

# Patient Experiences In Antiretroviral Therapy Programmes In KwaZulu-Natal, South Africa

P. Stanley Yoder  
Sibongile Mkhize  
Siyabonga Nzimande

March 2009



---

**Patient Experiences In  
Antiretroviral Therapy Programmes  
In Kwazulu-Natal, South Africa**

---

P. Stanley Yoder  
**Macro International Inc., Calverton, MD USA**

Sibongile Mkhize  
Siyabonga Nzimande  
**Health Systems Trust, Durban, South Africa**

**March 2009**

**SR-09-57**

MEASURE Evaluation is funded by the U.S. Agency for International Development (USAID) through Cooperative Agreement GPO-A-00-03-00003-00 and is implemented by the Carolina Population Center at the University of North Carolina at Chapel Hill, in partnership with Constella Futures; John Snow, Inc.; Macro International Inc.; and Tulane University. The authors' views expressed in this publication do not necessarily reflect the views of USAID or the United States Government.

**Suggested citation:**

Yoder, P. Stanley, Sibongile Mkhize, and Siyabonga Nzimande. 2009. *Patient Experiences in Antiretroviral Therapy Programmes in KwaZulu-Natal, South Africa*. Durban, South Africa: Health Systems Trust and Calverton, Maryland, USA: Macro International Inc.

# CONTENTS

---

<b>Acknowledgments .....</b>	<b>vii</b>
<b>Acronyms .....</b>	<b>viii</b>
<b>Executive Summary .....</b>	<b>1</b>
Introduction .....	1
Methods .....	1
Study Findings .....	2
Systematic Data Collection for Programme Improvement .....	3
<b>Chapter 1: Introduction .....</b>	<b>5</b>
1.1 Context and Rationale for Study .....	5
1.2 Institutional Collaboration .....	6
1.3 Study Objectives .....	7
<b>Chapter 2: HIV Prevalence and ART Services in KwaZulu-Natal.....</b>	<b>9</b>
2.1 HIV Prevalence Rates .....	9
2.2 Antiretroviral Therapy Services in KwaZulu-Natal .....	11
<b>Chapter 3: ART Programmes and Measures of Adherence.....</b>	<b>13</b>
3.1 Provision of ART .....	13
3.2 Importance of High Adherence to ART.....	14
3.3 Measurement of Adherence to ART .....	15
3.4 Determinants of Adherence .....	15
3.5 Monitoring Retention and Attrition Rates in ART Programmes .....	17
3.6 Focus on Patient Experiences in Taking ARVs .....	18
<b>Chapter 4: Methodology.....</b>	<b>19</b>
4.1 Overview .....	19
4.2 Research Questions and Assumptions .....	19
4.3 Research Sites .....	21
4.4 Sampling .....	21
4.5 Training .....	22
4.6 Data Collection .....	23
4.7 Data Processing and Analysis .....	24
4.8 Ethical Considerations .....	25
<b>Chapter 5: Perspectives of Health Care Providers on ART Programmes .....</b>	<b>27</b>
5.1 Topics of Discussion.....	27
5.2 Concerns of Patients about ART.....	28
5.3 Remembering to Take Pills.....	28
5.4 Effective Strategies for High Adherence .....	29
5.5 Ways to Facilitate Adherence .....	29
5.6 Suggestions for Programme Improvement .....	30
5.7 Conclusion .....	31

<b>Chapter 6: ART Patients Without a History of TB .....</b>	<b>33</b>
6.1 Introduction.....	33
6.2 Demographic Circumstances .....	33
6.3 Enrolment in an ART Programme .....	34
6.4 Disclosure to Others.....	36
6.5 Effects of Taking ARVs.....	38
6.6 Remembering to Take ARVs.....	39
6.7 Missing Doses .....	40
6.8 Overall Situation .....	41
<b>Chapter 7: ART Patients with a History of TB.....</b>	<b>43</b>
7.1 Introduction.....	43
7.2 Demographic Circumstances .....	43
7.2.1 Marital Status .....	43
7.2.2 Sexual Relations.....	44
7.2.3 Household Income .....	44
7.3 Learning about HIV Status .....	45
7.4 Expectations from the ART Programme.....	47
7.5 Disclosure of Being on ART.....	47
7.6 Missing Doses, Strategies, and Reminders .....	49
7.6.1 Side Effects and Health Effects .....	50
7.6.2 Lack of Money .....	50
7.7 History of TB Treatment.....	51
7.8 Comparison of ART and TB Treatment .....	51
<b>Chapter 8: ART Patients who Dropped Out of an ART Programme .....</b>	<b>53</b>
8.1 Introduction.....	53
8.2 Demographic Circumstances .....	53
8.3 Disclosure of Being on ART.....	54
8.4 Experiences of Being on ART .....	56
8.4.1 Health Effects.....	57
8.4.2 Missing Doses.....	57
8.4.3 Sexual Relations.....	58
8.5 The Circumstances of Dropping Out .....	59
8.5.1 Side Effects .....	59
8.5.2 Lack of Money .....	61
8.5.3 Moving Away .....	63
8.5.4 Other Circumstances .....	63
8.5.5 Returning to an ART Programme .....	64
8.6 Overall Situation .....	64
<b>Chapter 9: Conclusion.....</b>	<b>65</b>
9.1 Summary of Findings.....	65
9.1.1 Three Groups of Patients.....	65
9.1.2 Overall Findings.....	66
9.2 Recommendations for Programme Improvement.....	68
9.3 Patient Assessment for Programme Improvement.....	70
<b>References.....</b>	<b>73</b>

## **APPENDICES**

---

Appendix A: ART Patient Conversation Guide (English and isiZulu)

Appendix B: Conversation Guide for Health Care Personnel (English Version) Health Care Providers (Physicians, Nurses); Counsellors; Pharmacists

Appendix C: Patient Recruitment Log

Appendix D: Assessment of Patient Situation

## **TABLES**

---

- Table 2.1 HIV Prevalence by Province from a National Survey in South Africa
- Table 2.2 HIV Prevalence Among Antenatal Clinic Attendees by Province in 2007 in South Africa
- Table 2.3 Patient Regimens for ART in KwaZulu-Natal
- Table 4.1 Study Site Locations in KwaZulu-Natal Province

## ACKNOWLEDGMENTS

---

This research involved numerous persons in different positions in the KwaZulu-Natal Department of Health (KZN DoH), the Health Systems Trust (HST), and MEASURE Evaluation over an extended period. The authors are extremely grateful for the participation of all those persons. Within the KZN DoH, we want to thank S'celo Dlamini, manager of HAST monitoring and evaluation, for his enduring interest, assistance, and helpful suggestions as the study progressed. Within HST, we are particularly grateful to Dr. Irwin Friedman, Director, Research Programme and Jaine Roberts, Deputy Director, Research Programme for their continual support and encouragement. And from MEASURE, we want to thank Dr. Philip Setel for his early guidance and the MEASURE team at UNC for their support and understanding. We want to give credit and special thanks to Heidi O'bra and Win Brown of the USAID Mission in Pretoria, who periodically encouraged the study team and who showed great interest in the findings.

We are greatly indebted to all the ART patients and former patients who were willing to speak with the research assistants about their experiences in taking antiretrovirals. We want to thank the health care providers for giving generously of their time and telling us freely about their work within the ART programmes. The findings of this study depended very much on the participation of ART patients and the health care providers. And finally, we are very thankful for the efforts made by the ten research assistants doing the fieldwork as they tirelessly spoke to patients in the five research sites and transcribed the recorded conversations. The research and report has truly been a team effort.

## ACRONYMS

---

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral
DoH	Department of Health
EMS	Electronic Monitoring Systems
HAART	Highly Active Antiretroviral Therapy
HCP	Health Care Provider
HIV	Human Immunodeficiency Virus
HST	Health Systems Trust
IRB	Institutional Review Board
KZN	KwaZulu-Natal
NGO	Nongovernmental Organisation
PEPFAR	[The] President's Emergency Plan for AIDS Relief
RA	Research Assistant
SSS	Sentinel Surveillance Site
TB	Tuberculosis
USAID	United States Agency for International Development
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

# EXECUTIVE SUMMARY

---

## Introduction

This report presents the methods and findings of a qualitative study of the experiences of patients taking medication for HIV infection as part of an antiretroviral therapy (ART) programme in five sites in KwaZulu-Natal (KZN), South Africa. The study, known as the ADHERE Project, was designed by MEASURE Evaluation and implemented in collaboration with Health Systems Trust to provide information to the KwaZulu-Natal Department of Health for use in expanding and improving their ART services.

The ADHERE Project focused on taking a patient-centered perspective on factors that either enhanced or hindered an individual's ability to attain desired levels of adherence to antiretroviral therapy, and to participate in treatment programs over the long-haul. The work focused first on the development and testing of a data collection instrument that could provide information about patient experience in taking medication for HIV infection, beginning with the issue of how disclosure of HIV related to adherence. The instrument was to draw on methods of study that focus on the participant in order to capture the complex experiences of patients with ART, their treatment supporters, and health care providers (HCPs). The instrument would be used to generate data to inform programme managers about the strengths and weaknesses of their ART adherence support services in an effort to assist in programme improvement. A first round of data collection took place among patients attending one urban hospital in Durban.

In a second round of data collection in five sites operated by the provincial government of KwaZulu-Natal, MEASURE Evaluation expanded the goals of the research to include not only the formulation of an instrument to collect information about the ART programme, but also to better understand patient experiences in taking antiretrovirals (ARVs). Interest in disclosure remained, but disclosure became one of a number of topics of interest. Therefore, in this second round of research just completed, ADHERE had both a methodological and a strategic objective. The methodological objective was to develop an instrument that could be used by health care facilities directed by the Department of Health to collect information on programme operation related to patients taking ARVs. The strategic objective of ADHERE was to understand the strategies that patients develop in order to achieve high adherence. Some strategies fail while others succeed, and this study was interested in any strategy that patients have tried for maintaining adherence.

This study is qualitative in that it collected narratives of patient experiences in taking ARVs and examined the social context of taking ARVs. The research also included semi-structured interviews with HCPs who provided ART services. The study was designed and implemented to understand how ART patients managed to remain on ARVs for a long period of time, as well as how and why some patients miss doses from time to time and still others stop altogether. The results identify the information most essential to understanding how well an ART programme is functioning and ways in which it could be improved.

## Methods

This research relied largely on individual interviews with ART patients to provide the information necessary for achieving the study objectives. Individual interviews with HCPs

working in ART programmes were also conducted to add another perspective on ART service delivery and patient experiences. The study interviewed patients and HCPs in five sites in five of the 11 districts of KwaZulu-Natal. Each site was a government hospital that had initiated ART services in 2004.

The target sample for ART patients was a total of 180 ART patients from the five sites: 60 without a tuberculosis (TB) history, 60 with a TB history, and 60 who had missed two or more appointments for collection of medications. The latter were considered dropouts. The two research assistants (RAs) at each site had a quota for each category of patients to interview in order to arrive at a total of 36 patients per site. The target sample for HCPs was six ART staff at each facility. The study came very close to reaching the numbers targeted.

## **Study Findings**

Health care providers understand that patients remind themselves to take their medicines with cell phones, watches and alarm clocks, and with the help of treatment supporters. Most HCPs agree that there are two keys to high adherence: having a committed and informed treatment supporter, and disclosing to people who know the patient. HCPs suggested that the patients who tend to default were those who had been in the treatment for a long period, or those who found they were feeling much better. Their explanations for how and why patients stop taking their ARVs focused on the social and economic problems patients face.

The HCPs interviewed emphasized five main issues to be addressed for overall programme improvement: severe shortage of space, insufficient numbers of staff, the ambiguities around the administration and distribution of disability grants, the need for more detailed and more accurate information about patients in their programme, and the need to trace patients quickly who miss appointments. The instrument developed by this study responds to the last two concerns of HCPs.

The five research sites followed the same policy for getting people tested and enrolled in their ART programme. Individuals who tested HIV-positive are asked to come for further blood tests to assess their CD4 count and viral loads. They are then invited to join an ART programme if their CD4 count is below 200. Enrolment involves attending three sessions of training classes accompanied by a “treatment supporter,” a person who lives in the same household and who is able to remind and counsel the ART patient. In the ART classes, informants learned about the different kinds of pills that they would be taking as well as how and when they were to take them.

This study interviewed a sample of three types of ART patients in the five research sites: those who had never had TB, those who had had TB in the past, and those who had dropped out of an ART programme for at least two months. ART patients with a TB history were treated as a separate group to explore whether they had benefited from adhering to a TB treatment regimen in their adherence to ART. The study did not find evidence to support this expectation.

Many patients in all three groups experienced financial problems: problems in obtaining appropriate food and paying for transportation to the facility to pick up medication. About half of patients without a TB history were employed, somewhat less than half of those with a TB history, and about one-fifth of those who had dropped out were employed. Nearly one-third of all patients had benefited at some point from a government grant of some kind.

Patients in the three groups all used the same strategy for reminding themselves of when to take their medication: cell phone alarms, alarm clocks, and radio and TV programmes. Some patients had a family member remind them as well. About half of those interviewed said they never missed a dose. Most patients disclosed to at least one family member. Individuals still in an ART programme had managed to deal with their side effects.

Patients who stopped taking their ARVs (dropouts) were particularly vulnerable both socially and economically. That is, very few of them had an adequate and dependable source of income, and they had few sources of social support. Some informants reported they had stopped taking their ARVs when their disability grant ended; they had become dependent on the grant for their income. One-fourth of dropouts interviewed cited side effects as their major reason for no longer taking ARVs. Others dropped out because they lacked the resources needed to eat well and make their monthly pickup of drugs. Individuals in this group had stopped taking their ARVs for between 2 and 30 months.

The findings indicate that achieving high adherence judged by not missing doses depends less on a particular strategy for remembering when to take ARVs than on how that strategy is maintained within a household. They suggest that ART programmes should examine how individuals are situated within their household in considering the assistance patients need to maintain high adherence.

## **Systematic Data Collection for Programme Improvement**

One of the objectives of this study was to produce an instrument that can be used to collect data on factors that impact adherence in ART programmes. Such an instrument needed to be narrowly focused, simple and easy to use by personnel with minimal experience in research, and cannot require many additional resources. Ideally, it should build on what HCPs and patients are already doing. It should also focus on the factors that most affect adherence. The topic guide used for this study provided rich data on patient strategies for taking ARVs and on their own circumstances that affected adherence, and has allowed us to identify the issues most critical in maintaining adherence. However, not all topics in this larger instrument are needed in the patient assessment form to be used for monitoring patients over time.

The data collection instrument developed by this study builds directly on the main findings. The findings from ART patients as well as from HCPs indicate that adherence is most contingent on the following: having a treatment supporter who attends classes with the patient; dealing with side effects; and a household situation that includes an income adequate for providing food and transportation expenses. A treatment supporter should not only remind patients to take their ARVs, but also discuss changes necessary in life style. While the majority of ART patients were able to deal with side effects eventually, one-fourth of those who dropped out stated that side effects were the primary reason they stopped. The lack of resources for food and transport was often cited as a factor that made adherence difficult.

Having identified the factors that most affect adherence and retention in ART programmes (treatment supporter, side effects, household income), the study has formulated an instrument for use in monitoring ART patients over time with regard mainly to these factors. This instrument can be used periodically to assess the situation of patients and provide valuable information on how well patients are doing and what assistance they most require. This instrument—a one-page form for recording information—appears in this report as

Appendix D: Assessment of Patient Situation. It has been reviewed by the Department of Health of KZN.

The topics in the assessment of patients derive from parts of the larger instrument, or topic guide, used in this study. The responses will be recorded on one page as a check list with space for notes. This patient assessment form can be used to generate an overall assessment of a patient's situation periodically. The form is designed to be used right after a patient has completed ART classes, and the assessment would become part of the patient's file. The assessment will show areas where patients might encounter problems with adherence. However, the situation of households changes over time as individuals find or lose jobs or grants, and the health status of patients also changes over time. Therefore, counsellors can use this form for doing an assessment every three months with their patients.

Through conversations with about 200 individuals (patients and HCPs) about ART programmes in which they had participated, the study has been able to identify aspects of taking ARVs that patients find most troubling. Those topics are addressed in the instrument for periodic collection of information about patient experiences in taking ARVs to anticipate problems in taking doses on time and remaining in a programme.

# CHAPTER 1: INTRODUCTION

---

## 1.1 Context and Rationale for Study

The global scale up of antiretroviral therapy (ART) is providing assistance to millions of people who are living with HIV/AIDS and who need long-term chronic care. ART is being made available in unprecedented numbers in countries with limited resources. However, the rapid scale up of ART also presents enormous challenges: ensuring an adequate and consistent supply of medications for patients; setting up a system of enrolment and monitoring of patient health and adherence over time; and creating a mechanism for drug distribution that patients can afford. Nearly perfect adherence is necessary to build up an immune system, achieve viral suppression, and protect against the development of drug-resistant strains of the virus. The system of drug provision and patient monitoring must function smoothly to be effective.

The public health literature on adherence contains an abundance of articles on how adherence can be measured and on models of what are called “determinants” of adherence. One of those determinants is usually called “patient variables,” which refers mostly to the association of certain characteristics of individuals with adherence outcomes. Such studies provide important information about the statistical associations between various characteristics of patients with their ability to adhere to an antiretroviral (ARV) regimen. Analyses of this type can provide estimates of how adherence varies with such characteristics as age, education, gender, residence, or income.

It is also important to consider the experience of patients taking medications in order to understand what factors matter most to them in taking ARVs. Although narratives of patient experiences might be considered as part of what is termed “patient variables,” data on patient perspectives are of a different type. The data take the form of narratives that place individuals in specific contexts. The analysis identifies the kinds of strategies for adhering that are effective, and the kinds of challenges patients face in taking their drugs as prescribed without fail. This study examined these strategies as described by patients.

A careful consideration of the views of both patients and health care providers (HCPs) can suggest ways to best focus interventions for improvement of adherence. Information on aspects of an ART programme that facilitate adherence or fail to promote high adherence from the perspective of ART patients can inform the development of appropriate interventions in both clinic and community settings which are necessary to support patients in adhering to ART.

This report presents the methods and findings of a qualitative study of the experiences of patients taking medication for HIV infection in five sites in KwaZulu-Natal (KZN), South Africa. The study is qualitative in that it collected narratives of patient experiences in taking ARVs) and examined the social context of taking ARVs. The research also included semi-structured interviews with health care providers who provided ART services. The study was designed and implemented to understand how ART patients managed to remain on ARVs for a long period of time, as well as how and why some patients miss doses from time to time and still others stop altogether. The study, known as the ADHERE Project, was funded by USAID and designed and directed by MEASURE Evaluation.

An understanding of the strategies used by patients to take ARVs regularly—those that succeed and those that fail—provides a basis for identifying the kind of assistance patients need most to achieve good adherence as well as remain in the programme for the long term. The guidelines and instrument were developed in a way that focus on patients to show which elements of their experience with taking medications (e.g., interaction with a health care provider, the cost of medications, the experience of side effects, the recognition of improved health, the support of others) affect their ability to take the medications as prescribed.

The ADHERE study implemented in the five research sites in KZN province interviewed ART patients individually to learn as much as possible about their entire experience with HIV infection: how they discovered they were HIV-positive, how they were initiated into an ART programme, how they sought to take their medications every day, how they coped with side effects, and how they returned monthly to replenish their stock of pills. The researchers assumed that the social and economic context would play a role in how individuals were able to attain high adherence and remain in the ART programme over time. They also assumed that adherence would change over time, and that some persons would quit the ART programme. The study made a special effort to locate individuals who dropped out to better understand how that had occurred. Some patients do drop out after several months or several years; researchers were able to interview some of them and better understand how they dropped out of ART programmes.

## **1.2 Institutional Collaboration**

MEASURE Evaluation<sup>1</sup> received funds from the U.S. Agency for International Development (USAID) and the President's Emergency Plan for AIDS Relief (PEPFAR) to collect, evaluate, and disseminate data to improve programme planning and policymaking in the areas of population and health. The project has been working around the world since 1997 to strengthen the capacity of host-country programmes to collect and use population and health data. The ADHERE Project was assigned core funds and field support funds from PEPFAR through the South Africa country USAID mission in Pretoria to conduct this research and to suggest recommendations for programme improvement to the provincial Department of Health (DoH).

As part of MEASURE Evaluation, the ADHERE Project in South Africa has examined the provision of ART from the viewpoint of both health care providers and the experience of taking medication from the viewpoint of patients. Disclosure of HIV status has been assumed to be closely connected to treatment support in one's social network, and thus a main determinant of adherence. Therefore, the ADHERE Project focused initially on how ART patients disclosed their situation to others in one urban hospital in Durban. Also important was the development of guidelines and an instrument for collecting information from patients about how they took their medications. The data collection instrument was to draw on methods of study that focus on the participant to capture the complex experiences of patients with ART, their treatment supporters, and health care providers. A preliminary version of such guidelines and an instrument was used in a first round of research by HIVAN (Centre for HIV/AIDS Networking, University of KwaZulu-Natal) to interview patients on ART.

---

<sup>1</sup> MEASURE Evaluation is a project of USAID and directed by the Carolina Population Center of the University of North Carolina.

For the second round of data collection, MEASURE Evaluation contracted with the Health Systems Trust<sup>2</sup> (HST) as a partner to participate in the design and direction of the study as well as to conduct the data collection, to collaborate in the data analysis and writing of the final report, and the dissemination of the results in KZN. HST is a non-profit organization that employs approximately 80 professional and support staff in three programme clusters in the country with the main office in Durban, KZN. The organisation actively seeks to build South African capacity for health systems research and health systems planning, development, and evaluation.

### **1.3 Study Objectives**

In the second round of data collection, MEASURE Evaluation decided to expand the goals of the research to include not only disclosure to others and the formulation of guidelines and an instrument to collect information about ART programmes, but also to understand patient experiences in taking ARVs. This report presents the findings from this second round of data collection and analysis. ADHERE in this round had both a methodological and a strategic objective. The methodological objective was to develop an instrument that could be used to collect information on programme operation related to patients taking ARVs. The strategic objective was to understand the strategies that patients develop in order to achieve high adherence. Some strategies fail while others succeed, and this study was interested in any and all strategies that patients have tried while on ART. A secondary objective was to compare the adherence experiences of patients with a tuberculosis (TB) history with those who never had TB.

Because of the critical importance of TB in KZN, the study also looked at the experiences of patients with a TB treatment regimen. In consultation with HST and the Provincial DoH of KZN, researchers decided to interview ART patients with a history of TB and those without such a history to compare their experiences in adhering to a treatment regimen. It was thought that patients who had followed a TB treatment course and were cured might approach adherence to ARVs somewhat differently than those without such experience.

The results of this study identify aspects of taking ARVs that patients have found most problematic in taking their drugs without missing doses and in remaining in the programme for the long term. The data collection instrument developed by the study is focused on challenges patients face, and has provided critical information about patient experience in taking ARVs over time. Health care providers such as ART programme managers and counsellors can use this knowledge to better provide assistance to patients in their ART programme.

---

<sup>2</sup> HST is an independent non-profit organisation created to conduct research on health issues and to promote community development projects in South Africa.



## CHAPTER 2: HIV PREVALENCE AND ART SERVICES IN KWAZULU-NATAL

---

### 2.1 HIV Prevalence Rates

As with other countries in Africa, statistics on HIV prevalence at national levels in South Africa are derived from two main sources: national household surveys and anonymous testing of pregnant women attending antenatal clinics. Depending on sample size, credible provincial data may be derived from household surveys or antenatal data. The standard age group used for reporting HIV prevalence rates is adults 15-49 years of age. Household surveys that use a representative sample of adults can thus provide valid and reliable data on adult HIV prevalence. Household surveys with sample representative of adults can provide more accurate estimates of rates among adults than those from antenatal clinics, but the surveys are conducted only periodically.

A great deal of antenatal data on HIV infection has been available for the past 15-20 years from sentinel surveillance sites (SSS) in many African countries. These data show trends over time because they are collected annually, but do not accurately reflect the prevalence among adults 15-49 years of age. Prevalence data from SSS may be used in modelling exercises for estimating national prevalence rates for HIV. A comparison of prevalence from household surveys versus antenatal data have consistently shown that survey data yields somewhat lower prevalence rates than antenatal clinic data; pregnant women are not typical of all women, and HIV infection rates are usually higher among females than among males. Estimates of HIV prevalence rates from both sources are provided in this chapter to show how rates in KZN compare with those of other provinces.

The South African National HIV Survey of 2005 visited 12,581 households across the country and achieved a household response rate of 84 percent. Among eligible respondents in participating households, 65 percent agreed to take a blood test. Individuals who were homeless, living in police or army barracks, or in prisons, hospitals and educational institutions were not included in the sample. The survey estimated that the national prevalence rate for HIV among adults 15-49 years of age was 16.2 percent (Shisana et al., 2005). Table 2.1 shows prevalence estimates by province from the 2005 household survey for respondents 15-49 years old.

**Table 2.1: HIV Prevalence by Province from a National Survey in South Africa**

Province	Prevalence %
Mpumalanga	23.1
KwaZulu-Natal	21.9
Free State	19.2
North West	18.8
Gauteng	15.8
Eastern Cape	15.5
Limpopo	11.0
Northern Cape	9.0
Western Cape	3.2
<b>National</b>	<b>16.2</b>

Source: South Africa HIV & AIDS Statistics, URL: <http://www.avert.org/safricastats.htm>

The table shows that KZN has the second highest HIV prevalence rate among South African provinces, just one percentage point below that of Mpumalanga, while the lowest figure, 3.2 percent, is found in Western Cape.

The province of KZN is divided into 11 administrative districts. Table 2.2 displays national and provincial data from antenatal clinics to show the ranking of the nine provinces as well as trends over time. These data also reveal that prevalence rates in 2007 were highest in KZN (37.4%), followed by the Free State (33.5%) with Mpumalanga (32.0%) not far behind. Western Cape again showed the lowest rates of all. The table also shows that prevalence rates among antenatal clinic attendees may have peaked in 2004.

**Table 2.2: HIV Prevalence Among Antenatal Clinic Attendees by Province in 2007 in South Africa**

Province	2001 %	2002 %	2003 %	2004 %	2005 %	2006 %	2007 %
KwaZulu-Natal	33.5	36.5	37.5	40.7	39.1	39.1	37.4
Mpumalanga	29.2	28.6	32.6	30.8	34.8	32.1	32.0
Free State	30.1	28.8	30.1	29.5	30.3	31.1	33.5
Gauteng	29.8	31.6	29.6	33.1	32.4	30.8	30.3
North West	25.2	26.2	29.9	26.7	31.8	29.0	29.0
Eastern Cape	21.7	23.6	27.1	28.0	29.5	29.0	26.0
Limpopo	14.5	15.6	17.5	19.3	21.5	20.7	18.5
Northern Cape	15.9	15.1	16.7	17.6	18.5	15.6	16.1
Western Cape	8.6	12.4	13.1	15.4	15.7	15.2	15.1
<b>National</b>	<b>24.8</b>	<b>26.5</b>	<b>27.9</b>	<b>29.5</b>	<b>30.2</b>	<b>29.1</b>	<b>28.0</b>

*N.B. The 95% CI was used because statistically the true estimated value falls within the two confidence limits and therefore assures us that there is 95% certainty that the estimated value is not by chance.*

Source: National Department of Health, 2008

Figures from antenatal clinics in 2007 in KZN show relatively small differences in HIV prevalence by district; prevalence varies from a high of 42 percent in Ethekewini and iLembe to a low of 32 percent in Umzinyathi.

## **2.2 Antiretroviral Therapy Services in KwaZulu-Natal**

The KZN DoH oversees the delivery of ART as well as other health services for the province. According to the KZN Epidemiology Unit (2005), when ART was introduced in South Africa, a review of the health care facilities was undertaken to assess their resource base and suitability to provide this service. After completion of the review, a system of accreditation was established for clinical sites that sought to begin offering ART. For approval, a site needed to show adequate infrastructure, capability for data collection and monitoring, and adequate personnel. These requirements were set out in the Operational Plan of 19 November 2003 (KZN Epidemiology Unit 2005).

Before May 2004, the KZN DoH had no public health facility providing ARV treatment, although most facilities were offering voluntary counselling and testing (VCT), ART prophylaxis for pregnant women, as well as management of opportunistic infections (KZN Health, 2006). An article by David Wilson and colleagues suggested that the delay in initiating ART in KZN was due in part to the need to carefully consider ethics and fairness in the distribution of services before approvals for ART provision could be granted (Wilson et al., 2006). However, by 2007, the DoH had more than 75 sites in full operation serving more than 107,000 patients (Mbangwa, 2007). Rollout was rapid, and KZW became the first province in South Africa to provide more than 100,000 patients with ARVs by 2007.

In May 2004, the KZN DoH initiated the ARV rollout programme in eight hospitals with 100 patients receiving ARVs. The recorded number of people on this ART programme soon reached more than 54,000. The rollout involved two regimens, divided into regimens 1a and 1b, and regimen 2 (see Table 2.3). Regimen 1a is dispensed to all adult patients except for women who still intend to bear children, and male shift workers working at night. For these, regimen 1b is used. Regimen 2 is given as a second-line drug when regimens 1a and 1b fail.

The KZN DoH subscribes to the National Government's Comprehensive Plan for the management of HIV and AIDS as approved by the National Cabinet in 2004 (Nkonyeni, 2006). This Comprehensive Plan is based on the policy that only people with AIDS and/or a CD4 count less than 200 are eligible for ART (KZN Health, 2006). The DoH states that the objectives of HIV/AIDS care and support programmes should be as follows:

- To ensure equitable access to diagnosis, medical care, pharmaceuticals, and supportive services
- To reduce morbidity and mortality from HIV/AIDS and related complications
- To promote prevention opportunities within care and support service delivery
- To improve the quality of life of both adults and children living with HIV/AIDS and their families.

**Table 2.3: Patient Regimens for ART in KwaZulu-Natal**

<b>Adult Patient Regimens</b>			
<b>Regimen 1a</b>	<b>Regimen 1b</b>	<b>Regimen 2</b>	<b>Special Regimen</b>
<ul style="list-style-type: none"> <li>• Lamivudine (3TC)</li> <li>• Stavudine (d4T)</li> <li>• Efavirenz (EFV) (stocrin)</li> </ul>	<ul style="list-style-type: none"> <li>• Lamivudine (3TC)</li> <li>• Stavudine (d4T)</li> <li>• Nevirapine (NVP)</li> </ul>	<ul style="list-style-type: none"> <li>• Didanosine (ddI)</li> <li>• Zidovudine (AZT)</li> <li>• Lopinavir/otonavir (LPV/r)</li> </ul>	<ul style="list-style-type: none"> <li>• Any combination of treatment as a replacement of drugs from 1a or 1b</li> </ul>

  

<b>Paediatric Patient Regimen</b>			
<b>Regimen 1</b>		<b>Regimen 2</b>	
<b>&lt;3yrs</b>	<b>&gt;3yrs</b>	<b>&lt;3yrs</b>	<b>&gt;3yrs</b>
<ul style="list-style-type: none"> <li>• Lamivudine (3TC)</li> <li>• Stavudine (d4T)</li> <li>• Kaletra</li> </ul>	<ul style="list-style-type: none"> <li>• Lamivudine (3TC)</li> <li>• Stavudine (d4T)</li> <li>• Efavirenz (EFV)</li> </ul>	<ul style="list-style-type: none"> <li>• Didanosine (ddI)</li> <li>• Zidovudine (AZT)</li> <li>• Efavirenz (EFV)/ Nevirapine (NVP)</li> </ul>	<ul style="list-style-type: none"> <li>• Didanosine (ddI)</li> <li>• Zidovudine (AZT)</li> <li>• Kaletra</li> </ul>

Source: KZN Epidemiology Unit 2005

The five research sites all follow the DoH guidelines for service delivery. They use the regimes shown above, and they have the same requirements for enrolling patients in an ART programme: a CD4 count below 200, attendance in enrolment classes, and the designation of a treatment supporter, someone who can attend the classes with the patient and who can also assist them in adhering to the regimen and to lifestyle changes required. They have all set up the same “patient pathways” to initiate services as follows. The patient is referred from the VCT unit to register and be screened for CD4 count results. They then participate in a treatment counselling session for two consecutive days. Then they return for clinical assessment and their CD4 and viral load results. They also are given bactrim before receiving ARVs. Adherence classes then commence on the next visit. Once the three classes are completed, the patients receive their first round of medication. From then on patients return every four weeks for renewal of their medications.

In 2006, an evaluation of the ART programme in KZN was conducted through collaboration between the KZN DoH, the Italian Cooperation, and the University of KZN (Vella et al., 2008). The evaluation examined the operation of ART programmes in 32 delivery sites around the province. The evaluation examined a representative sample of 2,835 patient records, and interviewed health care providers and patients. The evaluation report found that the system of tracking defaulters was weak. It also found that 20 percent of patients had dropped out after one year on medication and 25 percent after two years. The report stated that clinic records showed that 5.8 percent of patients had died after two years in the programme (Vella et al., 2008:39).

This evaluation of the ART programme in KZN made a series of recommendations for programme improvement. Among the recommendations offered were several that concerned improved systems to identify patients who miss scheduled appointments, better information about patients likely to default, and better systems to trace patients. This study directly contributes to implementing those recommendations by offering an instrument for monitoring patients and by better understanding the challenges faced by patients on ART.

## CHAPTER 3: ART PROGRAMMES AND MEASURES OF ADHERENCE

---

This chapter discusses issues related to the establishment, monitoring, and evaluation of these antiretroviral therapy (ART) programmes in African countries to serve as a background to the current study. The issues include efforts to make antiretrovirals (ARVs) available at sustainable prices, the measurement of adherence, evidence about adherence levels in African countries, factors that affect adherence, rates of retention in ART programmes, and the study of patient experiences in taking ARVs over time.

### 3.1 Provision of ART

The development in 1996 of highly active antiretroviral therapy (HAART) to treat HIV infection has reduced both illness and death related to the HIV virus (Palella et al., 1998). These drugs were initially expensive and the drug distribution and monitoring system was complex. Therefore, their use was at first confined to resource-rich countries with well-developed health services. In these countries, the first-line HAART drugs demonstrated their effectiveness with patients who displayed high adherence to the regimen.

Many public health specialists were initially skeptical about offering ART in the developing world, which was characterized as resource-poor, since the provision of ARVs was complex, expensive, and required health services not always available in these settings. Schwartländer and his colleagues have described the “10-year struggle” to offer ART in these settings, describing the roles and activities of individuals, institutions, pharmaceutical companies, activists, and donors to provide low-cost generic ARV drugs (Schwartländer et al., 2006). The launching of the “3 by 5” Initiative in 2003 by the World Health Organization had a major impact on expanding ART access to people in resource-poor settings even though it failed to achieve its objective of reaching 3 million patients by 2005. But the combined efforts of major donors, international agencies, nongovernmental organisations (NGOs) and governments, along with lower-cost drugs, have succeeded in a rapid scale-up to ART in a number of countries.

Early studies conducted in Brazil, Haiti, Malawi, Senegal, and South Africa demonstrated that it was possible to provide ART and to achieve high adherence in patients in resource-poor settings (Orrell et al., 2003; Lanière et al., 2003; Farmer et al., 2001; Bastos et al., 2006; Tassie et al., 2003). More recent studies have confirmed these results (Mills et al., 2006; Stringer et al., 2006). In their meta-analysis of 84 studies, Mills and colleagues found that on average, 82 percent of African patients reported taking 95 percent or more of their prescribed doses in the last 28 days compared with 55 percent of American patients (Mills et al., 2006). However, in a review of adherence in African countries, Jaffar and colleagues suggest that measures of adherence that rely on patients who remain in programmes may overestimate adherence because an important proportion of patients are lost to follow-up, and are thus not part of the samples (Jaffar et al., 2008). As ART programmes mature, studies of the attrition rates will contribute to a more precise assessment of adherence and the success of ART programmes.

The attention of researchers has now focused on factors that affect adherence and retention of patients in ART programmes, and on interventions that can improve patient adherence. Brinkhof and colleagues recently conducted a comprehensive review of patients lost to

follow-up in 15 ART programmes in Asia, Africa, and South America (Brinkhof et al., 2008). The review considered outcomes among a total of 5,491 patients. The study classified the patients into two groups: those simply lost to follow-up (no contact), and those with one contact after not returning for drugs. They found that 21 percent of patients had been lost to follow-up after six months. The authors suggest that in a context of limited resources, it may be better to spend resources to facilitate patient access to treatment rather than try and trace patients who do not return. They suggest also that programme success should be measured not only by the number of patients enrolled, but also by the numbers that remain in long-term care. Thus the numbers that are lost to follow-up become an important indicator of success of an ART programme.

### **3.2 Importance of High Adherence to ART**

Adherence is usually taken to mean the proportion of doses prescribed that are actually taken at the recommended time (Goudge et al., 2004). The World Health Organization defines adherence as “the extent to which a person’s behaviour—taking medication, following a diet, and/or executing lifestyle changes—corresponds to agreed recommendations from a health care provider” (WHO, 2003). Studies have shown that adherence to ART is a strong predictor of HIV outcomes. Maintaining a high level (95%) of adherence is critical to programme success, for only high adherence can reduce viral loads, enhance CD4 counts, improve health, and avoid the development of drug resistance for patients (Golin et al., 2002). A comprehensive discussion of the importance and the measurement of adherence to ART can be found in chapter 3 on adherence to antiretroviral therapy in a recent WHO publication on HIV testing and treatment and generic tools for operations research (Obermeyer et al. 2009).

The published literature on adherence to ART over the past 10 years has clearly established the close link between high adherence to a treatment regimen and clinical outcomes: on viral load, on CD4 T-cell counts, and on the strength of the immune system (Turner, 2002). Since a number of studies have reported that missing more than 5 percent of prescribed doses may lead to a loss of viral suppression, the cut-off point of 95 percent is being used as the definition of adequate adherence. Although there are many variations of medications available and in use, the most common combination in current use is some form of HAART. For HIV infection to be transformed from a fatal condition to a manageable disease condition, high adherence is absolutely necessary.

While high adherence is essential for positive outcomes in many domains, suboptimal adherence may lead to the development of viral strains that are resistant to the first-line drugs offered to ART patients. This possibility has both medical and economic implications, because second-line drugs are far more expensive, more complex, and may have greater side effects (Negredo et al., 2006). The impact of adherence of viral load may be related to the drug regimen, with some able to achieve viral suppression even with moderate adherence (Weiser et al., 2004; Maggiolo et al., 2005). Several studies have found that 80-90 percent adherence was associated with higher risks of drug-resistant mutations (Bangsberg et al., 2004; King et al., 2005). However, Bangsberg and his colleagues caution against assuming a simple relationship between poor adherence and the development of drug-resistant strains, for resistance varies according to the regimen in question (Bangsberg et al., 2004).

### **3.3 Measurement of Adherence to ART**

Because almost perfect adherence is necessary to achieve full viral suppression and guard against the development of drug-resistant strains of the virus, researchers from many disciplines have been studying ways to assess adherence and to assist patients in improving their adherence actions. However, finding ways to measure adherence in both developed and developing countries has proved to be an ongoing challenge. In her review of factors that affect adherence, Margaret Chesney (2000) describes four main methods of measuring adherence, each with advantages and limitations. The most common method used is some form of self-report by patients, in which individuals fill out a form or a questionnaire about the dosages taken recently. While this is a flexible and inexpensive method, many researchers are convinced that self reports provide inflated estimates of adherence.

A second method often used is pill counts done when patients return to renew their medication because the return of excess pills theoretically allows a calculation of the doses taken. However, for this method to be effective, patients must remember to return the original containers with their medications, and that does not always happen. Patients may also choose to keep a number of pills to appear compliant. Thus pill counts are also thought to overestimate adherence. A third method applicable to clinical trials uses drug assays to measure recent doses taken, but such tests are expensive and not widely available. Finally, some programmes have used electronic monitoring systems (EMS), whereby a computer chip is inserted into the cover of the drug bottle caps to record the date and time of the opening and closing of the cap.

Several studies have compared two or more methods for accuracy with mixed results. For example, Bangsberg et al. (2001) compared an EMS with unannounced home visits for pill counts in San Francisco, California. By adding patient interviews about the use of the bottle cap, researchers found measures of adherence that were close to those found in the pill counts. Other studies have compared several methods with varying results. Yet, despite the possible bias inherent in the self-report methods developed, some form of self-report is the most commonly used method for programme monitoring and evaluation.

### **3.4 Determinants of Adherence**

The public health literature on adherence contains numerous articles on how adherence can be measured and on the “determinants” of adherence, or variables from survey data linked to adherence outcomes. In their review of the adherence literature, Ickovics and Meade (2002) proposed a model of adherence that involves five categories of variables: disease characteristics, treatment regimen, patient-provider relationship, clinical setting, and patient variables. The suggestion that disease characteristics serve as a determinant is based on evidence from other chronic diseases more than on studies of HIV infection.

One of the determinants found in models of adherence is usually called “patient variables,” which refers to the association of certain characteristics of individuals with adherence outcomes. In most cases age, sex, and education are not associated with a particular outcome. In studies conducted in Botswana and Uganda, the cost of medications was a major factor contributing to non-adherence, indicating that income or personal assets play a role (Weiser et al., 2003; Byakika-Tusiime et al., 2005). Several studies, including those of the French team in Senegal (Desclaux, 2004), have found that the patient-provider relationship affects adherence directly. The importance of the clinical setting will vary greatly from one context to another, but it includes ease of access, treatment of patients, and adequacy of referrals. The

treatment regimen has also been found to affect adherence, as the simpler treatment regimens facilitate adherence.

It is common to consider health system, health status, social context, and patient variables in the examination of adherence. The way drugs and services are provided, just as the health status of patients, can affect adherence. It is less clear what is meant by “patient-related factors,” because that label can be applied to all the dimensions.

One could consider “patient variables” to be those factors that affect patients in different contexts in order to group determinants of adherence: patients in the context of health care delivery, patients in the context of being sick and dealing with symptoms of illness, and patients in the context of developing a strategy for taking drugs regularly and seeking social support for their actions. This approach still allows us to examine the health system and how it is organized to deliver drugs and counselling to ART patients. It also allows us to consider the health status of patients and how that affects pill consumption, but the principal advantage of this framework is the placement of patients within various contexts and the emphasis on their experiences in negotiating tasks related to the procurement of drugs, taking pills at certain times, enlisting the support of others, and deciding to let (some) others know about their situation.

A prospective study of adherence among ART patients in Belo Horizonte province in Brazil more or less followed the WHO framework in its design: an emphasis on health systems, health status and side effects, social context and support, and patient variables. Researchers followed 417 ART patients for up to 12 months after they began treatment (Bonolo et al., 2005). The variables examined included socio-demographic characteristics, behaviour characteristics, health service variables, and clinical characteristics. Adherence was measured through self report with a standardized questionnaire. The authors found that the cumulative incidence of non-adherence was 37 percent and that most cases occurred during the first six weeks of treatment. They also found that non-adherence was closely related to health service and clinical variables. These findings suggest that outcomes can be improved by modifying service delivery and by focusing on the initial weeks of ARV provision.

While such studies can provide important information about trends over time, it is also important to examine the experience of patients taking medications for understanding what kinds of strategies for adhering are effective, and what kinds of problems patients face. Information on aspects of an ART programme that facilitate adherence or fail to promote high adherence can inform the development of appropriate interventions in both clinic and community settings, which are necessary to support patients in adhering to ART. Consideration of factors related to patient experience needs to be specific to countries or societies, because social and economic situations differ so widely.

Information on patients’ experiences taking ART and the behaviours and perspectives of their support group is useful for informing interventions to improve ART adherence. In their review of ART adherence intervention studies, Côté and Godin (2005) identified 16 studies, with the most common interventions focusing on improving patients’ understanding of their situation and of ART. Only 2 of the 16 studies reviewed included interpersonal constructs. Samples of the included studies were small (10-74) and results were inconclusive.

In her overview of adherence, Nancy Reynolds (2004) discusses determinants of adherence and efforts to improve it, but notes that there is little research on interventions designed to increase adherence. After citing two studies of interventions with little impact, she writes:

“While these and other preliminary reports demonstrate varying degrees of success with different intervention approaches, the relative efficacy of the strategies has not been established and the mechanisms by which the interventions promote adherence are not well understood” (Reynolds, 2004:210).

The qualitative research that has been conducted on ART adherence, primarily in the United States, offers a more complete picture of patients’ adherence behaviours. Studies have found that adherence is influenced by integration of ART use with daily life activities and reconciling contradictory demands such as work and sleep schedules and food prohibitions (Golin et al., 2002; Maticka-Tyndale et al., 2003; Ryan and Wagner, 2003). They have also highlighted how discrimination and fear of involuntary disclosure of HIV status can serve as an impediment to adherence (Golin et al., 2002; Kumarasamy et al., 2005) and how receiving social support may facilitate adherence (Malcolm et al., 2003; Kumarasamy et al., 2005).

Many studies of adherence assume that 100 percent adherence is the ideal and the norm, and thus they examine why patients fail to achieve high adherence. Studies seek to identify “barriers” to high adherence or barriers to “good behaviour” (Murphy et al., 2003; Remien et al., 2003). This study of adherence in KZN focused less on barriers to good behaviour and more on the identification of the strategies that worked best for patients. The study solicited accounts of how individuals took their pills over time according to accounts in the words of the patients themselves.

### **3.5 Monitoring Retention and Attrition Rates in ART Programmes**

Studies and statistics on the fate of ART patients, including those no longer coming for their drugs, are just beginning to appear. Several reasons for their being so few should be noted. One, many ART programmes in developing countries are no more than a few years old, so statistics on the number of those who dropped out are just becoming available for countries and regions. Two, because those who leave a programme are often hard to locate, conducting studies of their ART experiences presents special challenges. And three, one can do studies of what happens to ART patients only in settings with a reliable information system about patients that includes accurate data about phone numbers and addresses as well as their medications and exam results.

Perhaps the most comprehensive recent review of ART patients who remain in a programme and those who dropped out was written by Sidney Rosen and colleagues (2007) who called their article “a systematic review.” After extensive searches of the literature, the authors identified 22 articles and 10 conference abstracts that reported on the status of ART patients at six, 12, or 24 months after initiation into an ART programme. The texts reported on 74,289 patients in 33 patient cohorts from 13 countries in Africa. The authors speak of “rates of retention” and “rates of attrition” of ART patients. All studies included gave at least one indicator of patient retention after a six-month period or more following the beginning of ART.

The term “retention” refers to “patients known to be alive and receiving highly active ART at the end of a follow-up period” (Rosen et al., 2007:0002). “Attrition is defined as discontinuation of ART for any reason, including death, loss to follow-up, and stopping ARV medication while remaining in care” (ibid.:0002). Though very few patients interrupted ARVs while remaining in care, the major categories of attrition were “loss to follow-up” and death. Among all the cohorts, the main contributors to attrition were “loss to follow-up”

(56 percent) and death (40 percent). The category “loss to follow-up” undoubtedly includes some patients who just stopped their medication and have no intention of continuing in the future, but it also includes some unrecorded deaths, some patients who transferred to another ART programme, and a few who just interrupted their ARVs for a brief period.

The mean retention rates for the 33 cohorts of this analysis were 80 percent at 6 months, 75 percent at 12 months, and 62 percent at 24 months. An attrition rate of 35-40 percent of ART patients in two years seems high, with 15 percent of patients lost through death. However, some studies from Europe and North America show even higher rates of attrition. A study from northern Malawi showed that men present for HIV testing with further advanced stages of AIDS than women, and thus they are more likely to die before they begin ART as well as during the first few months of treatment (Chen et al., 2008). This study suggests that mortality among ART patients can be reduced by earlier initiation of ART.

Because high adherence is so critical for positive outcomes, researchers will continue to conduct studies of levels of adherence in ART programmes in African countries and elsewhere. At the same time, we are likely to see studies of rates of attrition that seek to identify the circumstances that contribute to dropping out of an ART programme. It may well be that studies of attrition will become more important than studies of adherence as ART programmes become more numerous and more efficient.

### **3.6 Focus on Patient Experiences in Taking ARVs**

Scholars have noted that research is needed to better understand the reasons that ART patients either miss doses or stop treatment (Jaffar et al., 2008; Rosen, 2007). Researchers in public health and communication have examined factors at various levels of service provision, while anthropologists have more often focused on patient experience in taking ARVs. One of the more insightful examples of a study of patient experiences in taking ARVs comes from Anita Hardon and her colleagues. Their three-country study (Botswana, Tanzania, and Uganda) of the challenges patients face in achieving adherence used rapid appraisal techniques (individual interviews and focus group discussions) to understand how patients took their pills (Hardon et al., 2007). The authors note that studies of adherence in resource-poor countries have found that economic factors play a major role. While facilities in these countries provide ARVs free of charge, there are other costs that must be paid to remain on an ART programme. In fact, their study found that patients struggle with transport and user fees, long waiting times, lack of food, side effects, stigma, and poor counselling. The authors suggest ways to reduce workloads, reduce costs, and to improve the supervision of patients in their first weeks of treatment.

A second study in a similar vein was conducted by Norma Ware and her colleagues in three countries: Nigeria, Tanzania, and Uganda (Ware et al., 2009). The research teams interviewed patients on ART, their treatment partners, and health care providers from ART programmes to learn how patients managed to take their drugs. The researchers found that scarcity of resources was a constant problem in adherence, and that patients often had to beg or borrow or otherwise struggle to find funds for transport to obtain their monthly medication.

## CHAPTER 4: METHODOLOGY

---

### 4.1 Overview

This research relied largely on individual interviews with ART patients to provide the information necessary for achieving the study objectives. Individual interviews with health care providers working in ART programmes were also conducted to add another perspective on patient experience. While the overall goal of the ADHERE Project in KZN was to provide information to ART programmes that can be useful for programme improvement, the project had two distinct objectives, one methodological and one strategic: 1) to develop a tool and guidelines that will assist provincial-level managers and health providers in monitoring and improving adherence, and 2) to understand patients' strategies for maintaining high adherence. The tool can be used to generate data to inform programme managers about the strengths and weaknesses of their ART services in an effort to assist in programme improvement. An understanding of the strategies used by patients to take ARVs regularly—those that succeed and those that fail—provides a basis for identifying the kind of assistance patients need most to achieve good adherence.

Both HIV/AIDS experts and TB specialists have long understood the synergistic affect between HIV infection and TB: HIV dramatically reduces resistance to the TB bacillus, and many patients with HIV may die of TB. In some societies, TB has become stigmatized as a sign of HIV as the numbers of patients with TB have dramatically increased. In seeking informants for the study sample, researchers distinguished between ART patients who were on TB treatment or had been in the past, and those patients who had never had TB. The protocol hypothesized that ART patients with a history of TB treatment would do better with adhering to ARV medication than those who had never taken TB treatment, for they would have learned how to take drugs regularly.

ART patients with a TB history were considered as a separate group to determine whether they had benefited from adhering to a TB treatment regimen in their adherence to ART. Following a TB treatment is different from taking ARVs in that there are no introductory classes to orient patients, and the treatment usually lasts only six months.

### 4.2 Research Questions and Assumptions

For the methodological component, the general question is:

What sort of instrument would be able to effectively collect the information most essential for assessing how well patients are doing in taking ARVs? The general question is composed of a series of more specific questions:

- What form will the guide take?
- How do we determine what is relevant?
- What aspects of patient experiences are most critical for remembering doses and remaining in the programme?
- How do we collect data in such a way that the different sources of data (ART managers, counsellors, patients) will be complementary?

For the strategic component, the general question is:

- How do some patients develop effective strategies for good adherence while others have difficulty or stop participating in the programme altogether?

The general question is composed of a series of more specific questions:

- What strategies do patients on ART develop to achieve optimal levels of adherence?
- What factors or circumstances cause patients to miss a dose of medication?
- What circumstances cause patients to stop participating altogether?
- How do patients enlist the support of individuals to achieve ideal adherence?
- How do patient interactions with counsellors and other health care providers affect their capacity to follow a treatment regimen?
- What aspects of ART delivery might be changed to improve adherence?
- Does previous TB treatment influence ART adherence?

There are also several issues related to the contact between patients and health care providers as patients initiate treatment. These questions are:

- How were individuals recruited into the system for receiving ART?
- What benefits were expected from taking ART at the beginning?
- What is the treatment regimen recommended?
- What is the role of patients in the choice of a treatment regimen?

In the process of designing research, participants always make certain assumptions about the phenomena they plan to study. Some of those assumptions may be articulated, while others are not recognized. Whether articulated or not, assumptions do shape the research questions and sometimes the methods as well. Among the assumptions made by the study design team for the ADHERE Project were the following:

- The relationship between the patient and the primary health care provider has a direct effect on a patient's ability to take the medication as prescribed.
- The simpler the treatment regimen in terms of number of pills and times per day they are taken, the easier patients will find taking the medications.
- The impact of side effects on adherence depends a great deal on what the patient has been told to anticipate and the actual expectations of the patient.
- Individuals who have one or more persons involved in their taking of medications will almost always do better than those who have no one to assist them.
- Some aspects of the experience of patients—some things that matter a great deal to them—will not be anticipated by the study design.
- Since the daily routine of patients varies tremendously in terms of work and leisure, time spent alone and with others, spending practices, and family life, we will find a great many different strategies developed by individuals to assist them in taking their medication.

The first four assumptions have often been discussed in adherence studies over the past few years (Alice et al., 2001; Read et al., 2003; Golin et al., 2002; Desclaux, 2004). The fifth and sixth assumptions have been included to recognize the importance of the local context in shaping how patients cope with taking ARVs. We were reminding ourselves to take seriously what patients told us was relevant to their experience in taking ARVs. And since many studies have emphasized the importance of providing medication in ways that “fit with the

daily routine” of patients, we expected to find a great many different strategies developed to improve adherence.

Investigation of the research questions and evidence related to study assumptions has provided us an opportunity to test elements of data collection tools. In addition to these questions focused on patients, the study also examined issues related to the delivery of ART by the health system: the way the facility recruits patients into ART, the view of health care providers about problems of adherence, and their perspectives on how adherence could be improved.

### 4.3 Research Sites

KZN DoH first initiated ART in eight government hospitals in the province in 2004. KZN is divided administratively into 11 districts. The DoH requested that this study be conducted in five sites in five different districts. MEASURE Evaluation, in collaboration with the DoH, conducted a standardized assessment of ART services in seven sites in order to choose five for the study in five districts of KZN. Interviews were conducted with ART coordinators, doctors, TB coordinators, and pharmacists to determine what data on patients and service delivery were being collected, how TB and ART services were organized, and to identify aspects of the programmes that were successful and challenges that remained unresolved. Both MEASURE and the DoH wanted the five sites to come from both urban and rural areas of the province; they also wanted the sites to be widely distributed across the province.

The health care providers interviewed were informed of the likelihood of the study to be conducted in their facility at the time of this initial visit. After the sites were selected, the DoH sent letters to the heads of these facilities and to the ART coordinators with more information about the organisation of the study along with a request for collaboration with MEASURE, the DoH, and HST. The following five sites were selected to participate in the research:

**Table 4.1: Study Site Locations in KwaZulu-Natal Province**

Name of Facility	Town	Urban or Rural	Date Programme Began
Mahatma Ghandi	Durban, eThekweni	Urban	March 2004
Ngwelezane	Empangeni	Semi-urban	May 2004
Madadeni	Newcastle	Semi-urban	July 2004
Church of Scotland	Tugela Ferry	Rural	April 2004
Mosvold	Ingwavuma	Rural	August 2004

### 4.4 Sampling

The basic factors judged likely to affect adherence among adult patients included gender, length of time in an ART programme, and whether or not a patient had a history of TB. Therefore, the study used a purposive sample to ensure that there were equal numbers of informants in each of the classifications from each site: male and female, with and without a TB history, and shorter and longer periods of enrolment in an ART programme. Informants who were receiving TB treatment at the time of the interview were considered as having a history of TB. Regarding duration of enrolment, patients were selected for the study if they had been in an ART programme for 3-6 months (one group), and 18 months or more (second

group). These factors (gender, TB history, duration of enrolment) were not used to judge the eligibility of dropouts, for they were difficult to contact.

The target sample was a total of 180 ART patients from the five sites: 60 without a TB history, 60 with a TB history, and 60 who had missed two or more appointments for collection of medications. The latter were considered dropouts. Researchers considered that a person who misses one appointment may return and continue ARVs, while a person who has missed two consecutive monthly appointments is far less likely to return. The two research assistants (RAs) at each site had a quota for each category of patients to interview in order to arrive at a total of 36 patients per site. For example, at each site, the RAs needed to interview 18 women: six with a history of TB, six without such a history, and six dropouts. The categories of those with and without a TB history were further divided into those enrolled for shorter or longer periods.

Clinic staff in charge of recordkeeping referred patients who satisfied the criteria sought to RAs who then asked the patients if they would be willing to participate in the study. The form used to guide the selection of informants is found in Appendix C.

The final sample of informants with transcribed interviews came close to the targeted numbers: 62 patients with a history of TB, 58 patients without such a history, and 52 patients who had dropped out. In two sites, the RAs were able to interview only 8 dropouts rather than 12, the targeted number. Therefore, the total number of patients with completed interviews was 172 rather than 180.

The study also planned to interview six health care providers (HCPs) in each site for a total of 30 interviews with personnel involved in service provision in ART programmes. The personnel were identified by the facility director or the ART coordinator. The persons interviewed included doctors, nurses, ART coordinators, ART counsellors, and pharmacists. The principal investigators from HST were able to interview six HCPs in four of the five sites and five in one site for a total of 29 HCP interviews.

## **4.5 Training**

RAs who conduct semi-structured interviews in an open-ended manner must above all be able to get interviewees to talk freely about their own experience. They must also understand the objectives and the procedures of the study very well. With this in mind, participatory techniques were used extensively throughout the training so that the study directors could observe the skills displayed by trainees over the training period.

The training of research assistants, directed by MEASURE in close collaboration with HST, was conducted in Durban over a period of 10 days. The HST screened candidates who lived in the area of each of the five sites and selected three persons from each site to attend the training. Attendees first learned about principles and usefulness of qualitative research, about ART programmes in KZN, about the research questions and objectives of the study, and about effective ways to interview individuals. The training then turned to a study of the conversation guide in English and isiZulu. Formulated originally in English, the guide was translated by HST into isiZulu and examined for accuracy and appropriateness. It was assumed that nearly all patients would want to be interviewed in isiZulu. Trainees participated in editing the translation so they would be comfortable asking general questions in an appropriate manner. The guide was divided into thematic sections; each section was

introduced by a general question followed by a series of specific items, a check list that was to be covered in the conversation. The section themes began with topics about family and residence, education and work, before passing on to getting tested for HIV and then taking ARVs. The table for asking about taking pills the last three days in the conversation guide was taken directly from early versions of the WHO Client Instrument, Adherence Module (Obermeyer et al. 2009: Annex A, p. 71).

Most of the rest of the training was devoted to practice interviewing sessions, discussions of how to pursue topics and solicit more information, and the playing out of scenarios in isiZulu with local situations and dialogue. During the training period, isiZulu was used increasingly as participants focused on the interview process and ways of getting patients to talk freely. The training also involved the use of tape recorders and the administration of the informed consent statement. The final two days of training were devoted to pretesting and making final adjustments to the materials. The instruments were pretested in two of the five sites where data were collected. Two research assistants were chosen for each site from the group of 15 persons trained.

## **4.6 Data Collection**

The process of interviewing began in the weeks following the training as HST personnel visited each field site, discussed the objectives and procedures of the study with health care personnel once again, and assisted the RA teams in setting up a research routine and the identification of eligible participants. Once the person in charge of record keeping for ART patients understood the selection criteria for interviewees, they easily identified patients who satisfied those criteria and pointed them out to the RAs. For patients no longer in the programme (dropouts), clinic staff provided the names and contact details to research assistants who then attempted to phone them and make an appointment for an interview. Some former ART patients were interviewed in the health facility when they returned for medical care and were identified by clinic staff.

Each RA had three main tasks to perform each work day: conduct one interview and record it with permission, write notes about what transpired, and transcribe the interview in isiZulu. Every two weeks the tapes and transcriptions completed were sent to the head office of HST in Durban. The interviewing and transcription required from six to eight weeks of fieldwork. The location of dropouts to be interviewed extended the time of fieldwork by two to three weeks.

Finding individuals to interview who had dropped out of an ART programme proved to be a major logistical challenge, for most had to be contacted in their homes. The nurses who serve the ART patients at the research sites identified former ART patients for the research assistants. The nurses identified such patients in two ways: by providing names and addresses of individuals who had missed at least two monthly appointments, and who could then be visited in their homes, and by sending patients who had dropped out to research assistants when they returned to a health facility for medical care. Three of the five sites had tracer teams formed to contact patients who had missed their appointments. In these three sites, the research assistants accompanied the tracer teams and contacted former patients after they had spoken with the facility team and asked if they would be willing to speak to them. This method was sometimes successful, but not always, for the phone numbers and addresses given were not always valid.

Interviews with health care providers were conducted by the two main HST researchers in the hospitals that participated in the study. Letters from the KZN DoH granting permission for conducting the study were sent to the health care facilities before any study activities began, and appointments were made by telephone before each site visit. The HCPs who participated were doctors, nurses, hospital managers, ART coordinators, pharmacists, and ART counsellors. Limitations of time, space, and staff meant that conversations were often interrupted for brief periods. Conversations were recorded with permission and then transcribed and translated into English if the interview was conducted in isiZulu. A total of 29 interviews were conducted in the five research sites.

A conversation guide in English and isiZulu was prepared in outline form to provide some structure to the interviews (see Appendix B). HCPs were asked to talk about their professional training and experience, their role in the ART programme, and details about the ART programme itself. Some time was also spent in discussing the nature of their contact with patients to provide a context for their comments, for each type of HCP has a particular role to play with patients. They were also asked to comment on the concerns of patients and on their knowledge of how patients remind themselves to take their medications.

#### **4.7 Data Processing and Analysis**

Once the transcriptions were delivered to the HST offices, they were kept in a locked closet with restricted access. The transcribed texts were gradually translated from isiZulu to English for analysis and typed in Word. The process of translation proved to be a very lengthy and time-consuming task completed in about five months time. Once completed, however, the texts in English clearly showed how patients describe the process of taking their ARVs and the challenges they face in so doing. Also available were the notes from observations made during the interviews as well as the recordings from discussions with the 29 HCPs. Those conversations were also nearly all in isiZulu, so they required transcription and then translation into English.

After several rounds of reading, the interviews with patients were hand-coded according to certain themes and circumstances derived from the research questions. Descriptions of patient responses to key issues were written in a separate file for easy referral. A one- or two-page profile of each patient was prepared, including descriptive summaries of what was said and direct quotes related to key questions. Topics in these profiles included their family situation (standard demographic variables), household composition, getting tested for HIV, enrolment into ART, disclosure to others, the effects of taking ARVs on their health, remembering to take the drugs, and missing doses. Careful attention was paid to the language used by patients to describe their own situation, and to the logical connections they made themselves between elements of their experience.

The creation of patient profiles that include quotes made it easy to see how patients described their own situation, and it facilitated the consideration of patients within their own social situation (household circumstances). That is, a patient profile allows the analyst to see what patients said about getting tested and disclosing test results in the context of their household situation, as well as what was said about taking ARVs.

Separate profiles were prepared for patients with a history of TB, those without such a history, and for dropouts. Descriptions of disclosure to others were also prepared in tabular form to facilitate comparison and summarizing. Systematic differences by categories of

patient (sex, time on ART, facility, TB and not TB, enrolled and dropped out) were investigated as part of the analysis.

#### **4.8 Ethical Considerations**

ART patients who were potential participants in the study were assured that the information they provided would be anonymous and confidential before they gave their consent. Informed consent was obtained verbally after all questions had been answered. Names were replaced by numbers in the translated interviews to ensure anonymity. The study protocol was approved by the Institutional Review Board (IRB) of the University of North Carolina in Chapel Hill, North Carolina, USA; by the IRB of Macro International Inc. of Calverton, Maryland, USA; by the Ethics Review Committee of Stellenbosch University of Stellenbosch, South Africa; and by the Department of Health of KwaZulu-Natal, Durban, South Africa.



## CHAPTER 5: PERSPECTIVES OF HEALTH CARE PROVIDERS ON ART PROGRAMMES

---

One of the factors often mentioned in studies of adherence to ARVs is the doctor/patient relationship or the interaction between clinic staff and patients as they return to a health care facility for services. Because health care providers in ART programmes see ART patients every day, we wanted to gain their perspective on both their ART programme in general, and their views of how patients were coping with adherence. Therefore, we targeted six HCPs in each site for a conversation about their work and their contacts with patients.

### 5.1 Topics of Discussion

Interviews with HCPs were conducted in the hospitals that participated in the study. The HCPs who participated were doctors, nurses, hospital managers, ART coordinators, pharmacists, and ART counsellors. They gave their time and shared their experiences and expertise very generously. HCPs were asked to talk about their professional training and experience, their role in the ART programme, and details about the ART programme itself (ART classes, drug regimen, ART promotion, contact with the community, tracing patients who miss appointments). Some time was also spent in discussing the nature of their contact with patients to provide a context for their comments, for each type of HCP has a particular role to play with patients.

HCPs were asked to comment on the concerns of patients and on their knowledge of how patients remind themselves to take their medications. They also talked about the kinds of strategies that work best for patients to maintain high adherence, strategies that fail patients, reasons for missing doses and dropping out, and ways to help patients improve adherence. Finally, HCPs were asked to suggest ways that their ART programme might be improved. The conversations were loosely structured around these topics.

Counsellors spend more time with patients than other HCPs, for they see patients as they first enrol, take them for adherence classes, and then see them periodically as they return for medications or need assistance in dealing with side effects or other challenges to adherence. Counsellors see the patients before they collect their medications at the pharmacy. Because of staff shortages, some counsellors also check vitals (e.g., blood pressure, weight, temperature) while patients are waiting to be seen by the medical staff (nurses and doctors). They reported spending about 20 minutes with patients on average and they see at least seven patients per day. They said that patients speak with them freely because they see each other periodically and thus develop a good social relationship over time.

Pharmacists see patients once a month when they return for their drugs, and they check the patients' calendars, dispense drugs, and check drug containers to see how many pills remain from the number provided one month earlier. ART coordinators oversee ART services, conduct periodic medical exams, and prepare patient files for use by doctors. All of the HCPs have opportunities to counsel patients from time to time. Doctors interpret the results of blood tests, decide on the diagnoses and prescriptions, and deal with applications for disability grants for those with CD4 counts of less than 200. They also adjust the drug regimen when necessary.

## **5.2 Concerns of Patients about ART**

The issues of greatest concern that patients presented to counsellors were the long waits for service, their financial problems, difficulties with a disability grant, and using condoms. Patients do spend time in queues for blood test results, for medicines for opportunistic infections, and for obtaining their ARVs. Many patients talked about their financial difficulties in paying for transportation for themselves and their treatment supporter (if they had one) when they returned to the clinic to collect their monthly drug allotment. Patients with a disability grant<sup>3</sup> often did not understand how and when the grants would be given or withdrawn. Finally, female patients told counsellors that they find it hard to disclose their HIV status to their partner and ask him to use a condom, as they fear that they will lose him. Those who say they did disclose to their partners often found that their partners still refused to use a condom. However, not all patients experienced problems with condom use; some used them as prescribed.

Counsellors as well as other HCPs reported that they often had the chance to reassure patients about their fears of the effects of taking ARVs. HCPs counsel patients when they want to change their medication because of side effects. Many do not like to take stocrin because it gives them bad dreams, makes them see things, or makes them drowsy. Some patients told them they are afraid they will die quickly if they begin ARVs; others are afraid they will gain a great deal of weight or suffer from debilitating side effects. HCPs also discuss the importance of coming with a treatment supporter who is close to them and available to assist them. Several mentioned that younger patients may bring a friend rather than a family member, and those friends are not likely to be available to assist in the long run. A treatment supporter need not be a family member, but does need to be someone who lives in the same household or next door. They also stress the importance of disclosing their HIV status to family members. HCPs reported that older patients perform better with disclosure than younger patients.

## **5.3 Remembering to Take Pills**

Researchers who study adherence have focused on ways that patients remind themselves when to take pills morning and evening because timely pill taking is essential for reaping any benefits from ARVs and for avoiding the development of resistant strains of HIV. HCPs' statements about how patients remind themselves can be summarized as follows. Patients remind themselves in two main ways: 1) by using a cell phone, alarm clock, watch, or similar instrument; 2) by having a treatment supporter who faithfully reminds the patient and checks on him or her every day.

However, the doctors emphasized that the treatment supporters were the "key" to good adherence. They said that all of the patients who had good and committed treatment supporters never had adherence problems, for treatment supporters are steady in offering advice and reminding patients of what they must continue to do. With this recognition, some doctors now choose to spend time with treatment supporters as well as with patient to encourage them to continue their support of patients. Counsellors made the same sort of declarations as did doctors about the critical importance of a faithful treatment supporter.

---

<sup>3</sup> A grant from the South African government given for a period of six months to individuals with a CD4 count of less than 200, for they are often too sick to work.

## **5.4 Effective Strategies for High Adherence**

According to HCPs, treatment supporters do much more than remind patients when to take their medication. They also remind patients of the importance of staying on the regimen and following the advice provided in the ART initiation classes. Because most of them began their supportive role by attending the ART classes with the patient, they learn the same information as do patients about what is essential to benefit from taking ARVs, including timely taking of pills, but also eating nutritious food, avoiding alcohol and tobacco, and disclosing their situation to others. So having a treatment supporter greatly increases chances of maintaining high adherence.

Counsellors and ART coordinators emphasized that patients need to disclose their HIV status to their family and, hopefully, to others as well. Most of them argued that patients who disclosed and accepted their statuses were the ones who performed the best with adherence. Counsellors thought that the more people disclosed the more assistance they received, and this assistance helped them to succeed. Some counsellors also said that patients who had treatment supporters who were related to them or very close to them had the fewest adherence problems.

## **5.5 Ways to Facilitate Adherence**

Health care providers suggested that the patients who tend to default were those who had been in the treatment for a long period, or those who found they were feeling much better. Some HCPs suggested that the curriculum for adherence classes should be revised to include more information about the needs of patients who remain on ARVs for a long period of time. Most importantly, all of the doctors who were interviewed said that patients defaulted because of social problems, and some of those were linked to the disability grant. The interviewees thought that some patients deliberately defaulted to keep their CD4 counts below 200 cells, so that they could retain their grants.

The rules and restrictions of the disability grant have led to many complications within the ART programme. Many patients do not understand the rules and restrictions that govern the disbursement of funds. Those complications have become the source of problems that lead to patients missing appointments and dropping out of treatment. Several doctors argued that if the patients received food parcels, there would be much less need for disability grants for patients.

Regarding ways of assisting patients to adhere to their treatment, interviewees suggested that transport should be provided to the patients who reside in remote areas and there should be home visits and follow-ups for patients who do not present for appointments and those who are clinically affected and so cannot reach a clinic. More importantly, treatment supporters should be encouraged to support patients to the fullest potential, as they are the ones patients confide in. On a more clinical side, one doctor argued that it would be better if they had more access to information to monitor viral loads as well as CD4 counts. This would improve adherence because there would be no delays before changing the patients to another regimen. The delay in change of regimens can lead to patients dropping out of treatment because it is difficult to contact patients after they have been put off treatment.

HCPs also discussed the key function of counselling patients in the maintenance of high adherence and remaining in the programme for the long term. All HCPs counsel patients in service delivery, and they expressed concern about the challenges patients face in taking

ARVs. However, the extent and quality of counselling is partly a function of the time available. The shortage of staff that all HCPs mentioned reduces the time available for counselling patients.

## **5.6 Suggestions for Programme Improvement**

The HCPs interviewed emphasized five main issues to be addressed for overall programme improvement: severe shortage of space, insufficient numbers of staff, the ambiguities around the administration and distribution of disability grants, the need for more detailed and more accurate information about patients in their programme, and the need to quickly trace patients who miss appointments.

First, observations by both RAs and HST staff demonstrated that HCPs do not have adequate private space or human resources to treat and counsel patients properly. The shortage of space may derive in part from the newness of the ART programmes in these facilities that lack the office space necessary to respond to the high demand for ARVs. In some sites, mobile home type offices have been brought in to fill in the gaps.

Second, HCPs frequently spoke of having to fill in for other staff members. Most likely, staff shortages stem in part from the fact that ART programmes are relatively new in KZN, and that it takes time to post qualified personnel as they roll out the new service in these facilities.

Third, South African government grants that have provided direct or indirect support for ART patients include the following: 1) a disability grant given for six months to individuals who are HIV-positive with a CD4 count below 200; 2) a child-support grant to those with minimal incomes who care for young children; 3) and an old-age pension grant for elderly without other sources of income. ART patients may benefit from these grants directly or indirectly: directly when they are the grantee and indirectly when a member of the household receives a grant. Doctors working in ART programmes complete their part of the disability grant application forms for patients whose CD4 count is below 200 as well as those who are clinically weak due to HIV infection. Because grant administration is complicated, and patients may not always understand the rules, many patients have become frustrated with waiting for the grant to come through, or with losing the grant once their CD4 count surpasses 200. HCPs would like to revise the rules and regulations of the disability grant so that it better serves patients in need.

Fourth, HCPs reported that they would benefit from an improved system of collecting information about patients in their ART programme. They need not only more accurate information about contacting patients, but also information about the problems patients face as they seek to remain on the programme. The current recording system does not provide sufficient information about patients lost to follow-up: some patients have died, some have stopped their ARVs without further contact with the health system, and a few have stopped ARVs but still come for other health services. An information system that would be able to communicate patient problems with taking ARVs as they occur, and that would inform the programme on the fate of those lost to follow-up, would improve programme performance.

Fifth, health care facilities may or may not have a team to trace those who miss appointments, but often the information provided by a patient—cell phone number and residential address—is not accurate, or the cell phone number is no longer functional. HCPs would like more attention paid to tracing patients who miss appointments to update their files and to better

respond to patients' need for assistance. At the moment, facilities may find it difficult to calculate attrition rates for their programme.

## **5.7 Conclusion**

Health care providers currently work very long hours in the delivery of ARVs. They understand that patients remind themselves to take their medications with cell phones, watches and alarm clocks, and with the help of treatment supporters. Most HCPs agree that there are two keys to high adherence: having a committed and informed treatment supporter, and disclosing to people who know the patient. There are elements in the interviews with patients that provide a more nuanced picture on taking medications on time. The emphasis on disclosure provides a focus on the series of relationships of the patient with family members and friends, as patients explain who knows and who does not. A good counsellor may well make good use of that knowledge by helping the patient to consider expanding the circle of those who know and accept his or her situation.

Explanations for how and why patients stop taking their ARVs focus on the social and economic problems that patients face. Patients have told counsellors about the challenges they face in depending on a disability grant, on finding food every day, and in paying for transport for themselves and their treatment supporter for renewing their medications. HCPs stressed the benefits of providing food to patients. Health care facilities have tried two mechanisms to provide food assistance: the distribution of food parcels to patients, and the serving of lunch to ART patients. They are looking for ways to assist patients with both food and transport to the health facility.

The HCPs interviewed readily spoke about their contacts with their ART patients and their efforts to achieve high adherence. Their perspective suggests that programme improvements need to give more attention to the social and economic context of individual patients than to individual characteristics. A comparison of their perspective with that of patients will provide a clearer picture of patient experiences with ARVs over the long term.



## CHAPTER 6: ART PATIENTS WITHOUT A HISTORY OF TB

---

### 6.1 Introduction

This study interviewed a sample of three types of ART patients in the five research sites: those who had never had TB, those who had had TB in the past, and those who had dropped out of the ART programme. This chapter reports on the experiences of the 58 patients without a history of TB in taking ARVs that they collected each month. The patients interviewed were purposively selected from the clinic ART files by ART programme personnel.

The interviews were guided by questions that prompted patients to talk about their family situation, the beginning of ART, disclosure to others, effects of taking ARVs on their health, remembering to take ARVs, missing doses, and their current health and social situation. Most of the patients were open and excited to talk about their experiences taking ARVs. A few were rather uneasy and uncomfortable, and therefore ended up providing less information about themselves than some others.

### 6.2 Demographic Circumstances

The ART patients were invited to talk about themselves and their family situations. Equal numbers of men and women were interviewed. The informants varied in age from 18 to 63 years of age, though the majority was between 30 and 50 years old. A total of 16 informants (16 of 58, or 27.6%) were married or lived with a steady partner: six men and five women were married, and five informants lived with a partner. The rest were single, divorced, or widowed. While one man lived alone and a few households had only five or fewer people, most households were composed of six or more persons.

The large majority of informants had attended school at least up to standard seven, while ten had finished secondary or higher. Approximately half were unemployed at the time of the study, and seven said they were self-employed or working part time. Fourteen of the 58 informants were receiving a government grant: a disability grant or a child-support grant. The rest of the respondents were dependent on neighbours or family members for funds with which to survive.

A few informants spoke of the dire economic situations made worse by the loss of a spouse, parent or sibling to HIV/AIDS. Some reported that they were in desperate straits because they had lost a government grant they had earlier received. A man who has been on the ART programme for three years described his situation as follows:

*Inf: My living situation is very bad. The disability grant that I was receiving was stopped after six months. Mosvold Hospital promised that we would get food parcels for six months, but we got them for only two months. This made it difficult to take my medication properly. I took drugs on an empty stomach because I wanted to live. The stocrin that I took made me dizzy, which made me fall into the fire and burn my elbow. I once decided to stop taking these drugs, but eventually I changed my mind. I told the doctor to stop giving me drugs because I do not have enough food to eat.*

Int: *At one point you mentioned the doctor; did you manage to see him?*

Inf: *Yes, I did.*

Int: *What did he say?*

Inf: *He said I should not stop taking drugs and then he referred me to another room where I would get food parcels. The health care providers there told me that there were no more food parcels left, so I had to borrow money from others.*

When a 33-year-old woman was asked about her living situation, she said:

*I am staying in Nonjinjikazi; I have three children, but their father passed away. My children are receiving a child-support grant of about R600. I got food, fortunately. My children receive a grant which is not enough because my children are in school, and this money only covers their needs. Because of this, I may take ARVs without food, and they cause a lot of problems in the stomach. Usually, I lack the curry sauce because this money is not enough.*

### 6.3 Enrolment in an ART Programme

The comments in this section apply to all the informants interviewed whether they had a history of TB or not, or were still enrolled in the programme or had dropped out. The conditions of enrolment thus apply equally to the patients discussed in this chapter and to those in the following two chapters.

The five research sites all followed the same policy for getting people tested and enrolled in the ART programme. Individuals who tested HIV-positive are asked to come for further blood tests to assess their CD4 count and viral loads. They most often wait for one week before receiving the results of the CD4 blood count test. They are then invited to join an ART programme if their CD4 count is below 200.

Enrolment involves attending three sessions of training classes accompanied by a “treatment supporter.” Prospective ART patients were advised to bring someone that could actually assist them, most often a close family member. Only a doctor could bypass these standard procedures by making exceptions. The classes comprised three long sessions spaced over three weeks.

In the ART classes, informants learned about the different kinds of pills that they would be taking, as well as how and when they were to take them. Moreover, they learned about different foods that they should eat and ways of protecting others against HIV infection if they chose to engage in sexual relations. Most informants began taking their ARVs as soon as the classes ended.

Some informants said that it was hard to accept that they were HIV-positive, so a small number had put off taking classes and enrolling in ART after getting tested for HIV. A few did not want to initiate taking ARVs because they were not sick, and therefore did not see the need to take medications. Others thought that if they took ARVs without being sick, they would become sick. Informants who were very ill, however, saw ARVs as their salvation.

It is worth noting that most of the men we interviewed had first used traditional medication before entering the ART programme. While a few women had also tried traditional medicine, men were far more numerous than women. For example, a 51-year-old married father of three children explained his consultations with traditional healers as follows:

Int: *Have you consulted any traditional healers?*

Inf: *Yes, they tried, but they failed. I went to Swaziland since I was travelling anyway for my work. I even went to Mozambique. They took my money; sometimes I would pay R800, R1000, R300 or R500. If you want help, it is easy to pay them; you are also working. These pills have helped without me having to pay.*

A 56-year-old divorced father of four children said:

Int: *Let's go back to finding out about your status, when was it?*

Inf: *It was a long time ago. I have even forgotten. I denied at first that I was HIV-positive. I tried using muthi to cure myself. Then I started getting really sick. One person advised me to go and check since I was also losing weight. Then I went and took a test. We can say it's been seven years or so.*

Participants were asked about the advice offered to them in the ART classes. This example shows what many individuals said about the foods they should eat:

Int: *Could that be the only things they told you, if you can still remember?*

Inf: *They said many things.*

Int: *What else could it be, if you can still remember?*

Inf: *What shall I say, because even food they told us about it?*

Int: *What did they say about food?*

Inf: *They said we must eat food like vegetables and beans, and we must get fruits, etc., so to improve our immune system.*

A widow with four children reported that she had been told to expect side effects with the pills:

*At first they tell you that perhaps when you started, the pills may be incompatible with you and that there are side effects. I was confused by all this, my child. I did not even know what that was. When I started taking these pills, there was one I was supposed to take at night that made me crazy and overheated, and I could not sleep for the whole night, so I used to sleep during the day.*

Overall, the informants reported being advised to do the following:

- to take their treatment at the same time every day
- to take their treatment with meals, and not on an empty stomach
- to eat healthy nutritious foods to avoid complications
- to always use condoms when engaging in sexual intercourse
- to bring their partners along so that they can be tested for HIV
- to disclose their status to at least one person in the household
- to refrain from alcohol and smoking

Refraining from smoking and alcohol is not always easy. The case below shows a man who recalls the advice given quite clearly, but his circumstances keep him from following completely:

Int: *But did you manage to stop?*

Inf: *Well, with me I cannot just automatically stop something. I have totally stopped “hot drinks,” but I have not managed to stop beer because it helps me when I am stressed. I just feel like one beer and things get better.*

Another woman often takes her treatment without meals because of the financial difficulties of their household. She depends on child-support grants to survive. However, taking ARVs without food has adverse effects on her body:

Int: *What were your expectations before you started the ARV treatment?*

Inf: *What I see is that my life is going on.*

Int: *Do you see that happening?*

Inf: *Yes, also hunger. The treatment makes my stomach hurt if I take them without eating anything.*

Int: *How does that happen?*

Inf: *It is as though they are the one eating me if I have not eaten.*

It seems important to consider the possibility that if many patients were not following what was recommended, they failed to understand the teaching in the ART classes. However, most of the examples of non-adherence to advice were accompanied by an explanation for why they were not able to follow. The two examples above illustrate this point. Of course there are always cases when the class curriculum may be incomplete and needs improvement. However, because the responses of informants to questions about what they recall from the classes were quite consistent, we assume that the classes are largely effective in communicating their main messages.

## **6.4 Disclosure to Others**

Informants found disclosing their HIV-positive status very difficult, but essential if they wanted people to assist them when they get seriously ill. They reported that they disclosed mostly because they wanted people to be aware of their illness and remind them to take their pills, and because they did not want people to speculate that they were bewitched. They also said that disclosing helped them to reach out to people for social and financial support, as most of them could not easily afford to go to the hospital to pick up their medications.

A 33-year-old mother of three who receives a child-support grant had the following to say about disclosing her status:

Int: *Is there anyone who knows you are taking ARVs?*

Inf: *My parents know about my status because I was staying at my husband’s place. I had to go to my parents’ home to tell them. After that I also told them where I and my husband stay. I did this because I wanted them to understand so that they cannot think I am bewitched. In addition, so that they can tell my children if something happens, because they were still young.*

Only two people out of this group of informants reported not disclosing to anybody. One is an unemployed mother of two children who lives with her mother. She stated that she has not disclosed to anybody, as she feels that the disease is still new to her and she is not ready to disclose. The other is a 55-year-old divorced man who lives alone. He said he did not need to disclose to anybody because he lives alone; his four children live with his ex-wife. One informant said that he did not tell anyone about his status, but his treatment supporter went off and told his family without his consent.

The majority of informants said that they had disclosed to their immediate families only, arguing that they did not want to be stigmatized. Some said they disclosed to their friends; a few said they disclosed to everybody. Two informants—one man and one woman—disclosed only to their spouse. A few informants disclosed to a friend or family member but not to their spouse or lover.

A 29-year-old unmarried woman, who was attending a tertiary institution, said the following about her situation:

Int: *To whom did you disclose after testing positive?*

Inf: *For some time I just told nobody. One day while tidying up the room in which I stayed, my boyfriend searched and came across my results.*

Int: *Who searched?*

Inf: *My boyfriend, my lover, searched and found the results. He had come over to see if I had gone to work. Having seen the results, he asked why I had hidden my state from him. I told him I had had no way to disclose to him. He went to test and tested positive.*

It is also worth noting that informants found it easy to disclose to people who were also HIV-positive and were comfortable with discussing issues involving their status with them. Overall, most respondents thought of disclosing as a useful thing to get support that would encourage them to take their medication on time and to get social and financial support. A small number of informants found that disclosure was a useful tool for educating people about the existence and importance of HIV/AIDS.

When a 35-year-old widowed mother of three was asked why she had disclosed to some people and not others, she said:

Inf: *I can't explain that because I can't say this person knows or they don't know; some people know even if you have not told them but you found out that they are talking whatever they want about someone.*

Int: *Do you have people who you told personally besides your mother?*

Inf: *It's the only person I told you about. I cannot run away if they know or when they are talking.*

Int: *Why did you disclose to that lady and to your mother?*

Inf: *I told them, especially my mother, because I might have a problem. (I might) get sick and can't look after myself and I have to take the tablets. When I can't take them by myself, she must be able to know my tablets so that she will be able to help me and know what are they for.*

A 30-year-old single man who lives with his mother, nieces, and nephews said:

Int: *Who knows about your status?*

Inf: *My family!*

Int: *Yeh...*

Inf: *My family, close friends, my girlfriend and most of my relatives know. In fact some of them are positive as well so...even my little brother knows. I have not hidden my status from anyone.*

Int: *What made you decide to disclose your status?*

Inf: *Well, in 2004 I needed the support from my family and I needed to let them know so that they can help me. I didn't want to keep it a secret because I thought it might lead to depression, and I didn't want that. So I saw it best to tell them.*

## 6.5 Effects of Taking ARVs

Most informants suffered from a wide range of side effects, particularly in the initial phase of taking ARVs. Informants mentioned suffering from skin rash, swollen stomachs and breasts, sore feet, dizziness, nausea, laziness, an increased appetite, and loss of interest in sexual activities. Most informants said that the initial stages of the treatment were the worst, but as they got used to them, the side effects went away. A very few said that the ARVs did not give them any side effects; in fact they enabled them to regain their lost weight. There were even a few cases where respondents argued that ARVs made their hormones hyperactive and made them crave sexual activities or enhanced their sexual performance.

When a single 33-year-old father of two children living with his parents was asked about the effects of his medication, he said:

*Int: Since you have been using your pills, did you see any changes?*

*Inf: Yes, during my first days I felt tired, they drugged me in the evening, but as the time went on I was fine, and now I am used to them.*

However, there were a few informants who said that they regretted ever joining the ART programme, stating that they had lost their “biological shape” and that the side effects of their medication has made them even more sickly. For example, a 41-year-old married mother of two children said that she regretted being enrolled into the ART programme because ARVs have caused her to lose her beauty.

A 28-year-old mother of two children had this to say:

*Int: Okay. You said that your body is no more what it used to be. It was not the same anymore.*

*Inf: I'm not the same. I have no bums, no hips, my standing was good before. I'm good-looking when I'm facing that way. But now I'm just a bowl, something you don't know. My stomach is getting big, people are saying I'm pregnant but I'm not.*

*Int: Is that the only change or there is something else?*

*Inf: Yes, that the only problem I have with the treatment, nothing else.*

An unemployed 30-year-old man, who lives with his parents said:

*Int: Do you ever find difficulties in taking your pills, especially when going somewhere?*

*Inf: When going somewhere I take my pills with me and I always have valpre or water to drink my pills and I do not hide my ARVs when taking it or drinking it. I do not see a need to hide my pills.*

*Int: Now that you are taking ARVs, how is your health and your life in general?*

*Inf: My health has improved very much since I started my treatment, but the only problem I have is that I keep on thinking about my family, especially because it's Christmas or festive season, families will be together and I will be alone. I always comfort myself by that at least I know where they are, I can see their graves, but besides that, life is good.*

## 6.6 Remembering to Take ARVs

This section examines the various ways and methods that the patients use to take their medication as prescribed. When asked about the methods they use to remember to take their medication, a large majority of patients said that they use their cell phone alarms to remind themselves when it is time to take their pills. These alarms are either set by their children or by themselves. Some stated that radio and TV programmes reminded them; as a particular programme comes on, they then know that it is time to take their medicines. A few respondents stated that they use watch alarms or merely wear watches, which they check frequently when it is near the time to take their medication. A small number said they were reminded by a family member; a few spoke of having a sense in their body that it was time to take their pills.

A mother of five children, who has never gone to school, explained how she remembers to take her pills:

*Int: How many tablets do you take the whole day?*

*Inf: In the morning I take two, in the afternoon I take three, so that means they are five, and there are those they said I must use.*

*Int: What are the rules you have set for yourself in taking your treatment?*

*Inf: I will take them till the end of my life.*

*Int: How do you remember when it's time to take your tablets?*

*Inf: My children set the alarm for my cell phone so when it's time to take my tablets, it will ring.*

Besides being reminded by instruments to take their ARVs at certain times, a considerable lot of informants reported being assisted by other people. Most of those doing the reminding were family members, as they were the ones most closely associated with the informants. A few patients were reminded by their friends, neighbours, and more distant relatives. One lady stated that she was assisted by an NGO that calls itself "Onompilo," which assists people who are HIV-positive.

An example below illustrates the importance of having someone to remind you. When an unemployed 51-year-old man was asked about how he takes his ARVs, he reported the following:

*Int: Thinking about last month, can you evaluate yourself as someone who took them every time, sometimes or none at all?*

*Inf: Since I started taking them, I have been taking them as prescribed. When I visit my relatives, I put them in my bag and travel with them. Last week I was in Ladysmith for my relative's funeral. I took them with me. I make no mistake.*

*Int: Which ways helped you to manage to take your ARV's? Is there anyone who helps you?*

*Inf: By reminding me; my wife reminds me; since she also takes them, she asks me whether I have taken my medication, and I also remind her. Some days when she washes our clothes outside having left her cell phone inside the house, I remind her, especially since I am still sick; I spend a lot of time at home. Even when I take a walk, I take it during the day, not early in the morning.*

Surprisingly, there were a substantial number of patients who argued that they did not need anything or anyone to remind them, for they felt it either in their blood, their mind, or conscience that it was time to take their medication. This was usually reported by patients who had been taking their pills for a long period.

Some people reported that they did not need help from anyone else because they knew that they should take their medicines to stay alive. Another interesting argument raised by one of the respondents was that one should ensure that they take their medication at a time convenient to them because awkward times lead to people missing doses. When patients were asked what times they took their pills, most of them said they took their ARVs at 07:00, which they found convenient; others took them at 08:00, which was mostly aligned with popular TV and radio shows, like “Generation.” Only a few took them before 06:00 and after 8:00.

## **6.7 Missing Doses**

Obtaining reliable information about missing doses proved to be somewhat of a challenge to research assistants, because so many patients claimed to never miss a dose. Actually, half of informants said they had always taken their medications as prescribed. Another 11 said they always took their prescribed dose, but that they were sometimes a bit late in doing so. Another eight said they had occasionally missed doses because they forgot or they left their medications at home when they travelled. Some explained that they took their pills so faithfully simply because they would otherwise die.

Patients who missed their doses explained their actions as follows:

A 55-year-old divorced man, who lived alone said:

*Int: So when we go back from last month how do you see yourself? Do you see yourself as a person who forgets to take their dose every day?*

*Inf: Last month (December) there was a mistake. I was called to Newcastle. When we finished our work they said there was another work at Ladysmith. We must rush there so I left them there at home and I couldn't take them.*

*Int: How long did it take you, how many days?*

*Inf: It was one month. We came around the 24th of December.*

An unmarried 35-year-old woman who lives with her partner said:

*Int: Okay; do you ever happen to forget to take your pills?*

*Inf: I do; like when I happen to have had an early morning errand, hoping to return early, only to delay—I skip the dose and take one for the evening.*

*Int: Okay; then you take the next dose in the evening?*

*Inf: Yes.*

A 28-year-old single man who lives alone and has two children said:

Int: *Do you drink alcohol?*

Inf: *Sometimes we do but it is very rare.*

Int: *Do you sometimes find that taking your ARVs get disturbed when you drink?*

Inf: *Sometimes it happens!*

Int: *How does that happen?*

Inf: *Well, people are forgetful and sometimes I also forget. Like when I have to take them in the evening, I'll forget when I start drinking.*

Some informants also seemed to be casual about taking their medication, meaning that they did not think of their tablets as something that one had to take strictly at a particular time. One said that he was meant to take his medication at eight in the evening, but took them anytime between eight and midnight because he was told that he had a six-hour leeway to take his medication.

## 6.8 Overall Situation

Most of the respondents stated that they were well and could see great improvement in their lives since they had been on ARVs. For instance, a man who lives with his wife, and who receives a disability grant, said that he felt that he was recovering slowly. He used to be in a wheelchair, but now he is walking. A 33-year-old women with three children said that she felt much better and stronger after being on the ART programme. Some even argued that they felt normal and did not even feel like they were ill, saying that they felt as if they were cured. A 47-year-old married man with three children said that he was well and felt like everybody else, for his health had improved so much. These informants had greatly benefited from taking their ARVs more or less as prescribed.



## CHAPTER 7: ART PATIENTS WITH A HISTORY OF TB

---

### 7.1 Introduction

Given the salience of both TB and HIV infections in KZN, this study chose to interview both ART patients with a history of TB and those without a TB history in equal numbers. We thought it possible that ART patients' experience with being on TB treatment may have an impact on the way they take their ARV medication. This chapter discusses the strategies and experiences of ART patients with a history of having followed a TB treatment regimen. Though most patients with a TB history had completed treatment, some patients interviewed were taking both TB treatment and ARVs at the same time.

### 7.2 Demographic Circumstances

The targeted sample of patients who are on ART with TB history was 12 from each of five sites for a total of 60 patients. Two additional patients were interviewed for a total of 62: 31 males and 31 females. Patient ages varied from 27 to 59, but 12 participants said that they do not know their age. Among those who gave their age, 22 are in the age group 27 to 35, 18 from 36 to 45, and seven were from 46 to 59 years of age. The majority of patients (35) had some schooling or had completed secondary school, two had tertiary education, and three had never been to school.

Nearly all participants reported having children. The number and ages of children may affect a person's strategy for taking medication, because some reported that one of their children reminded them when to take their ARVs. Among the 55 who reported on having children, only two had no children; 30 had one or two, 16 had three or four, and the rest had more than four children.

#### 7.2.1 Marital Status

The majority of these patients (47 of 62) were not married at the time of the interview; only 15 were married. However, 42 of the 62 participants reported they had a sexual partner. Those who reported being widowed (4) also reported having partners. Several reported breaking up with a partner or deciding to abstain from sex after learning they were HIV-positive. As one woman said:

*I don't want anything to do with male friends or love affairs.*

A young man explained the impact of a diagnosis of being HIV-positive:

*I have a four-year-old child; I separated from his mother after I was diagnosed as HIV-positive, but currently I have already found someone else.*

Another man also reported a breakup of his marriage but finding a girlfriend:

Int: *Are you married or not?*

Inf: *I was married to a lady from Gauteng (Johannesburg). But when I lost my job, my marriage was over. I can say that because she didn't want to come back home.*

Int: *So, whom do you stay with at home?*

Inf: *I am alone, but I have a girlfriend.*

Int: *Is she staying nearby?*

Inf: *No, she stays near that container on which is written Coca-cola and we have a child.*

Int: *You have a child with her?*

Inf: *Yes, I was already infected with HIV but my son is okay.*

### **7.2.2 Sexual Relations**

Most participants maintained sexual relationships with their partners. Life goes on in the presence of the virus. However, they have learned to protect their loved ones, as one man explained:

Int: *Does your wife take the treatment too?*

Inf: *No, my wife is not taking the treatment because since I came back, I have not slept with her because I did not have power and my penis could not become erect. When I started the treatment I was told to use a condom so that she will not get infected. I haven't slept with her ever since I came back.*

Participants reported that they have been educated during the adherence classes that they have to take precautions when engaging in sexual intercourse. They were advised to use condoms all the time with their partners to avoid re-infections. Those who are sexually active reported that they are using protection all the time they engage in sex. As in the example above, some participants have partners who do not engage in sex with them, for many reasons, including their ill health. Others are not sexually active because they do not have partners.

### **7.2.3 Household Income**

About 60 percent of participants reported that they were unemployed and 20 percent were engaged in income-generating activities, including temporary jobs and formal employment. Examples of employment include photography, plumbing, security, sign manufacturing, electrician jobs, and petty trading. Some participants who did not have any kind of employment stated that they receive state grants. Nine participants were receiving a disability grant which was given to them because of their low CD4 count. As one man reported:

*The doctor gave me a grant for a few months but it was supposed to be 12 months. This is why I became better, because I was getting enough food and everything that can make you healthy.*

A few participants stated that they depend on an old-age pension granted to elderly persons in the household. One man explained:

Int: *I would like to know how do you guys manage at home to get food?*

Inf: *Well, my mother and father are getting a pension because they are old. They are not that old, but they are receiving a grant.*

A second man acknowledged the financial support he receives as well as emotional support in the household:

Int: *How do you manage now that you do not work anymore?*

Inf: *There is a granny where I live and she is receiving an old-age pension. She is the one who usually provides for the house and is also very supportive towards me.*

Several participants also stated that their households depend on child-support grants to make a living. As seen in the following sections, many participants struggled to find funds for their food.

### 7.3 Learning about HIV Status

People learned about their HIV status in different ways. A few women in our sample learned through being tested during their antenatal visits. If the woman agrees, her partner will be told and will be advised to get tested, but the majority of these participants were tested for HIV and learned they were positive after they had sought health care at a health facility, without realizing that they were infected with HIV. They had become ill and had come for a medical examination. As this father said:

*I have 10 children...I have never been sick my entire life up until one of the days when I smashed my car while I was trying to turn, and my family noticed that there was something wrong. I then got sick and I was taken to the hospital. I had to stay there for some time and doctors recommended that I go for HIV testing, and I didn't hesitate. They discovered that I had TB, that I was HIV-positive, and diabetic...*

Others learned their status after the death of a loved one:

*I knew that I may be positive because I knew that my husband died of AIDS.*

Persons who have lost a partner to AIDS usually wait some time before getting tested. They may eventually make a connection between a death resulting from AIDS and their own situation, but initial denial is the most common response.

### *Case of Delaying an HIV Test*

*Interviewer: How did you know that you were HIV+*

*Interviewee: My husband was sick. He was coughing slightly and came to this hospital and got better after a few days. I then suffered from the flu and a rash and decided to see a doctor. This doctor advised me to have an HIV check-up; I then received the results which were positive. I threw the results in the bin because I knew I was not positive and understood that HIV/AIDS only affects those females who are up and down with males. Because of this, I could not even tell my husband. I then got pregnant and in the process of giving birth, my baby got sick and I brought him here and was admitted to one of Ethekwini hospital. They told me that they wanted to check the baby. They found that he was HIV-positive. I threw away those results too. In 1995 my baby passed away; then I thought maybe it was time I started taking these results seriously, but since I knew that I was not sleeping around, I neglected it.*

*In 2000 my husband got sick and was taken to hospital, and unfortunately he passed away in January. This is when I sat down and made up my mind about all these events. It also crossed my mind that my husband passed away due to this disease. I then went for a check-up in 2001, but prior to this I had a talk with one of the HIV-positive women here around my home. She said she went for a HIV test and was told that she was positive, and I asked her where she acquired it, and even suggested that I cannot acquire it since I have only one partner. Then I remembered about the post checking incidents. I then went for a test and found that I was HIV-positive. It was difficult, I could not eat or sleep for a week, and it was even difficult to tell my children.*

*I stayed home awhile and I heard about a support group which operated here in the hospital, and the counsellor asked us to come by. At my arrival on the specific date, there were lots of people attending, and I felt as if there was something moving out of my body such that after the meeting I felt better. I realized that there were lots of people who are sick. We then introduced ourselves one by one and we went on to discuss when each individual found out that they had this disease. What made me feel even better was to see the priest from the neighbourhood in that support group meeting. I then told myself that this disease is reality, and that is when I accepted that I am sick. The time I went home, it felt like I was healed, as from that day I have accepted it. Doctors then found that I also had TB. I took TB treatment before beginning the ART. They suggested that I should reveal to one of my family members, and I decided to tell my nephew that I was on ART.*

When some people learn about their HIV-positive status, they accept it and take their treatment as advised. There are cases where others remain in denial for some time, regardless of the symptoms and circumstances, as shown in the box above. The woman stated that she was told about her status but she did not believe it. Her child died as well as her husband, but she did not respond right away. She thought that HIV affects only women with many partners, and she had only one sexual partner, her husband.

## 7.4 Expectations from the ART Programme

Participants were asked about what they were expecting to happen when they enrolled in the ART programme. Their expectations range from the philosophical to accounts of what they were told during the adherence classes, as well as mentioning rumours they had heard. Some were positive about ART:

*I was expecting to find out if I was going to live or die, because there were only two things that I was expecting: to live or to die.*

*I am waiting to see what will happen, for I have started my treatment to be better.*

For other respondents, being enrolled in an ART programme brought uncertainties because they heard lots of information from many sources. Some of this information consisted of rumours, as this man indicated:

*I was expecting that I would lose weight, or die, because of the rumours from people. I was also expecting to have heart disease or liver disease. All those side effects scared me. But after I took them, I had those bad dreams a few nights; two weeks after that I was normal.*

The adherence classes taught ART patients that they might experience side effects, that those effects would go away with time, and that they must not stop taking their drugs when they experience those side effects, as related below:

Int: *What is happening to your body that you think is caused by taking the treatment?*

Inf: *When I first took them I nearly stopped taking them, because I had a rash over my whole body. I had more of a rash than I had before, so that even the medicine that I was using was not helping. It seemed like I was not doing anything, but they told me that the tablets will have some side effects in the beginning, and they were going to cause some sores, but they will disappear.*

## 7.5 Disclosure of Being on ART

Evidence about disclosure of HIV status and the fact that they are on ARVs is critical for understanding adherence because of the need for social and other kinds of support to take the medications appropriately for the long term. Half of these patients told their “whole family” about their situation. In this context, the term “family” refers to anyone related to the patient who lives in the same household. There were no differences by gender. In this group of 62 patients, no one said that they had not disclosed to anyone at all. This may be a result of the emphasis placed in classes on coming to ART with a “treatment supporter.” In some cases the patient himself or herself informed everyone and in other cases someone else informed family members. Sometimes a patient had no choice because of the obvious illness. This man had little choice in disclosing to people in his household:

Int: *Who knows about your illness?*

Inf: *My family knows and the people in my area, because when I came back I was thin like this finger. In a way that I was white in all this parts (in my chin and face). The skin was coming off, and people were asking what was wrong because I have come back. So most people in my area know, and all the members of my family.*

Another man had the following to say:

*My entire family knows about my status because I did not want to go through this alone. I need the support so I had to tell them.*

Some participants did not disclose to their children because they did not want their situation to hurt their children in any way:

*I started by telling my mother and I told my cousin. I only left out my child. I did not tell her because I thought it was going to hurt her, for we have lost my father, and I have also come out with this HIV thing. I thought she was going to have stress at school.*

The majority of participants talked of a desire to limit the knowledge of their situation to one or more family members, or even to a spouse. People still fear being discriminated against or troubling those who they believe could not take the news.

We found four participants—three women and one man—who disclosed only to their spouse or lover. A 34-year-old unemployed married woman who has a tenth-grade education level said she disclosed her status to her husband only and added that she does hide the news about her status from other people. She stated her reasons as follows:

Int: *Why did you tell him?*

Inf: *Because he is very close to me and he is very supportive. He reminds me to take my medication whenever I forget.*

The response above shows that support and trust informed her decision. The whole situation about HIV infection does not seem problematic in this couple's relationship. A 30-year-old female was in a rather different situation. She stated that it was very difficult for her to tell her husband about her status because she thought she was going to be blamed, as she was not a virgin when she got into their relationship. She lied to him saying that the doctor invited him to test for TB, and that she also had TB. After doing nothing for a long time he mentioned that he knows that he does not have TB, and he knows that this was not about TB. However, he was prepared to take medications if needed.

A 40-year-old male participant living alone and away from home because of employment told his wife of his status because she needed to know.

Int: *What made you tell your wife?*

Inf: *I had to tell her because it would seem as if I was destroying her life. The virus was going to spread more if she did not know and what forced me was that if we were going to start using condoms, she was going to ask why we are using it now.*

Most of these participants, who disclosed only to their partners, do not have major financial difficulties. They manage to get by. Only one participant stated that she depends on child-support grants for three children in the household. She is the one who presented a rather difficult financial situation:

Int: *Do you get food usually?*

Inf: *We do not usually get it; usually, we suffer for it.*

Int: *What do you do when you take your tablets without having eaten anything?*

Inf: *I take them in the morning without eating anything. Then I will take them in the afternoon before I eat some food.*

Int: *Do you take them when you are going to eat in the morning?*

Inf: *Sometimes even if I am not going to eat, I eat maybe in the afternoon.*

Most informants disclosed their status to at least one family member, more often to a mother or sister than to a male relative. Judging from what patients said, making only minimum disclosure does not appear to have been a factor in problems related to adherence.

## 7.6 Missing Doses, Strategies, and Reminders

Most participants stated that they take their medication as advised. Judging from their discourse, people are committed to their recovery and living as best they can:

Int: *What are the things that remind you that it is time to take your pills, besides your children?*

Inf: *I do not forget that it is time to take my pills.*

Informants gave a number of revealing reasons why they choose to adhere to their treatment. Some reasons focused on being alive to see their children grow and the importance of their children to them:

Int: *Have you ever forgotten to take your treatment?*

Inf: *I do not forget to take my pills because I told myself what I want is my life.*

Participants reported using a number of strategies to take their treatment. The following participant explained how he manages:

Int: *Which things remind you to take your pills?*

Inf: *I usually just remember; there is no other thing which helps me to remember. I am also reminded by the bus that passes by at 9:00 in the morning. I take my pills at night; I am reminded by the arrival of my brother who usually arrives at 21:00 at night; then I take my treatment.*

In addition to the strategies mentioned above, participants said that they set their cell phones, clock or watch alarms, or use certain radio or television programmes. Some also rely on treatment supporters and household members like their children, parents, and spouses. The following woman relies on her children:

Int: *You said your children know about your status?*

Inf: *I even tell them to remind me if I'm busy with something; also to check and tell me it may be it is 06:00 and I've not taken them.*

Int: *Your children remind you and what else?*

Inf: *And my watch also reminds me; and also beside that I always know that I have to take medication.*

It is important to note that as patients get used to taking their medication, they do not rely heavily on the reminders mentioned above. Rather, their body system “tells them” that it is time. One woman explained that she “feels” it in her body when it is time:

*We were taught to choose specific times at which we'll take our medication. I have a watch and a cell phone that remind me. When I was still new on treatment, my sister used to give me a missed call to remind me, but now I can just feel in my body even without looking at the time that it is time for medication.*

Having someone to remind participants to take their pills has helped them to adhere correctly. Some of them are fortunate in getting used to their treatment and times in such a way that they find themselves not needing treatment supporters or any other kind of reminders. They report that their strategies are effective in adherence to the medications as advised.

Of course, not all participants managed to take their pills at the same time as advised, either because they forgot or were detained somewhere. In these instances, they would quickly take their medication as soon as they realised that they had forgotten.

*Int: How did you take your ARV drugs yesterday?*

*Inf: Yesterday I took my ARV drugs accordingly, but in the evening I was a bit late because I was in a meeting, but it was before an hour passed.*

### **7.6.1 Side Effects and Health Effects**

Participants reported that they suffered side effects with treatment, but they had been warned about those side effects and assured that they would go away with time. Side effects included rash, itchiness, nausea, and severe headaches. Sore feet, changes in body shape, and weight loss were also reported. A woman reported on her weight loss:

*I used to weigh 43 kilograms but now I weigh 39.*

A man reported his own side effects:

*...It is only my feet that are hot. I do not know whether this is due to the medication or some other disease...I go to sleep and wake up with a headache and it goes away during the course of the day.*

The origin of side effects may not be clear, as indicated by the participant above. However, a 37-year-old female who has two children was very specific because she knew what caused the side effects she was experiencing. She said that the effects were caused by her treatment:

*My feet get sore every time I take my pills. I get burning sensation and also fatigue. I get tired after taking my pills.*

### **7.6.2 Lack of Money**

Household financial insecurity has an effect on the way patients take their treatment. The main obstacles to taking pills on time are related to the financial situation of their households. They reported that they have been advised to eat healthy food and then take their treatment. They were told that taking their treatment on empty stomachs will give them problems. In situations like these where they do not have enough money to buy basic needs like food, adherence is a major challenge. As one woman remarked:

*The living situation at home is not right, because when you are not working it is not right. Food is the big problem, especially now that my child is taking TB drugs and ARVs because he has to eat now and then....*

A 28-year-old male reported that because of financial constraints, he suffered from two TB episodes. He could not get transport fare to go to the clinic for his treatment and checkups, and so defaulted.

There are households without any apparent source of income, which creates serious problems for those on ARVs because they have to eat to be able to take their medication. There are others who depend on state grants like old-age pensions, disability grants, and child-support grants to survive. When their CD4 count rises to a certain level, the disability grant is discontinued, leaving the patient, and perhaps the whole household, in a difficult situation.

## 7.7 History of TB Treatment

Participants discussed in this section are those who are on ART with a history of TB. They are either taking ARVs together with their TB treatment, or they have completed their TB treatment and are continuing with their ARVs. One man responded to questions about his TB treatment:

Int: *Was it the TB that you were suffering from when you first came here?*

Inf: *Yes. It was the coughing which was TB. They gave me the containers to cough on, and I brought them back and I went for the X-rays and they found TB. I was given the TB tablets to take them and do the checking every little while. The doctor ended up telling me that I was fine now and I also felt that I was not coughing anymore, but I couldn't stop taking the treatment without being told by the doctor.*

Int: *How long did you take the TB treatment?*

Inf: *I took them for six months.*

Some participants had one TB episode and were then cured, but others had had more than one episode of TB. The interviews showed that most participants who are on TB treatment take it for six months and are cured. There are, however, extreme cases where participants did not get cured after six months of treatment. They are put back on treatment for an additional three months or even more. The following is an example of a man who had two episodes of TB:

Int: *How long did you take pills for TB?*

Inf: *Six months.*

Int: *What symptoms did you notice or perhaps had?*

Inf: *I was just ill. Actually TB attacked me twice. In the first instance doctors did not tell me the diagnosis. Regarding the second attack, I could not regularly go to fetch the pills, as my aunt that I stayed with at home would not give me the fare.*

## 7.8 Comparison of ART and TB Treatment

We needed to understand two things from these participants in addition to information about taking ARVs in general: 1) did their experience with taking TB treatment for a long time prepare them better to be able to adhere to ARVs, and 2) what difference they could articulate in comparing TB treatment with ARVs. Participants were asked directly to compare their experience of taking TB treatment with that of taking ARVs. The following respondent said that TB treatment did not help her because she had another attack while she was on treatment. For her, ARVs are better, but that was because the TB pills failed to cure her:

Int: *Which would you say are easier to take between pills for TB and ARVs?*

Inf: *Do you mean the pills for TB and the current ARVs?*

Int: *Yes.*

Inf: *I think the ARVs are better. In spite of the TB pills, I still had two attacks. So I was to replace them with ARVs.*

The view is in contrast with what the participant below had to say. She said that TB treatment is much better compared with ARVs because of the expected duration of the treatment:

*Int: Okay, now by comparison between TB pills and the ARVs, which would you say are easier to take?*

*Inf: Well, I would say...TB pills. TB pills are better because they have a time limitation. ARVs are never to be stopped once you have started with them, and are compulsory to take at specific times (of day).*

Given the contrasting views, it is important to note that some participants did not differentiate between the two:

*Int: If comparing the TB pill with the ARV what can you say in terms of taking them?*

*Inf: I'm not having problems with either of them because I'm keeping them separate, TB on the table and for ARVs in my wife's room, but for TB, I only take them up to Friday and for ARVs forever.*

We wanted to learn whether there is any impact of having had experience in taking TB treatment on their taking ARVs. The following participant reported that the strategy he used when taking TB treatment is the same strategy he uses with ARVs, and it had worked well for him:

*Int: Do you ever forget to take your medication?*

*Inf: No I never miss a treatment because I set my cell phone alarm to remind me. This system has always worked for me because even when I was on TB treatment, my cell phone would remind me to take my pills.*

We cannot confidently argue that if a patient has been on TB treatment before enrolling in ARVs there is a guarantee that this patient will be able to adhere to ARVs. This is because some participants experienced problems with TB drugs, and some had a number of TB attacks and had to be put on TB treatment more than once. The participant below reported that he found himself forgetting to take TB treatment, and the same has happened with ARVs:

*Int: How are you taking your pills and do you ever forget to take them?*

*Inf: I forget to take my TB pills. It sometimes happens to ARVs and sometimes not. I did not forget to take my TB pills because there was no specific time in taking them. I did not do anything special before taking my TB drugs; they just gave me the pills. They gave me advice about food, that we must eat spinach.*

This response also draws the discussion to strategies put in place by health facilities to manage TB as well as HIV. When patients are enrolled in ART, they are sent to adherence classes to prepare them for treatment. When patients enrol in TB treatment, they are given instructions on how and when to take the medications, but there is no further orientation given. More research would be helpful to determine what needs to be done to better prepare TB patients to take their treatment appropriately.

The interviews do not show that patients who have experience with TB treatment learn lessons about how to adhere successfully to ART, for their responses simply vary too much. Some find TB treatment unbearable, while others preferred it because the requirements for taking them are more relaxed when compared with ARVs. Still others said the two treatments were not different. The individual circumstances of patients are more important for adherence than having had the experience of adhering to TB treatment for six months or more.

## CHAPTER 8: ART PATIENTS WHO DROPPED OUT OF AN ART PROGRAMME

---

### 8.1 Introduction

This chapter examines the personal circumstances of individuals who stopped taking their antiretrovirals (ARVs) for two months or more. Circumstances that were thought to be relevant to both adherence and dropping out at the beginning of the study were the living situation in a household, the sources of household income, the presence of social support for taking pills, and the effect of taking ARVs on a person's health, including side effects. An examination of the circumstances of those who dropped out of antiretroviral therapy (ART) programmes allowed us to better understand what combination of factors led to their dropping out, and what set of factors could promote adherence for the long term.

Finding individuals to interview who had dropped out of an ART programme proved to be a major logistical challenge, for most had to be contacted in their home. The nurses who serve the ART patients at the various research sites identified former ART patients for the RAs by providing names and addresses of individuals who had missed at least two monthly appointments, and who could then be visited in their homes; and by sending patients who had dropped out to research assistants (RAs) when they returned to a health facility for medical care. In the three sites with tracer teams formed to contact patients who had missed their appointments, the RAs went with the team and interviewed former patients after team members had spoken with them. In sites without tracer teams, the nurses provided the RAs with the names and addresses of patients who had missed appointments, and the RAs contacted these patients in their homes.

Despite these difficulties, the RAs were able to interview 52 individuals who had stopped taking ARVs: some for two months or more, some for two years or more. The goal for each site was to identify and interview 12 such individuals. Three of the five sites were able to interview 12 such persons, while two sites interviewed only eight former patients.

The conversations with informants who dropped out followed the same themes as interviews with other ART patients: their household situation, getting tested for HIV, disclosing test results to others, the effect of taking ARVs on their health, how they managed to take ARVs every day, and their situation when they stopped their medication. Some informants also talked about the effect that stopping the pills had on their health, and their thoughts about the possibility of resuming ART. Informants were asked directly to describe how they stopped taking the pills in order to obtain information about their general situation and to provide specific explanations for quitting an ART programme.

### 8.2 Demographic Circumstances

Informants were asked to describe their household situation and their source of income to obtain information on the social context of their daily lives. Most informants lived with their close family or other relatives. Only two (men) said they were living alone. Informants varied in age from 21 to 63 years of age. Very few of these informants had a steady income they could count on. About one-third (16) benefited directly or indirectly from a government grant: a disability grant, a child-support grant, or a pension grant. A total of ten were

employed, although only three of these had work that provided what they considered to be an adequate living. Some had been employed previously but were now too ill to work regularly.

Most (47 of 52) of these informants were not married at the time of the interview. Four informants lived with a partner. Individuals on ARVs are more likely than the general population to be unmarried because some of them were persons who had lost a spouse to AIDS. This group of 52 informants included four widows and four widowers, but the cause of death was not necessarily stated or recognized in the interview. Approximately one-third of the others reported that they had a boyfriend or girlfriend.

The lack of a steady and dependable income for informants supposed to be taking ARVs turns out to be particularly critical, for pills must be taken with food. Many of these informants stated that they did not always have food, and that this situation made it difficult to take pills at the appropriate times. The majority of these former patients also understood that they were supposed to eat not just any food, but food that provided energy: beans, meat, vegetables, and fruit. A number of patients also spoke gratefully about receiving food at a hospital from time to time.

Food security was definitely a problem for many of these former patients. Those who reported that they stopped taking their pills because of a lack of money often mentioned that they were unable to obtain food. For some, access to a government grant made it possible for them to eat regularly, and thus do better with pill taking. Several informants stated that they stopped taking their pills when their grant ended, and that with a grant, they would be able to continue.

### **8.3 Disclosure of Being on ART**

Experts agree that patients on ART should find ways to accept their situation and share the news of their sero-status and use of ARVs with others to improve their chances of remaining on ART for the long term. We assume that the more individuals speak to others about their taking ARVs, the more opportunity they will have for social support, and thus the more likely it will be that they remain in an ART programme. This assumption suggests that those who have dropped out of an ART programme were not as likely to disclose as those who remain in a programme. Most likely, the hesitancy to disclose has mostly to do with their sero-status, and not simply taking ARVs.

These informants can be placed on a continuum of more or less disclosure to others, with those who tell no one at one end and those who speak freely about their situation at the other. Most of these 52 informants sought to limit knowledge of their situation. The groups they identified as knowing or not knowing were generally a lover or spouse, family members, especially mothers and sisters, friends, and neighbours. Informants fall into four main categories in relation to disclosure: those who tell no one, tell only a lover or spouse, tell family members, and tell anyone and everyone. The conversation with informants often specified individuals or groups who knew or did not know about their situation. Occasionally someone mentioned that others suspect that he or she was on ART.

It seems useful to ask about the informants on each end of the disclosure continuum: those who told no one, and those who told everyone. Only two individuals said that they had told no one: an older widower who lives with two children, and a young man who lives alone. The older man explained things as follows:

Int: *Who did you tell that you are taking ARVs?*

Inf: *Nobody.*

Int: *You mean nobody.*

Inf: *They only know that I am taking TB pills, but nothing about ARVs. Even if I am taking ARVs, they tell themselves that I am taking TB pills.*

Int: *Why don't you tell them?*

Inf: *I am scared.*

The young man said:

Int: *Who knows that you are taking the ART treatment?*

Inf: *I never told anyone because even here in my room I am hiding them.*

Int: *You are hiding them, why are you hiding them?*

Inf: *I hide them because I don't want people to know that I am taking these tablets. When people know that you are taking these tablets they discriminate against you and laugh at you.*

These two men told no one because they were afraid of possible discrimination. Three informants interviewed said they told only their lover (boyfriend, partner): a young woman who lives with her boyfriend, another woman who lives with her child, and a man who lives with his parents. This man did not have a treatment supporter and missed his doses fairly often. The two women said that their family members did not know about their status.

The large majority told only a few people, usually several family members, and perhaps a close friend as well. The accounts of revealing to others that they are HIV-positive and on ART show a great deal of fear: fear of possible discrimination, and fear that people outside the family would hear about the news. Although expressed in various ways, there was an enduring concern that others would learn about their situation.

The following example from a 23-year-old single man illustrates the importance of disclosing to someone who might take care of you:

Int: *What advice did they give you when you got tested?*

Inf: *They told me to be safe by using a condom.*

Int: *How many people know about your HIV status?*

Inf: *Only my grandparents know!*

Int: *What made you decide to tell them?*

Inf: *I saw that I may need their support.*

A 63-year-old widower with six children explained his situation:

Int: *Who knows that you are HIV positive?*

Inf: *I told my children. I called them all and I disclosed to them. I didn't want them to suspect that I have been bewitched by someone when I die.*

Int: *That was your aim of disclosing?*

Inf: *Yes, because they can suspect people that I was killed for my grant. I told my kids that this disease is the same as cancer, and it's the same as diabetes. There is no disease that you can say it's better than another one, only when you are following the procedures you can live.*

A woman with five children had the following to say about what others knew of her situation:

Int: *Who knew that you once used ARVs?*

Inf: *Only my children who used to accompany me to the clinic.*

Int: *Which shows that it is only your children who knew?*

Inf: *Yes, it is just because if you have this disease and tell someone, it never ends because he/she will tell someone else and also to someone else and it ends up being known by everybody around. This causes a lot of distress while you are awaiting help from others.*

Finally, a few people who had dropped out had told many of those around them of their situation: family, friends and neighbours all knew they were taking ARVs. A married man who told many people said his wife, children, and grandchildren help him take his pills. He still has girlfriends but said he always uses condoms with them; the counsellors advised him to do so. Another man who gives educational talks about HIV and AIDS said that lots of people know about his situation. A woman living with her children told family, friends, and neighbours because she was advised to tell others she was HIV positive. She said people have accepted her. She had taken ARVs for 26 months.

The example of the woman above was an exception to the overall pattern. ART counsellors told prospective patients that they need to disclose to a treatment supporter, to someone who could take care of them, and to a sexual partner. The reason most commonly given for disclosure was to have someone who will care for them when they become sick. Only seven or eight people failed to disclose to a family member. Disclosure was most often to a mother or a sister, the most likely caretakers. For example, an unmarried man living with his aunt and his grandmother told them both he was HIV positive and was on ARVs, but his friends and his neighbours do not know. A woman who lives in a household with many family members said all the females in the household know about her situation, but none of the males know. She said the counsellor advised her to tell people at home.

The majority of these individuals who had dropped out of an ART programme did not want their friends and neighbours to learn about their status. It is nearly certain that more people know about the sero-status of these individuals than were mentioned; a few informants said that others may suspect they have HIV and are taking ARVs. However, many are simply afraid of losing a job or being ridiculed if others, especially people outside the family, learn they are taking ARVs. Such individuals need assistance to come to terms with their own situation.

## 8.4 Experiences of Being on ART

Roughly half of those who dropped out of an ART programme reported that the pills made them feel better or had a positive effect on their health. A widower who lives next to his relatives took ARVs for one year, but stopped two years ago because he had no income and was feeling better. He commented on the effect of taking ARVs:

Int: *I would like to know what you anticipated would happen to you once you started ARVs and how did the tablets treat you?*

Inf: *Since I started taking them I never had any bad experience.*

Int: *Oh, you have never had any bad experience?*

Inf: *They treated me well.*

Int: *Was there anything that you were awaiting to happen to you?*

Inf: *I was waiting to get well only. I was expecting death but that did not happen.*

This man was considering returning to an ART programme after being off for two years, for he was beginning to feel sick once again.

#### **8.4.1 Health Effects**

A young woman who lives with her one child and who receives money to support herself from her father and her boyfriend had this to say:

*Int: How were you expecting the ARVs to treat you?*

*Inf: I was in class and learned about ARVs. I started to feel better and I stopped using the treatment. Now I don't feel so well again and I am thinking of resuming my treatment.*

*Int: How did the treatments treat you?*

*Inf: They treated me OK.*

*Int: How many people knew that you were on ARVs?*

*Inf: It was just my boyfriend.*

A 43-year-old married man with six children reported that the pills saved his life:

*Int: How has taking the tablets changed your life?*

*Inf: It has changed, because if I had not taken my ARVs, I would be dead by now. Those that I started my treatment with have passed away because people take the treatment and then stop it if the grant has stopped.*

As shown in the following sections, many individuals reported severe side effects from the pills. However, more individuals reported positive results than negative ones from taking ARVs.

A number of informants reported that they struggled with taking their pills early on. A man who lives with his mother expected the ARVs to improve his health, but it was a struggle for him:

*Int: What were the difficulties that you encountered when taking your pills that caused you not to take your pills in the correct way?*

*Inf: The difficulties that I had were taking the pills day by day as I saw this very tiring and stressful. The pills certainly disturbed the mind because sometimes I would have the feeling that I was going to die and that my life depended on these pills, as I have to take them every day, and I therefore felt like I am becoming a slave of these pills. So I think that really disturbed my mind, as you would find sometimes that I would not want to take them, but also feel that I need to take them to be better, so that really messed up my mind. It sometimes was very difficult to take them in the morning and evening.*

This man took the pills for more than a year and then stopped 12 months ago when he moved to Johannesburg for awhile. He also mentioned that sometimes he had trouble finding money for transport for the monthly pickup.

#### **8.4.2 Missing Doses**

Discussions with dropouts about how they took their ARVs produced accounts from a number of individuals who said they missed doses. When asked directly about missing doses sometimes, nearly all informants said they took their ARVs regularly at a certain time morning and evening, and that they did not miss taking their pills. Sometimes several questions were required to obtain a more nuanced reply. One married man said he missed doses sometimes because he was so tired from his farm work. He has been taking ARVs

sporadically because he does not always have food. Another married man whose income comes from farming and raising cattle sometimes missed doses but says he never stopped altogether. An unmarried woman with two children said she sometimes just ignores her alarm and thus takes her pills a few hours late. A widow who lives with two children and three grandchildren said she skipped doses sometimes because the pills made her sick.

With only a few exceptions, informants did not mention problems in remembering the time to take their pills. One man took his pills right after having tea in the morning with his children, and he said that when the tea was a bit late, pill taking would also be delayed. But nearly everyone said they used the alarm on their cell phone or a watch to remind them when to swallow the tablets morning and evening. Many also had a family member who lived in the household remind them.

Given so few examples of people who admitted to missing doses among the dropouts, it would be tempting to say that dropping out of an ART programme did not originate in a series of missed doses. One woman who had taken ARVs for two years said, "I never encountered a problem of forgetting them until I dropped out." Indeed, most of the explanations given for stopping taking ARVs did not include the missing of doses. However, it is not certain that informants told interviewers the truth about missing doses. Some were quite adamant about how careful they were in taking ARVs on time; others said they had gotten tired of taking the ARVs every day. Informants in the latter group almost certainly missed doses from time to time.

A few persons spoke of being resigned to their fate that they expected soon to die. A 38-year-old man lives a fairly solitary existence, judging from his description. The woman he lived with passed away, and his one child was taken by his in-laws. He lives alone, and he told only his sister and two nurses about taking ARVs. He had TB earlier and completed a six-month treatment. He understands that he is supposed to eat beans, eggs, chicken, meat, and fish. He said he was afraid of the pills because they made him crazy and gave him dreams about snakes and animals. When asked about his future plans, he said "I don't have any future plans. I have given up on myself."

He described his situation this way:

*Int: Is there anything else that they taught you except using the condom?*

*Inf: They told us we should be careful because condoms may expire, and that we should take care of ourselves, and not to sleep with a woman without a condom. But I don't have any woman anymore, and I don't have anything to do with women anymore. I am waiting for my death.*

The lack of social relationships in this man's life may have contributed to his resignation and discouragement about his life in general.

### **8.4.3 Sexual Relations**

The effect of taking ARVs on peoples' sexual relations was mixed. It should be noted that many of these persons were ill and thus may be less interested in sexual relations. A number of people said they continued having sex, albeit usually with a condom, after they began taking ARVs. A small number said they had lost their sexual desire since they had begun taking ARVs. Two older married men said they had several girlfriends. Many informants reported that they had been told by ART counsellors to use condoms, and all but three individuals involved in sexual relations said that they did indeed use condoms.

The exceptions to condom use were three women unable to persuade their boyfriends to use condoms. One woman, who lives with her extended family and two children, and never attended school, is unable to persuade her boyfriend to use condoms. Another woman, who lives with her two children and her mother, continues sexual relations with the father of her children, and he refuses to use condoms. A third woman failed to use condoms with her boyfriend and got pregnant. One woman also reported using condoms with her boyfriend while she was taking ARVs, but then they stopped using condoms when she dropped out of the ART programme.

## **8.5 The Circumstances of Dropping Out**

Conversations with informants no longer taking ARVs provided numerous explanations for dropping out of an ART programme. While most individuals mentioned a variety of elements as relevant to dropping out, the ones most often mentioned were side effects and lack of money. The side effects varied but were found to be debilitating. The responses related to lack of money mentioned the lack of funds for food, for transport to the hospital, and for paying fees at the hospital. Several in this category cited the loss of a government grant to explain their lack of funds. We found seven examples of people who moved away from the area where they had been obtaining ARVs, and who simply did not return for their medications. Other explanations included a conversion to a Christian faith and prayer for healing, taking traditional medicine, and a request from a doctor to stop ARVs. Several persons stopped because they were feeling healthy and did not see the importance of continuing. Another reason given was that their social support had disappeared.

The period of time on ARVs varied from two months to four years. We found eight cases of individuals who had been on ARVs for three or four years before they stopped. The average time spent in an ART programme in our sample was 14.1 months. Though the majority of the dropouts had been off for only a few months, the overall average time since dropping out of an ART programme was 7.3 months.

One may wonder why a person would drop out after being on ART for three or four years. One woman stopped after three years because she was feeling very healthy, saying there was no other special reason for stopping. An older man stopped when he moved to Capetown where he tried to continue ARVs but failed. At the time of the interview, he had returned to KZN and resumed taking ARVs three weeks earlier. Two women stopped because they became more religious and decided to seek healing through prayer rather than take their pills. Two others stopped because the family members who had been helping them take their pills were no longer around. Finally, a woman who was sick from time to time over several years could no longer tolerate the side effects.

### **8.5.1 Side Effects**

A few informants said they experienced side effects when they first took their pills, and then the effects diminished or disappeared, so they continued taking ARVs. The three training sessions that prospective ART patients attend before beginning their treatment include information about the kinds of side effects that can be expected, and how to respond to them. Several informants mentioned that they had been warned to expect some side effects from the medication.

About one-fourth of the informants said they stopped taking ARVs because the pills made them sick. The expression used by a number of them was “The pills do not treat me right.” A woman living with her child and her mother who received a child-support grant said the pills made her sick. This woman eventually began taking traditional medicine instead, “a bottle of Zulu medicine that was strongly recommended” and that did not have side effects. She also said they could not always find the money for transport to the hospital.

Another woman who had taken ARVs for three years found herself in a similar situation.

*Int: What is it that caused you to stop taking your pills?*

*Inf: Well I discovered that the pills were not treating me well because at times I would just have a discharge out of nowhere. Another thing was that these pills made me lose my appetite. The main reason was the fact that my mom brought me some Zulu medication called “unwele” and suggested that I try it out and in trying it out I had to stop taking my pills and that is how I stopped ARVs.*

Yet another woman had taken ARVs for more than a year, but stopped in 2005 because of the effects on her body.

*Int: When did you stop taking your medication?*

*Inf: I stopped in 2005 because it caused me a lot of pain in my feet. The side effects were very severe. My weight would fluctuate, I would vomit and I had blisters on my feet and my face as well and I had rash. My stomach would sometime swell-up. Sometimes I would gain weight and just when I see that I am beautiful and guys are going to propose to me. I just happen to lose weight again and become thin and therefore be forced to wear long sleeved clothing in order to hide my out-showing bones.*

Several informants complained about the effects of stocrin. A woman who stopped taking the drug for about two months described her experience as follows:

*Int: When you started taking them, what effect did you have or what happened to you?*

*Inf: There is that one that I didn't like and they called it stocrin.*

*Int: What was the effect?*

*Inf: It makes you to lose your mind.*

*Int: How do you lose your mind, what did you do that makes you lose your mind and how can you see that you lost your mind?*

*Inf: It makes you talk too much.*

The informant continued to say that stocrin gives you bad dreams. Eventually her doctor prescribed nevirapine instead of stocrin.

The descriptions of those who suffered from side effects sometimes included comments about feeling discouraged and tired of dealing with poor health. A widow who had taken ARVs for two years and who stopped several months earlier had this to say:

*Int: Why did you stop taking your ARVs?*

*Inf: I suffered from different kinds of side effects. The other reason is that I was sick and tired of taking these pills everyday and I told myself that let the Will of God be done especially because my husband passed away due to this virus.*

*Int: Can you tell me what your expectations were the first time you started to take your ARVs?*

*Inf: I expected a good life but they were too strenuous for me to carry on taking them.*

The individuals suffering from side effects did not often consult their doctor. One woman who did check with her doctor said:

*Int: When you stopped did you take that decision yourself?*

*Inf: No, I did not decide that myself. It was just that I was vomiting them back all the time, I went to the doctor because when I ate, it would just come back up, and the doctor said I must stop taking them. But I was scared after that. The way people spoke about the pills, I thought I was going to die, but with the good Lord I became well after that.*

*Int: Was there anything else bad that the pills did to you, the time you were taking them, besides that you would throw up?*

*Inf: I don't know because this sickness that I had was strange, or it was these opportunistic infections or if it was the pills because I was very sick.*

A widow who took ARVs for 11 months before stopping took comfort in religion after she decided that side effects were too much for her. She said:

*Int: Okay, after quitting the ARVs, how did you feel?*

*Inf: I felt much better and managed to sleep well. I believed that my life was in God's hands. When he wanted for me to die, I would die, because, after all, my life did not depend on pills. I believed I could live without pills, and it is the case right now. I believed God can cure me. I took a decision to pray for God's help every Wednesday.*

We found only one man who stopped ARVs mainly because of the side effects. The other examples were all women. The man was living on a disability grant and had taken ARVs for five months. He stopped because of the diarrhoea, itching, and what he described as “cuts on my body.” He began treatment for TB and for HIV infection at the same time.

### **8.5.2 Lack of Money**

Very few of these informants had a steady income they could count on. It is reasonable to assume that their poor health over the past few years kept them from working. About one-third (16) benefited directly or indirectly from a government grant at some point: a disability grant, a child-support grant, or a pension grant. But they still needed an income to eat regularly, to care for their children, to pay for their medical expenses, as well as to pay for hospital fees and transport for picking up their medications monthly.

Informants who talked about lack of money to explain their dropping out of an ART programme nearly always mentioned a number of factors that together caused them to drop out. The following situation of an unmarried woman who cares for two children was typical:

*Int: What do you think was the cause of you dropping out of medication, as in stopping ARVs?*

*Inf: Before, I used to receive a grant which used to help; now that I no more receive the grant, I find it very difficult and therefore decided to stop fetching the pills. And the money I have is not enough, it ends up being used up by the children.*

*Int: If the grant was still around would you be taking your medication?*

*Inf: Yes, I would continue because you must know that these pills make you hungry...you must make sure you have eaten because you cannot take them on an empty stomach. Knowing that I will have nothing to eat made me stop taking them and caused me to default.*

A second example of dependence on a disability grant comes from an unmarried woman who lived with her brother:

Int: *You say you stay with your little brother, is there no one else that you stay with?*

Inf: *No, my mother left us to go look for employment and she has never come back. She left when I had started my ARVs and she could see that I was getting better. Because she was the only one working and I received a grant, I decided to stop taking ARVs because I could see that my CD4 was going to rise and then my grant would stop.*

Int: *When did you stop using your medication?*

Inf: *I stopped using them in 2006.*

Int: *Was there any other reason that made you stop taking your medication besides the grant?*

Inf: *No, there wasn't any other reason. I didn't know how we would survive without the grant, because I left work when I got ill, and I couldn't go back because the work I did was very tiring.*

In some cases, informants simply said they did not have the money needed to buy food. They understood that they could not take the pills without food. The following two examples, both involving unmarried men, illustrate this situation:

Int: *Okay, how is the situation at home, your well being?*

Inf: *Just what worries us is food. Even the reason I stopped taking pills because of hunger, because when you get grant money but too little at R800 and you support others on it, the R800 is not enough, too little for food and a problem, so I cannot force them to cook if there is nothing. I thought it better to stop taking pills seeing that I can't continue with the pills when not eating.*

Int: *What was really the problem that made you to stop taking the ARV tablets?*

Inf: *They are making me very hungry and I am not working, so what am I going to eat? So I thought it was better that I stop for a while, the paraffin cost R7.00, everything is money.*

Even a married man had trouble obtaining the food necessary for taking pills. This was a man with six children staying with their grandmother who received government grants for child support. The man skips doses when there is no food. He explained his situation as follows:

Int: *What is the situation that makes it hard for you to take your tablets...?*

Inf: *The most critical thing is that when I don't have anything to eat; these pills need me to eat. If I haven't eaten it's difficult. They used to give us porridge but that also gets finished because you eat it every day.*

A woman with two children had worked until several months before the interview, but did not pick up her pills the preceding two months because she could not afford to pay the doctor. She used to receive a child support grant. The pills are free but patients at that site pay the doctor to pull their file. Another woman from the same site said that she stopped because it cost 20 rand to see a doctor, and she did not have the money.

Informants need money to live and support their families, to obtain food every day, to pay for medical care, and for transport to pick up their pills once a month. The grant application process takes time, and some people do not understand how to obtain grants or the limits and conditions of the grants. The disability grants are provided for six months and can be renewed as long as the CD4 count remains below 200. We interviewed several persons who stopped taking ARVs in order to keep their CD4 count low enough to continue their grant eligibility.

The fact that one-third of the informants had benefited from a government grant in the past two to three years suggests that many needed financial assistance to live from day to day. The

study team interviewed one person who said that she had a good salary as a civil servant. She stopped for two months and then resumed. She stopped because of the side effects (tiredness, bad dreams, making her feel crazy) and because she did not want people to see her picking up her pills at the hospital. The items that informants were unable to pay for in order to continue their medications were food, transport to and from a hospital, and certain hospital fees (although drugs were free).

### **8.5.3 Moving Away**

A number of informants stopped picking up their pills when they moved to another location, either in search of a job or to live with other family members. The fact that they moved away to a location too far to return monthly for pill pickup was always one element in a series given to explain their dropping out. A young man living with his mother and his one child survive on his mother's old-age grant. Initially he was troubled by side effects, and sometimes he could not find the money needed to pick up his pills on time. He said:

*Well, in the beginning, maybe two weeks into treatment, my head seemed disturbed a bit. It was like I was going to lose my mind. You would find that my feet would hurt, like there was something in them that hurts. In fact my whole body was not feeling right. As time went on, I got used to them and I adapted to the fact that I have to take them every day.*

A 23-year-old man who lives with his grandparents took ARVs for several months and then moved away four months ago. He would like to resume his drugs but will need to take classes again. A 36-year-old man took ARVs for nine months before moving away and dropping out of the programme. He too would like to resume taking his medication, but he will first need to take training sessions again. A young woman living with her boyfriend took ARVs for one year. When she and her boyfriend broke up, she moved back to her parents' house where no one knew she was HIV-positive. She has been off ART for about 28 months now.

All ART programmes lose patients from time to time when they move to another location and stop contacts with a health care facility. The individuals we interviewed who had stopped ARVs for some time when they moved away were contacted by the research team when they returned to a health care facility to inquire about what they should do next.

### **8.5.4 Other Circumstances**

Several informants had stopped taking ARVs on their doctor's orders. One doctor stopped ARVs for fear of damage to the pancreas, two others for fear of damage to the liver, and a fourth stopped ARVs so the patient could better take his TB drugs. Several informants stopped because they felt good, they felt healthy, and so decided they no longer needed to take ARVs. All three were young and unmarried: two women and one man. Two women, each with four children, stopped their ARVs and began to pray for healing instead. Finally, three informants were interviewed who stopped taking ARVs when they no longer had people around them to support them in taking their medication.

The study identified only a few individuals who chose to use traditional medicine instead of ARVs. One person was persuaded by a grandfather, one by a well-known healer, and a third just because he did not like the pills and wanted to try something from his own culture.

### **8.5.5 Returning to an ART Programme**

A small number of informants spoke of a desire to return to an ART programme after having been off of ARVs for some months or even a year or two. They all said that they were feeling sick again and thus wanted to take ARVs again. Several had already contacted an ART programme and had been told they need to take the orientation classes again before receiving their drugs. Several said they would take their pills again if they could find the necessary funds from a grant or some other source.

## **8.6 Overall Situation**

The accounts provided by individuals who stopped taking their ARVs show that they were socially and economically more vulnerable as a group than current ART patients. Very few of them had an adequate and dependable source of income, and they had few sources of social support. They lived in a social and economic situation that was marginal, relying heavily on family members for social and financial support. Most of these informants were neither married nor employed, both attributes that may be considered signs of social and economic stability. Many of them were looking for work, even part-time or temporary jobs, to make a living. Not many were able to tell friends and neighbours about their situation.

These individuals stopped their ARVs when they could no longer manage to keep taking the pills. They described pill taking as a struggle, a burden, and a cross to bear. They knew perfectly well that they needed to take their pills with proper nutrients and not just any food; that they should not take traditional medicine at the same time as the ARVs; that they should expect side effects; and that they needed to use condoms in sexual relations. The exceptions were those few individuals who decided they were healthy or could rely on prayer for healing. Mostly, they failed to remain in the programme because they simply could no longer manage the various elements needed to keep going, whether social or financial, or they moved away. The social, medical, and economic structures proved insufficient to sustain them.

## CHAPTER 9: CONCLUSION

---

This study of patient experiences on antiretroviral therapy (ART) was designed to identify adherence strategies that succeeded or failed in helping patients to take antiretrovirals (ARVs) on time, as well as to develop an instrument to collect data that would be used for programme improvement. Health care providers (HCPs) in ART programmes offered their perspectives on ways that patients took ARVs and offered suggestions for improving their ART programme. Information about ART patients with a history of TB were examined separately from those without such a history to look for evidence that adhering to TB treatment might facilitate adherence to ART. Interviews with former patients allowed the researchers to consider patients' strategies for taking ARVs and to identify circumstances that might have led to their dropping out.

This concluding chapter is divided into three sections: a) a summary of the main findings from interviews with current and former ART patients as well as with ART health care providers; b) a series of recommendations for ART programme improvement; c) a description and rationale for the use of the patient assessment instrument developed. Findings from each of the three groups of patients (those without a history of TB; those with a history of TB; dropouts) are reported separately and then combined. The instrument developed responds to the main recommendations for programme improvement.

### 9.1 Summary of Findings

#### 9.1.1 *Three Groups of Patients*

The group of ART patients without a TB history was able to tell interviewers about the advice they had been given during their ART classes. They had learned in their classes to expect side effects as they began treatment. These patients talked to the RAs about the side effects they had initially experienced, but indicated that the side effects diminished or disappeared after a short time. Most of them disclosed to others who could remind them to take their pills or provide care if they became ill, but four patients told only one person and two said they had told no one. Informants used cell phone alarms, watches, and radio/TV programmes to remind them to take their medication. Their strategy of reminding themselves with alarms and being assisted by family members worked for them; half of them said they never missed a dose. A good number of patients who had been taking their ARVs for a longer period (> 18 months) said they knew when to take their pills without being reminded: they knew the time, or they "felt in their bodies" that it was time to take their pills.

ART patients currently on TB treatment or with a history of TB, just as did those without such a history, gave detailed accounts of the advice given during their ART classes, including the need to always use condoms when sexually active. The group included a few individuals who originally delayed entering ART for some time. All of the informants in this group disclosed to someone, and half said they told their "whole family," indicating that everyone in their household knew of their situation. However, the majority still sought to limit knowledge of their situation to family members, fearing discrimination. They reported initially suffering from side effects, which disappeared with time. The strategies used to remind themselves were the same as for the group without a history of TB. They used cell phone alarms, watches, radio programmes, and family members who served as treatment supporters.

The soliciting of comments from patients to compare TB treatment with ARVs produced a wide range of responses. Some preferred TB treatment, while others said taking ARVs was easier. A few informants said they had used the same strategy to remind themselves of when to take their ARVs as they had for their TB medications. Although a few may have benefited from their experience in taking TB treatment, for most, there was no indication that the experience of a cycle of TB treatment assisted them in achieving high adherence.

The group of former ART patients (dropouts) did not differ from current ART patients in their initiation into ART, or in their reporting of the advice they received in their classes. The great majority were well aware of the following: they needed to take their pills with food high in nutritional value; they should not take traditional medicine at the same time as the ARVs; they should expect side effects; and they needed to use condoms in sexual relations. As with current patients, these informants had used cell phone alarms, watches, and radio programmes to remind them when to take their pills. Many had children remind them, but children would not have attended ART classes with them. In fact, patients reported that their children only knew that they needed to take pills regularly, but did not know the reason.

The group of former patients differed from current patients in that far fewer were married (only 5 of 52), fewer (only 10 of 52) were employed (3 fully employed and 7 part-time), and one-third benefited from a government grant (disability, child support, or pension). In addition, a number of them had no treatment supporter to assist them.

Although nearly all said initially that they never missed doses, when asked directly, at least a dozen of the dropouts said they had missed doses from time to time out of tiredness or forgetfulness. Many described pill taking as a struggle and a burden. Some informants reported they had stopped taking their ARVs when their disability grant ended; they had become dependent on the grant for their income. Many were looking for work, even part-time or temporary jobs, to make a living. These former patients told far fewer family and friends of their situation than did current ART patients. Mostly, they failed to remain in the programme because they simply could no longer manage the various elements needed to keep going, whether social or financial.

### **9.1.2 Overall Findings**

This study included discussions with patients of their own social and economic situation to see to what extent the social relations, household composition, marital status, and sources of income might affect adherence. A small proportion of ART patients were married at the time of the study: 22 percent of current patients and 9 percent of dropouts were married. While most informants lived with children or other family members, a small number lived with only their partner (spouse or lover), and 4 percent ( $n = 7$ ) said they lived alone. As expected, those who lived alone or with one other person only were less likely to disclose their HIV status, and less likely to have a treatment supporter with them.

Rates of employment were relatively low: 50 percent for patients without a TB history, 40 percent for those with a history of TB, and 20 percent for those who had dropped out of a programme. About 25 percent of current patients and 31 percent of dropouts had recently benefitted from a government grant: disability, child support, or old-age pensions. We should note that one-half of the dropouts reported no regular income, and lack of money was one of the main reasons given for stopping ARVs.

ART programmes in KwaZulu-Natal require that prospective enrollees attend initiation classes with a treatment supporter. Ideally, a treatment supporter will remind an ART patient to take their medicines morning and evening, and will speak to them about other actions necessary for a rapid recovery: eating nutritious food, avoiding tobacco and alcohol, and getting moderate exercise. One ART manager stated that their programme did not distribute the monthly supply of ARVs to a patient without the participation of such a supporter. However, occasionally a patient is enrolled in an ART programme without such a supporter. Many patients mentioned that their partner, one of their children, or some other family member helped remind them to take their pills, but it was not necessarily someone clearly identified as a supporter who had also taken the initiation class with the patient. If patients did not often mention “treatment supporters” as such, nearly all the health care providers considered that having a person identified as a treatment supporter was critical to maintaining high adherence. In their experience with ART patients, HCPs found that a treatment supporter can provide valuable advice as well as remind patients to take their pills.

Health care providers also emphasized the importance of patients disclosing their HIV status and treatment status to family and friends so that others could assist them in following the recommended regimen. The large majority of patients disclosed to family members and a few others; about 12 percent (N = 20) reported that they disclosed to no one or to one person only, usually their sexual partner. ART patients sometimes said that they disclosed to a certain person or persons because they expected they would need care in the future, and that person would be able to provide such care. However, patients did not usually make a connection between having disclosed to many people and doing well on adherence. The group of dropouts was less likely to have disclosed their status to family and friends. The degree of disclosure that a patient manages to achieve may be an indicator of how well he or she has accepted their situation. Being able to disclose that one is on ARVs and HIV-positive to family and friends brings far more than simply increased social support.

Nearly all patients who take ARVs suffer from some side effects early on, but they vary tremendously in type, frequency, and severity. The ART patients in KZN were taught which side effects to expect (rash, swollen stomach, dizziness, nausea, a change in appetite) and how to deal with them. Although a few informants interviewed stated that they had no side effects, the majority experienced unpleasant reactions to the ARVs when they began the treatment; after a few months they became accustomed to the symptoms, or they disappeared. However, about one-fourth of the patients who had dropped out said they stopped because they just felt too sick with the ARVs. They stopped without consultation with a doctor or health care provider for advice.

Explanations from HCPs for how and why patients miss doses or stop taking their ARVs focused on the social and economic problems patients face. Patients have told them about the difficulties they face in depending on a disability grant for an income, in finding good food every day, and in paying for transportation for themselves and their treatment supporter to attend the three ART classes as well as coming on their own for the monthly supply of their medications. The stories patients told research assistants follow the same line of reasoning. They struggled greatly to find funds for food and transport each month. Part of the economic hardship faced by ART patients comes from the loss of a job through illness or the costs of medical care for chronic sickness.

The findings indicate that achieving high adherence judged by not missing doses depends less on a particular strategy for remembering when to take ARVs than on how that strategy is maintained within a household. They suggest that ART programmes should examine the

household living situation of patients in considering the assistance patients need to maintain high adherence, and that since these circumstances change over time, counsellors need to track key elements (household composition, income sources, employment) of a patient's household circumstances. The use of an instrument to collect information periodically about the situation of patients will provide useful feedback for ART programmes.

Most HCPs agreed that there are two keys to high adherence: having a committed and informed treatment supporter, and disclosing to people who know them. However, patients did not emphasize the importance of treatment supporters in taking ARVs as did HCPs. HCPs also stressed the benefits of providing food to patients. Their perspective suggests that in addition to emphasizing the role of treatment supporters, interventions need to give attention to the social (disclosure) and economic situation (food and transportation) of individual patients. Of course, assistance to an ART patient in the form of food or funds will most often go to a household rather than an individual.

Health care facilities have tried two mechanisms to provide food assistance: the distribution of food parcels to patients and the serving of lunch to ART patients at the facility. HCPs mentioned that the contents of food parcels provided by the DoH have changed. In most cases, facilities have been receiving only e-pap, a nutrient supplement. The change in contents and sometimes absence of food parcels is said to be due to the lack of funds.

The accounts of ART patients as well as those of HCPs identified several aspects of ART programmes that could be improved: more emphasis on treatment supporters, more effective ways to deal with side effects, assistance with obtaining food, and funds for transportation to pick up medications. A focus on these aspects by government entities or outside donors would likely lead to improved programme performance. In short, the study found that the following elements affect patient adherence and programme retention:

- Role played by a treatment supporter
- Ability to disclose HIV test results and being on ARVs to others
- Management of side effects
- Judicious use of a government grant
- Ability to find nutritious food regularly
- Ability to find funds to pay for transportation cost for monthly pickup of pills.

One limitation of this study should be noted. Research assistants were not able to obtain detailed information from most patients about how many doses had been missed recently. Patients were asked in different ways about missed doses, and sometimes patients explained what happened. Other patients responded automatically, raising doubts about the declarations that they always took their doses on time. A study of levels of adherence should spend more time in a systematic way than this study managed to achieve, to ascertain just how patients took their medications.

## **9.2 Recommendations for Programme Improvement**

**Identification of treatment supporters.** The system of identifying individuals to serve as “treatment supporters” to ART patients must be strengthened to reduce the number of patients who begin ART without such a supporter and to monitor their interactions with patients over time. Although patients did not often refer to treatment supporters as important in taking pills, health care providers all considered their role as critical for high adherence.

Potential ART patients must understand the importance of having a treatment supporter and how to select someone to play that role as well find someone to bring to the initiation classes. A treatment supporter must be someone they see nearly every day and who is willing to be responsible to remind a patient of what is needed to benefit from taking ARVs. A person who lives by themselves or with one other person or with only children will have more difficulty choosing a suitable treatment supporter than one who lives with several adults. Ideally, a treatment supporter will be an adult living in the same household. Therefore, the persons who direct the ART classes could find ways to make patients understand the role that a treatment supporter can play.

**Disclosure to others.** Similarly, prospective ART patients must be helped to understand the importance of disclosing their HIV status to family members and friends, not only to increase the potential for social support and care, but also as a way to accept their situation. The directors of ART classes should verify that their curriculum addresses the importance of disclosure in an effective manner. In addition, the issue of disclosure should be addressed regularly by counselors who see patients when they return to fill their monthly prescriptions. Counsellors should help patients think about whom they told about their situation, who learned by some other means, who they do not want to hear about their situation, and why that may be. Counsellors can encourage patients to accept their own situation and let others know as well.

**Managing side effects.** ART patients need more assistance in monitoring and treating side effects as they arise, for the symptoms of illness brought on by ARVs may lead to skipping doses or stopping the medication altogether. Improving the management of side effects has several aspects: discussions during the ART classes so patients know what to expect; forceful discussion of side effects by counsellors and HCPs who inquire about health effects when patients return for their medication; a rapid and effective way to treat the symptoms as they arise to minimize the discomfort they produce. The impact of side effects can only be managed when all three elements are addressed at the same time.

**Provision of support grants.** Clarifying and streamlining the rules and qualification criteria for receiving a disability grant from the South African government would be useful for ART health care providers and for patients. Doctors fill out the grant application for ART patients with a CD4 count of less than 200, and advise patients to then send the application to the government grants office for processing. Doctors must also notify the government grants office when a patient's CD4 count rises above 200, since they are then no longer eligible for the grant. Some patients interviewed said their household became dependent on the grant for basic necessities, and their situation became difficult when the grant stopped. Several said they stopped taking ARVs because they no longer received the grant, thus making the grant itself a disincentive to optimal adherence. Addressing this (dis)incentive structure could be accomplished through discussions between the Department of Health of KZN and ART managers around the changes that could be made to better serve the needs of patients.

**Food security.** The majority of patients interviewed were not employed and thus were dependent on other family members or government grants for funds for food and transportation to a health facility as well as for other basic needs. The DoH and other support organizations could assist facilities to develop a programme of food assistance through the provision of food parcels or another approach to avoid situations in which patients miss doses or stop taking ARVs because they do not have food. ART managers currently lack the staff and the funds necessary to provide such food assistance.

**Funds for transportation.** Finding funds for a monthly visit to pick up medications can be problematic for some patients for brief periods. Counselors who know about their patients' household situation, and monitor it monthly, can assist them to develop a plan to finance their transportation when they lack funds.

**The use of tracer teams.** Using patient tracers appears to be an effective strategy for reducing default rates. Two of the five research sites had active tracer teams to visit ART patients who missed appointments. The process of tracing defaulters seems to be working very well for these sites, so it should be possible to achieve the same result elsewhere with additional resources. As the numbers of patients grow, so does the importance of tracking patients who appear to default. Funds are needed for staff time, record keeping, vehicles, and petrol to trace patients who miss appointments. By providing additional resources, the DoH could reduce default rates by through the use of tracer teams in all ART programmes.

**Need for information about patients.** Many of these suggested improvements depend on obtaining accurate information from patients, as their needs and resources change from month to month. Monitoring the social and economic situation of patients as they change over time can improve adherence if identified needs are addressed. A treatment supporter may move away, a patient may refuse to disclose to anyone at all, a person may need help in dealing with a side effect, a source of income may disappear, a patient may become ill. Therefore, we recommend that counsellors make a little time for discussions with patients as they return for their prescriptions each month. The study has developed a one-page form to guide such discussions.

### **9.3 Patient Assessment for Programme Improvement**

The development of an instrument that can be promoted by the KwaZulu-Natal Department of Health (KZN DoH) for use in ART programmes is a major challenge, for such an instrument must be simple and easy to use for personnel with minimal research experience, and cannot require many additional resources. Ideally, it should build on what HCPs and patients are already doing. It should also focus on the factors that most impact adherence. The topic guide used to interview patients for this study provided rich data on patient strategies for taking ARVs and on the personal circumstances that affected adherence, and allows us to identify the issues most critical in maintaining adherence. The instrument presented in Appendix D draws on the study findings from patients and from HCPs considered in the context of current DoH policy on ART.

The findings from ART patients as well as from HCPs indicate that adherence is most contingent on the following: having a treatment supporter who attends classes with the patient; dealing with side effects; and a household situation that includes an income adequate for providing food and transport expenses. A treatment supporter should not only remind patients to take their ARVs, but also discuss changes necessary in life style: eating nutritious food, using condoms in sexual relations, being patient with side effects, and avoiding alcohol and tobacco. While the majority of ART patients were able to deal with side effects eventually, one-fourth of those who dropped out stated that side effects were the primary reason they stopped. The lack of resources for food and transport was often cited as a factor that made adherence difficult.

Having identified the factors that most affect adherence and retention in ART programmes (treatment supporter, side effects, household income), the study has formulated an instrument

for use in monitoring ART patients over time with regard mainly to these factors. This instrument (Assessment of Patients' Situation) can be used periodically to assess the situation of patients and provide valuable information on how well patients are doing and what assistance they most require. This instrument can be found as Appendix D.

The topics in the assessment of patients derive from parts of the topic guide used in this study, but the responses will be recorded on one page as a checklist with space for notes. The overall purpose of the instrument is to generate a general assessment of a patient's situation. The instrument is designed to be used right after a patient has completed ART classes, and the assessment would become part of the patient's file. The assessment will show areas where patients might encounter problems with adherence. However, the situation of households changes over time as individuals find or lose jobs or grants, and the health status of patients also changes over time. Therefore, counsellors can use this instrument for doing an assessment every three months with their patients. Counsellors now have more contacts with patients than other HCPs, and this instrument would serve to systematize the assessments they may already be doing with patients when time is available.

The information collected by counsellors can also be used to revise the curriculum for the ART classes required for enrolment. A health care facility could review the patient assessments annually to identify which problems patients experience most often in taking ARVs and how they have found solutions to those problems. Those problems can then be addressed in ART classes for new ART patients.

The next step is to test whether the patient assessment tool developed from the findings of this study will be accepted and used by ART programmes, and whether counsellors find the instrument useful to monitor patient circumstances. If the tool is found useful, ART programmes will have reliable information about the assistance patients need to achieve high adherence and high programme retention.



## REFERENCES

---

- Adam, B. D., E. Maticka-Tyndale, and J. J. Collins. 2003. Adherence practices among people living with HIV. *AIDS Care* 15(2): 263-274.
- Bangsberg, D. R., F. M. Hecht, E. D. Charlesbois, et al. 2001. Comparing objective measures of adherence to HIV antiretroviral therapy: Electronic medication monitors and unannounced pill counts. *AIDS Behavior* 5: 275-281.
- Bangsberg, D. R., A. R. Moss, and S. G. Deeks. 2004. Paradoxes of adherence and drug resistance to HIV antiretroviral therapy. *Journal of Antimicrobial Chemotherapy* 53(5): 696-699.
- Bastos, F. I., C. M. Buchalla, J. R. Ayers, and J. J. da Silva. 2006. [Brazilian response to the HIV/AIDS epidemic]. *Revista da Saúde Pública* 40(Suppl): 1-4.
- Bonolo, P. de F., C. C. César, F. A. Acúrcio, M. G. Ceccato, C.A. Menendez de Pádua, J. Alvares, L. N. Campos, R. A. Carmo, and M. D. C. Guimarães. 2005. Non-adherence among patients initiating antiretroviral therapy: a challenge for health professionals in Brazil. *AIDS* 19(Suppl 4): S5-S13.
- Boulle, A., P. Bock, M. Osler, K. Cohen, L. Channing, K. Hilderbrand, E. Mothibi, V. Zweigenthal, N. Slingers, K. Cloete, and F. Abdullah. 2008. Antiretroviral therapy and early mortality in South Africa. *Bulletin of the World Health Organization* 86(9): 678-687.
- Brinkhof, M. W. G., F. Dabis, L. Myer, D. R. Bangsberg, A. Boulle, D. Nash, M. Schechter, C. Laurent, O. Keiser, M. May, E. Sprinz, M. Egger, and X. Anglaret. 2008. Early loss of HIV-infected patients on potent antiretroviral therapy programmes in lower-income countries. *Bulletin of the World Health Organization* 86(7): 559-567.
- Byakika-Tusiime, J., J. H. Oyugi, et al. 2005. Adherence to HIV antiretroviral therapy in HIV+ Ugandan patients purchasing therapy. *International Journal of STD and AIDS* 16(1): 38-41.
- Chen, S. C. C., J. Kwong-Leung, A. D. Harries, C.-N. Bong, R. Kolola-Czimadzi, T. S. Tok, C.C. King, and J. D Wang. 2008. Increased mortality of male adults with AIDS related to poor compliance to antiretroviral therapy in Malawi. *Tropical Medicine and International Health* 13(4): 513-519.
- Chesney, M. A., M. Morin, and L. Sherr. 2000. Adherence to HIV combination therapy. *Social Science & Medicine* 50: 1599-1605.
- Côté, J. K. and G. Godin. 2005. Efficacy of interventions in improving adherence to antiretroviral therapy. *International Journal of STD and AIDS* 16(5): 335-343.
- Desclaux, A, I. Lanièvre, I. Ndoeye, B. Taverne (eds.). 2004. *The Senegalese Antiretroviral Drug Access Initiative: An Economic, Social, Behavioural, and Biomedical Analysis*. Paris: ANRS, UNAIDS
- Farmer, P., F. Leandre, J. S. Mukherjee, M. Claude, P. Nevil, M. C. Smith-Fawzi, S. P. Koenig, A. Castro, M. C. Becerra, J. Sachs, A. Attaran, and J. Y. Kim. 2001. Community-based approaches to HIV treatment in resource-poor settings. *Lancet* 358(9279): 404-409.
- Golin, C., F. Isasi, J. B. Bontempi, and E. Eng. 2002. Secret pills: HIV-positive patients' experiences taking antiretroviral therapy in North Carolina. *AIDS Education & Prevention* 14(4): 318-329.

- Goudge, J., B. Ngoma, and H. Schneider. 2004. Adherence in anti-retroviral drugs: Theorising contextual relationships. Unpublished paper, Centre for Health Policy, School of Public Health, University of Witwatersrand, Johannesburg.
- Ickovics, J. R., and C. S. Meade. 2002. Adherence to antiretroviral therapy among patients with HIV: a critical link between behavioral and biomedical sciences. *Journal of Acquired Immune Deficiency Syndrome* 31(Suppl 3): S98-S102.
- Jaffar, S., P. Munderi, and H. Grosskurth. 2008. Adherence to antiretroviral therapy in Africa: how high is it really? *Tropical Medicine and International Health* 13(9): 1096-1097.
- King, M. S., S. C. Brun, and D. J. Kempf. 2005. Relationship between adherence and the development of resistance in antiretroviral-naïve, HIV-1-infected patients receiving lopinavir/ritonavir or nelfinavir. *Journal of Infectious Diseases* 191(12): 2046-2052.
- Kumarasamy, N., S. Safren, S. R. Raminani, R. Pickard, et al. 2005. Barriers and facilitators to antiretroviral medication adherence among patients with HIV in Chennai, India: A qualitative study. *AIDS Patient Care and STDs* 19(8): 526-537.
- KZN Epidemiology Unit. 2005. The Epidemiology Unit *Weekly Monitoring System of the Antiretroviral Therapy for HIV/AIDS in KZN; Kwazulu-Natal*. *Epidemiology Bulletin* 10. Pietermaritzburg.
- KZN Health. 2006. *KZN has highest number of people on ARV treatment*. Kwazulu-Natal Department of Health, Corporate communication, 21 August.
- Lanièce, I., M. Ciss, A. Desclaux, K. Diop, F. Mbodj, B. Ndiaye, O. Sylla, E. Delaporte, and I. Ndoeye. 2003. Adherence to HAART and its principal determinants in a cohort of Senegalese adults. *AIDS* 17(Suppl 3): S103-S108.
- Maggiolo, F., L. Ravasio, D. Ripamonti, et al. 2005. Similar adherence rates favor different virologic outcomes for patients treated with nonnucleoside analogues or protease inhibitors. *Clinical Infectious Diseases* 40(1): 158-163.
- Malcolm, S. E., J. J. Ng, R. K. Rosen, et al. 2003. An examination of HIV/AIDS patients who have excellent adherence to HAART *AIDS Care* 15(2): 251-261.
- Mbangwa, L. 2007. *KwaZulu-Natal province leads the way in HIV and AIDS treatment*. KwaZulu-Natal Department of Health, Corporate communications, 13 August.
- Mills, E. J., J. B. Nachega, D. R. Bangsberg, et al. 2006. Adherence to HAART: a systematic review of developed and developing nation patient-reported barriers and facilitators. *PLoS Medicine* 3(11): 203902064.
- Murphy, D., K. Roberts, W. Marelich, and D. Hoffman. 2000. Barriers to antiretroviral adherence among HIV-infected adults. *AIDS Patient Care* 14: 47-58.
- Negredo, E., A. Bonjoch, and B. Clotet. 2006. Benefits and concerns of simplification strategies in HIV-infected patients. *Journal of Antimicrobial Chemotherapy* 58(2): 235-242.
- Nkonyeni, N. P. 2006. *Report to Kwazulu-natal Parliament on HIV and AIDS*. KwaZulu-Natal Department of Health. Corporate Communications, 19 August.
- Obermeyer, C. Makhlof, S. Bott, P. Carrieri, M. Parsons, J. Pulerwitz, N. Rutenberg, and A. Sarna. 2009. HIV testing, treatment and prevention: Generic tools for operational research. Geneva: World Health Organization.
- Orrell, C., D. R. Bangsberg, M. Badri, and R. Wood. 2003. Adherence is not a barrier to successful antiretroviral therapy in South Africa. *AIDS* 17:1369-1375.
- Palella, F. J. Jr, K. M. Delaney, A. C. Moorman, M. O. Loveless, J. Fuhrer, G. A. Satten, D. J. Aschman, and S. D. Holmberg. 1998. Declining morbidity and mortality among patients with advanced human immunodeficiency virus infection. HIV Outpatient Study Investigators. *New England Journal of Medicine* 26; 338(13): 853-860.

- Remien, R. H., A. E. Hirky, M. O. Johnson, G. M. Le, D. Whittier, and L. S. Weinhardt. 2003. Adherence to medication treatment: A qualitative study of facilitators and barriers among a diverse sample of HIV+ men and women in four US cities. *AIDS and Behavior* 7(1): 61-72.
- Reynolds, N. R. 2004. Adherence to antiretroviral therapies: State of the science. *Current HIV Research* 2(3): 207-214.
- Rosen, S., M. P. Fox, and C. Gil. 2007. Patient retention in antiretroviral therapy programs in Sub-Saharan Africa: a systematic review. *PLoS Medicine* 4(10), e298:0001-0011.
- Schwartzländer, B., I. Grubb, and J. Perriens. 2006. The 10-year struggle to provide antiretroviral treatment to people with HIV in the developing world. *The Lancet* 368: 541-546.
- Shisana, O., T. Rehle, L. C. Simbayi, W. Parker, K. Zuma, A. Bhana, C. Connolly, S. Jooste, V. Pillay, et al. 2005. *South African HIV Prevalence, HIV incidence, Behaviour and Communication Survey*. Cape Town: HSRC Press.
- Stout, B. D., M. P. Leon, et al. 2004. Non-adherence to antiretroviral therapy in HIV-positive patients in Costa Rica. *AIDS Patient Care and STDs* 18(5): 297-304.
- South Africa HIV & AIDS Statistics. 2008. South African HIV & AIDS Statistics. URL: <http://www.avert.org/safricastats.htm>.
- Tassie, J. M., E. Szumilin, A. Calmy, and E. Goemaere, MSF. 2003. Highly active antiretroviral therapy in resource-poor settings: the experience of Médecins Sans Frontières. *AIDS* 17: 1995-1997.
- Turner, B. 2002. Adherence to antiretroviral therapy by human immunodeficiency virus-infected patients. *Journal of Infectious Diseases* 185(Suppl 2): S143.
- Ware, N. C., J. Idoko, S. Kaaya, I. A. Biraro, M. A. Wyatt, O. Agbaji, G. Chalamilla, and D. R. Bangsberg. 2009. Explaining adherence success in Sub-Saharan Africa: An ethnographic study. *PLoS Medicine* 6(1): 0039-0047.
- Weiser, S., W. Wolfe, D. Bangsberg, I. Thior, P. Gilbert, et al. 2003. Barriers to antiretroviral adherence for patients living with HIV infection and AIDS in Botswana. *Journal of Acquired Immune Deficiency Syndrome* 34: 281-288.
- Wilson, D. P., J. Kahn, and S. M. Blower. 2006. Predicting the epidemiological impact of antiretroviral allocation strategies in KwaZulu-Natal: The effect of the urban-rural divide. *PNAS* 103(38): 14228-33.
- World Health Organization. 2003. Adherence to HIV Treatment. World Health Organization Fact Sheet, Department of HIV/AIDS.



# APPENDIX A: ART PATIENT CONVERSATION GUIDE (ENGLISH AND ISIZULU)

---

## Imibuzo nezihloko ngezigu ze ART

### A) Personal history/Personal circumstances Umlando ngawe

Please tell me about how your life is going these days: where you live, with whom, your work, your relatives, etc.

Ngicela ungitshele ukuthi impilo yakho ihamba kanjani kulezizinsuku;uhlala kuphi;nobani; umsebenzi wakho; izihlobo zakho njalonjalo.

(Conversation check points)

- Living situation
- Isimo senhlalo
- Family and friends
- Umndeni nabangani
- Participation in groups and associations
- Ukubamba iqhaza emaqenjini nasezinhlanguweni
- Education
- Imfundo
- Plans for the future
- Izinhlelo noma amaqhinga ngekusasa

### B) Daily life/Daily routine Impilo yansukuzonke

We would like to hear about what you do from day to day to earn a living, pass the time entertain yourself, visit with others, etc. Please tell me about what happened yesterday.

Singathanda ukuzwa ukuthi yini oyenza usuku nosuku ukuziphilisa;ukuchitha isikhathi uzithokozisa;uvakasha nokunye njalonjalo.Ngicela ungitshele ukuthi kwenzekaleni izolo.

(Conversation check points)

- Daily activities
- Imisebenzi yansuku zonke
- Social gatherings and alcohol consumption
- Ukuhlangana gobungani nokuphuza omumpojwana
- Work and economic situation
- Umsebenzi nesimo somnotho
- Diet
- Izinhlelo zokudla
- Travel
- Ezokuthutha noma okokuhamba(imoto)

- Obtaining food to eat regularly
- Ukuthola ukudla okudla njalonjalo

**C) Learning they are HIV-positive**  
**Ukwazi ngesimo sabo sesandulela ngculazi**

Please tell me about the circumstances that led you to get an HIV test for the first time: where and when, and how it happened.

Ngcela ungitshela ngesimo ezekudonsela ukutheni uhlololwe isandulela Ngculazi okokuqala: kuphi futhi nini, ingabe kwenzeka kanjani.

(Conversation check points)

- Where and when they were tested
- Kuphi futhi nini bahlolwa igciwane
- Advice they were given when they received results
- Izeluleko abazithola ngenkathi bemukela imiphumela
- Who knows about their HIV status
- Ubani owaziyo ngesimo sabo ngegciwane
- How they learned, why they were told
- Bazi kanjani, batshelelwani

**D) Enrolment into the ART programme**  
**Ukungeniswa kuloluhlelo lwe ART**

Now we would like to hear about how you joined the ART programme in this facility; how you heard about it, what you expected, how it has been for you etc.

Manje singathanda ukuzwa ukuthi wajoyina kanjani kuloluhlelo lwe ART kulesisikhungo, wazi kanjani ngalo noma wezwa kanjani ngalo, yini owawuyilindele, kubenjani nje kuwena njll.

(Conversation check points)

- How they heard about the programme?
- Bezwa kanjani ngohlelo
- Expectations of ART
- Okulindelekile nge ART
- How they entered the programme?
- Bangena kanjani ohlelweni?
- How long they have participated?
- Sekuyisikhathi esingakanani beyingxenye yohlelo?

**E) ARVs they take**  
**Uhlobo lemishanguzo abalisebenzisayo**

Could you please tell me about the ARVs you take: which ones, how often, where you get them, etc?

Ungasitshela mayelana nemithi imishanguzo: imiphi yona, kujwayele kanjani, uyithola kuphi? Njalonjalo.

(Conversation check points)

- Specifics of taking the medications
- Imigomo yoku yoku phuza imithi
- Who knows about their taking ARVs
- Ubani owaziyo ngokudla kwabo imishanguzo
- How they learned, why they were told
- Bazi kanjani, batshelelwani
- How and how often they collect the drugs
- Ingabe ujwayele ukuyilanda kanjani futhi nini, imishanguzo
- Meeting with counsellors or health care providers at clinic
- Imihlangano nabaluleki bezempilo.

**F) Ways they have found to help them take their drugs  
Izindlela abazitholile zokubasiza ekuthatheni imishanguzo**

We are also interested in hearing about how people find ways to keep taking their drugs or don't take them anymore. How has this been for you?

Singathanda futhi ukwazi ukuthi bazithola kanjani izindlela zokuqhubeka nokuthatha imishanguzo.

(Conversation check points)

- Other people who assist them
- Abanye abantu ababasizayo
- Getting the food necessary
- Ukuthola ukudla okudingekayo
- Hiding from others that they take ARVs
- Ukufihla kwabanye ukuthi bathatha imishanguzo
- Things they have tried to help themselves that have failed
- Izinto abazizamise ukuzisiza ngazo, zangaphumelela

**G) Effects on them of taking the drugs  
Imithelela yokuthatha imishanguzo cabana**

Once you started taking the drugs regularly, how did the ARVs affect you and your life?

Mhla uqala ukuthatha imishanguzo ngendlela ngabe ama ARV'S akuphatha kanjani noma abanjani kuwe futhi nasempilweni yakho.

(Conversation check points)

- Their health
- Impilo yabo
- Their schedule
- Ngohlelo lwabo lwansukuzonke
- Their social relations
- Ngobudlelwane babo nabantu noma umphakathi

- Their sexual relations
- Ngobudlelwane babo ngokocansi
- Their daily activities
- Imisebenzi yabo yansukuzonke

**H) Circumstances that have made it difficult to take drugs regularly  
Izimo ezenza kwabanzima ukuthatha imishanguzo ngokujwayelekile**

What kinds of things made it difficult for you to take the drugs regularly?  
Ingabe iziphi izinto ezanza kube nzima ukuphuza amaphilisi ngokujwayelekile.

(Conversation check points)

- Having others know they take drugs
- Ukwazi kwabanye ukuthi bathatha imishanguzo
- Remembering the right time
- Ukukhumbula isikhathi esifanele
- Paying for the medication
- Ukuhlawulela noma ukukhokhela imithi
- Finding the right food to eat
- Ukuthola ukudla okufanele ukudle

**I) Three day recall of doses of medication (scripted)  
Izinsuku ezintathu ukhumbula imithi oyinikiweyo**

You have told me a lot about how you have been taking your drugs over the past months. We would not be surprised if you have missed taking some of your medications over the last few days, and this is helping us a great deal. We would also like to have information to write down about exactly what happened over the past three days. What did you take yesterday? The day before? Three days ago?

*(The following table should be completed according to the ARV medications prescribed that were taken over the last three days. Use prompts to help patients remember (“What did you do yesterday morning? Did you take any medications that morning?” If yes: “Which pills? How many?”) If the respondent missed a pill/dose, circle the cell)*

Name of pills Igama lomshanguzo	Number of pills given Inani lamaphilisi owanikiweyo	Number of pills taken Inani lamaphilisi owaphuzile		
		Yesterday izolo	Day before yesterday kuthangi	3 days ago izinsuku ezingu 3 ezedklule

- 1.
- 2.
- 3.
- 4.

For each of the doses missed, ask about the circumstances that made them miss taking the drugs.

Isilinganiso ngasinye esilibalekile, buza ngezimo ezabenza bakhohlwe ukuthatha imishanguzo.

**J) Think about taking drugs over the last month.**

Did you take the drugs at the right time:

a) All the time b) Sometimes c) Not at all?

Cabanga ngokuthatha imishanguzo ngenyanga edlule. Ngabe wayithatha ngesikhathi esikhathi esifanele:

a) Ngasosonke isikhathi, b) Kwesinye zikhathi, c) Nhlobo—qha sampela.

**K) Past experience with tuberculosis (TB)  
Ukubhekana nesifo sofuba kwaphambilini**

Now we would like to hear about your own experience with getting TB and finding and following treatment.

Manje singathanda ukuzwa ukubhekana kwakho nofuba ngesikhathi uluthola nokulunyanga.

(Conversation check points)

- Getting TB
- Ukuthola ukuthi unesifo sofuba
- Symptoms
- Izimpawu azibona
- Looking for treatment
- Lapho owaya khona ukuyofuna ukwelashwa
- Enrolment in TB programme
- Ukungena ohlelweni lokwelashwa kofuba
- Taking the TB drugs; and for how long
- Uwadla kanjani amaphilisi ofuba
- Things they did to help them take the drugs regularly
- Sekuyisikhathi esingakanani usohlelweni lokwelashwa kofuba
- Circumstances that made it difficult to take the drugs regularly
- Izindlela zokubasiza bathathe amaphilisi mihlayonke
- Getting cured of TB
- Ukwelapheka esifweni sofuba
- Comparison of taking TB drugs with taking ARVs
- Ukuqhathanisa phakathi kokuthatha amaphilisi ofuba nemishanguzo

Thank you very much for your time. Is there anything you feel I have left out or just anything that you feel I should know?

Ngiyabonga kakhulu ngesisakhathi sakho. Ingabe kukhuna yini ocabanga ukuthi ngikushiyele noma ocabanga ukuthi kufanele ngikwazi?

# **APPENDIX B: CONVERSATION GUIDE FOR HEALTH CARE PERSONNEL (ENGLISH VERSION) HEALTH CARE PROVIDERS (PHYSICIANS, NURSES); COUNSELLORS; PHARMACISTS**

---

## **Introduction for Interviewers**

Field workers will have conversations with individuals who have some sort of regular contact with ART patients in an official capacity, whether they be nurses, doctors, VCT/ART counsellors, community outreach persons, or another type of person who has regular contact with patients. Usually these people are known as health care personnel. Overall, we are interested in learning about their own work experience as it relates to ART, the nature of their interactions with ART patients, and how they classify patients into different categories. We will conduct interviews with six persons in each facility.

## **Interview Topics**

### ***I. General background***

Please tell me some things about your life and background: where you grew, up went to school, work experience before coming here.

- Basic demographic factors: age, nationality, education
- Training and work before coming to this facility
- Recruitment into current position

### ***II. Current work experience and responsibilities***

Now we would like to hear about your current job: what you do from day to day, things you enjoy about the job, etc.

- Training received that relates to current tasks performed
- Aspects of work activities that they find satisfying
- Aspects of their work situation they would like to change if they could
- Adequacy of resources at work: staff, equipment, etc.
- System of supervision of their work
- Other related activities they engage in currently

### ***III. Role in ART programme***

What are your activities that relate directly to the ART programme here?

- Official title
- Full- or part-time work
- Participation in enrolment process
- Contacts with local community representatives
- Contacts with support groups

#### ***IV. Promotion of ART services by facility***

How does the facility advertise its ART programme and encourage clients to come?

- Use of media, social mobilisation, volunteers
- Expectations of those who enrol on ART
- Assistance provided to access grants
- Other services offered to ART patients

#### ***V. Interaction with ART patients***

Please tell about your contacts with ART patients: where and when you see them, what you do together, etc.

- Time spent with ART patients per week
- Average time spent per episode with a patient
- Concerns often expressed by patients
- Description of the kinds of interactions they have with patients
- Description of the questions they ask of patients and those patients ask of them
- Strategies of adherence that work and that fail for patients

#### ***VI. Description of kinds of patients they see***

What kinds of patients do you often see? How do you divide them into groups?

- Differences between male and female patients
- Those who have had TB versus those who never had TB
- Other types of contrasts they have noticed

#### ***VII. Knowledge of how patients manage to take their medication or not***

Now we would like to hear some stories that patients have told you, or cases you know well, of patients who have done well with taking drugs, and others who have done poorly.

- Examples of patients who have done well
- Examples of patients who have struggled
- Strategies they think work well for patients
- Circumstances that make it difficult for patients to take their medication
- Experiences with patients who miss treatment
- Contacts with patients who have missed taking their drugs

#### ***VIII. Drug regimen commonly used to initiate ART***

What is the drug regimen used most often and how is that decided?

- Drug regimen used most often
- Guidelines for choosing drug regimen
- Role of patients in choosing drug regimen

***IX. Other comments to offer***

Do you have any other comments to add about anything?

- Information about patients that would be useful to them
- Information about the ART programme that would be useful to them
- Anything else?



## APPENDIX C: PATIENT RECRUITMENT LOG

TREATMENT	FEMALES	MALES
<b>12 ART without TB history</b>	<i>6 Participants</i>	<i>6 Participants</i>
	3: (3-6 months in programme)	3: (3-6 months in programme)
	<input type="checkbox"/> ..... (date)	<input type="checkbox"/> ..... (date)
	<input type="checkbox"/> ..... (date)	<input type="checkbox"/> ..... (date)
	<input type="checkbox"/> ..... (date)	<input type="checkbox"/> ..... (date)
	3: (18 months in programme)	3: (18 months in programme)
<input type="checkbox"/> ..... (date)	<input type="checkbox"/> ..... (date)	
<input type="checkbox"/> ..... (date)	<input type="checkbox"/> ..... (date)	
<input type="checkbox"/> ..... (date)	<input type="checkbox"/> ..... (date)	
<b>12 ART with TB history</b>	<i>6 Participants</i>	<i>6 Participants</i>
	3: (3-6 months in programme)	3: (3-6 months in programme)
	<input type="checkbox"/> ..... (date)	<input type="checkbox"/> ..... (date)
	<input type="checkbox"/> ..... (date)	<input type="checkbox"/> ..... (date)
	<input type="checkbox"/> ..... (date)	<input type="checkbox"/> ..... (date)
	3: (18 months in programme)	3: (18 months in programme)
<input type="checkbox"/> ..... (date)	<input type="checkbox"/> ..... (date)	
<input type="checkbox"/> ..... (date)	<input type="checkbox"/> ..... (date)	
<input type="checkbox"/> ..... (date)	<input type="checkbox"/> ..... (date)	
<b>12 Defaulters</b>	<input type="checkbox"/> (M/F)..... (date)	<input type="checkbox"/> (M/F)..... (date)
	<input type="checkbox"/> (M/F)..... (date)	<input type="checkbox"/> (M/F)..... (date)
	<input type="checkbox"/> (M/F)..... (date)	<input type="checkbox"/> (M/F)..... (date)
	<input type="checkbox"/> (M/F)..... (date)	<input type="checkbox"/> (M/F)..... (date)
	<input type="checkbox"/> (M/F)..... (date)	<input type="checkbox"/> (M/F)..... (date)
	<input type="checkbox"/> (M/F)..... (date)	<input type="checkbox"/> (M/F)..... (date)



## APPENDIX D: ASSESSMENT OF PATIENT SITUATION

Facility: .....  
 Patient Name: .....  
 Time on ART: ..... Years..... Months  
 Cell Phone: .....

Counselor: .....  
 Patient Number: .....  
 Address: .....  
 Alternative Number: .....

### INCOME

<b>Currently employed:</b>	Yes	<input type="checkbox"/>
	No	<input type="checkbox"/>
<b>Patient has reliable income in HH</b>		
	Yes	<input type="checkbox"/>
	No	<input type="checkbox"/>
Adults employed full-time in HH		...
Adults employed part-time in HH		...
<b>Disability grant</b>	Yes	<input type="checkbox"/>
	No	<input type="checkbox"/>
<b>Government grants in household</b>		
	Child Support Grant	<input type="checkbox"/>
	Old Age Pension	<input type="checkbox"/>
	Disability Grant	<input type="checkbox"/>
<b>Financial situation of patient:</b>		
	Very good	<input type="checkbox"/>
	Good	<input type="checkbox"/>
	Poor	<input type="checkbox"/>
	Very poor	<input type="checkbox"/>

### SOCIAL RELATIONS

<b>Marital Status:</b>	Single	<input type="checkbox"/>
	Married	<input type="checkbox"/>
	Live with partner	<input type="checkbox"/>
	Divorced	<input type="checkbox"/>
	Separated	<input type="checkbox"/>
<b>Household Composition:</b>		
	Adult males	<input type="checkbox"/>
	Adult females	<input type="checkbox"/>
	Children < 15 yrs. old	<input type="checkbox"/>
<b>Treatment Supporter (TM):</b>		
	Yes	<input type="checkbox"/>
	No	<input type="checkbox"/>
Name of TM: .....		
Relationship with TM: .....		
<b>Disclosure to others:</b>	Family	<input type="checkbox"/>
	Friends	<input type="checkbox"/>
	Others	<input type="checkbox"/>
	No one	<input type="checkbox"/>

Describe current situation about who knows.....  
 Current health status of patient.....  
 Experience of side effects.....  
 Response to side effects.....  
 Any problems with food.....  
 Source of money for transport to clinic.....  
 Possible problems for patient: (assessment of counsellor).....