon & Feist, 2000). As mentioned, health psychology provides models and theories of adherence to health behaviour. These models include the health belief model, the theory of reasoned action and the theory of planned behaviour. These models are briefly outlined below:

1.2.1. The Health Belief Model

The HBM is a psychological model that attempts to explain and predict health behaviours by focusing on the attitudes and beliefs of individuals. The HBM was first developed in the 1950’s by social psychologists Hochbaum, Rosenstock and Kegels working in the American Public Health Services (Conner & Norman, 1996) in response to the failure of a free tuberculosis health screening programme. Since then, the HBM has been adapted to explore a variety of long- and short-term health behaviours, including sexual risk behaviours and the transmission of HIV/AIDS. Since the early work of Geoffrey Hochbaum, several versions of the health belief model have been devised. The one that has attracted the most attention and generated the most research is that of Marshall Becker and Irwin Rosenstock (Strecher, Champion & Rosenstock, 1997).

The HBM is based on the assumption that a person will take a health-related action if that person feels or believes that a negative health condition can be avoided, has a positive expectation that by taking a recommended action, he/she will avoid a negative health condition (i.e. progressing to the final stages of AIDS) and believes that he/she can successfully take a recommended health action (i.e. can take treatment comfortably and with confidence).

The HBM comprises four constructs that represent the perceived threat and net benefits: These are (1) perceived susceptibility to disease, (2) perceived severity of the disease or disability, and (3) perceived barriers to health-enhancing behaviours. These concepts were proposed as accounting for people’s “readiness to act” (Conner & Norman, 1996: p. 53). The fourth concept, cues to action, was added to activate that readiness and stimulate overt behaviour. The HBM assumes that these four interactive belief states influence compliance to health-related behaviours.
The Health Belief Model has been used more than most other health behaviour models (Strecher, Champion & Rosenstock, 1997). The HBM suggests that patients who know most about a disease and its consequences should be more compliant than patients who are less knowledgeable. However, a study by Katz and Ashmore et al. (1998), found that dialysis patients who knew most about kidney disease were somewhat less likely to comply with established health practices than were patients with less knowledge of their disease. On a more positive note, a summary of earlier research (Strecher, Champion & Rosenstock, 1997) revealed some support for the HBM, with perceived barriers being the strongest and perceived severity of the disease the weakest predictor of the dimensions. Some studies have found the HBM to predict safe sex behaviours (Abraham & Sheeran, 1994; Zimmerman & Olson, 1994). However, studies that show the strongest predictive value of the HBM generally used an expanded version of the model, including cues to action, self efficacy, intentions to behave and perceived social norms. As a result, some researchers have begun to combine aspects of the health belief model with concepts from other models, including the theory of reasoned action.

This model has been used for this study as a theoretical framework to explore and explain the ability of certain individuals to adhere to their antiretroviral treatment while others are unable to do the same.

1.2.2. The theory of reasoned action

The theory of reasoned action assumes that people are quite reasonable and make systematic use of information when deciding how to behave. Furthermore, they “consider the implications of their actions before they decide to engage or not engage in a given behaviour” (Ajzen, 1985, p.5). A further assumption made by the theory is that behaviour is directed toward a goal or outcome and that people freely choose those actions that they believe will move them in the direction of that goal. They can also choose not to act if they believe that such an action would move them away from their goal.

The immediate determinant of the behaviour is the intention to act or not to act. These intentions are in turn shaped by two factors. The first one is one’s attitude toward the behaviours—that is personal evaluation of the behaviour. A person’s attitude can be determined by beliefs that the behaviour will lead to positively or negatively valued
outcomes. The second factor is one’s subjective norm - which is one’s perception of the social pressure to perform or not perform the action. The subjective norm is shaped by one’s perception of the evaluation that a particular individual places on that behaviour and one’s motivation to comply with the norms set by that individual.

The theory of reasoned action is useful in predicting certain health-related behaviours, including use of mammograms, breast self examination and attendance at health-information classes. In the study on mammograms by Montaña, Thompson, Taylor and Mahloch (1997) the intention to perform was a strong predictor of behaviour. However, past performance may be an even more powerful predictor of future performance. Although the study did not directly compare the usefulness of the theory of reasoned action with the health belief model, the results indicate that the theory of reasoned action is at least as adequate as the health belief model in explaining and predicting health-seeking behaviours. A key element in the theory of reasoned action seems to be the intention to perform behaviour.

1.2.3. The theory of planned behaviour

The theory of planned behaviour is an extension of the theory of reasoned action. Ajzen included the concept of perceived behavioural control. The primary difference between the theory of reasoned action and the theory of planned behaviour is the latter’s inclusion of the perception of how much control people have over their behaviour. The more resources and opportunities people believe they have, the stronger are their beliefs that they can control their behaviour. Predictions of behaviour can be made from 1) people’s attitude toward the behaviour, 2) their subjective norm and 3) their perceived behavioural control. All three components interact to shape people’s intentions to behave.

Perceived behavioural control is the ease or difficulty that one has in achieving desired behavioural outcome. It reflects both past behaviour and perceived ability to overcome obstacles. Perceived behavioural control works directly when the person has actual control over their behaviour. It operates indirectly to shape behaviour by influencing people’s intention to behave. The theory assumes that people who believe they can easily perform certain behaviours are more than likely to intend to perform that
behaviour than people who believe they have little control over performing that behaviour.

1.3. Problem Statement

The introduction of antiretroviral drugs (ARVs) or Highly Active Antiretroviral Therapy (HAART) in 1996 transformed the treatment of HIV and AIDS by improving the quality of and also greatly prolonging the lives of the many infected people in places where the drugs are available (UNAIDS, 2007). However, in low- and middle-income countries, especially Sub-Saharan Africa where the epidemic is most severe, only a minute proportion of infected individuals have access to the drugs. By September 2006, out of an estimated million (1 000 000) South Africans that needed antiretroviral therapy, only 181 754 were reported to be receiving it (WHO, 2007). However, access does not always mean that the individuals are compliant with their treatment. Research conducted by Bangsberg et. al. (2001) and Chesney (2000) suggested that this is due to scepticism about the effectiveness of the treatment as well as physical barriers among others. Because the study of adherence is in its infancy, study designs and end points vary widely, making study difficult.

This study will focus on both the external and internal factors that promote or prevent an individual’s ability to adhere to their antiretroviral treatment. On reviewing past literature on adherence it became evident that most research focused on TB or cancer treatment and most of the literature on antiretrovirals was based in overseas countries.

1.4. Aim of the study

Having set the stage for the motivation of this study, the main aim of the study is to explore and describe the factors contributing to adherence and non-adherence of HIV positive individuals to antiretroviral treatment.
1.5. Chapter Overview of the Study

Chapter 1 serves an introduction to the present study and outlines contextual background against which the study was conducted. The Health Belief Model is briefly explained and the motivation for this study outlined.

Chapter 2 looks at HIV/AIDS in the South African context. Antiretroviral treatments are discussed with regards to present literature as well as adherence to treatment. Factors that may affect adherence are discussed as well as known methods of monitoring a patients’ adherence levels are outlined.

Chapter 3 focuses on a detailed outline and discussion of the Health Belief Model in relation to adherence and non-adherence to antiretroviral treatment.

Chapter 4 outlines the research design and methodology of the present study. The sampling procedure, data analysis, and procedure followed in conducting the research are outlined. Ethical considerations in terms of the present study are also reviewed.

Chapter 5 outlines the results of the research. These results are discussed in relation to the literature.

Chapter 6 provides conclusions and recommendations based on the results of this research. The possible limitations of the research are also outlined in this chapter.

1.6. Conclusion

This chapter provides an introduction as well as an overview of this study. In so doing, it is the basis from which this study flows as it clearly states what this study entails.
CHAPTER 2

HIV/AIDS, Antiretroviral treatment and Adherence

2.1. Introduction

HIV/AIDS was first recognised on 1 December 1981 and has since become one of the most destructive pandemics in recorded history (Joint United Nations Programme, 2006). It was initially thought to be a gay-only disease and dubbed GRID (Gay-Related Immune Deficiency) but health authorities soon realised that nearly half of the people identified with the syndrome were not homosexual men. In 1982, the term AIDS (Acquired Immune Deficiency Syndrome) was introduced by the CDC (Centres for Disease Control and Prevention) to describe the syndrome. There are three main transmission routes identified for HIV: 1) sexual route, 2) blood or blood product route and 3) mother-to-child transmission. A HIV antibody test is used to ascertain the status of an individual in the form of either an ELISA test or a Polymerase Chain Reaction (PCR) test, which are both effective and reliable (Soul City, 2004). Over the years HIV/AIDS has progressed to be one of the biggest killers, especially in Sub-Saharan Africa (UNAIDS/WHO, 2007) where AIDS remains the leading cause of death.

There is currently no cure or vaccine for HIV/AIDS, but it is no longer the death sentence it once was. However, an antiretroviral treatment, known as post-exposure prophylaxis is believed to reduce the risk of infection if begun directly after exposure. The current treatment for HIV consists of antiretrovirals (ARVs) or Highly Active Antiretroviral Treatment (HAART). Since the introduction of ARVs in 1996 they have been highly beneficial for HIV infected individuals by reducing both the mortality and morbidity of the infection, but routine access to antiretroviral medication is not available in all countries.

It is estimated that adherence rates lower than 95% are associated with the development of viral resistance to antiretroviral medications (Nachega et. al., 2007). The first-line antiretroviral regimens now being taken in resource-limited settings are based
on nevirapine or efavirenz. Resistance to either drug can develop very easily if doses are missed (Alcorn, 2007). Therefore it is essential that patients do not miss more than three doses a month for a twice-daily regimen, and maintaining that level of adherence year after year.

2.2. HIV/AIDS in Sub-Saharan Africa

HIV (Human Immunodeficiency Virus) is considered to be the virus that causes AIDS. AIDS is the collection of illnesses or symptoms that ultimately result in death. In HIV-infected people, there is a weakening of the immune system caused by a gradual loss of CD4 positive T-cells which are the white blood cells that control the body’s immune response to disease (Soul City Institute for Health and Development Communication, 2004). This takes place over a long period during which the person is HIV positive (i.e. carrying the HI virus) but looks and feels well. It may take anything from 5-15 years before the immune system becomes weakened and symptoms of AIDS appear.

The danger from AIDS comes from the opportunistic infections that start when the immune system no longer functions effectively. As the immune system weakens, the person becomes vulnerable to opportunistic infections and each new infection wears down the body’s defences (Vincke & Bolton, 2002). These infections and cancers, such as fungal infections, Pneumocystis carinii Pneumonia (PCP) and Kaposi’s sarcoma (KS) are the real causes of death in HIV positive people. The weaker the person’s immune system, the shorter the life of the AIDS sufferer. Presently, two variants of the HI virus have been discovered, HIV-1, identified in 1984, causes most AIDS cases in the United States, and HIV-2, identified in 1985, is responsible for most AIDS cases in Africa, although some HIV-2 cases have appeared in the USA (Ogden, 2001).

HIV transmission in sub-Saharan Africa takes place mainly through heterosexual contact and, to a lesser extent through mother to child transmission. Intravenous drug infection and homosexual contact infection have a minimal effect on this region. Women are more affected by HIV in sub-Saharan Africa, with a prime reason being that transmission from male to female takes place more easily than female to male
transmission. Younger females, aged 15 to 19 years old are six times more likely to be infected than males, and this is often attributed to the practice of older men having sex with younger girls, as well as the fact that women are less likely to determine where, when and if sex takes place (UNAIDS, 1999).

2.3. HIV/AIDS in South Africa

The first recorded case of AIDS in South Africa was diagnosed in 1982, and although initially HIV infections seemed mainly to be occurring amongst gay men, by 1985 it was clear that other sectors of society were also affected. According to UNAIDS (2007) statistics, an estimated 5.5 million South Africans are living with HIV and AIDS, which represents about 12 percent of the population. With 1800 new infections occurring daily and 1700 AIDS related deaths daily, South Africa has the largest number of HIV positive people in the world. It is further estimated that by 2010 over 1 million people will be HIV positive, while 6 million will have died. The life expectancy in this country will drop to the age of 45 by 2010, compared with 70 years without AIDS, and 1 million children will be orphaned (Cichocki, 2007).

Table 1: Estimates for adults and children affected by HIV/AIDS in Sub-Saharan Africa

<table>
<thead>
<tr>
<th>ADULTS AND CHILDREN:</th>
<th>ESTIMATED NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Living with HIV in 2007</td>
<td>22.5 million</td>
</tr>
<tr>
<td>Newly infected with HIV during 2007</td>
<td>1.7 million</td>
</tr>
<tr>
<td>Deaths from AIDS during 2007</td>
<td>1.6 million</td>
</tr>
</tbody>
</table>

(UNAIDS/WHO, 2007)
South Africa is the country with the largest number of HIV infections in the world. The region accounts for 35% of all people living with HIV, one third (32%) of all new infections and AIDS deaths globally in 2007. At the end of 2007, there were approximately 5.7 million people living with HIV in South Africa, and almost 1,000 AIDS deaths occurring every day (UNAIDS/WHO, 2008). However the latest data gathered from the latest round of antenatal clinic surveillance suggests that HIV infection levels might be levelling off, with prevalence among pregnant women at 30% in 2005 and 29% in 2006 (Department of Health South Africa, 2007). In addition, the decrease in prevalence among young pregnant women (15-24 years) suggests a possible decline in the annual number of infections. The epidemic varies considerably between provinces, from 15% in the Western Cape to 39% in the province of KwaZulu-Natal. Table 1 gives the overall estimates of individuals living with, infected with and deceased as a result of HIV/AIDS in Sub-Saharan Africa in 2007.

Figure 1: Provincial distribution of new HIV infections and AIDS related deaths for 2008
The Eastern Cape, Western Cape, Northern Cape and Limpopo are further away from reaching the number where new infections and deaths will level off. The gap between new infections and deaths are higher in these provinces (see Figure 1). The HIV epidemic is still rapidly growing in these provinces where as in the other provinces the epidemic has stabilized with new infections and deaths cancelling out.

Table 2: Eastern Cape AIDS statistics

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Whole population</td>
<td>11%</td>
</tr>
<tr>
<td>Antenatal clinic estimate</td>
<td>29%</td>
</tr>
<tr>
<td>Adults (ages 20-64)</td>
<td>20%</td>
</tr>
<tr>
<td>People living with HIV</td>
<td>729,000</td>
</tr>
<tr>
<td>New HIV infections (over the year)</td>
<td>81,000</td>
</tr>
<tr>
<td>AIDS deaths (over the year)</td>
<td>44,000</td>
</tr>
<tr>
<td>Total people in need of ART (mid year)</td>
<td>111,000</td>
</tr>
</tbody>
</table>

The Eastern Cape has the third largest number of HIV positive people in the country. A total of 730 000 people (11% of the population) and one in every 5 adults are estimated to be HIV positive in 2008. The epidemic in the Eastern Cape has not reached a mature phase yet and is still growing (Nicolay, 2008).

2.4. Antiretroviral Treatment and Adherence

2.4.1. Antiretroviral Agents

As previously stated, antiretroviral agents (ARVs) are the treatments that have been applied to combat the HI virus in a bid to slow down the progression of AIDS and ultimately prolong the life of the infected individual. When the patient’s CD-4 count
reaches 200 or lower and their condition is life-threatening, it is recommended that they go onto a course of antiretrovirals (UNAIDS/WHO, 2006).

The drugs come in a variety of formulations designed to act on different stages of the life-cycle of HIV (Chesney, 2000; Stanic & Schneider, 2005). The AIDS virus mutates rapidly, which makes it extremely skilful at developing resistance to drugs. Thus, to minimise this risk it is essential for people with AIDS to be treated with a cocktail of ARVs that attack the virus on several fronts at once. There are up to as many as 250 possible combinations of “cocktails” with AZT or similar drugs such as HAART. In developed countries where ARVs are available, doctors assess their patients thoroughly: measuring the viral load, how fast their CD4 count declines and patient readiness for the treatment. They can then decide when to recommend starting treatment (Department of Health and Human Services, 2005). ARVs have proven effective at treating people with AIDS. However, they are not a cure and if treatment is discontinued the virus becomes active again, so a person on ARVs must comply with the treatment regimen for life (UNAIDS/WHO, 2006). Turner and McIntyre (1999) stated that it would take at least 10 years of combination drug therapy to kill off all the HIV in an infected person’s body, but that a sizeable percentage of HIV patients will never get close. Many of the patients can not tolerate the side effects of these cocktails and measurements show that the DNA “viral” burden does not decrease significantly (i.e. there is no viral suppression). This means that people taking ARVs will be on treatment for all their lives with the treatment having to be changed at intervals to avoid the body developing tolerance to the drugs thus making them ineffective. The toxicity of these drugs also makes it unlikely that anyone can take them for more than a few years (Garrett, 1999).

ARVs or HAART entail a cocktail of three drugs, typically entailing at least one nucleoside analogue reverse transcriptase inhibitor (NRTI), such as emtricitabine (Emtriva), and one non-nucleoside reverse transcriptase inhibitor (NNRTI). Both sets of drugs interfere with the reverse transcriptase enzyme, which is crucial for the early stage reproduction of the AIDS virus (Nattrass, 2003). NNRTIs attach themselves directly to the enzyme, and NRTIs are incorporated into the DNA strand created by the enzyme, thereby halting further growth of the sequence. The net result is that the reproduction of the AIDS virus is slowed dramatically (viral-loads typically fall to undetectable levels),
thus giving the immune system a chance to recover (Department of Health and Human Services, 2005). The internationally recommended HAART regimen entails two lines of treatment - i.e. two different triple therapy cocktails. This is in order to address problems related to toxicity, resistance and treatment failure.

In Africa the number of people on antiretroviral therapy more than doubled in 2005 alone, with roughly one in six people who needed treatment receiving antiretrovirals by December 2005. As a result of the South African government’s roll-out strategies, in only six years the number of people receiving antiretroviral medicines in low- and middle-income countries has increased ten-fold, reaching almost 3 million people by the end of 2007 (Figure 2).

![Figure 2: Number of people receiving antiretroviral treatment in low- and middle-income countries, 2002-2007](UNAIDS/WHO, 2008:17).

The South African government was initially hesitant about providing antiretroviral treatment to HIV-positive people, and only started to supply the drugs in 2004 – years after many other nations had begun to do so – following pressure from AIDS activists. Even since 2004, the distribution of antiretroviral drugs has been relatively slow, with only around 28% of people in need receiving treatment at the end of 2007. The slow provision of treatment has been linked to unconventional views about HIV and AIDS
amongst the South African government (WHO, 2008). In South Africa, the country with the largest population of people living with HIV, the number of people receiving ARVs grew from fewer than 5000 at the beginning of 2004 to roughly 190 000 by the end of 2005 (UNAIDS/WHO, 2006). Worldwide, it is estimated that between 250 000 and 350 000 deaths were averted in 2005 as a result of increased treatment access.

Sustaining effectiveness of antiretroviral therapies over time requires minimizing the risk of the virus becoming resistant to the drugs used to treat the infection. Resistant strains of HIV can be transmitted to others, potentially foreclosing or impeding the effectiveness of future treatment options for individuals who are newly infected (Stanic & Schneider, 2005). Efforts to control tuberculosis, malaria and respiratory infections have each been impeded by the growth over time of resistance to first-line therapies, underscoring the potential long-term danger of drug resistance to the global HIV response (Bates, et. al., 2004; Norrby, Nord & Finch, 2005; Okere, et. al., 2005). To prevent or significantly delay the emergence of drug resistance, it is critical that patients follow antiretroviral regimens exactly as prescribed. Adherence of 90% or greater is required to suppress viral activity and minimise drug resistance over time (Paterson et. al., 2000). Discontinuation or interruption of therapy is more dangerous than periodic non-adherence (Lucas, 2005).

2.4.2. Adherence in HIV/AIDS

Wikipedia free encyclopaedia defines compliance or adherence in a medical context and refers to a patient agreeing to and then undergoing some part of a treatment program as advised by a doctor or other healthcare worker. Andrews and Friedland (2000, p.1) define it as “the act of taking medications as prescribed...a highly complex clinical behaviour”. It has also been defined as “the extent to which a person’s behaviour (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical advice” (Haynes, 1979, p.2). This definition expands the concept of compliance beyond merely taking medications and includes maintaining healthy lifestyle practices, such as eating properly, getting sufficient exercise, avoiding undue stress, abstaining from smoking cigarettes, not abusing alcohol and always practising safer sex.
The word “adherence” is preferred by many health care providers, because “compliance” suggests that the patient is passively following the doctor’s orders. It is preferred that patients are not passive but rather follow a treatment plan based on a therapeutic alliance or contract between the patient and the physician (Levine, 1998). Practitioners and researchers alike recognise that patient adherence is associated with better outcomes than patient compliance. For the purpose of this research the term “adherence” is used rather than “compliance” although the researcher recognises that they are often used interchangeably.

An estimated half of patients who have been prescribed medicines do not take them in the recommended way (Levine, 1998). This may affect the health of patients when this lack of compliance results in complications from chronic diseases, formation of resistant infections, or untreated psychiatric illness. Patients may not accurately report back to their healthcare workers for fear of possible embarrassment, being chastised or seeming to be ungrateful for a doctor’s care.

Adherence can be improved by taking care to explain the benefits and adverse effects of a drug (Carter, 2004). In a busy clinic it is too easy for the prescribing healthcare worker or physician to give out a prescription with little or no explanation. Reducing the frequency of taking the medicine to once or twice a day can also help to improve adherence.

Once started, patients seldom take their medication as often as they should and seldom complete the course of treatment (Paterson et. al., 2000). It may prove difficult for a patient to remember to take their pills several times a day as they may forget due to the treatment not fitting into their daily schedule. On the other hand if the course of treatment works then the patient may feel that they do not need any more medication because the symptoms are gone and as a result they stop taking it. Negative side-effects and concerns over the long-term effects of treatment can also lead to a patient deciding to stop treatment. Others quit when the treatment is taken over a long period of time. It is important to note that the risk of a patient stopping long-term treatment grows greater when that treatment stabilises a condition, rather than giving relief from symptoms (Carter, 2004).
2.4.3. Adherence and ARVs

Adherence is the key to the effectiveness of the antiretroviral therapy because, in order to ensure that the viral load in a patient is kept at undetectable levels, high levels of adherence are required (Altice & Friedland, 1998; Bangsberg et al., 2001). In an acute illness, the rewards or benefits of complying with therapy are immediately apparent to the patient, thereby creating a sense of accomplishment that reinforces adherent behaviour (Hecht, 1998). Such a reinforcement may be lacking or may diminish over time in chronic diseases, as patients are required to remain adherent for prolonged or indefinite periods of time. Maintaining good adherence among patients requires vigilance. Research in Nigeria conducted by the University of Abuja Hospital and the University of Maryland Institute of Human Virology, found that one in five patients reported adherence of less than 95% (judged by how promptly people came back for more tablets, the so-called refill rate) (Farley, 2007).

Due to the complex drug regimen that AIDS patients are given, significant challenges are experienced by both the patient and the health-care providers with respect to adherence. Without adequate adherence, antiretroviral agents are not maintained at sufficient concentrations to suppress the HIV replication in infected cells and to lower the plasma viral load (Chesney, 2000). Poor adherence is associated with poor short-term virological response and accelerates development of drug resistant HIV. The principal factors associated with non-adherence appear to be patient-related, including substance and alcohol abuse. However, other factors may also contribute such as inconvenient dosing frequency, dietary restrictions, pill burden, and side effects; patient-health-care provider relationships; depression and psychiatric illness; and the system of care (Paterson et al., 2000). Although the price of ARVs has decreased, their cost also remains an obstacle to treatment access in the developing world (UNAIDS, 2006).

A growing body of evidence suggests that social and psychological variables, including social support, are amongst the most significant factors that influence adherence to medical therapy (Janis, 1983; Levy, 1995). Other factors that were identified include severity of illness, side effects of the medication, duration of the treatment and the complexity of the treatment. Past studies in a non-HIV setting that included social support as a variable showed a positive correlation between social support and adherence.
HIV-infected patients, because of their physical debilitation and the psychosocial impact of their infection, remain particularly vulnerable to social isolation (Namir, Wolcott & Fawzy, 1989). The study by Bangsberg et al. (2001) found a strong relationship between the level of adherence to ARVs and the risk of progression to AIDS in a population-based cohort of HIV positive, urban adults with a high risk of non-adherence. This indicates that failure to obtain scheduled pharmacy refills is associated with a more rapid progression to AIDS and death.

In recent research by Sanjobo, Frich and Fretheim (2008) the results identified the following barriers to adherence to antiretroviral treatment: lack of communication and information about ART, inadequate time during consultations, lack of follow-up and counselling as well as forgetfulness.

By 2005 there were 25 antiretroviral agents (including fixed dose combinations) that gained approval from the Food and Drug Administration and are currently available on the market for the treatment of HIV-1 infection. These newly licensed ARVs allow for lower pill burden and dosing schedule simplification, which can help improve adherence.

2.5. Methods for assessing adherence

Adherence to therapy is difficult to measure accurately. One has to ask the following questions when assessing adherence (Brannon & Feist, 2000): Firstly, how do researchers know the percentage of patients who fail to comply with their physicians’ recommendations? Secondly, how can one identify non-compliant behaviours? The answer to the former is that compliance rates are not known with certainty, and that any reported percentage is usually only an estimate. For the latter, there are at least five basic techniques that have been developed for quantifying adherence, all of which have limitations (Chesney, 2000; Hecht, Colfax, Swanson & Chesney, 1998):

2.5.1. Asking the clinician

This is the poorest method of them all. Physicians generally overestimate their patients’ compliance rates, and even when their guesses are not overly optimistic, they
are usually wrong. In general, the accuracy of the estimates made by physicians and other health care practitioners is only slightly better than chance (Blackwell, 1997).

2.5.2. Patient self-reports

Asking the patients themselves is a more valid procedure, but it also fraught with many difficulties. The advantage of this is low costs and flexibility of design. The data is easily collected and can help determine reasons why patients are non-adherent. A major limitation is that they reflect only short-term or average adherence and may overestimate it, both in the HIV setting and non-HIV setting (Haynes, McKibbon & Kanani, 1998). Patients may also lie to avoid the disapproval of their health care provider; secondly, they may simply not know their own rate of compliance. While under-reporting of poor adherence is common, so is over-reporting of good adherence. In addition some patients take more medication than is recommended, whereas others take less (Brannon & Feist, 2000). Thus for these reasons self-report measures have questionable validity and should usually be supplemented by other assessment methods.

Some studies show significant relationships between data from self reports and viral-load. Other studies that compare data from self-reports to pill counts or electronic measurements found differences, suggesting that self-reports provide inflated estimates of adherence behaviour (Chesney, 2000).

2.5.3. Incidences of missing or forgetting to take pills (Pill counts)

Patient reports on any incidences of missing or forgetting pills are almost always reliable, so self-reports can be helpful for understanding the dynamics surrounding missed medication. Pill counts have been widely used and the return of excess pills provides tangible evidence of non-adherence. However, this requires that the patients return the pill packaging but they tend to forget or inadvertently discard them (Berg, Dunbar-Jacobs & Rohay, 1998).

HIV patients are prescribed a number of antiretroviral agents and would be required to bring the container of every medication during every clinic visit. Given the large number of antiretroviral pills prescribed, pill counting for the entire regimen can be cumbersome and time-consuming (Berg et. al., 1998). Furthermore, many of the patients utilise pill
boxes rather than taking pills directly from the bottles. There have also been reports that patients other than those with HIV, aware of pill counts being conducted, engage in “pill dumping” to appear adherent. As a result, pill counting typically overestimates adherence. In general, 10% of patients report missing at least one antiretroviral dose on any given day and 33% report missing at least one dose within the past month (Bangsberg et. al., 2001).

2.5.4. Assays of drug levels

Assays have been used in clinical trials to measure the last dose taken, however these are often impractical because of their expense and lack of general availability. These assays also measure only recent doses and thus provide limited data. Adherence may be overestimated if patients are more conscientious about taking their medication before a clinic visit (Chesney, 2000). This method can seem ideal as there can be few errors in counting the number of pills absent from a bottle or drug dispenser. However, it can also be inaccurate because even if the required numbers of pills are gone, the patient may not have been compliant. This could be due to the patient discarding some of the pills for whatever reason or the patient may have taken all the pills but in a manner other than the prescribed one.

2.5.5. Electronic monitoring systems

Electronic monitoring systems such as the Medication Event Monitoring System (MEMS) are inserted into medication bottle caps and contain computer chips that record the date and time of opening and closing the bottle. Interpretation assumes that a single dose is taken each time the bottle is opened and may lead to inaccuracies if multiple doses are removed at once (Olivieri, Matsui, Hermann & Koren, 1991). However, the expense of electronic monitoring devices can be considered prohibitive—especially if adherence is monitored for the whole regimen and not just one specific drug.

Despite the limitations of these measurement techniques, adherence data are providing valuable insight into the association between drug taking and viral load, as well as approaches that may be useful for improving adherence (Berg et. al., 1998). For the purposes of this research, patient self-reports will be used.
2.6. Conclusion

The introduction of ARVs has transformed HIV infection into a chronic manageable disease (Altice & Friedland, 1998). Their importance in improving and prolonging the lives of those infected by the HI virus is abundantly clear. However, it is equally important to remember that not all the infected have access to these lifesaving drugs. On the other hand, those who do have access do not always benefit due to personal circumstances that interfere with their ability to adhere to the treatment.

Despite remarkable progress in the treatment of HIV infection noted during the past decade, significant challenges to therapy such as tolerability issues and emergence of drug-resistant strains remain (Stanic & Schneider, 2005). Therefore, new drug development has and should continue to focus on a design of drugs that work against the resistant strains of HIV and/or have a novel mechanism of action.
3.1. Introduction

It would be easy to assume that with all the health related information available to people today, individuals would be willing and able to follow the “doctor’s orders’ as it “would be for their own good”. Daily, people are faced with having to make health related decisions such as whether to take their medication or not, stop smoking or to practice safe sex.

Individuals who are on antiretroviral treatment are faced with the same health decisions. The sometimes severe side-effects of the ARVs can result in an individual deciding that the benefits are not worth all the pain. The Health Belief Model (HBM) holds the premise that the benefits of a healthy lifestyle encourage people to follow positive health regimes. However, there are still individuals who do not follow their treatment religiously. Further understanding of the HBM can assist in exploring why it is easy for some individuals to take their treatment while it is difficult for others. This chapter provides literature on the Health Belief Model and explains the role it plays in adherence.

3.2. Theoretical Framework: The Health Belief Model

3.2.1. Development of the Health Belief Model

The Health Belief Model (HBM) is a psychological model that was originally developed as a systematic method to explain and predict health behaviours. This is done by focusing on the attitudes and beliefs of individuals. The HBM was first developed in the 1950’s by social psychologists Hochbaum, Rosenstock and Kegels working in the American Public Health Services (Conner & Norman, 1996). It focused on the
relationship of health behaviours, practices and utilization of health services. During this
time the US public health services had began developing models which would identify
appropriate targets for health education programmes (Rosenstock, 1966). The health
setting during the early 1950s for the US Public Health Service was primarily oriented
toward prevention of disease and not treatment of disease. Medical care, which was
largely considered appropriate public health work, was not the focus during that time.
Thus, the public health concern for problems connected with patient's symptoms and their
compliance with medical regimens was slight (Sheeran & Abraham, 1999). The
originators of the HBM were concerned rather with the widespread failure of individuals
to engage in preventive health measures. The underlying concept of the original HBM is
that health behaviour is determined by personal beliefs or perceptions about a disease and
the strategies available to decrease its occurrence.

The model is influenced by the theories of Kurt Lewin which state that it is the world
of the perceiver that determines what an individual will and will not do (Lewis, 1999).
The originators of the HBM conducted major studies in the 1950s and 1960s meant to
systematically explain preventive health behaviour. Godfrey Hochbaum initiated the first
research on the HBM in 1952 by an attempt to identify factors underlying the decision to
obtain a chest x-ray for the early detection of TB. Therefore, the model was developed in
response to the failure of a free tuberculosis health screening programme. Since then, the
HBM has been adapted to explore a variety of long- and short-term health behaviours,
including sexual risk behaviours and the transmission of HIV/AIDS. As with HIV
prevention programming such as condom use, delay of sexual activity and treating
sexually transmitted diseases, the general consensus regarding ARV adherence is that
given the facts and presented with alternatives, people will adhere (Kagee, 2008).

The Health Belief Model (HBM) much like the social learning theory (social cognitive
theory), self-efficacy and locus of control, have all been applied with varying success to
problems of predicting and influencing health behaviour (Rosenstock, Strecher & Becker,
1988). From various researches using the HBM, there is clear evidence that demographic
variables such as socioeconomic status, gender, ethnicity and age affected the extent to
which people would adopt preventive health behaviours or use health services
(Rosenstock, 1974).
It is clear that effective health education depended upon identifying how the different socialisation histories, indexed by demographic variables, led to individual differences in the propensity to undertake preventive action and follow medical advice (Sheeran & Abraham, 1999). This required measures of modifiable psychological characteristics which were correlated with health behaviour. Thus, individual beliefs offered the ideal link between socialisation and behaviour. Beliefs are enduring individual characteristics which shape behaviour and can be acquired through primary socialisation. However, they are not fixed and can differentiate between individuals from the same background, making them the archetypal social cognitive construct (Sheeran & Abraham, 1999).

3.2.2. Variables of the Health Belief Model

The HBM consists of variables that look at perceived susceptibility, severity, benefits and barriers. Incentive to behave (health motivation) is also a component of the model. Locus of control is not included explicitly because it is believed to be incorporated within other elements of the model. The HBM is based on the assumption that a person will take a health-related action (i.e. treatment-ARVs) if that person (Champion, 1984a):

1. feels that a negative health condition can be avoided,
2. has a positive expectation that by taking a recommended action, he/she will avoid a negative health condition (i.e. progressing to the final stages of AIDS) and
3. believes that he/she can successfully take a recommended health action (i.e. can take treatment comfortably and with confidence).
As indicated above the HBM comprises four constructs that represent the perceived threat and net benefits: (1) perceived susceptibility to illness or health breakdown, (2) perceived severity of the consequences of such illness, (3) perceived barriers to enacting the behaviour. These concepts were proposed as accounting for people’s “readiness to act” (Conner & Norman, 1996: p. 53). The fourth (4) concept, cues to action, was added to activate that readiness and stimulate overt behaviour. The model further proposed that cues to action can trigger health behaviour when appropriate beliefs are held. These “cues” included a diverse range of triggers including individual perceptions of symptoms, social influence and health education campaigns. A recent addition to the HBM has been the concept of self-efficacy, or one’s confidence in the ability to successfully perform an action (Champion, 1984a; Glanz, Lewis & Rimer, 1997). This concept was added by Rosenstock and others in 1988 to help the HBM better fit the challenges faced by individuals on chronic medication or changing an individual’s habitual unhealthy behaviour, such as being sedentary, smoking or overeating.
3.3. Health Belief Model Constructs

As mentioned previously, perceived susceptibility, perceived seriousness, perceived benefits and barriers to taking action, self-efficacy and cues to action have been used to serve as the main constructs of the HBM. Each of these perceptions, individuality or combined, can be used to explain health behaviours. An in-depth discussion of the above-mentioned constructs follows with examples of how they translate into real life situations:

3.3.1. Perceived Susceptibility

Personal risk or susceptibility is one of the more powerful perceptions in prompting people to adopt healthier behaviours. Each individual has his/her own perception of the likelihood of experiencing a condition that would adversely affect one's health. Individuals vary widely in their perception of susceptibility to a disease or condition. This construct holds that the greater the perceived risk, the greater the likelihood of engaging in behaviours to decrease the risk. This is what prompts men who have sex with men to be vaccinated against hepatitis B (de Wit et. al, 2005) and to use condoms in an effort to minimise susceptibility to HIV (Belcher et. al, 2005).

Logically, when people believe they are at risk of disease, they are more likely to do something to prevent it from happening. Unfortunately, the opposite also happens. When people believe they are not at risk or have a reduced susceptibility, unhealthy behaviours tend to occur. This was found in older adults and HIV prevention behaviour. Older adults generally don’t perceive themselves at risk for HIV infection and as result many do not practise safer sex (Maes & Louis, 2003; Rose, 1995). This was found to also be true for Asian-American college students. They tended to view HIV as a non-Asian problem and therefore they had a low susceptibility view to HIV infection. Therefore, they had a lower chance of practicing safer sex behaviours (Yep, 1993). With regards to adherence to ARVs, the individual must believe that he or she is susceptible to HIV disease progression if the treatment is not taken as prescribed.
3.3.2. **Perceived Seriousness**

This refers to the beliefs a person holds concerning the effects and seriousness of a given disease or condition. While the perception of seriousness is often based on medical information or knowledge, it may also come from beliefs a person has about the difficulties a disease would create or the effects it would have on his or her life in general (McCormick-Brown, 1999), for instance, pain and discomfort, loss of work time, financial burdens, difficulties with family, relationships, and susceptibility to future conditions. It is important to include these emotional and financial burdens when considering the seriousness of a disease such as HIV.

3.3.3. **Perceived benefits of and barriers to taking action**

3.3.3.1 **Benefits**

Taking action toward the prevention of disease or toward dealing with an illness is the next step to expect after an individual has accepted the susceptibility of a disease and recognized it is serious. The direction of action that a person chooses will be influenced by the beliefs regarding the action. People tend to observe healthier behaviour when they believe the new behaviour will decrease their chances of getting a disease. With breast cancer, it is a known fact that the earlier the cancer is found the greater the chances of survival. It is also known that a breast self exam (BSE), when done regularly, is an effective means of early detection. An individual has to believe that adopting this behaviour is beneficial (Graham, 2002). In HIV, the individual’s belief that adherence to ARVs will reduce their susceptibility to HIV disease progression is essential in determining the level of adherence.

3.3.3.2. **Barriers**

However, action may not take place, even though an individual may believe that the benefits to taking action are effective. This may be due to barriers. Barriers relate to the characteristics of a treatment or preventive measure which may be inconvenient, expensive, unpleasant, painful or upsetting. These characteristics may lead a person away from taking the desired action. In order for a new behaviour to be adopted people have to
believe that the benefits far outweigh the consequences of continuing the old behaviour (Centres for Disease Control and Prevention, 2004). With all the benefits to doing a regular BSE, the barriers to performing it exert a greater influence over the behaviour than does the cancer itself (Champion, 1993; Champion & Menon, 1997; Umeh & Rogan-Gibson, 2001). Some of these barriers include difficulty with starting a new behaviour or developing a new habit, fear of not being able to perform BSE correctly, carrying having to give up things in order to do BSE, and embarrassment (Umeh & Rogan-Gibson, 2001). These barriers translate to ARV adherence when the individual believes that the materials, physical and psychological costs of adhering to ARVs outweigh the benefits they are less likely to follow their treatment as prescribed.

Other barriers identified through research conducted by Kagee (2008) in South Africa are poverty, poor health literacy, stigma and fear. With poverty, financial resources may need to be redirected elsewhere and thus patients may be unable to pay for transport to ARV clinics. The stress associated with poverty and difficult life circumstances may encourage non-adherence (Simoni, Frick, Lockhart & Liebovitz, 2002). Poor health literacy and minimal knowledge about HIV have been associated with low levels of understanding of medical instructions and adherence to ARVs (Kalichman, Benotsch, Suarez, Catz & Miller, 2000). Stigma and fear of permanent lifestyle changes also contribute to an individual’s ability to adhere. HIV positive individuals who have not disclosed their status are less likely to adhere to their treatment because they do not want to be seen taking ARVs out of fear of negative treatment from those around them.

3.3.4. Self-efficacy

Self-efficacy was added to the Health Belief Model in 1988. It is a term used to describe how a person views their own ability to carry out a particular action. This includes the patient’s perception on how likely they are to change particular behaviours (Bandura, 1977). People generally are not willing to try something new unless they think they can do it. If someone believes the new behaviour is useful (perceived benefit) but does not think he or she is capable of doing it (perceived barrier), chances are they will not try it. As with ARVs if an individual does not believe that they can successfully
adhere to the treatment this barrier will not be overcome and they are unlikely to adhere effectively.

3.3.5. Cues to Action

An individual's perception of the levels of susceptibility and seriousness provide the force to act. Benefits (minus barriers) provide the path of action. However, it may require a 'cue to action' for the desired behaviour to occur. These cues may be internal or external. Cues to action can be people, events or things that move people to change their behaviour. These could be the illness of a family member, media reports, mass media campaigns (Graham, 2002) advice from others, reminder postcards from a health care provider (Ali, 2002) or health care warning labels on a product that prompt adherence to ARVs.

The HBM suggests that the individual’s perception of reality has greater value than the actual reality concerning behaviour change (Hurley, 1990). In health care settings, patients weigh the recommendations of their health care provider against their estimate of the potential outcomes of both adherence and non-adherence (Kendra, 2004). The HBM states that both internal and external motivation is necessary to produce change, but requires significant endorsement of the procedure required to produce change (Strecher, Champion & Rosenstock, 1997).

Positive correlations exist between the patient’s adherence and their health beliefs. It has been suggested that health beliefs have a causal relationship with adherence. Thus by addressing the patient’s perceptions about illness and treatment regimens, physicians may potentially be able to predict their patients’ level of adherence (Glanz et. al., 1997). It is further recommended that to enhance adherence, strategies to modify current maladaptive health beliefs and perceptions by addressing patients’ attitudes regarding their illness and current regimes, be implemented. Gentili, Maldonato, Grieco and Santini (2001) ascertain that health care providers must not only provide direct treatment interventions, but they must also address patients’ concerns and potential barriers to adherence regarding their medication regimens.
3.4. Application of the Health Belief Model in adherence research

The Health Belief Model has been applied to a broad range of health behaviours and subject populations. Three broad areas were identified by Conner and Norman (1996), namely: (1) preventive health behaviours, such as health promoting (e.g. diet and exercise) and health risk (e.g. smoking) behaviours as well as vaccination and contraceptive practices; (2) sick role behaviours, which refers to compliance with recommended medical regimens (e.g. ARVs), usually following professional diagnosis of the illness; and (3) clinic use, which includes physician (or clinic) visits for a variety of reasons.

The HBM constructs are used to investigate congruent and incongruent beliefs held by HIV positive individuals with regards to antiretroviral drugs. Research on conditions such as diabetes and hypertension has shown that patients from diverse populations often have complex mixes of medically accurate and inaccurate beliefs. Thus, the HBM is relevant in the South African context with a medley of cultures with their various beliefs and superstitions. These beliefs have been found to have contributed to delayed presentation at hospitals and clinics as well as adherence failure (Llongo, 2004).

3.5. Advantages and Limitations of the Health Belief Model

The HBM has provided a useful theoretical framework for investigators of the cognitive determinants of a wide range of behaviours for more than 30 years. The common sense and expectancy-value framework of the HBM simplifies the health related representational processes. Its constructs are easy for non-psychologists to assimilate and apply and it can be readily and inexpensively operationalised. It has focused researchers’ and health care professionals’ attention on modifiable psychological prerequisites of behaviour and provided a basis for practical interventions across a range of behaviours (Jones, Jones & Katz, 1987). Qualitative distinctions between beliefs encompassed by each construct may be important to understanding why an individual does or does not
undertake a specified behaviour - in this case adhering to their ARV treatment regimen (Sheeran & Abraham, 1999; Weinstein, 1998).

As with all models or theoretical frameworks, there are limitations to the effectiveness of the Health Belief Model. The model does not articulate anticipated relationships between cognitions (Sheeran & Abraham, 1999). Health belief and reasoned action models are often used to explain psychosocial aspects of health behaviours. However, they seldom provide robust predictors of behaviour since they often fail to address, or control for, the impact of the task involved or the context or setting within which these behaviours occur (Ladd, Hamel, Gilmore & Pepler, 1998). The model also excludes cognitions which have been shown to be powerful predictors of behaviour. It fails to address the importance of intention formation or the influence that other’s approval may have upon behaviour. It portrays individuals as social economic decision-makers and consequently fails to account for behaviour under social and affective control.

3.6. Conclusion

The Health Belief Model has been an attempt to explain health behaviours that influence prevention and promotion of personal health (All, Nishakawa, Vinson & Huycke, 2004; Champion, 1984b). It assumes that good health is a goal of most persons and that their perception of susceptibility, seriousness, benefits, barriers and self-efficacy impact the likelihood of a person taking an action that is health related by adhering to prescribed ARV treatment.

The research done with other models has provided many insights into the determinants of people’s motivations to adopt a whole range of health-related behaviours (Becker, Haefner & Maiman, 1977). There are clearly positive correlations that exit between patients’ adherence and their health beliefs.

The HBM is particularly applicable to adherence issues in HIV positive individuals. Therefore, this study will apply the HBM in an effort to demonstrate the relationship between adherence, the health beliefs of HIV positive individuals and how these influence their subsequent health behaviours by identifying the factors that may be impacting on their ability to be adherent to treatment.
CHAPTER 4

Research Design and Methodology

4.1. Introduction

This chapter outlines the research design and methodology that guided this study. The research design is introduced, and the setting, population and sample are described. A brief overview of the measures used to gather data is included. As data collection remains an important aspect of any research study, this chapter provides a thorough description of the methods of data collection and analysis used in the study.

4.2. Primary Aim of the Study

The primary aim of the present study was to identify, explore and describe factors contributing to adherence and non-adherence to treatment in individuals currently on antiretroviral treatment. The ultimate goal is to gain insight into the factors that influence individuals’ ability to adhere effectively to their antiretroviral treatment.

4.3. Research Design and Methodology

This research study was exploratory-descriptive in nature using the quantitative method.

4.3.1. Quantitative Research

Quantitative research is a formal, objective and systematic process in which numerical data are utilised to obtain information about the world (Cormack, 1991). It deals in numbers and logic, and is objective. It seeks to explain the occurrence of particular
phenomena. Quantitative research methods are generally very easy to replicate and hence have a high reliability (Aiken, 2003). The results of quantitative research tend to be simple in that they are generally reduced to a few numerical statistics and interpreted in a few short sentences. The researcher can remain objective though gaining, analysing and interpreting quantitative data as this means that he or she does not get involved in the situation of the research or with the participants (Babbie, 1992; Babbie & Mouton, 2001). Quantitative research can be deductive, which is to say it tests theory and the results obtained can be generalised to other situations. These results are often based on a large sample size that is representative of the population. On the other hand, a disadvantage to quantitative research is that the more structured data collecting approach may cause stress to participants, thus not showing accurate reflection of results (Neuman, 2003).

### 4.3.2. Exploratory-Descriptive Research

Exploratory research can be quite informal, relying on secondary research such as literature and data reviews. The results of exploratory research are not usually useful for decision-making by themselves, but can provide significant insight into a given situation.

A descriptive research design aims to utilise precise measurements and reports on the characteristics of some population or a phenomenon that is under study (Babbie, 1990). Whitley (2002) added that it also provides a summary and description of a relatively large set of data. It can be used to develop theory, identify a problem with current practices, justify current ones, make judgements or identify what others in similar situations do. It does not involve any manipulation of variables nor does it attempt to establish causality.

Therefore, the research was exploratory and descriptive in nature. Exploratory-descriptive research sets out to observe, record, and describe the behaviour that is of interest. This is a primary and necessary goal for the development of scientific knowledge (Cozby, 2004). An exploratory research design aids in gaining familiarity with a phenomenon. Tentative results are drawn and thus the value of this type of research lies in the fact that it provides further research topics within the field of the present research (Babbie, 1990; Mullins, 1995).

Exploratory-descriptive research gives increased flexibility when looking at complex relationships between variables. It allows one to explain what takes place behaviourally
without having to explain the cause of the behaviour. This type of research helps determine the best research design, data collection method and selection of participants. However, the disadvantage is that eventually the cause will have to be explained and understood and looking at the antecedents and outcomes of that behaviour will be required to better understand the behaviour (Rosnow & Rosenthal, 1993). Other disadvantages of this type of research include the inability to determine causal relationships, decreased generalisability and the inability of the researcher to manipulate the variables (Schiller, 2000). A further disadvantage is that it can be very expensive as it attempts to test concepts before they are released to the majority of the public.

4.3.3. Questionnaires as a survey method

Questionnaires were used for collecting data. Questionnaires are a form of survey research. Survey research involves the collection of primary data about subjects, usually by selecting a representative sample of the population under study through the use of questionnaires. There are three basic types of surveys, namely, telephone, self-administered and interview surveys (Whitley, 2002). The advantages of this form of research are that many different types of information can be collected including aspects of attitude, motivation, behaviour and perception. It allows for standardisation and uniformity both in the questions asked and in the method of approaching subjects, making it easier to compare and contrast answers by the respondent group. Higher reliability is also ensured in survey research than with some other techniques. It can also be an efficient and accurate means of determining information about a given population and the results can be given quickly. Depending on the sample size and the methodology chosen they are relatively inexpensive (Struwig & Stead, 2001).

Surveys also have a number of disadvantages. Firstly, there is the possibility of response error where the respondent may give false information, thus it will not be valid. Secondly, there could be non-response bias, which is the willingness or ability of the participant to impress the researcher, and this can become a problem (Babbie & Settle, 1995). The information might be considered sensitive or intrusive which will lead to a high rate of refusal to answer the question. On the other hand the question could be so specific that the respondent is unable to answer, even though they are willing. The best
way to overcome these two is by carefully wording the questions. Lastly, there could be interviewer bias whereby the interviewer inadvertently influences the responses elicited from the participants through comments made or by stressing certain words in the question itself (Whitley, 2002). In interview surveys the interviewer can introduce bias through facial expressions, body language or even the clothing that is worn.

### 4.4. Participants and Sampling Procedure

Participants were chosen based on non-probability, purposive sampling. This sampling method refers to procedures directed towards obtaining a certain type of participant (Dane, 1990), such as a person currently on ARV treatment for six months or more. Non-probability purposive sampling has the advantage that the researcher has to use his or her own judgement and chooses those participants who will best fit the purpose of the study. Furthermore the researcher can reach a targeted sample quickly, thus this type of sampling is convenient and more affordable. A disadvantage is that since the probability that a person will be chosen is unknown, the investigator cannot claim that his or her sample is representative of the larger population (Whitley, 2002), and furthermore the sampling error cannot be estimated (Dane, 1990). External validity is not highly important due to the fact that the study is descriptive and exploratory.

Snowball sampling follows on from purposive sampling in that participants who are selected from purposive sampling are asked to nominate other potential participants who meet the specified criteria and who they think would be willing to participate (Struwig & Stead, 2001; Whitley, 2002). Referrals from these participants are then obtained, thus increasing the sample size (Neuman, 2003). The researcher stops sampling either when no new people are nominated, or if the sample size becomes too large for the study (Neuman, 2003). Disadvantages of snowball sampling include potential researcher bias as well as difficulty in generalizing results to the larger population (Struwig & Stead, 2001). Another disadvantage is that the chain can become broken thus making it difficult to increase the sample size (Strydom, 2005). Advantages of purposive and snowball
sampling are that the sample meets a specific purpose. Snowball sampling is also particularly useful in locating members with specific characteristics.

The study targeted 100 individuals currently on antiretroviral treatment for at least six months and over the age of 21. The participants were of all races and both genders, and were proficient in English to ensure that they could understand the questionnaire. The participants’ participation was voluntary and they were approached through Wellness clinics, where HIV positive people receive their treatment and support groups for HIV positive people in Port Elizabeth and surrounding areas. People from the surrounding areas were used in an attempt to increase the probability of getting a big enough sample especially since the stigma attached to being HIV positive could be a contributing factor in preventing individuals from filling in questionnaires despite the guarantee of anonymity and confidentiality. A total of 100 questionnaires were distributed and returned of which 81 met the criteria.

4.5. Measures

A biographical questionnaire as well as a questionnaire exploring factors affecting adherence to ARVs, was used in the study and once collected the information gathered was consolidated into a more comprehensive but easy to interpret report. The measures are discussed next:

4.5.1. Biographical section

A biographical questionnaire (see Appendix D) was designed by the researcher and aimed to gather identifying data about the participants such as age, gender, marital status, residence, job, education, income and home language. The purpose of this section was to obtain essential demographic and background information pertaining to the participants. This information was necessary for the meaningful and contextual interpretation of the results.
4.5.2. Health Beliefs and Adherence section

A questionnaire (see Appendix D) was designed that looked at the following aspects highlighted by the health belief model:

1. Perceived susceptibility to developing life threatening opportunistic diseases due to AIDS (health)
2. Perceived severity of HIV/AIDS stage (health)
3. Perceived benefits to taking the treatment (treatment)
4. Perceived barriers to taking the treatment (treatment)
5. Cues to action, which looks at strategies that one has put into place to promote adherence (support system)
6. Self-efficacy, which is one’s ability to follow through and adhere to the treatment (support system).

This questionnaire was designed in consultation with the Nelson Mandela Metropolitan University Campus Health Clinic and the Mathematical and Statistical Department of NMMU, as well as current literature that has looked at adherence to other chronic medications (Berg & Arnsten, 2006; Vincke & Bolton, 2002). The questionnaire had no known reliability as this is a new study thus a pilot study was conducted to ensure its validity.

Pilot studies are conducted to test the logistic feasibility of the procedures that will take place in the definitive study (Steward, 2007). Pilot studies can also be used for pre-testing of a particular research instrument (Baker, 1994). All tests need to be valid, reliable, unbiased, have appropriate norms and issues of fairness need to be considered (Foxcroft, 2004). Reliability refers to the consistency with which a measure actually assesses what it is supposed to assess. Validity refers to what was being measured and how well it is measuring what it should. Reliability and validity are both important factors to take into consideration when conducting research (Foxcroft, Roodt & Abrahams, 2001).

Once reliability and validity of the questionnaire was established, the questionnaires were administered to a larger sample. The questionnaire had four sections; biographical, health (with a reliability and validity of Cronbach’s alpha .64), treatment (Cronbach’s alpha .62) and support (Cronbach’s alpha .57). Peat, Mellis, Williams and Xuan (2002)
state that contamination can occur when the data from the pilot study is included in the
main results or when pilot participants are included in the main study, but new data is
collected from these people. Thus, the pilot sample was not included in the main study to
avoid contamination of the final results.

4.6. Procedure

The researcher obtained the names and locations of wellness clinics that are registered
as ARV sites. Initially a verbal request was made and once permission was granted a
further written request was given to the clinics’ Managers for official usage. Furthermore, support groups that were known to the researcher were approached and the
purpose of the research explained to them. Those who were interested in filling out the
questionnaires were approached and given the questionnaires. All questionnaires had a
consent form attached that the participants had to sign before filling in the questionnaire.

At the wellness clinics the sister-in-charge explained the purpose of the study to the
potential participants and had those who were interested meet with the researcher so as to
get their questionnaires. The participants were able to fill in the questionnaires at the
clinics and had the researcher on hand to answer any questions. Thus the researcher was
able to get the questionnaires back on the same day.

The members of the support group opted to take the questionnaires home and return
them when they were filled in. As a result the researcher had to send them reminders two
weeks after they took the questionnaires to return the questionnaires. In some instances,
arrangements were made for the researcher to personally pick up the questionnaires from
the participants. Due to ethical principles recruitment was not random but based on
voluntary participation and informed consent. In the event that selected individuals were
unwilling to participate, other participants were identified. Coding of all data was used to
uphold privacy and confidentiality. The individuals who participated were treated with
respect and thanked for their participation on returning the questionnaires.

Nineteen questionnaires had to be excluded from the study as 6 were incomplete and
13 were on treatment for less than the stipulated time period. Consequently, 81
individuals participated in the present research. The researcher was responsible for the coding and capturing of the questionnaires. Once the questionnaires had been double checked and the spoiled questionnaires were separated from the usable ones, the data was ready for analysis. The following section addresses the analysis of the data.

4.7. Data Analysis

The data gathered was analysed by means of descriptive statistics. Descriptive statistics describes the data by investigating the description of scores on different variables and how they are related to each other, if at all. This is usually conducted first to gain an initial impression of the data (Meyer, Moore & Viljoen, 1997). Descriptive statistics provide summary measures of the data contained in all elements of the sample (Rossouw, 1996). Descriptive statistics refer to the values describing the sample and these numerical values summarizing the data are called statistics (Strydom, du Plessis & Strydom, 2002). There are two categories of descriptive statistics namely, 1) measures of central tendency and 2) measures of dispersion or variation and spread (Cozby, 2004). Measures of central tendency refer to the typical score, where the scores bunch or group together and measures of dispersion refer to the amount of variability among scores in the group (Breakwall, Hammond, Fife-Shaw & Smith, 2006) and comprises numerical values that refer to the centre of the distribution (Howell, 1998).

Furthermore, Lindsey (1993) described three measures of central tendency namely the mean, median and the mode and these can be used to obtain a profile of the sample (Barker, Pistrang & Elliot, 1994). The mean is the arithmetic average which is obtained by the sum of the values divided by the sample size. The median is the point in the distribution that has exactly the same number of scores above it as below it when all scores are arranged in order. The mode is an indicator of the most frequent score or interval obtained in the sample group. Descriptive statistics are used not only to summarize data, but also used as an estimate of population parameters (Smyth, 2004). The advantage of using the mean is that it estimates a population mean better than other measures that assess central tendency such as median and mode, while a disadvantage is
that extreme scores influence it. Descriptive statistics and frequency counts were used to
analyse the data obtained through the biographical questionnaire. The data analysis was
done by the NMMU Mathematical Statistics Department.

4.8. Ethical Considerations

In this research, and any other, it is important for the researcher to consider the rights
and well-being of the participants and certain ethical considerations have to be borne in
mind (Harvey & MacDonald, 1993). The research only commenced after the proposal
was presented to and approved by the Ethics Committee (Human) of the Nelson Mandela
Metropolitan University (NMMU). The questionnaires used were administered in a
standardised manner to ensure reliability and validity. A registered psychologist
supervised the research.

Participation in the study was voluntary and written informed consent was given by
the participants. The anonymity of the participants was ensured through a coding system
known only to the researcher. This further guaranteed the confidentiality as only the
researcher has access to the final research material. Furthermore, the research participants
were treated in a courteous and respectful manner. The ethical issues for consideration
are discussed next.

4.8.1. Informed consent

Informed consent is a key element in ethically conducted research and it is described
as a process which includes both informing prospective participants of what their
participation in the research will likely entail and obtaining their written agreement to
participate (Cone & Foster, 2006). Salkind (1997) stated that this might be the most
important requirement in behavioural research. Informed consent provides research
participants with sufficient information to judge for themselves if they want to be part of
the intended study (Elmes, Kantowitz & Roediger, 2003; Foxcroft & Roodt, 2001). A
covering letter (see Appendix B) was given to all potential participants informing them
about the researcher, the nature and purpose of the study and addressing issues of
confidentiality and the voluntary nature of the research. The covering letter also indicated the value and benefit of the research to participants. The researcher’s contact number was included in the covering letter should any questions have arisen regarding the information provided. The letter also notified the participants of their right to withdraw from the study at any time without fear of recriminations from the researcher or clinic (Russell & Roberts, 2001). A consent form was also included with the questionnaires.

4.8.2. Coercion

Another ethical concern is that of coercion. Coercion refers to whether participants were forced or pressurised by a researcher or someone that has authority or influence over them to participate in a study (Cozby, 2004; Salkind, 1997). The researcher can avoid coercion by giving participants all the necessary information about the study, and refraining from making exaggerated claims that fuel participants’ expectations about their participation in the study (Russell & Roberts, 2001). In order to ensure that participants were not coerced in any way to participate in the current study, the researcher emphasized the voluntary nature of the research in a covering letter given to participants. In addition, the researcher also reiterated their freedom to participate or withdraw at any time without consequences.

4.8.3. Privacy and Confidentiality

The maintenance of privacy and confidentiality are also among the ethical guidelines. Privacy refers to anonymity. Anonymity is ensuring that no uniquely identifying information is attached to the data. The loss of privacy can be described as any question related to intimate or personal matters that are not usually discussed in public and could trigger feelings of anxiety, guilt or shame (Huysamen, 1994). Anonymity can only be guaranteed when the participants do not request feedback. It is essential for the researcher to know the identities of those participants that request feedback in order to facilitate the provision of feedback.

Confidentiality refers to the fact that the data obtained may only be used for the purposes of the study and may not be revealed to others (Leary, 1991). Confidentiality was maintained through the coding of questionnaires with the participants’ particulars
made available only to the researcher. The covering letter sent to all participants emphasized the importance of confidentiality in the study, reassuring participants that their privacy would be protected by ensuring that their personal identities would not be revealed in the reporting of the research.

4.9. Conclusion

This chapter focused on the methodology used in the research process. It explained quantitative research as a method used for gathering and analysing data. It showed how the data was collected, using questionnaires. The questionnaire had a biographical section as well as a section that looked at adherence and health in individuals comprising closed questions. A non-probability purposive sample was used in order to collect data. The ethical considerations mentioned above were taken into consideration for the purpose of the study. The researcher gave significant attention to ethical procedures and practices, such as informed consent, coercion and maintaining privacy and confidentiality, while governing the activities of the research in an attempt to secure the well-being of research participants. Questionnaires were personally handed out at wellness clinics and support groups. The questionnaires were then collected, coded, and analysed using descriptive statistics to describe the mean and standard deviation of the factors influencing the respondents’ ability to effectively adhere to their antiretroviral treatment. The analysis of the data required a level of inductive reasoning based on the research data collected. The results that arose from the research are discussed in the following chapter.
CHAPTER 5

Results and Discussion

5.1. Introduction

Before the results obtained from the research can be discussed it is essential to first revisit the aims of the research. The initial aim of this research was to explore and describe the factors affecting adherence and non-adherence to antiretroviral treatment in HIV positive individuals in Port Elizabeth.

The results obtained from the data analysis are discussed in this chapter. In discussing the results, the biographical data has been described to obtain a comprehensive picture of the sample. Thereafter, the results of the questionnaire will be presented in the form of tables and graphs, and discussed in detail. The two sections, Biographical and Adherence, will be used in conjunction with the each other to respond to the aim.

5.2. Biographical Description of the Sample

The biographical variables that are discussed specifically pertain to the information obtained from the biographical questionnaires. The variables included gender, age, ethnicity, home language, marital status, employment and salary. All questions in this measure were close-ended. A total of 81 (N=81) participants successfully completed the questionnaires and discussion of the results follows below.

5.2.1. Gender

The majority of participants were female while males made up 27% of the participants. The gender distribution of the sample is presented in Table 3.
Table 3: Gender distribution of participants (N=81)

<table>
<thead>
<tr>
<th>Gender</th>
<th>Frequency</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>59</td>
<td>73</td>
</tr>
<tr>
<td>Male</td>
<td>22</td>
<td>27</td>
</tr>
<tr>
<td>Total</td>
<td>81</td>
<td>100</td>
</tr>
</tbody>
</table>

Note: Percentages were rounded off.

5.2.2. Age

The majority of the respondents fell into the 31-40 age groups with the minimum age range being 21-25. The age distribution of the sample is presented in Table 4.

Table 4: Age distribution of participants (N=81)

<table>
<thead>
<tr>
<th>Age</th>
<th>Frequency</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>21-25</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>26-30</td>
<td>23</td>
<td>28</td>
</tr>
<tr>
<td>31-40</td>
<td>37</td>
<td>46</td>
</tr>
<tr>
<td>&gt;40</td>
<td>16</td>
<td>20</td>
</tr>
<tr>
<td>Total</td>
<td>81</td>
<td>100</td>
</tr>
</tbody>
</table>

Note: Percentages were rounded off.

5.2.3. Ethnicity

The ethnic distribution of the sample is indicated in Table 5.
Table 5: Ethnic distribution of participants (N= 81)

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Frequency</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>African</td>
<td>77</td>
<td>95%</td>
</tr>
<tr>
<td>White</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Coloured</td>
<td>4</td>
<td>5%</td>
</tr>
<tr>
<td>Indian</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>Total</td>
<td>81</td>
<td>100</td>
</tr>
</tbody>
</table>

Note: Percentages were rounded off.

The majority of the participants were Black (95%), with no White or Indian participants and a minority of Coloured participants (5%). This may be viewed as a limitation of the study as the sample was not evenly distributed between the different ethnic groups represented in the Eastern Cape.

5.2.4. Home Language

The home language distribution of the respondents is indicated in Table 6.

Table 6: Home language distribution of participants (N=81)

<table>
<thead>
<tr>
<th>Language</th>
<th>Frequency</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Afrikaans</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>English</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Xhosa</td>
<td>75</td>
<td>93</td>
</tr>
<tr>
<td>Sesotho</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>81</td>
<td>100</td>
</tr>
</tbody>
</table>

Note: Percentages were rounded off.
The majority of the participants’ home language was Xhosa, with Afrikaans second and Sesotho being the least. The questionnaire was available in English. None of the respondents had English as a first language, but had it as a second language. This was an unexpected development as the identified clinics were located in areas accessible to all ethnic and language groups, who are proficient in English. This can be viewed as a limitation as it excluded those that did not have English as a first or second language. It is also important to acknowledge that this could have affected the participants’ responses if they did not fully understand the items.

5.2.5. Marital Status

The marital status of the participants in the sample varied between married, single, divorced or cohabiting, with the majority of the sample being single. The marital status of the sample is presented in Table 7.

Table 7: Marital status distribution of participants (N=81)

<table>
<thead>
<tr>
<th>Marital status</th>
<th>Frequency</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>22</td>
<td>27</td>
</tr>
<tr>
<td>Single</td>
<td>53</td>
<td>65</td>
</tr>
<tr>
<td>Divorced</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Cohabiting</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>81</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

*Note: Percentages were rounded off.*

5.2.6. Employment

Table 8 represents the employment distribution of the respondents. 35% of the participants were employed, while the majority 62% was unemployed and 4% was self-employed.
Table 8: Employment distribution of participants (N=81)

<table>
<thead>
<tr>
<th>Employment</th>
<th>Frequency</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed</td>
<td>28</td>
<td>35</td>
</tr>
<tr>
<td>Unemployed</td>
<td>50</td>
<td>62</td>
</tr>
<tr>
<td>Self-employed</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>81</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Note: Percentages were rounded off.

5.2.7. Salary/Income per month

Of the 31 participants that had employment, the majority (12) earned less than R2000 a month, while only 6 earned more than R10000 a month. Table 9 represents the salary distribution of the sample.

Table 9: Salary distribution of participants (N=31)

<table>
<thead>
<tr>
<th>Salary</th>
<th>Frequency</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;R1000</td>
<td>5</td>
<td>16</td>
</tr>
<tr>
<td>R1000 – R1999</td>
<td>12</td>
<td>39</td>
</tr>
<tr>
<td>R2000 – R4999</td>
<td>6</td>
<td>19</td>
</tr>
<tr>
<td>R5000-R9999</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>+R10000</td>
<td>6</td>
<td>19</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>31</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

Note: Percentages were rounded off.
5.3. Results of the Measure

The HBM was used as a framework for this study. What follows is a discussion of the results within the Health Belief Model. Section B of the questionnaire looked at the participants’ perceptions and experiences of their general health, Section C at how they experience their treatment, its effects and the participants’ ability to maintain the treatment regime and Section D focused on familial and social support. These sections were comprised of yes and no questions as well as questions on a 5-lickert scale with one (1) being strongly disagree and five (5) strongly agree.

5.3.1. Section B: HEALTH

The section on health looked at general wellbeing in terms of psychological functioning and any medical conditions that the participants could have. This also includes conditions such as depression. The standard deviation, mean and median of the health section were obtained by using the experimental items of the lickert scale questions B1, B2 and B3. The descriptive statistics in terms of the mean and standard deviation obtained on the health section is indicated in Table 10 and provides information on how the sample perceives their health.

Table 10: Mean and Standard deviation of Health Section

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>X</th>
<th>MINIMUM</th>
<th>MEDIAN</th>
<th>MAXIMUM</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>HEALTH</td>
<td>81</td>
<td>4.03</td>
<td>2.67</td>
<td>4.00</td>
<td>5</td>
<td>0.39</td>
</tr>
</tbody>
</table>

N= sample size X = mean SD= standard deviation

The sample reported a mean score of 4.03. This is higher than the average (median) of 4. This indicates that the participants experience their health and well-being in a positive light. These results suggest that the sample perceived their health, with regards to their beliefs and the need to maintain a positive lifestyle health-wise, as slightly above average.
Given the multiple stressors that poor communities face, the absence or inadequacy of appropriate support mechanisms, and poor access to professional psychiatric treatment, the prevalence of untreated depression among South African communities is likely to be high (Kagee, 2004). Patients who exhibit symptoms of depression are likely to be less adherent than their non-depressed counterparts. Questions 1 to 3 of section B explored the participants’ own perceptions of their health. None of the participants reported any major depressive feelings. Only 4% said that they do not feel very happy all things considered in relation to 83% who experience happiness in spite of their life situation (Table 11). This overall positive response was to be expected given their high mean score.

<table>
<thead>
<tr>
<th>N=81</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 I am able to concentrate on what I am doing.</td>
<td>0</td>
<td>5</td>
<td>0</td>
<td>84</td>
<td>11</td>
</tr>
<tr>
<td>2 I feel capable of making my own decisions about things.</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>83</td>
<td>16</td>
</tr>
<tr>
<td>3 I feel reasonable happy, all things considered.</td>
<td>0</td>
<td>4</td>
<td>6</td>
<td>83</td>
<td>7</td>
</tr>
</tbody>
</table>

Note: Percentages were rounded off.

Section B question 4 of the Health Beliefs and Adherence (HBA) questionnaire explored the incidence of substance use of the participants. None of the participants reported the use any recreational drugs, such as marijuana, cocaine, mandrax, heroin or tik (crystal meth).

Question 5 of the section determined 16% of the participants were taking medication for hypertension and 2% were still on treatment for tuberculosis (TB). The addition of other medications can be viewed as pill burden, especially for those who are already taking a lot of pills in the ART.

Question 6 explored the quantity and frequency of alcohol consumption among the participants. The majority reported that they do not consume alcohol during the week or the weekend (94% and 67% respectively), with 1% having six to ten glasses in a sitting
(Refer to figure 4). However, 33% of the participants consume alcohol over the weekend, with 17% consuming six to ten glasses in one sitting.

Figure 4: Alcohol consumption of participants

The intake of alcohol has an adverse effect on treatment adherence. This kind of behavior can lead to irresponsibility on the part of the patient as people often fall into a deep slumber while drunk, and may miss the time they are supposed to take their dosage. As most of the respondents who drink usually do it over the weekend it is safe to assume that adherence rates go down over weekends. This might suggest that more doses than reported are actually missed monthly. ARVs work for a certain duration in the body and when that duration elapses, the individual needs to take another dose, so if you they fall asleep and miss the time for another dose, the virus is being given a chance to get active and replicate (Neondo, 2009). Furthermore, alcohol is also an enzyme inducer, meaning it is an agent that increases the activity of enzymes in the body resulting in an increase in metabolism and therefore decreasing the serum concentration of the drug.

The metabolic impact may increase the toxicities seen with certain HIV drugs. Excessive alcohol intake may cause nausea, vomiting and inflammation of the lining of the stomach (or gastritis) and this may make tolerating an HIV regimen more difficult.
Question 7 of the section determined that the majority (85%) of the participants do not smoke. Fifteen percent reported smoking 1-10 cigarettes per day.

The last question for Section B, question 8, was used to determine the cd4 count of the participants at the start of ART.

The CD4 count (Figure 5) determines the type of regimen that an individual will be put on and can affect adherence. This will be discussed further in the next section. The majority of participant’s CD4 counts were in the 150-240 range. The South African treatment guidelines are that ART can be started when the individual’s CD4 count is below 200.

5.3.2. Section C: TREATMENT

The descriptive statistics in terms of mean and standard deviation obtained for the treatment section of the questionnaire are presented in Table 12. These were obtained by using the experimental items of the lickert scale questions C6.1 to C6.6.
Table 12: Mean and Standard deviation of Treatment Section

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>X</th>
<th>MINIMUM</th>
<th>MEDIAN</th>
<th>MAXIMUM</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>TREATMENT</td>
<td>81</td>
<td>4.24</td>
<td>3.33</td>
<td>4.00</td>
<td>5</td>
<td>0.36</td>
</tr>
</tbody>
</table>

N= sample size X = mean SD= standard deviation

The sample reported a mean score of 4.24 which is higher than the median. This indicates that the participants have a positive experience of their treatment. These results suggest that the sample perceived their treatment, with regards to their ability to maintain the routine, being motivated to take the treatment regularly as instructed and the positive effects of the treatment on their health, as above average. An in-depth explanation of the results follows.

There are two types of treatment available: 1st and 2nd line treatment. The South African guidelines have first- and second-line ARV regimens. The first-line regimen includes 3TC, d4T and Efavirenz or Nevirapine. The majority (27%) of the sample was on this treatment with the rest being on various combination drugs. As reported, the CD4 count (Figure 5) determines the type of regimen an individual is placed on, thus this can affect adherence. The majority of participant’s CD4 counts were in the 150-240 range. Thus, they would have been placed on first line treatment thereby being on three pills twice daily.

Section C, question 1 required that the participants state the type of pills they were on and the number of pills it consisted of (question 2) as the level of treatment complexity also impacts on adherence levels. The participants reported 11 different types of treatment combinations, with one individual taking 1 pill once a day to 22% taking more than four pills twice a day. The majority of the participants (74%) were on regimens that consisted of three pills also administered twice a day. Howard, et. al. (2002) examined the relationship between complex antiretroviral regimen and medication adherence among women. They observed poorer adherence as the complexity of the treatment regimens increased, indicating that more simple regimens may likely optimize patients’ adherence. These findings suggest that adherence levels are likely to be disease specific.
and that patients whose treatments involve complex regimens are likely to be less adherent than those patients whose treatments are relatively simple.

Figure 6: Number of years on treatment

<table>
<thead>
<tr>
<th>Duration</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 1 year</td>
<td>25%</td>
</tr>
<tr>
<td>Less than 2 years</td>
<td>35%</td>
</tr>
<tr>
<td>Less than 5 years</td>
<td>31%</td>
</tr>
<tr>
<td>Less than 10 years</td>
<td>7%</td>
</tr>
<tr>
<td>13 years</td>
<td>2%</td>
</tr>
</tbody>
</table>

Question 3 of Section C asked the participants to state the number of years that they have been on treatment. The majority (35%) of the participants have been on treatment for two years or less with 2% being on treatment for 13 years. Question C4 regarding missing dosages asked how often the participants miss their doses in a month. Most of the participants (57%) reported that they do not miss their doses at all in a month while 32% reported to miss their doses at least once a month (this included those who have been on treatment the longest). Question 5 determined that the treatments were taken in the morning and the evening 12 hours apart on a daily basis.
Table 13: Percentage (%) of Treatment responses

<table>
<thead>
<tr>
<th>Question</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.1 I remember to take my treatment on time.</td>
<td>0</td>
<td>11</td>
<td>0</td>
<td>65</td>
<td>23</td>
</tr>
<tr>
<td>6.2 I am motivated to take my treatment regularly.</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>67</td>
<td>32</td>
</tr>
<tr>
<td>6.3 Taking my treatment will help me get better.</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>59</td>
<td>88</td>
</tr>
<tr>
<td>6.4 My treatment programme is easy to follow.</td>
<td>0</td>
<td>1</td>
<td>4</td>
<td>88</td>
<td>7</td>
</tr>
<tr>
<td>6.5 Taking my treatment interferes with my daily life.</td>
<td>4</td>
<td>84</td>
<td>2</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>6.6 I have to hide from others when taking my treatment.</td>
<td>2</td>
<td>88</td>
<td>2</td>
<td>6</td>
<td>1</td>
</tr>
</tbody>
</table>

Note: Percentages were rounded off.

Question 6 explored self-efficacy. As already described in chapter 3 this is a factor in the HBM and refers to the individual’s belief in their own ability to carry out a particular action (refer to table 13). In this instance it refers to the participants’ ability to execute and maintain their treatment regimens successfully. Eighty eight percent of the participant reported the treatment as easy to take and 84% of these further reported that it does not interfere with their daily functioning. However, 7% of the sample did report that they have to hide from others when taking treatment. This can impact adherence in that they may skip a dose in an effort to avoid being seen taking the treatment and therefore having to answer questions they are not willing to answer. Patients who have a greater level of confidence in being able to carry out a doctor’s instructions are likely to engage in such activities to a greater extent than those who do not. Thus, self-efficacy has also been associated with improved levels of adherence (Miller, Ogletree & Welshimer, 2002; Williams & Bond, 2002). Yet, several factors interact to affect self-efficacy. Chief among these are the patients’ level of comfort with interacting with the healthcare system, their relationship with medical personnel (Roberts, 2002) and the complexity of the treatment regimen (Kubeck, 2002). Together with health literacy, the competing demands of daily living and limited financial resources, these factors impact on adherence self-efficacy in a manner that may be unique to primary care patients residing in historically disadvantaged South African communities.
Like most medicines ARVs can have many different side effects (beatit, 2009). The extent to which the patient’s quality of life is compromised by the treatment regimen is also a factor to consider. Factors such as drug toxicity or intolerance (Park, Scalera, Tseng & Rourke, 2002), discomfort associated with side effects, and dissatisfaction at having to make changes in terms of diet, exercise activities and work habits play an important role in the patient’s quality of life (Rodham, 2002). In some cases, diagnosis may have occurred at a pre-symptomatic level and medication or behavioural changes prescribed. Under these circumstances, there are few directly perceived benefits associated with adherence. Combined with poor quality of life brought on by the side-effects of medication, the absence of a perceived benefit of the medication or of behavioural adherence may be a further barrier to adherence (Schuman, et. al., 2001).

Question 7 of Section C focused on the side effects (and their severity) experienced by the participants as a result of taking ARVs. Various side effects were listed as being present by the participants regardless of how long they had been on treatment. These included reduced appetite (which in itself is a barrier to taking treatment that requires that it be taken on a full stomach), lipodystrophy, aching muscles and joints, nausea and vomiting. As stated in chapter 3, in order for a new behaviour to be adopted the individual has to believe that the benefits far outweigh the consequences of continuing the old behaviour (Centres for Disease Control and Prevention, 2004). Thus, severe side-effects may be seen as too high a risk by individuals who find them an inconvenience and a barrier to continuing with their daily life. Proper counseling about the warning signs and symptoms of side effects as well as management strategies, may help prevent non-adherence and early drug self-discontinuation (Dong, 2007).

5.3.3. Section D: SUPPORT SYSTEM

Section D addressed the issue of support systems and to whom the participants had revealed their HIV status. The descriptive statistics in terms of mean and standard deviation obtained for the support section of the questionnaire are presented in Table 14. These were obtained by using the experimental items of the lickert scale questions D5.1, D5.2 and D5.3.
The sample reported a mean score of 4.05 for support. This is higher than the median and indicates that the participants experience positive support from those who constitute their support system. These results suggest that the sample perceived the support that they received from their families, friends and health care providers as above average. These results are discussed further below.

Considerable research has been conducted, that shows that perceived social support is a strong predictor of medical adherence (Bearman & La Greca, 2002). As mentioned in chapter 3, the HBM asserts that both internal and external motivation is necessary to produce change that will encourage the individual to adhere to their treatment (Strecher et. al., 1997). This includes external encouragement from family and friends for the patient to cooperate with the recommendations and prescriptions of a health care professional (DiMatteo, 2004). The assumption is that the expression of concern from loved ones will motivate them to engage in health promoting behaviours, including medication adherence, and may also combine with social desirability needs on the part of the patient to yield higher rates of medical cooperation (adherence) based on their desire to impress their health care providers and others in their support system.

Currently, in South Africa patients need to have disclosed their HIV status to at least one other person in order to be eligible for antiretroviral treatment (Coetzee, et al., 2004). Question 1 of Section D aimed to determine how many of the participants had disclosed their status to family and friends. Fifty two percent of the participants reported that they had disclosed either to their spouses or partners, 63% to immediate family members, 22% to extended family and 20% had disclosed to friends or colleagues. This can be seen as a demonstration that the patient has accepted their status but also minimises the likelihood that lapses in adherence will occur as the family members they have disclosed to can help...
to remind and motivate them to take their treatment. Furthermore, they can assist with meal preparations and making sure that clinic or doctor appointments are kept.

Question 2 and 3 explored how many meals they ate and who prepared them for them respectively. Fifty six percent of the sample reported that they had three meals a day while 25% reported having more than three meals a day. Twenty percent reported that they eat twice a day and this can be due to the majority of the sample being unemployed. For the same reason it can be assumed that although the others do eat three meals a day, the quantity of the food may not be adequate as the food required may not be easily affordable (Kagee, 2008). The majority of the participants (91%) reported that they prepared their own meals while the rest of the sample either had their spouses, friends or other family members help prepare their meals.

Positive social support, including being married, is associated with adherence to ARVs (Holstad, Pace, De & Ura, 2006). Twenty seven percent of the participants were married which could explain their reported positive adherence. The majority were single, but reported receiving adequate support from family, such as siblings, parents, friends and even neighbours. The need for this support was explored further by question 4 which asked the participants how they remembered to take their treatment. The majority of 89% reported that they were able to remember on their own. However, the remaining 11% reported that their spouses, friends or family members would remind them. Where family support is poor a compromised adherence rate is visible (Wood, Tobias & McCree, 2004), but this is not the case with this sample as the majority have reported good support systems from both their families and their healthcare providers.

Table 15: Percentage (%) of Support responses

<table>
<thead>
<tr>
<th>N=81</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.1 I receive enough support from my immediate family.</td>
<td>0</td>
<td>4</td>
<td>1</td>
<td>64</td>
<td>31</td>
</tr>
<tr>
<td>5.2 I receive enough support from my extended family.</td>
<td>0</td>
<td>7</td>
<td>7</td>
<td>74</td>
<td>11</td>
</tr>
<tr>
<td>5.3 I receive enough support from my health care provider.</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>88</td>
<td>10</td>
</tr>
</tbody>
</table>

Note: Percentages were rounded off.
Questions 5.1 and 5.2 of Section D explored the issue of perceived external support further. Table 15 shows that the majority of participants (64% agree and 31 strongly agree) reported that the familial support they received was adequate while 74% of the sample went on to say that they received support from their extended families. Four percent and 7% reported not receiving support from their immediate families or extended families respectively.

An issue related to social support, the relationship between the doctor and patient has also been shown to be strongly associated with adherence. Data obtained by Roberts (2002) showed that physicians viewed communicating with patients about adherence issues as important. While the doctor-patient relationship may ostensibly constitute an example of social support, it also extends beyond this. The medical professional is most often seen as a person in authority, in the possession of specific expertise that is unobtainable elsewhere, and as someone in whom the patient solely invests hope for assistance in the recovery process.

In the context of South African primary healthcare clinics, most patients receive treatment from nurses, with medically trained doctors providing oversight, supervision and medication management, but less often direct care. Question 5.3 explored this issue and 88% of the participants agreed that they received adequate assistance and support from their health care providers while 10% strongly agreed to the same question.

The relationship between the patient and the health care provider has also been identified as a possible barrier to adherence. The majority of the participants reported that they received adequate support from their health care providers. This might have impacted positively on the reported levels of adherence as some of the health care providers at the clinic at times do home visits and the clinic provides them with food stuffs from time to time.

5.4. The Health Belief Model applied to the results

In order to understand the relationships indicated in the previous section, it is necessary to discuss the relationships within the context of the theory pertaining to HIV/AIDS and
adherence, as discussed in chapter 2, and the theory pertaining to the Health Belief model, as discussed in chapter 3.

The biographical information discussed here relates to the biographical questionnaire completed by the participants. The variables obtained from the questionnaire include age, gender, home language, occupation and marital status. Due to the small sample size it is not feasible to investigate any possible relationships between biographical variables and the results of the questionnaires.

The majority of the participants fell within the 31-40 age range, with 21-30 being a close second. The common home language was isiXhosa with Afrikaans being the other language spoken. These were included for statistical purposes as one of the criteria set in chapter 4 concerning participants was that they have a command of the English language as the questionnaires were only available in English. The total sample for the study was 81. The factors that were identified as potential barriers to optimal treatment adherence follow next.

The highest mean was obtained for the treatment section. Thus the participants consider their adherence to ART to be high. This is reflected in the statistics as 57% of them reported that they never miss their doses. Research in Nigeria conducted by the University of Abuja Hospital and the University of Maryland Institute of Human Virology, found that one in five patients reported adherence of less than 95% (judged by how promptly people came back for more tablets, the so-called refill rate) (Farley, 2007).

As discussed in chapter 2, the HBM holds that adherence will be optimal when three things are present (Rosenstock, Strecher & Becker, 1988). These are 1) the existence of motivation to make health issues salient. The motivation can come from family members, family friends and health care providers as demonstrated by the sample. The second highest mean was for support as indicated by the majority of the sample reporting adequate and positive familial and social support. 2) The belief that one is susceptible to a serious health problem - that is a sense of perceived threat. Literature regarding the benefits of the treatment would have been provided to the sample prior to commencing ART. Therefore, it can be assumed that they are aware that the benefits of testament outweigh the reason for not taking treatment. 3) The belief that following a particular health recommendation would be beneficial in reducing the perceived threat at an
acceptable cost—that is the perceived barriers that must be overcome in order to follow the health promotion. The sample reported that taking the treatment will contribute to the improvement of their overall health.

5.5. Conclusion

The results of this study have been discussed in relation to the aim set out for this study. A quantitative method was employed for this study as it best suited the aim of the research. In addition, a description of the sample was provided. Where possible the researcher has linked the findings to literature cited in previous chapters where various concepts have been discussed in more depth. The researcher has also linked the results to various studies that have been discussed in a previous chapter on HIV/AIDS and adherence. The conclusions, limitations and recommendations for future research relating to this study will be outlined in the next chapter.
CHAPTER 6

Recommendations, Limitations and Conclusions

6.1. Introduction

The results of the study were presented and discussed in the previous chapter therefore it is necessary to draw conclusions based on those findings. As a result a summary of the main findings in this study will be provided in this chapter. The limitations and contributions of this study are also discussed and recommendations for future research are outlined.

6.2. Aims of the Study Revisited

When drawing conclusions based on the results of the study, it becomes necessary to structure the discussion to follow according to the aims of the study. The aims and results obtained will be discussed next.

6.2.1. The factors influencing adhere to treatment

The primary aim of the study was to explore and describe factors contributing to adherence and non-adherence to antiretroviral treatment. Quantitative research methods were used in a manner that incorporated sampling, the data collection methods and data analysis techniques. The ultimate goal was to gain insight into the factors that influence an individuals’ ability to adhere or fail to adhere to their antiretroviral treatment.

The research showed that both psychosocial and economic factors can positively or negatively affect adherence levels. Unemployment, which goes hand-in-hand with poverty, can make it difficult for individuals to access treatment sites on a regular basis. Furthermore, difficulty with affording regular meals make it hard to take the treatment as
food is required and this can make side effects more severe. Alcohol abuse can cause them to forget to take their medication on time. Alcohol abuse can also impact adversely on familial relationships severing family ties. Therefore, this cuts down on the amount of support that the individual has.

6.2.1.1. Unemployment/Poverty

The majority of the sample was unemployed, leading to the assumption that they are living in some level of poverty. Consumers of health care who have formal white-collar employment typically have medical aid plans and may thus access the private health care system. South Africans who are unemployed, under-employed, and those below a certain income threshold, on the other hand, attend primary health care clinics that are often overcrowded, under-resourced and staffed by overworked health care professionals (Kagee, 2004). Therefore, life circumstances such as unemployment may hinder an acknowledgement of the importance of complying with the treatment regimen in general (Simoni, et. al., 2002). In addition to this, food required to be taken alongside medication may not be easily affordable and money for external prompts such as alarms and diaries may not be available.

In townships and rural areas where the transport infrastructure is poor, the lack of proper transportation may prevent individuals from returning to clinics for their treatment. These transport problems along with needing to take time off work, without pay, to attend clinic appointments were serious barriers to adherence among patients with hypertension and diabetes, to the extent that many failed to arrive for appointments or fill prescriptions (Kagee, Le Roux & Dick, 2007).

6.2.1.2. Substance abuse

Alcohol can affect familial relationships negatively thus making it difficult for them to receive their much needed support. ART requires a high level of cognitive functioning and impairments in these domains are likely to seriously impact treatment outcomes as substance abuse affects concentration and motivation leading to poor adherence (Levine et. al., 2006). Alcohol abuse can lead to a break in the family structure leading to a lack
of essential support from loved ones. Furthermore, alcohol consumption can lead to forgetfulness and results in individuals not taking their treatment at the required times.

### 6.2.1.3. Support

Familial support, spousal, friends, neighbour, colleagues, health care provider = increased adherence. As mentioned in chapter 3, support from family and friends can be a ‘cues to action’ (Graham, 2002). These external voices act as motivation or push for the patient to adhere to their treatment. This is the motivation that the patient needs to continue with their treatment.

### 6.3. The Value of the Research

The current study contributes to the body of research that focuses on adherence/non-adherence and compliance/non-compliance to various antiretroviral agents. While other studies into adherence focused on specific antiretroviral agents (Paterson et al., 2000; Stansell et al., 2001) this study did not specify the ARVs but instead looked at all treatment agents. At present there are few South African studies on adherence to antiretroviral treatment. This research has contributed to the body of research in the field of adherence to chronic medication and serves as an opportunity for further research on this topic in a South African context.

The results of the research have yielded a number of implications. Investigations into providing effective means of support for patients need to be conducted. It has been widely assumed that disclosure enhances adherence, even though there hasn’t been a controlled study to determine the relationship between the two constructs. It is even possible that disclosure could have detrimental effects, resulting in physical and psychosocial harm to patients. When talking about disclosure another topic that comes up is that of stigma and discrimination. This is also an aspect of adherence that needs to be carefully studied.
6.4. Limitations of the Research

There are various limitations to this research. One of the methodological shortcomings of this research is that non-probability purposive sampling was used in order to collect the data. Since the probability that a person would be chosen was unknown, it cannot be claimed that the sample is representative of the larger population. Therefore the non-representative nature of the sample means that the results cannot be generalised to the general population of HIV positive people currently on antiretroviral treatment.

Despite the fact that 100 questionnaires were distributed to potential participants, only 81 met the criteria set out by the researcher. Also, those questionnaires that were taken home by participants were not all returned. This small sample size reiterates the fact that the findings cannot be generalised to the general population. The small sample size and unequal groupings also do not allow for the researcher to explore whether the biographical variables of the sample are significant in relation to the measure.

The questionnaires were only available in English, but the majority of the respondents were first language Xhosa speakers. Although one of the requirements of the study was that participants be English first or second language speakers it is no guarantee that they did not have difficulty in understanding some of the items.

A high level of adherence was reported, however literature shows that patients consistently overestimate adherence, both in the HIV setting and non-HIV setting tend to misreport usually in an effort to please the health worker or researcher (Haynes, et. al., 1998). Therefore a way to counter this might be to encourage questionnaires to be taken home and returned or once filled in to be placed into a sealed box, thus confirming that there is no way of the researcher or health care workers knowing which questionnaire belongs to whom.
6.5. Recommendations

It is recommended that this study be replicated in the future with certain changes. Firstly, in subsequent studies of this nature a larger sample should be used that is more representative so that the results can be more generalisable to the larger population of individuals on antiretroviral treatment. Larger cell sizes are also recommended in order to explore critical biographical variables. Much of the research cited in this study comes from international sources. This indicates a need for South African research in this area in light of the ARV roll-out programme.

Secondly, the development of theories contextually relevant to a South African audience in order to guide further research might assist in further research to enhance adherence to ART (Kagee, 2008). Theory development will benefit from a multidisciplinary effort of sociologists, medical providers, psychologists and others. Interventions by medical practitioners, social service providers, health care providers and policy makers can effectively enhance the likelihood of adequate adherence. This is an area of research that can be explored further in the future. Third, the questionnaire should be made available in other languages (e.g. Xhosa, Afrikaans) to increase the sample size.

The researcher also recommends including an item in the biographical questionnaire that ascertains whether the respondents receive their treatment from public clinics or private doctors (out of pocket) as there has been research conducted that demonstrated that there is a difference in the level of adherence. It might further be beneficial to include other measures such as the Beck Depression Scale, to confirm the respondent’s emotional well-being. The results of the study can be are to work towards developing programmes in clinics to help improve and maintain adherence.

It is also recommended that further replication of this study include qualitative information into the data collection as this will serve to confirm and enrich quantitative data. As qualitative research focuses on specific context settings of interactions it could be valuable in the replication of this study in understanding the factors that impact on optimal adherence to antiretroviral treatment in the South African context.

As demonstrated by the research findings, a patient’s adherence to ART is influenced by a wide variety of factors related to patients’ beliefs and behaviour, the health system,
and social and cultural issues. Finally, the researcher recommends that further research is needed, including participant observations and capturing the actual interactions between patients and their health care providers. These findings can inform the design of behavioural research focused on psychosocial, social, and cultural factors that affect adherence and contribute to a deeper understanding of ways in which to overcome these potential barriers to ART adherence. Long-term success in responding to the epidemic will require sustained progress in reducing human rights violations associated with it, including gender inequality, stigma and discrimination.

6.6. Conclusion

This study was an attempt to explore and describe the factors that influence adherence in HIV positive individuals in the Port Elizabeth area. Although the results cannot be generalised, there are valuable contributions that have been made by this study. While an important contribution has been made to adherence/compliance research in general, this study has also paved the way for research aimed at improving adherence to antiretroviral treatment research in a South African context.
REFERENCES


APPENDICES
Appendix A
Cover letter for permission to conduct research
Contact person: Ms Kgomotso Quentinne Masokoane

Dear Sir/Madam

REQUEST FOR PERMISSION TO CONDUCT RESEARCH

I am a student at the Nelson Mandela Metropolitan University (NMMU) studying towards a Masters degree in Counselling Psychology. As part of the requirements of my degree I am required to complete a treatise or research study. The study aims to explore and describe the factors contributing to adherence and non-adherence to antiretroviral treatment.

To achieve this I would like to request participants from your clinic to fill out two questionnaires, namely a biographical questionnaire and an adherence questionnaire. Prior to the commencement of the study, the participants will be provided with information regarding possible risks and benefits, and their rights as research participants. Written consent will be requested and confidentiality of the participant’s identity will be guaranteed by using codes instead of the participants’ names.

The results of the research will be made available to your clinic. You have the right to query concerns regarding the study at any time. Telephone numbers of the researcher are provided. Please feel free to call these numbers.

The study has been approved by the Research Ethics Committee (Human) (REC-H) of the NMMU. The REC-H consists of a group of independent experts who have the responsibility to ensure that the rights and welfare of participants in research are protected, and that studies are conducted in an ethical manner. Studies cannot be conducted without REC-H’s approval. Queries with regard to your rights as a research subject can be directed to the REC-H where you can call the Director: Research Management at (041) 504-4536.

If you have any further concerns, you may write to: The Chairperson of the Research, Technology and Innovation Committee, PO Box 77000, Nelson Mandela Metropolitan University, Port Elizabeth, 6031.

Participation in this research project is completely voluntary and patients are not obliged to participate, neither will they be negatively affected by withdrawal at any stage, from the research project. The study may be terminated at any time by the researcher, the sponsor or the REC-H who initially approved the study. Although the participants’ identity will at all times remain confidential the results of the research study may be presented at scientific conferences or in specialist publications.
Your assistance in this regard is highly appreciated.

Yours sincerely

Ms Kgomotso Quentinne Masokoane
RESEARCHER

Dr Diane Elkonin
SUPERVISOR

Prof Mark Watson
HOD (PSYCHOLOGY)
Appendix B

Cover letter for participants
Dear Participant

Your participation is required in a research study that aims to explore and describe the factors contributing to adherence and non-adherence to antiretroviral treatment. You will be provided with guidelines that include the risks, benefits, and your rights as a research participant. Please feel free to ask the researcher to clarify anything that is not clear to you.

To participate, you will be asked to provide written consent that will include your signature, date and initials to verify that you understand and agree to the conditions.

You have the right to query concerns regarding the study at any time. Immediately report any new problems during the study to the researcher. Telephone numbers of the researcher are provided. Please feel free to call these numbers.

The study has been approved by the Research Ethics Committee (Human) of the university. The REC-H consists of a group of independent experts that has the responsibility to ensure that the rights and welfare of participants in research are protected, and that studies are conducted in an ethical manner. Studies cannot be conducted without REC-H’s approval. Queries with regard to your rights as a research subject can be directed to the Research Ethics Committee (Human) where you can call the Director: Research Management at (041) 504-4536.

If no one could assist you, you may write to: The Chairperson of the Research, Technology and Innovation Committee, PO Box 77000, Nelson Mandela Metropolitan University, Port Elizabeth, 6031.

Participation in research is completely voluntary. You are not obliged to take part in any research. If you choose not to participate in medically related research, your present and/or future medical care will not be affected in any way and you will incur no penalty and/or loss of benefits to which you may otherwise be entitled.

If you do partake, you have the right to withdraw at any given time during the study without penalty or loss of benefits. However, if you do withdraw from the study, you should return for a final discussion or examination in order to terminate the research in an orderly manner.

If you fail to follow instructions, or if your medical condition changes in such a way that the researcher believes that it is not in your best interest to continue in this study, or for administrative reasons, your participation may be discontinued. The study may be terminated at any time by the researcher, the sponsor or the Research Ethics Committee (Human) that initially approved the study.
Although your identity will at all times remain confidential the results of the research study may be presented at scientific conferences or in specialist publications.

This informed consent statement has been prepared in compliance with current statutory guidelines.

Yours sincerely

Ms Kgomotso Quentinne Masokoane  Dr Diane Elkonin
RESEARCHER  SUPERVISOR

Prof Mark Watson
HOD (PSYCHOLOGY)
Appendix C
Consent form
Title of the research project
ADHERENCE AND NON-ADHERENCE TO ANTIRETROVIRAL TREATMENT IN HIV POSITIVE INDIVIDUALS IN PORT ELIZABETH

Reference number (for official use)

Principal investigator
Ms Kgomotso Quentinne Masokoane

Address
PO Box 77000
Nelson Mandela Metropolitan University
Port Elizabeth
6031

Contact telephone number (private numbers not advisable)
076 *** ****

A. DECLARATION BY OR ON BEHALF OF PARTICIPANT
(Person legally competent to give consent on behalf of the participant)

I, the participant and the undersigned (full names)
I.D. number
OR
I, in my capacity as
of the participant
I.D. number
Address (of participant)

A.1 I HEREBY CONFIRM AS FOLLOWS:

1. I, the participant, was invited to participate in the above-mentioned research project that is being undertaken by
Ms Kgomotso Quentinne Masokoane
of the Department of Psychology
in the Faculty of Health Sciences
of the Nelson Mandela Metropolitan University.

2.2 Procedures: I understand that participating in this study will aid in achieving the above mentioned objective.
### 2.3 Risks: None

### 2.4 Possible benefits: As a result of my participation in this study I will receive no monetary benefits.

### 2.5 Confidentiality: My identity will not be revealed in any discussion, description or scientific publications by the investigators.

### 2.6 Access to findings: Any new information/or benefit that develops during the course of the study will be shared in the form of a written document.

### 2.7 Voluntary participation/refusal/discontinuation:

- My participation is voluntary: YES [ ] NO [ ]
- My decision whether or not to participate will in no way affect my present or future care/employment/lifestyle: TRUE [ ] FALSE [ ]

### 3. The information above was explained to me/the participant by

(name of relevant person) in Afrikaans [ ] English [ ] Xhosa [ ] Other [ ]

and I am in command of this language/it was satisfactorily translated to me by

(name of translator)

I was given the opportunity to ask questions and all these questions were answered satisfactorily.

### 4. No pressure was exerted on me to consent to participation and I understand that I may withdraw at any stage without penalisation.

### 5. Participation in this study will not result in any additional cost to myself.

### A.2 I HEREBY VOLUNTARILY CONSENT TO PARTICIPATE IN THE ABOVE-MENTIONED PROJECT
B. STATEMENT BY OR ON BEHALF OF INVESTIGATOR(S)

I, Kgomotso Quentinne Masokoane declare that

- I have explained the information given in this document to
  (name of patient/participant)
  and/or his/her representative
  (name of representative)

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

- this conversation was conducted in
  (Afrikaans) [ ] (English) [ ] (Xhosa) [ ] (Other) [ ]
  and no translator was used

- I have detached Section C and handed it to the participant
  YES [ ] NO [ ]

Signed/confirmed at

Signature of witness

Signature of interviewer

Full name of witness

C. IMPORTANT MESSAGE TO PATIENT/REPRESENTATIVE OF PARTICIPANT
Dear participant/representative of the participant

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

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

Kindly contact Kgomo Quentinne Masokoane
at telephone number 076 *** ****
(it must be a number where help will be available on a 24 hour basis, if the research project warrants it)
Appendix D

Biographical and Health Beliefs Questionnaire
## Health Beliefs and Adherence Questionnaire

### Section A – Biographical Information

1. **Gender**
   - Female
   - Male

2. **Age**
   - 21-25
   - 26-30
   - 31-40
   - >40 years

3. **Ethnicity**
   - African
   - White
   - Coloured
   - Indian

4. **Home language**
   - Afrikaans
   - English
   - Xhosa
   - Other: (specify)

5. **Marital Status**
   - Married
   - Single
   - Divorced
   - Co-Habiting

6. **Employment**
   - Employed
   - Un-employed
   - Self-Employed
   - Other: (specify)

7. **Salary**
   - <R1000
   - R1000-R1999
   - R2000-R4999
   - R5000-R9999
   - + R10000

### Section B – Health

Please indicate to what extent you agree with each of the statements below by circling the appropriate number.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am able to concentrate on what I am doing.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I feel capable of making my own decisions about things.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>I feel reasonably happy, all things considered.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
4. Are you using any of the following substances?  
<table>
<thead>
<tr>
<th>Substance</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.1 Marijuana (Dagga)</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>4.2 Cocaine</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>4.3 Mandrax</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>4.4 Heroin</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>4.5 Tik</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>4.6 Other (specify):</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

5. Are you taking medication for the following?  
<table>
<thead>
<tr>
<th>Condition</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.1 High blood pressure</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>5.2 Depression</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>5.3 Cardiac (heart) condition</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>5.4 Diabetes</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>5.5 Other (specify):</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

6. What is your average, alcohol consumption per week?  

<table>
<thead>
<tr>
<th>Day of Week</th>
<th>0</th>
<th>1-2</th>
<th>3-5</th>
<th>6-10</th>
<th>&gt;10</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.1 Monday to Thursday</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6.2 Friday to Sunday</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

7. On average, how many cigarettes do you smoke per day?  
<table>
<thead>
<tr>
<th>Number per day</th>
<th>1</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td>7.1 Never</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.2 1-10</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>7.3 11-20</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>7.4 &gt;20</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>
8. What was your CD-4 count when you started treatment?

| 8.1 | <50 | 1 |
| 8.2 | 50-149 | 2 |
| 8.3 | 150-249 | 3 |
| 8.4 | 250-349 | 4 |
| 8.5 | >350 | 5 |

Section C – Treatment

1. Give the name(s) of the treatment you are on:

2. How many pills does your treatment dose consist of? One Two Three >3

3. I have been on treatment for...
   
   year  Months

4. I miss my dosage
   
   Never  1/month  2/month  3/month  >3/month

5. When in the day do you take your treatment? Give time(s) for each period
   
   5.1 Morning
   
   5.2 Afternoon
   
   5.3 Evening

6. For the following statements: SD- strongly disagree  D- disagree
   
   N-Neutral  A- agree  SA- strongly agree.

   | 6.1 | I remember to take my treatment on time. | 1 | 2 | 3 | 4 | 5 |
   | 6.2 | I am motivated to take my treatment regularly. | 1 | 2 | 3 | 4 | 5 |
   | 6.3 | Taking my treatment will help me get better. | 1 | 2 | 3 | 4 | 5 |
   | 6.4 | My treatment programme is easy to follow. | 1 | 2 | 3 | 4 | 5 |
   | 6.5 | Taking my treatment interferes with my daily life. | 1 | 2 | 3 | 4 | 5 |
   | 6.6 | I have to hide from others when taking my treatment. | 1 | 2 | 3 | 4 | 5 |
7. Indicate the side effects (if any) that you experience. You can choose more than one (specify severity):

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>Minor</th>
<th>Major</th>
<th>None</th>
<th>Minor</th>
<th>Major</th>
</tr>
</thead>
<tbody>
<tr>
<td>7.1</td>
<td>Abdominal pain</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>7.14</td>
<td>Fat loss/deposit</td>
</tr>
<tr>
<td>7.2</td>
<td>Reduced appetite</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>7.15</td>
<td>Malaise</td>
</tr>
<tr>
<td>7.3</td>
<td>Joint pain</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>7.16</td>
<td>Irregular menstruation</td>
</tr>
<tr>
<td>7.4</td>
<td>Chills</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>7.17</td>
<td>Muscle pain</td>
</tr>
<tr>
<td>7.5</td>
<td>Constipation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>7.18</td>
<td>Nausea</td>
</tr>
<tr>
<td>7.6</td>
<td>Depression</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>7.19</td>
<td>Kidney stones</td>
</tr>
<tr>
<td>7.7</td>
<td>Diarrhoea</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>7.20</td>
<td>Neurological symptoms</td>
</tr>
<tr>
<td>7.8</td>
<td>Dizziness</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>7.21</td>
<td>Pain/tingling in arms/legs</td>
</tr>
<tr>
<td>7.9</td>
<td>Fatigue</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>7.22</td>
<td>Inflamed pancreas</td>
</tr>
<tr>
<td>7.10</td>
<td>Fevers</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>7.23</td>
<td>Numbness, prickling</td>
</tr>
<tr>
<td>7.11</td>
<td>Gas &amp; bloating</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>7.24</td>
<td>Rash</td>
</tr>
<tr>
<td>7.12</td>
<td>Headache</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>7.25</td>
<td>Seizures</td>
</tr>
<tr>
<td>7.13</td>
<td>Insomnia</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>7.26</td>
<td>Vomiting</td>
</tr>
<tr>
<td></td>
<td>7.27</td>
<td>Other (specify):</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>

Section D – Support System

1. Who knows about your status?

1.1 Spouse/partner

1.2 Family in the household

1.3 Extended family

1.4 Friend/Colleague

1.5 Other (specify)

2. On a daily basis I have ...

1 meal | 2 meals | 3 meals | >3 meals
3. Who usually prepares your meals?

<table>
<thead>
<tr>
<th>Option</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friend/neighbour</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meal-delivery</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (specify):</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4. Who usually reminds you to take your treatment?

<table>
<thead>
<tr>
<th>Option</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friend</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cell-phone reminder</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (specify):</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

5. For the following statements: SD- strongly disagree  D- disagree  N- Neutral  A- agree  SA- strongly agree.

<table>
<thead>
<tr>
<th>Statement</th>
<th>SD</th>
<th>D</th>
<th>N</th>
<th>A</th>
<th>SA</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.1 I receive enough support from my immediate family.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5.2 I receive enough support from my extended family.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5.3 I receive enough support from my health care provider.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Thank you for completing this questionnaire