

**ADHERENCE AND SUSTAINED ACCESS TO
ANTIRETROVIRAL
TREATMENT IN THE FREE STATE PUBLIC HEALTH
SECTOR: A GENDER PERSPECTIVE**

by

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DECLARATION

I declare that this thesis submitted for the degree of Philosophiae Doctor at the University of the Free State is my own, independent work and has not previously been submitted by me at another university/faculty. I furthermore cede copyright of the thesis in favour of the University of the Free State.

Chantell de Reuck
Bloemfontein
November, 2008

For the infected and affected

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LIST OF ACRONYMS AND ABBREVIATIONS

AIDS	Acquired immunodeficiency syndrome
ARV	Antiretroviral
ARVs	Antiretroviral drugs/medications
ART	Antiretroviral treatment
BDI	Beck Depression Inventory
CBOs	Community-based organisations
CES-D	Center for Epidemiological Studies-Depression Scale
CHSR&D	Centre for Health Systems Research & Development
CI	Confidence interval
DoH	Department of Health
DRT	Drug-readiness training
FBOs	Faith-based organisations
FSDoH	Free State Department of Health
HAART	Highly active antiretroviral therapy
HADS	Hospital Anxiety and Depression Scale
HIV	Human immunodeficiency virus
MEMS	Electronic monitoring devices
NGOs	Non-governmental organisations
NNRTIs	Non-nucleoside reverse transcriptase inhibitors
NRTIs	Nucleoside reverse transcriptase inhibitors
OR	Odds ratio
PHC	Primary Health Care
PI	Protease inhibitor
TB	Tuberculosis
TBPT	Tuberculosis preventive therapy
UNAIDS	Joint United Nations Programme on HIV/AIDS
UFS	University of the Free State
WHO	World Health Organization

TABLE OF CONTENTS

Acknowledgements	i
List of acronyms and abbreviations	ii
Table of contents	iii
List of tables	vii
List of figures	viii
List of maps	viii

CHAPTER 1 : INTRODUCTION TO THE STUDY

1.1	Background	1
1.2	Research problem and objectives	2
1.3	Overview of research design and research methodology	4
1.4	Value of the research	5
1.5	General limitations	7
1.6	Authorisation and ethical concerns	8
1.7	Dissemination of research findings	9
1.8	Chapter outline	10

CHAPTER 2 : FACTORS INFLUENCING ADHERENCE AND SUSTAINED ACCESS TO ANTIRETROVIRAL TREATMENT

2.1	Introduction	12
2.2	Effect of adherence on clinical outcomes	14
2.3	Factors affecting adherence	16
2.3.1	Demographic characteristics	16
2.3.1.1	Sex	17
2.3.1.2	Age	17
2.3.1.3	Race/Ethnicity	18
2.3.1.4	Education	18
2.3.1.5	Employment and income	19
2.3.1.6	Housing	19
2.3.2	Psychosocial/behavioural characteristics	20
2.3.2.1	Poor mental health	20
2.3.2.2	Drug and alcohol use	21
2.3.2.3	Social support	21
2.3.2.4	Patient attitudes and beliefs	22
2.3.3	Clinical aspects	22
2.3.3.1	Side-effects	23
2.3.3.2	Regimen complexity	23
2.3.3.3	Treatment duration	24
2.3.4	Health-care administration and delivery	24
2.3.4.1	Service delivery	25

2.3.4.2	Regular medication supply	25
2.3.4.3	Patient-provider relationship	26
2.3.4.4	Adherence strategies	26
2.4	The role of sustained access for effective treatment	27
2.5	Factors affecting sustained access to treatment	30
2.5.1	Demographic characteristics	30
2.5.1.1	Sex	30
2.5.1.2	Age	31
2.5.1.3	Race/ethnicity	31
2.5.1.4	Education	32
2.5.1.5	Employment and income	32
2.5.2	Psychosocial/behavioural characteristics	33
2.5.2.1	Poor mental health	33
2.5.2.2	Drug and alcohol use	33
2.5.2.3	Social support	34
2.5.3	Clinical aspects	34
2.5.3.1	Symptoms and disease stage	35
2.5.3.2	Treatment duration	35
2.5.4	Health-care administration and delivery	36
2.5.4.1	Service delivery	36
2.5.4.2	Appointment scheduling and monitoring	37
2.5.4.3	Patient-provider relationship	37
2.6	Summary	38

CHAPTER 3 : A GENDER PERSPECTIVE FOR EXPLORING AND EXPLAINING ADHERENCE AND SUSTAINED ACCESS TO ANTRIRETROVIRAL TREATMENT

3.1	Introduction	41
3.2	Sex and the social construction of gender	43
3.3	Why the need for a gender perspective?	45
3.4	Biological sex and social gender: Implications for successful treatment	47
3.4.1	Biological sex	48
3.4.1.1	Reproductive systems	49
3.4.1.2	Disease progression	50
3.4.1.3	Adverse drug reactions	53
3.4.2	Masculinity: The 'want-to-be' hegemonic man	54
3.4.2.1	Access to and control over resources	55
3.4.2.2	Decision-making power	57
3.4.2.3	Gender roles and activities	59
3.4.2.4	Gender norms and identities	61
3.4.3	Femininity: The subordinated woman	63
3.4.3.1	Access to and control over resources	64
3.4.3.2	Decision-making power	65
3.4.3.3	Gender roles and activities	67
3.4.3.4	Gender norms and identities	70
3.5	Summary	72

CHAPTER 4 : GENDER DISPARITIES AND SIMILARITIES IN MEDICATION ADHERENCE AND SUSTAINED ACCESS TO TREATMENT: DATA ANALYSIS

4.1	Introduction	74
4.2	Methodological biases in gender analysis	75
4.2.1	Single-sex studies	75
4.2.2	Differences and similarities between men and women	76
4.2.3	The 'sex = gender' variable in research	77
4.2.4	A quantitative gender methodology for the analysis of sustained access and adherence	79
4.3	Research design and research methodology	79
4.3.1	Sample	80
4.3.2	Research instrument	82
4.3.3	Recruitment and training of data gatherers	82
4.3.4	Data gathering and quality control	83
4.3.5	Measures	84
4.3.5.1	Outcome measures	84
4.3.5.2	Validity of outcome measures	86
4.3.5.3	Predictor variables: demographic characteristics	86
4.3.5.4	Predictor variables: psychosocial/behavioural characteristics	87
4.3.5.5	Predictor variables: clinical aspects	89
4.3.5.6	Predictor variables: health-care administration and delivery	89
4.3.6	Statistical analysis	91
4.4	Results	92
4.4.1	Descriptive characteristics of men and women compared	93
4.4.2	Validity of outcome measures	94
4.4.3	Comparison of ARV medication adherence and scheduled appointment adherence	96
4.4.4	Factors associated with non-adherence to ARV medications in men and women	97
4.4.4.1	Comparison of ARV-medication adherence between men and women	97
4.4.4.2	Factors associated with medication non-adherence in men	97
4.4.4.3	Factors associated with medication non-adherence in women	101
4.4.4.4	Multivariate analysis of factors associated with ARV medication non-adherence	105
4.4.5	Factors associated with non-adherence to scheduled appointments in men and women	107
4.4.5.1	Comparison of scheduled appointment adherence between men and women	107
4.4.5.2	Factors associated with scheduled appointment non-adherence in men	107
4.4.5.3	Factors associated with scheduled appointment non-adherence in women	111
4.4.5.4	Multivariate analyses of factors associated with non-adherence to scheduled appointments	115
4.5	Summary	117

CHAPTER 5 : SUMMARY OF FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

5.1	Introduction	120
5.2	Discussion of research findings	121
5.2.1	Demographic differences and similarities	121
5.2.2	Adherence and sustained access to ART in the Free State	121
5.2.3	Sustained access is positively related medication adherence	122
5.2.4	Predictors of ARV medication non-adherence	123
5.2.4.1	Access barriers	123
5.2.4.2	Treatment knowledge	123
5.2.4.3	Tobacco use	124
5.2.4.4	Stigma	125
5.2.5	Predictors of poor sustained access to ART	125
5.2.5.1	Depression and anxiety	126
5.2.5.2	Access barriers	126
5.2.5.3	Service satisfaction	127
5.2.5.4	Service needs	128
5.3	Recommendations for future research	128
5.3.1	Gender sensitive outcome measures	129
5.3.2	Improving treatment knowledge	130
5.3.3	Risky behaviour among women: smoking tobacco	130
5.3.4	Stigma avoiding alternatives	131
5.3.5	Difficulties experienced in visiting health care facilities	131
5.3.6	Comprehensive study of depression and anxiety	131
5.3.7	Closer examination of service needs	132
5.3.8	Quality assessment of services rendered	132
5.4	Implications for policy and practice	132
5.4.1	Monitoring adherence among patients	132
5.4.2	Improving access to treatment information	133
5.4.3	Reducing HIV/AIDS-related stigma	133
5.4.4	Improving mental health	134
5.4.5	Addressing unmet service needs	134
5.4.6	Monitoring quality of services	135
5.5	Strengths and limitations of the study	135
5.6	Concluding remarks	137
	List of references	138
	Synopsis	155
	Key terms	159
	Annexure A: Letters of authorisation	160
	Annexure B: Patient questionnaire	170
	Annexure C: Clinical data collection	180
	Annexure D: Non-sex-disaggregated analyses	183

LIST OF TABLES

Table 1:	Demographic characteristics between men and women on ART in the Free State public health sector compared	93
Table 2:	Validity of self-reported outcome measures	95
Table 3:	Self-reported ARV medication adherence by sex	97
Table 4:	Factors associated with non-adherence to ARV medications among men on ART in the Free State public health sector	98
Table 5:	Reported substance use by ARV medication adherence among men on ART in the Free State public health sector	100
Table 6:	Factors associated with non-adherence to ARV medications among women on ART in the Free State public health sector	102
Table 7:	Reported substance use by ARV medication adherence among women on ART in the Free State public health sector	104
Table 8:	Logistic regression analysis of factors associated with non-adherence to ARV medications among men (n = 452)	106
Table 9:	Logistic regression analysis of factors associated with non-adherence to ARV medications among women (n = 1042)	106
Table 10:	Self-reported scheduled ART appointment adherence by sex	107
Table 11:	Factors associated with non-adherence to scheduled appointments among men on ART in the Free State public health sector	107
Table 12:	Reported substance use by scheduled appointment adherence among men on ART in the Free State public health sector	110
Table 13:	Factors associated with non-adherence to scheduled appointments among women on ART in the Free State public health sector	112
Table 14:	Reported substance use by scheduled appointment adherence among women on ART in the Free State public health sector	114
Table 15:	Logistic regression analysis of factors associated with non-adherence to scheduled ART appointments among men (n = 428)	115
Table 16:	Logistic regression analysis of factors associated with non-adherence to scheduled ART appointments among women (n = 870)	116
Table 17:	Synoptic table of identified similarities and differences in medication adherence by sex	117
Table 18:	Synoptic table of identified similarities and differences in medication adherence by sex	118

LIST OF FIGURES

Figure 1:	Comparison of mean viral load (copies/ml) over time for men and women	96
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LIST OF MAPS

Map 1:	Geographical distribution of ART facilities in the Free State	81
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CHAPTER 1 – INTRODUCTION TO THE STUDY

1.1 BACKGROUND

In 2005 the Joint United Nations Programme on HIV/AIDS (UNAIDS, 2005) reported that more than 60% (25.8 million) of all HIV-infected persons reside in sub-Saharan Africa. Women, however, are disproportionately infected in this region, with approximately 60% of infections occurring among women (Gyves, 2006). This disparity is also evident in South Africa where HIV prevalence is substantially higher among women (15.0%) than men (11.5%), aged 15 years and older (Shisana & Simbayi, 2002). The disproportionate spread of the epidemic reflects the underlying gender inequalities present in society. Various studies have highlighted the interaction between biological and social susceptibility factors that deem women more vulnerable than men to both the infection and the effects of AIDS. For example, Albertyn (2003: 597) points out that, whilst physiological vulnerability is acknowledged, it is also “women’s lack of power over their bodies and their sexual lives, reinforced by their social and economic inequality, that makes them so vulnerable to contracting HIV/AIDS”.

In South Africa, the estimated number of cumulative AIDS deaths is predicted to exceed six million and more than one million infected people are estimated to be sick with AIDS by 2010 (Dorrington et al., 2001). Without a cure for HIV/AIDS, antiretroviral treatment (ART) remains the only hope for many to reduce the progression of the disease towards death. However, to effectively benefit from ART, patients should be in a position to access treatment successfully (Box et al., 2003) and be empowered to adhere to their regimens (Kaygay et al., 2004; De Olalla et al., 2002).

Various studies have shown that patients are required to maintain an adherence rate of at least 95% to their antiretroviral (ARV) drug regimens for treatment to be successful at reducing AIDS-related mortality and the development of drug resistance (Orrell et al., 2003; Paterson et al., 2000; Sethi et al., 2003). With respect to the influence of gender on adherence to ARV medications, women have been reported to be less adherent than men (Berg et al., 2004; Turner et al., 2003). The practical barriers related to household responsibilities and caring for children have been cited as factors associated with poor adherence among women (Mehta et al., 1997; Mellins et al., 2003).

Unfortunately, studies examining adherence to ARV medications usually presume patients have access, and as Bangsberg et al. (2006: 141) point out, “Lack of access to therapy and failure to adhere to therapy are different problems requiring different solutions. The former calls for stable drug supply and distribution, whereas the latter calls for interventions to sustain individual behaviour”. Although studies examining sustained access to treatment - measured by appointment adherence - are limited, it has been shown that missing more than 15% of scheduled appointments predicts an incomplete clinical response to treatment (Clough et al., 1999). In respect of gender and sustained access, studies are even more limited; however, it has been shown that, among patients not yet on ART, men are less likely to return for appointments than women (McClure et al., 1999). These findings are indicative of the need for further research into the gendered patterns of the response to ART as they pertain to adherence and sustained access to treatment.



1.2 RESEARCH PROBLEM AND OBJECTIVES

The call for closer attention to sex and gender in health research is not new. According to Doyal (2001: 1062), “[I]f health services are to be equitable and efficient

greater sensitivity will be needed to sex and gender concerns. This will need to be reflected in research, in patterns of service delivery, and in wider social and economic policies". Similarly, the World Health Organization (WHO, 2003: 5) claims that the "effectiveness of HIV/AIDS programmes and policies is greatly enhanced when gender differences are acknowledged, the gender-specific concerns and needs of women and men are addressed, and gender inequalities are reduced." In the *Operational Plan for Comprehensive HIV and AIDS Care, Management and Treatment for South Africa* compiled by the Department of Health (2003), this Department concurs with these statements by recognising that men and women may experience HIV and AIDS differently. Yet, the Department also concedes that investigation into the gender dimensions of HIV/AIDS treatment, care and support by the local research community is lacking.

Planning for antiretroviral treatment, care and support in South Africa has clearly not sufficiently taken into consideration gender differences that may serve as a barrier to sustained access and adherence to ART. Providing the same standardised treatment, care and support to men and women as though they constitute one homogenous group, without considering the underlying gender dynamics, may not result in equitable and efficient treatment benefits. Thus, this study aimed to examine how gender influences adherence to ARVs and sustained access to treatment among patients in the Free State public health sector. This study was deemed particularly necessary in the Free State context, where no previous research of this kind had been conducted before.

To determine the influence of gender on adherence to ARV medications and sustained access to treatment among patients on ART in the Free State public health sector, the following research objectives were pursued:

- To determine, by review of current literature, the factors that predict non-adherence to ARV medications and impede sustained access to ART;
- To determine the differences and similarities that exist between men and women in ARV-medication adherence and sustained access to treatment;

- To describe gender differences in non-adherence to ARV medications and poor sustained access from a gender perspective;
- To examine empirically which factors contribute toward non-adherence of ARV medications and to poor sustained access among men and women on ART in the Free State;
- To determine whether the same factors affect adherence and sustained access for men and women;
- To determine whether sustained access to treatment plays a role in ARV medication adherence among men and women; and
- To explore gender-sensitive interventions to improve adherence and sustained access among ART patients in the Free State.



1.3 OVERVIEW OF RESEARCH DESIGN AND RESEARCH METHODOLOGY

This section briefly describes the strategy and methodology employed to meet the objectives of this study. Foremost, it should be noted that this study was, in essence, a study within a larger ongoing study in the field of HIV/AIDS and ART conducted by the Centre for Health Systems Research & Development (CHSR&D). The CHSR&D embarked on a study, in partnership and collaboration with the Free State Department of Health (FSDoH), to document, monitor and evaluate the implementation of the National ARV Treatment Plan in the Free State. Synchronisation of this study with this larger project was important since a large sample of ART patients were already being interviewed by the CHSR&D, and it served to avoid the expense of conducting a second similar survey with the same patients and with a similar type of instrument. This study makes use of the cohort data collected as part of the larger study to assess adherence to ARV medications and sustained access to ART among patients already on treatment.

The sample of patients qualifying for ARV treatment were randomly sampled from each of the five districts in the Free State. Written, informed consent was obtained from patients to conduct semi-structured face-to-face interviews and to access patients' medical files to collect clinical data. Cohort patients were interviewed at baseline and then followed-up at six-month intervals to complete a total of six interviews.

The newly developed research instrument¹ elicited information regarding predictors of non-adherence and poor sustained access, including demographic characteristics, psychosocial/behavioural characteristics, clinical aspects, and factors relating to health-care administration and delivery. The questionnaires were administered by trained fieldworkers in the home language of the patient.

The two main outcome measures assessed in this study include self-reported adherence to ARV medications and self-reported adherence to scheduled appointments as a measure of sustained access to ART. All data, including outcome measures and predictor variables, were sex-disaggregated for analysis purposes. Bivariate analyses were performed to determine whether any significant gender differences were associated with the various predictor variables. Multivariate logistic regression analyses were performed separately for men and women to determine which predictor variables were independently associated with sustained access to ART and adherence to ARV medications.



¹ The research instrument was designed by the CHSR&D to gather information about various aspects of the roll-out of ART and the use of ARVs by patients in the Free State public health sector. It should be noted that, although this researcher was not involved in the initial instrument design process, she was involved in all subsequent evaluation and adaptation of the instrument.

1.4 VALUE OF THE RESEARCH

Several studies with respect to ARV adherence have been conducted in South Africa (Nachega et al., 2004; Orrell et al., 2003). However, no such study has been carried out in the Free State. Furthermore, these studies have assumed that patients do indeed have access, by not assessing whether or not patients can and do adhere to treatment-related appointments. Researchers have argued that adherence to drug regimens is not possible without first attending appointments (Catz et al., 1999; McClure et al., 1999). Unlike other studies on adherence where appointment adherence is either ignored completely or only analysed as a dependent variable, this study assesses the various factors associated with both ARV medication and appointment adherence independently.

This study also assesses adherence and sustained access to treatment separately for men and women. Bird & Rieker (1999: 751) claim that the inequities in the health of women and men cannot be addressed appropriately if sex and gender differences, including the interaction between the two, are not understood. The adoption of a gender perspective in the analysis of patient access and adherence to ART facilitates the identification and understanding of gender-related disparities present in the Free State's ART programme. This allows the opportunity for appropriate gender-sensitive efforts to be made to correct and/or eliminate any identified gender-related disparities, thus allowing for more appropriate delivery of AIDS-related health care services that meet the health needs and priorities of both men and women. Therefore, this study has the potential to aid in the provision of gender-sensitive information, which policymakers can use in the development of future policies and guidelines to make the benefits of ART equitable to both men and women.



1.5 GENERAL LIMITATIONS

This study is limited to HIV/AIDS services and patients in the Free State who were on ARVs that were received through the public health sector. Patients qualifying for ARV treatment had already made use of the many HIV/AIDS-related services offered within the public sector, meaning that they were more qualified to give a response concerning both adherence to medication and sustained access to treatment. However, since the study made use of a sample of patients that had only recently entered into the governments ART programme, results will not be generalisable to patients who have been on treatment for longer periods of time. Furthermore, this study falls short of assessing the full continuum of adherence behaviours that may have a significant bearing on successful treatment outcomes. For example, it does not assess aspects such as adherence to food restrictions or in respect of adherence to schedule (i.e. taking medication doses on time).

Children² are excluded from the study for numerous reasons. Firstly, paediatric ARV treatment differs from that of adults, which means that results would not be comparable to those of adults. Secondly, ART for children was rolled out slower than ART for adult patients in the Free State, which would have posed major fieldwork coordination problems. Thirdly, the sample size would have been too small to be representative, and lastly, the research process would have been complicated by legalities such as obtaining consent of a child's immediate guardian. Understanding the specific needs of children on ART as they relate to treatment adherence, was viewed as being better served by the initiation of a separate, rather than a combined child-adult study.

Furthermore, gender is not constant. The socially constructed values and traditions of a society that influence gender constantly change – thus where gender issues are identified as significantly influencing access and/or adherence to ART at present, this may not be the case in the future. Furthermore, gender norms also vary by

² For the purposes of the CHSR&D study, children were defined as those patients requiring ARV treatment who are under the age of 18 years.

geographical location, social class, ethnicity and age (Mane & Aggleton, 2001: 32). Thus, the results obtained from this study may have no bearing on service delivery ten years from now, and therefore similar studies will have to be undertaken periodically.



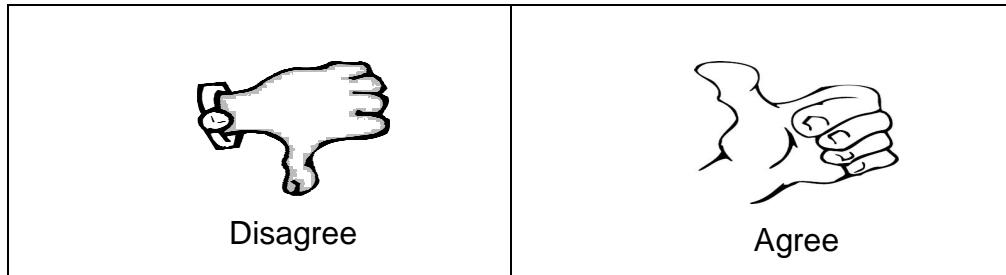
1.6 AUTHORISATION AND ETHICAL CONCERNS

The CHSR&D's ongoing project, which seeks to document, monitor, evaluate and facilitate the introduction, implementation and rollout of the ARV Treatment Programme in the Free State public health sector, is conducted in partnership with the Free State Department of Health. Authorisation to conduct the research³ in assigned treatment, assessment and combined sites was therefore secured from the top management of the provincial Department of Health, as well as from the appropriate district management structures, local authorities, and concerned facilities. Furthermore, the study protocol for the CHSR&D's project was approved by the Ethics Committee of the University of the Free State's (UFS) Faculty of Humanities.

In respect of all patient interviews, the following ethical principles were endorsed by all researchers and fieldworkers working at the CHSR&D (Babbie & Mouton, 2001: 529-531; Baker, 1994: 81-82; Neuman, 2000: 283-285):

- No deceiving of subjects and informed written consent: Respondents were informed about the purpose of the research and that their participation in the survey was voluntary. Informed (as far as possible) written consent was obtained after the client's review of a letter of introduction, fully explaining the nature and the purpose of the research and the ethical obligations of the research team. In the case of illiterate respondents, the letter of introduction was read and explained by the interviewers. Even so, such illiterate respondents were asked to consent to the interview by indicating one of the following symbols:

³ Refer to Annexure A for all relevant letters of authorisation and ethical clearance for this project.



- No harm to research subjects: Completion of interviews with ill and/or fatigued patients was interrupted and postponed until such time that they feel fit to continue.
- Beneficence: All actions of the researchers were directed at improving the well-being of research subjects and the community at large.
- Respect of patient privacy: Given the highly private and sensitive nature of HIV/AIDS, all researchers and field workers were obliged to maintain patient confidentiality. Under no circumstances was client information imparted to anyone without prior permission from the patient.



1.7 DISSEMINATION OF RESEARCH FINDINGS

Given that this research forms part of a larger study on HIV/AIDS and ARV rollout in the province undertaken by the CHSR&D, plans for dissemination of research results and recommendations are the same as for the larger project. The project as a whole obliges researchers to contemplate appropriate ways and means to convey the results and recommendations to the relevant stakeholders and role players and, furthermore, to assist these stakeholders and role players in implementing recommendations.

Each year of data gathering is therefore followed by subsequent research feedback at both the provincial and district levels. Research feedback workshops are inclusive of managers, co-ordinators and health-care workers engaged in ARV treatment and

other relevant Primary Health Care (PHC) programmes, as well as patients, non-governmental organisations (NGOs), faith-based organisations (FBOs) and community-based organisations (CBOs). In this way, six research feedback sessions are conducted annually (towards the end of each year), one centrally for the Free State Department of Health, and one for each of the Free State's five health districts.

On completion of this study, gender-related results, conclusions and recommendations will be made available to the Free State Department of Health and each of the five health districts by means of the above-mentioned research feedback sessions. Also, findings will be made available through the publication of at least two articles from the research in an accredited journal.



1.8 CHAPTER OUTLINE

The chapters of this study are arranged as follows:

- Chapter 1 serves as an introduction to the study and outlines the problem statement, aim and objectives, research design and methodology, value of the research, study limitations, dissemination of research findings, and authorisation and ethical concerns.
- Chapter 2 elaborates on the importance of adherence to ARVs for successful clinical outcomes that result in improved patient survival. In addition, this chapter also links literature on sustained access to treatment, by examining how non-adherence to scheduled appointments relates to ARV non-adherence and incomplete clinical outcomes. An overview of the various factors that recent studies have shown to be associated with ARV non-adherence and sustained access was made in respect of demographic characteristics,

psychosocial/behavioural characteristics, clinical aspects, and health-care administration and delivery.

- Chapter 3 explores and explains how the social construction of gender influences the health-care behaviour of men and women infected with HIV and AIDS. It is argued that taking gender into account, particularly in the context of treatment, care and support for HIV-infected patients, is crucial for effective health services that result in successful treatment outcomes and ultimately patient survival. This chapter focuses on the definitions and understandings of the concepts *sex* and *gender*, and how these concepts are related to the health of men and women. It also explores why a gender perspective is both relevant and necessary for the provision of medical treatment and services for AIDS patients. This is followed by an exploration of how socially constructed masculinity and femininity influence the health behaviours of men and women, especially with respect to access and adherence to medical treatment.
- Chapter 4 provides an overview of common methodological biases in the quantitative analysis of gender, followed by a detailed description of the strategy and methodology, including the sampling methods, research techniques and instruments, recruitment and training of data gatherers, data gathering and quality control, while analysis of data is also provided. This is followed by a synopsis of the research findings of this study.
- Chapter 5 includes a discussion of the identified gender disparities and similarities in access and adherence among patients in the Free States ART programme. A summary of the implications for health-care policy and practice to ensure equitable treatment outcomes is made and recommendations for future research are given.

CHAPTER 2 – FACTORS INFLUENCING ADHERENCE AND SUSTAINED ACCESS TO ANTIRETROVIRAL TREATMENT

2.1 INTRODUCTION

It has been established that the introduction of highly active antiretroviral therapy (HAART), also referred to as ART, can effectively reduce AIDS-related morbidity and mortality rates (Anastos et al., 2002; Cole et al., 2003). A study by Charurat et al. (2004) found that HAART has the ability to reduce disease progression to death by as much as 70% over a period of 12 months. In South Africa, Coetzee et al. (2004) found patient survival rates among a cohort of patients on ART to range between 64.6% and 90.0%. This finding and those of similar research in other parts of Africa demonstrates that ART is as effective in South Africa as it is in both more resourced developed countries and resource-limited developing countries (Frater et al., 2002).

Despite the proven success of ART as an effective treatment for reducing morbidity and mortality rates, adherence to ARV medications remains vital for treatment success (Chesney et al., 2000a; Frater et al., 2002; Mugavero et al., 2006). According to Yun et al. (2005: 432) adherence refers not only to “the extent to which a person’s behaviour coincides with medical advice”, but “is a multifactoral process involving the individual patient, the treatment regimen characteristics, and the quality of the patient-provider interaction”. It is thus important to differentiate the term “adherence” from other terms that are used synonymously, such as the terms “compliance” and “self-efficacy”, but which rather refer to a specific aspect of adherence’s multifactoral processes.

Compliance, for example, refers to a patient’s submissive role in obediently following the instructions or prescriptions given by a physician or health-care provider (Garcia &

Côté, 2003). Compliance, which reflects the role of the patient-provider interaction, has increasingly been replaced by the term “adherence” due to recent reflections of mutual or interactive and shared responsibility between patient and health-care provider in medical or health advice being consistent with the behaviour of a patient (Garcia & Côté, 2003; Irvine et al., 1999). “Self-efficacy”, on the other hand, more commonly reflects the role of the individual patient in the multifactorial process, and it generally describes a patient’s own “perception of their ability to carry out a task in a particular situation” (Garcia & Côté, 2003: 39). In respect of adherence, self-efficacy is usually assessed in terms of a patients intention and confidence in implementing the required health-related behaviours (Mellins et al., 2003).

For the purposes of this literature overview and study, the term *adherence* is preferred as it simultaneously reflects both the patients autonomy in carrying out the approved health-related behaviours, as prescribed by his or her physician or health-care provider, required for treatment to be effective. Thus, adherence broadly denotes the “extent to which the patient follows a prescribed regimen” (Mehta et al., 1997: 1665). However, the characteristics of the ARV-treatment regimen are complicated by a multitude of factors which include, among others, patients having to take several different types of medications, with different dosing frequencies for each medication, and with each medication possibly requiring varying food restrictions or requirements (Chesney et al., 2000a; Paterson et al. 2000). Non-adherence to this complex array of regimen characteristics may result in the reduced clinical benefit of these life sustaining drugs. It is therefore crucial that any factors that may result in non-adherence be identified and adressed.

This chapter, firstly, intends to give an overview of the importance of adherence to ARV medications for improved treatment outcomes (i.e., the effect of adherence on clinical outcomes), as well as, the various barriers that may lead to poor medication adherence among ART patients. Secondly, this chapter will also include an overview of the role that sustained access to ART (measured as appointment adherence) plays with respect to treatment success, and how it is linked to medication adherence. This

is followed by an outline of the barriers that have been associated with poor sustained access to ART. To establish which demographic, psychosocial/behavioural, clinical, or health-care administration and delivery factors are differently associated with medication adherence and sustained access to treatment in men and women, significant associations are also identified from the existing literature.



2.2 EFFECT OF ADHERENCE ON CLINICAL OUTCOMES

Understanding the factors that affect adherence is of concern in view of the fact that failure to adhere to drug regimens is known to be closely linked to various clinical outcomes that indicate treatment failure, relapse in illness and progression towards death. Successful clinical outcomes among patients on ART include viral suppression and increased CD4+ cell counts, while treatment failure may result in the development of drug resistant strains of the virus.

Firstly, numerous studies have shown that poor adherence to drug regimens are associated with continued viral replication in patients (Gifford et al., 2000; Halkitis et al., 2003; Haubrich et al., 1999; Lucas et al., 1999; Paterson et al., 2000). For example, a study by Halkitis et al. (2003) found that undetectable viral loads were significantly associated with fewer reported missed doses of medication among a cohort of HIV-infected men. Other studies have shown that to achieve virological success, or viral suppression, a patient needs to maintain an adherence rate of at least 95% or more (Orrell et al., 2003; Paterson et al., 2000).

Failure to adhere to drug regimes has similarly been associated with declining CD4+ cell counts (Haubrich et al., 1999; Mannheimer et al., 2002; Paterson et al., 2000). A decreased CD4+ cell count is an immunologic outcome that has been associated with increasing viral loads among patients on ARVs (Anastos et al., 2002; Bart et al., 2000; Coetzee et al., 2004). Progression to death has been associated with CD4+ cell

counts of lower than 200/ μ L (Anastos et al., 2002; Hogg et al., 2002), however, as with virological success, a near perfect adherence rate of 95% is necessary for CD4+ cell counts to increase (Paterson et al., 2000).

Lastly, non-adherence to ARV medications has also been shown to lead to treatment failure or the development of drug resistance (Lucas et al., 2003). According to Chesney et al. (2000b: 1599), the development of resistant strains is not only a problem "...for the patient affected but also to the public health, as these strains can be transmitted to others, limiting treatment alternatives". Although drug resistance may be of great concern for public health, Bangsberg et al. (2000) contend from their study that, although adherence is a strong predictor of viral suppression, poor adherence of less than 50% would not readily lead to drug resistance. However, a more recent study by Sethi et al. (2003), examining the long-term effects of non-adherence, found that adherence of between 70% and 89% was significantly associated with drug resistance.

Decreasing CD4+ cell counts and high levels of viral load are strong predictors of disease status, vulnerability for opportunistic infections and disease progression toward death (Remor et al., 2007). As a result, long-term ARV-medication adherence among patients is essential for reducing drug resistance and disease progression (Abbas et al., 2006; Charurat et al., 2004; De Olalla et al., 2002). However, numerous studies have found adherence rates among patients to be below the 95% required for good clinical outcomes, indicating that adherence to ART is not as desired. For example, using several timeframes and measures of adherence, Murphy et al. (2004) found adherence levels to be poor among a sample of 115 HIV/AIDS patients in Los Angeles. They found self-reported adherence over a three and seven day period to be as low as 42% and 35% respectively. In addition, Mannheimer et al. (2002) report that adherence to medications significantly decreases over time among patients.

Thus, the question remains one of how to keep patients adherent to their medications. Patients are expected to adhere in spite of complex drug regimens that have to be

taken chronically. These regimens include taking several different types of medications in varying forms (pills, tablets and/or capsules) at various times and with varying food restrictions or requirements (Chesney et al., 2000a). Although clinical factors such as these negatively influence adherence, adherence is shaped by a multitude of factors. The various factors are outlined in the following section.



2.3 FACTORS AFFECTING ADHERENCE

In order to increase the survival of AIDS patients on ART and to minimize the development of resistant strains of HIV, as well as for making of appropriate treatment decisions by health care providers, factors associated with poor adherence to ARV drug regimens need to be well understood. It should, however, be noted that a multitude of ways of assessing adherence rates or non-adherence among patients on ART exist. Chesney et al. (2000a), for example, highlight two main ways in which assessment of medication adherence varies among studies, namely measurement and time period. Measurement components include self-report, pill counts, and electronic monitoring devices or MEMS. Time periods over which missed doses are measured range from the past day, to past seven days, to the past month. Regardless of the method used, optimal adherence remains a crucial factor for treatment success. Factors associated with poor adherence are discussed below, using categories previously reviewed by Mehta et al. (1997). Accordingly, categories of factors associated with poor or improved adherence include: demographic characteristics, psychosocial/behavioural characteristics, clinical aspects, and health-care administration and delivery.

2.3.1 Demographic characteristics

Demographic characteristics such as sex, age, race/ethnicity, educational level, income and housing have been found to be significant poor predictors of adherence

among patients on ART. However, findings have not been consistent across studies (Murphy et al., 2004; Stone, 2001). Ferguson et al. (2002: 416) conclude from their study findings that “demographic characteristics are generally poor predictors of antiretroviral adherence; however, it does emphasize that demographic groups may face somewhat different challenges and barriers to adherence”. Demographic factors that have been found to have an association with ARV adherence are outlined below.

2.3.1.1 Sex

The majority of studies of ARV adherence among patients have found no correlation between sex and adherence (Ferguson et al., 2002; Haubrich et al., 1999; Simoni et al., 2002; Weiser et al., 2003). Associations between sex and medication adherence have, nevertheless, been reported. Earlier adherence studies have reported men to be less adherent than women (Mehta et al., 1997). However, the converse has been reported in more recent studies. For example, Turner et al. (2003) examined ARV-medication adherence among a sample of patients with similar socio-economic backgrounds; they found that women were significantly less likely to adhere to their medications than men. Similarly, Berg et al. (2004) found women (46%) to be less adherent than men (73%), although this finding may be confounded by drug-related behaviours, given that the sample was composed of current and former opioid users. These findings draw attention to the need for further research to identify the sex-specific factors that result in poor medication adherence among men and women on treatment.

2.3.1.2 Age

The association between age and adherence to ARVs is varied across studies, especially with respect to younger and older patients on ART, although it should be noted that no association between age and adherence has also been found (Haubrich et al., 1999; Simoni et al., 2002; Weiser et al., 2003). Younger age has been associated with both non-adherence (Ammassari et al., 2001; Carballo et al., 2004; Moatti et al., 2000) and adherence (Stone et al., 2001). However, a linear relationship seems to exist between younger age, as a predictor of poor adherence, and with older

age, especially being older than 40 years of age, to be predictive of adherence (Mannheimer et al., 2002; Murphy et al., 2004; Nemes et al., 2004; Paterson et al., 2000). Murphy et al. (2004: 480) state: “It may be that those who are older have greater stability in their lives, and such stability may positively impact adherence”. Although it is not clear whether younger age is predictive of non-adherence in South Africa, increasing age has been associated with improved adherence (Orrell et al., 2003).

2.3.1.3 Race/Ethnicity

The association between adherence and race/ethnicity has not been consistent across studies either, with some studies reporting no association with adherence (Ferguson et al., 2002; Halkitis et al., 2003; Haubrich et al., 1999; Stone et al., 2001), while other studies have found race/ethnicity to be a contributor to poor adherence (Gifford et al., 2000; Mannheimer et al., 2002). A study by Frater et al. (2002), comparing clinical outcomes between European and African cohort patients, showed that African patients had an increased viral load after nine months of ART. Poor adherence, as a result of cultural and language barriers experienced by emigrant populations, was given as an explanation for the reported difference. The relationship between race and medication adherence among patients on ART in South Africa has not been studied.

2.3.1.4 Education

Numerous studies have reported that educational level is not a significant predictor of adherence (Halkitis et al., 2003; Simoni et al., 2002; Stone, 2001; Weiser et al., 2003). Conversely, an association between educational level and non-adherence has been found in as many studies (Aloisi et al., 2002; Gifford et al., 2000; Nemes et al., 2004), however, the correlation between adherence and educational level has been varied. For example, Gifford et al. (2000) reported that better adherence to ARVs among a sample of 133 ART patients in California was associated with a higher level of education, especially having a college degree. Similarly, Nemes et al. (2004) reported that very low levels of education were predictive of non-adherence in Brazil. Although

not significant, Weiser et al. (2003) found the converse to be true in a study of adherence barriers in Botswana: the lower the level of education, the higher the adherence. Data with respect to whether level of education plays a significant role in adherence behaviour of ART patients in South Africa is limited.

2.3.1.5 Employment and income

With employment and income factors, Chesney et al. (2000a) found that working outside the home, and having no income, were associated with non-adherence among a convenience sample of 75 ART patients. They claim that this finding is a result of the difficulties related to remembering or making time to take medications when busy outside the home. However, other studies have reported no relationship between income, work status or low socio-economic status and adherence (Halkitis et al., 2003; Orrell et al., 2003; Weiser et al., 2003). Not having health insurance or medical aid is another factor linked to non-adherence. A study by Mugavero et al. (2006) confirms that non-adherence is more likely among uninsured patients, citing problems with regularly acquiring medications as a contributing factor. Investigating the determinants of adherence in Botswana, Weiser et al. (2003) have shown that the removal of barrier costs (i.e. the cost of ARVs to the patient) can improve adherence up to as much as 20%. They also highlight additional medical expenses, lack of food, and lack of money for clothes for their families as other economic constraints faced by patients. In South Africa no association was found between socio-economic status and adherence among a sample of 289 ART patients in Cape Town (Orrell et al., 2003). They maintain that this finding is different to what has been found in the rest of sub-Saharan Africa since financial barriers, such as the purchasing of medications and payment for routine medical care, were offset ed by the provision of free treatment.

2.3.1.6 Housing

Housing has been associated with adherence, especially in respect of long-term and stable housing. A study in New York among current and former HIV-positive drug users on ART, conducted by Berg et al. (2004), found an association between long-

term housing (i.e. living in the same residence for three years or more) and adherence among both men and women. A more recent study by Carballo et al. (2004) found an association between home stability – defined as living in stable housing as opposed to non-permanent housing such as a social institution or hostel – and adherence. It is not clear from the literature whether long-term, stable housing (as opposed to temporary housing and homelessness) would have an effect on the adherence among ART patients in the South African context.

2.3.2 Psychosocial/behavioural characteristics

Various psychosocial or behavioural characteristics have been linked to non-adherence to ARV regimens among patients, including lifetime trauma, depression, drug and alcohol use, and poor social support or relationships. These factors and their relationship with non-adherence are outlined below.

2.3.2.1 Poor mental health

An association between non-adherence to ART and lifetime traumatic events, such as sexual or physical abuse, murder of a close family member, or death of an immediate family member, was found in a study conducted by Mugavero et al. (2006). Findings revealed that non-adherence increased for each additional lifetime traumatic event experienced by a patient. Depression was found to be a significant predictor of non-adherence in this same study (Mugavero et al., 2006), as well as in other studies (Safren et al., 2001; Simoni et al., 2002; Turner et al., 2003; Yun et al., 2005). Yet, there are studies that have found no correlation between depression and adherence (Gifford et al., 2000; Halkitis et al., 2003; Stone et al., 2001). Where depression is clinically diagnosed, patients report higher rates of adherence to ARV medications. Turner et al. (2003) report improved adherence in relation to the diagnosis of depression and claim that this may be as a result of most patients with the diagnosis receiving psychiatric care. They also report that receiving mental health services had a stronger association with adherence among women than men.

2.3.2.2 Drug and alcohol use

Drug use by patients on ART has consistently been associated with poor adherence, and is a factor in unsuccessful viral load suppression and lower mean increase in CD4+ cell counts among HIV-infected patients (Gebo et al., 2003; Haubrich et al., 1999; Kerr et al., 2004; Lucas et al., 1999; Wagner et al., 2004). However, there have been studies that have documented no association between adherence and drug use (Paterson et al., 2000; Safren et al., 2001; Stone et al., 2001). Among a sample of injection drug users in Canada, forgetting and sleeping through dose times were the most frequently mentioned reasons for not taking medications (Kerr et al., 2004). Similarly, the consumption of alcohol has been significantly associated with non-adherence in a number of studies (Chesney et al., 2000a; Haubrich et al., 1999; Mellins et al., 2003; Moatti et al., 2000; Murphy et al., 2004; Wagner et al., 2004). According to Halkitis et al. (2003: 98), "[i]t is possible that non-adherence is associated with alcohol use because health-seeking behaviours such as keeping medical appointments are impeded by alcohol use, as are perception of time and maintenance of routines". This same argument may hold true for patients using drugs while on treatment. Examining ARV adherence and specific drug and alcohol use among a sample of men and women opioid users, Berg et al. (2004) found that worse adherence was associated with alcohol use among women, while worse adherence among men was associated with active crack or cocaine use.

2.3.2.3 Social support

Various studies have shown that social support has been positively associated with adherence to medication regimens (Gifford et al., 2000; Murphy et al., 2004; Safren et al., 2001). Social support in the form of a family member or friend appointed as an adherence monitor⁴, who either administers or oversees that the patient takes his or her medications, has been viewed as an effective means of ensuring that patients adhere to medication regimens within the home setting (Bartlett, 2002). A study by Murphy et al. (2004: 481), which assessed social support as a facilitating factor for adherence found that patients with "higher levels of reassurance of worth" and "who

⁴ Referred to as a 'treatment buddy' in South Africa.

reported reliable alliances with others” were more likely to be adherent. With respect to social relationships, Halkitis et al. (2003) found that having HIV-positive friends was significantly associated with adherence. Satisfaction with the social support a patient receives has also been found to be positively associated with adherence (Safren et al., 2001).

2.3.2.4 Patient attitudes and beliefs

Adherence may be negatively affected by patient attitudes and beliefs with respect to medications. For example, a study by Gifford et al. (2000), which assessed factors influencing adherence, found that patients who believe that they had the ability to adhere to medications and patients who believe that non-adherence leads to resistance, were more adherent to their medications. However, a CD4+ cell count of more than 500/ μ L has been associated with increased non-adherence (Stone et al., 2001). This may be related to the perceptions held by patients regarding their behaviour and feeling healthy. In this regard, feeling healthy and having good laboratory test results have also been cited as a reason for patients not taking their medications as prescribed (Murphy et al., 2000). A South African study conducted by Nachega et al. (2005), among HIV/AIDS patients in Soweto, revealed that 65% believed that missing ART doses could lead to disease progression. However, this knowledge was found to be significantly higher among HIV/AIDS patients not on ART. The researchers state that this finding may be indicative of non-adherence among some participants without any clinical consequences. Findings such as these are indicative of the need to encourage an accurate understanding among patients about ART and the dangers of non-adherence.

2.3.3 Clinical aspects

The clinical aspects of ART which may be associated with poor adherence, outlined below, relate mainly to patient symptoms and progression of the disease. Three main clinical factors have repeatedly been associated with non-adherence among patients on ARVs: medication side-effects or toxicity, complex medication regimens, and treatment duration.

2.3.3.1 Side-effects

Side-effects from ARVs are known to have a negative effect on adherence among patients (Ammassari et al., 2001; Berg et al., 2004; Gifford et al., 2000; Murphy et al., 2004). Bartlett (2002: S7) points out that “[i]ronically, as a direct by-product of the survival-enhancing effectiveness of current antiretroviral regimens, side-effects are increasingly emerging as an issue that affects adherence”. The number of side-effects as well as the type of side-effects experienced by a patient has been found to affect adherence. For example, Berg et al. (2004) found that experiencing two or more medication side-effects was associated with worse adherence. Various side-effects have been significantly associated with non-adherence; these include nausea and vomiting, vision problems, anorexia, gastrointestinal upset, insomnia, abnormal fat distribution and mouth-hand numbness (Ammassari et al., 2001; Fong et al., 2003; Murphy et al., 2004). Furthermore, the more bothersome or intense a side-effect is perceived to be, the less adherent a patient on ARVs will be (Altice et al., 2001; Gifford et al., 2000; Simoni et al 2002). Similarly, in a study by Chesney et al. (2000a), as many as 24% of non-adherent patients gave “wanted to avoid side-effects” as the reason for skipping their medications. Women have been found to be 40% more likely than men to discontinue at least one ARV medication as a result of differing reactions to the drugs experienced (Murri et al., 2003). Fortunately, it has been found that over time the number of symptoms patients experience decreases (Préau et al., 2004).

2.3.3.2 Regimen complexity

Increased regimen complexity is associated with decreased adherence. However, prescribed regimens can be complicated in a number of ways, such as different types of medications, increased dosing frequency, higher pill burden, and food restrictions or requirements (Bartlett, 2002; Chesney et al., 2000a; Nemes et al., 2004; Stone et al., 2001). With regard to dosing frequency, for example, Paterson et al. (2000) found that patients who were taking medications twice-daily were more adherent than patients taking medications three-times-daily. Similarly, a South African study of adherence among HIV-positive and antiretroviral naive patients, found that a three-

times daily ARV dosing schedule was an independent predictor of increased viral loads and was associated with poor adherence (Orrell et al., 2003). Furthermore, a relationship between correctly understanding medication instructions and regimen complexity has also been observed (Stone et al., 2001). Already complex regimens are further complicated when patients must simultaneously take medications for other conditions, such as diabetes or heart problems (Murphy et al., 2000). Thus, until regimens can be simplified in terms of the above factors, the complex medication regimens that ART patients are required to follow will continue to be an issue affecting adherence.

2.3.3.3 Treatment duration

The length of time on ART has been shown to be negatively associated with adherence. A study by Nemes et al. (2004) shows that a linear relationship between non-adherence and treatment duration existed among a sample of 322 Brazilian ART patients. They report that being on treatment for more than 6.5 years was associated with non-adherence to ARVs. Similarly, a longitudinal study of adherence consistency showed a significant decrease in adherence among patients who were 100% adherent at the start of the study and adherence in subsequent months of follow-up (Mannheimer et al., 2002). According to Stone (2001), decreasing adherence over time may be a result of patients experiencing 'treatment fatigue', losing their motivation, or because they become complacent. An understanding of these factors are of importance, especially given that patients are expected to adhere to treatment for the rest of their lives.

2.3.4 Health-care administration and delivery

The effective delivery of ART through the health care system requires that various factors be in place, including health facilities, health care workers, health service management, partnerships with relevant organisations (i.e. non-governmental organisations), and referral systems (Furber et al., 2004; Schneider et al., 2006). However, studies have shown that numerous health care delivery and administrative factors can have a negative influence on patient adherence to ARVs. Delivery of

services, supply of medications, the relationship between the patient and the health care provider, and adherence strategies are the most prominent factors identified in the literature, as having an influence on ARV medication adherence. These are briefly outlined below.

2.3.4.1 Service delivery

Various factors of health service delivery have been investigated in relation to adherence. Factors reported not to be associated with patients' adherence to medications include, level of quality of care (Nemes et al., 2004), and receiving treatment at public or private facilities (Halkitis et al., 2003). Service delivery factors having an effect on patients' adherence mainly relate to facility size and language barriers. In Brazil, smaller health service facilities, especially those serving fewer patients (≤ 100), were found to be predictive of non-adherence in a study of ARV adherence by Nemes et al. (2004). Language differences between health care staff and patients have also been linked to poor ARV medication adherence. A South African study revealed that patients who spoke the same language as health care staff adhered to medications better than patients with a different home languages (Orrell et al., 2003).

2.3.4.2 Regular medication supply

A regular supply of ARV drugs has been cited as a critical factor for sustainable adherence (Furber et al., 2004; Laurent et al., 2002). Shortages and interruptions in medication supply are also known to disrupt adherence, and thus can be as a result of either the health care system or the patient. From the patient's side, gaining access to additionally required medications has been shown to be problematic. Qualitative findings from a study by Murphy et al. (2000) revealed that gaining prescription/medication refills were problematic for patients who had lost, misplaced or ran out of ARV medications while away from home. Furthermore, forgetfulness also poses a problem to medication supply on the part of the patient. A study of patient-perceived barriers to adherence by Ferguson et al. (2002) found that women were more likely to forget to refill their medication prescriptions than men. A study of

government's ART initiative in Senegal by Laurent et al. (2002), found that 87.9% of patients reported $\geq 80\%$ adherence to their ARV medications, while viral resistance only occurred in two patients (3.4%). Not having disruptions to ARV drug supply was given as a reason for the low levels of drug resistance among this sample of ART patients.

2.3.4.3 Patient-provider relationship

Various aspects of the patient-provider relationship have been identified as barriers to adherence, including inadequate communication by health care providers (Murphy et al., 2000; Murphy et al., 2004). Inadequate communication affects adherence if health care workers do not adequately explain correct dosing instructions and the possible side-effects that may be experienced, including the duration of any side-effects (Murphy et al., 2000). This communication aspect may be of particular concern in South Africa given that Nachega et al. (2005) found that 36% of an HIV/AIDS patient sample from Soweto believed ART would not cause side-effects. Another aspect associated with the patient-provider relationship is patient satisfaction with health care providers (Murphy et al., 2000; Roberts, 2002; Wagner et al., 2004). A study by Burke-Miller et al. (2006) found a relationship between increased satisfaction with health care providers and having both a regular care provider and more frequent visits. However, no association has been reported between perceived frequency of health care providers talking to patients regarding adherence and actual adherence rates (Halkitis et al., 2003).

2.3.4.4 Adherence strategies

According to Murphy et al. (2000: 51), adherence strategies are defined as "...any behavioural action or use of a physical object to help participants remember their medication". A qualitative study by Gerbert et al. (2000) which examined challenges facing health care providers, reported on some of the diverse strategies employed by health care providers to enhance adherence among patients on ART. Some of the strategies employed included educating patients (how ART works and consequences of non-adherence), medication trial runs using placebos (such as jelly beans),

teaching patients to use certain cues as reminders, anticipating and addressing adherence problems with patients, and telling patients to contact the health care provider with any medication-related queries. Similarly, Murphy et al. (2000) give an account of the most frequently reported strategies employed by patients to help keep them adherent to their medications. Although not reflective of successful adherence, the strategies employed, included the use of storage and transport containers, getting clarification on medication dosages from a health care provider, and keeping food and water for taking the ARVs. Findings from a study in South Africa showed that the necessary levels of adherence for treatment success can be achieved without formal interventions aimed at increasing adherence (Orrell et al., 2003).



2.4 THE ROLE OF SUSTAINED ACCESS FOR EFFECTIVE TREATMENT

While much attention has been given to the barriers and facilitators of adherence to ARV medications for improved clinical outcomes and reduction in AIDS-related morbidity and mortality, far less attention has been paid to the role of access among patients already on ART. Studies examining adherence to ARV medications, however, usually presume patients have access. Bangsberg et al. (2006: 140-141) point out: “Lack of access to therapy and failure to adhere to therapy are different problems requiring different solutions. The former calls for stable drug supply and distribution, whereas the latter calls for interventions to sustain individual behaviour”. However, this narrow interpretation of access neglects the role played by the individual patient in acquiring the needed drug supply and related services, as well as any interventions that may be required by the patient to sustain this individual behaviour. Looked at in this way, lack of access and failure to adhere may be more similar than different.

The concept of access should rather be viewed as involving two distinct components namely, elements of the treatment programme or system level components, and

individual level components as they relates to the actual use of the treatment programme by patients. Access, as it relates to the system level, is more commonly understood as “a function of policy decisions such as those about where to locate facilities or how to finance health care-making; that is, decisions about the supply of health care” (Gilson & Schneider, 2007: 28). It is in this context that Bangsberg et al. argue for the provision of a stable drug supply and distribution to improve access. Although this is necessary for an effective and efficient ART programme, it is of no value if ART patients cannot repeatedly access a regular ARV drug supply and related health care services.

For the purposes of this study, the term “sustained access” is used to refer to this behavioural component of access on the part of patients, and entails the continued adherence to any necessary medical care for ART to be successful. It involves adhering to related appointments with health care providers, be they to see the physician, for blood tests, or refilling medication prescriptions (Aloisi et al., 2002; Catz et al., 1999; Chesney et al., 2000b; Ferguson et al., 2002). Various researchers have pointed out that, although adhering to medical appointments may not be adequate to guarantee adherence to drug regimens (which is necessary for successful treatment outcomes), they argue that adherence to drug regimens is not possible without first attending medical appointments (Catz et al., 1999; McClure et al., 1999). Attendance of medical appointments is thus viewed in this study as an adherence-related behaviour, which is as fundamental to treatment success as adherence to ARV medications; a behaviour which needs to be consistent over a prolonged period of time.

Many similarities exist between adherence to ARV medications and adherence to ART-related appointments with health care providers. Just as non-adherence to ARV medications can result in poor clinical outcomes, poor adherence to scheduled medical visits can result in serious consequences for clinical outcomes. Numerous studies have shown that missing scheduled appointments with health care providers is significantly associated with increased viral replication, lowered CD4+ cell counts,

and an increased risk of AIDS-related morbidity and mortality (Catz et al., 1999; Lieb et al., 2002; Lucas et al., 1999; Park et al., 2007; Rastegar et al., 2003; Sethi et al., 2003; Wood et al., 2003). Clough et al. (1999) examined clinical and behavioural factors that were predictive of incomplete response to ART over a 20 week period. They found that missing more than 15% of appointments was predictive of an incomplete clinical response to ARV medications. This finding is of concern given the poor adherence to medical appointments discernable from the literature.

Rates of appointment non-adherence have been found to vary between 30% and 37% (Catz et al., 1999; McClure et al., 1999; Palacio et al., 1999). However, a more recent study shows even lower consistent attendance of medical appointments. A study in Korea by Park et al. (2007) followed 387 patients for a year after they had started HAART to assess adherence to clinic visits, where patients were expected to attend approximately five to seven appointments during their first year on treatment. They reported that 34% of patients had missed one or two appointments and a further 8% of patients had missed three or more appointments during the year after they started HAART. Examining clinic appointment adherence over a twelve-month period, McClure et al. (1999) report that as many as one in three clinic appointments were missed by patients.

Furthermore, studies have shown adherence to scheduled appointments to be significantly associated with medication adherence (Fong et al., 2003; Wagner et al., 2004). For example, Wagner et al. (2004) showed medication adherence among a sample of ART patients to be significantly lower when patients reported at least one missed clinic appointment over a three-month period. They found that the 59% of patients who attended all medical appointments had an ARV medication adherence rate of more than 90%. Nemes et al. (2004: S17) point out that a linear trend exists for both previous non-adherence to ARVs and missed appointments: "The higher the previous non-adherence, the higher the current non-adherence". Fong et al. (2003: 137) had similar findings and claim that "[m]issing clinic appointments may thus be used as a surrogate marker for suboptimal drug adherence".

All in all, if ART is to be successful, the question becomes one of how to keep patients adherent to their ARV medications, as well as adherent to scheduled medical appointments. Although the relationship between adherence to ARV medications and medical appointments, as well as the link between missed appointments and good clinical outcomes is clear, an understanding of the possible barriers and facilitators of sustained access to treatment are critical for effective treatment.



2.5 FACTORS AFFECTING SUSTAINED ACCESS TO TREATMENT

The purpose of this section is to give an overview of factors that have been reported to have an effect on patients' sustained access to ART, measured by non-adherence to ART-related appointments. Factors are outlined using the same categories used above to discuss non-adherence to ARVs namely, demographic characteristics, psychosocial/behavioural characteristics, clinical aspects, and health-care administration and delivery.

2.5.1 Demographic characteristics

The relationship between demographic characteristics and missed medical appointments, like adherence to ARVs, is highly inconsistent across studies. This section gives an overview of the various demographic factors associated with missing ART-related appointments among HIV/AIDS patients.

2.5.1.1 Sex

Early clinic attendance among HIV patients not yet on ART has shown significant differences between men and women, with men being less likely to return for appointments. McClure et al. (1999) reported that, of the 9% of HIV patients not returning for at least one appointment within the six months after their initial

appointment with a health care provider, 91% were male and 9% were female. Sex-disaggregated data on appointment adherence is very limited with respect to patients already on ART, and where available, no association between sex and appointment adherence has been found (Catz et al., 1999). With respect to refilling medication prescriptions, women, however, have been reported to be more likely than men to forget to refill their prescriptions (Ferguson et al., 2002). In addition, the frequencies of clinic assessments have been found to vary between men and women. Moore et al. (2002) followed 643 HIV-positive patients over 13 months after starting HAART, and reported that women had a greater frequency of clinic assessments than men.

2.5.1.2 Age

Younger age has been found to be predictive of appointment non-attendance (Aloisi et al., 2002; Catz et al., 1999), while older age, especially being older than 45 years, has been consistently associated with being more adherent to medical appointments (Lucas et al., 1999; Palacio et al., 1999). With respect to the association with younger age, Catz et al. (1999: 371) give possible explanations including “lack of previous medical contact or perceived invulnerability to death among young adults, or differences in lifestyle factors such as drug use or regularity of daily schedules”. Older age, on the other hand, “may be a marker for greater maturity, lifestyle stability, and disease-specific education; these factors are likely to profoundly affect long-term adherence to therapy” (Lucas et al., 1999: 85). In South Africa, Orrell et al. (2003) found that that older age showed a relationship with remaining on treatment, however, it is not clear whether older or younger age is predictive of adherence to ART-related appointments.

2.5.1.3 Race/Ethnicity

Although some studies have revealed no association between race/ethnicity and missed appointments (Giordano et al., 2003; Mellins et al., 2003), the rate of missed appointments among ART patients have been significantly associated with race/ethnicity in numerous other studies (Catz et al., 1999; Lucas et al., 1999). The association between race and appointment adherence seems to be confounded by a

multitude of patient dynamics. For example, Lucas et al. (1999: 85) report an association between increased age and adherence to clinic visits, however, this finding was more predominant among non-white patients. Furthermore, a strong correlation between non-white ethnicity and other behavioural risk factors (i.e. drug use) was also found. It is not clear whether race is predictive of appointment non-adherence in South Africa.

2.5.1.4 Education

The importance of education in relation to various aspects of treatment have repeatedly been highlighted. For example, education is viewed as critical for correcting misconceptions about ARVs (i.e., the idea that ART is a cure for HIV/AIDS), to ensure medication adherence, or for enabling patients to successfully care for themselves in their home setting (Attawell & Mundy, 2003; Mills & Sullivan, 1999). However, level education has not been found to be a significant predictor of appointment non-adherence among HIV-infected patients in numerous studies (Catz et al., 1999; McClure et al., 1999; Mellins et al., 2003; Sethi et al., 2003). Although such findings may be indicative of patients understanding the implications of appointment adherence for treatment success among the patients in these studies, educational level has not previously been assessed as a predictor of appointment non-adherence in South Africa.

2.5.1.5 Employment and income

Employment and income have not been significantly associated with missed medical appointments in several studies (McClure et al., 1999; Mellins et al., 2003; Sethi et al., 2003). A study in France, examining factors related to appointment attendance among HIV-infected women after childbirth by Lemly et al. (2007), found that employment status was not significantly related to appointment adherence in multivariate analysis. It is believed that this finding may be an effect of free access to HIV care. Since employment status was found to be significant in univariate analysis, they further argue that financial stability, afforded by employment, does not necessarily equate

with increased appointment adherence, adding that these women may find it difficult to take time from work to schedule and attend appointments.

2.5.2 Psychosocial/behavioural characteristics

Access to and retention in HIV/AIDS treatment programmes have been linked to several psychosocial factors including poor mental health, drug and alcohol use, and social support. The relevant associations between these factors and non-adherence to ART-related appointments are highlighted below.

2.5.2.1 Poor mental health

A study of treatment adherence among HIV-seropositive mothers found that the presence of a psychiatric disorder, including depression, panic, post-traumatic stress disorder, anxiety or psychosis, was predictive of non-adherence to medical appointments (Mellins et al., 2003). Although depression and anxiety were not reported to be significant predictors of appointment non-attendance by McClure et al. (1999), they did, however, report elevated levels among their sample of patients. These findings may represent the need to make psychological assessment and mental health services available to patients on treatment.

2.5.2.2 Drug and alcohol use

Numerous studies have found a relationship between substance use, including alcohol and various types of illicit drugs, and missed health care appointments (Clough et al., 1999; Giordano et al., 2003; Halkitis et al., 2003; Lucas et al., 1999; McClure et al., 1999; Mellins et al., 2003). Looking at current and former drug users on HAART, Sohler et al. (2007) found that patients using drugs, irrespective of the type of drug, had suboptimal use of health care services over the previous six months, which included missing at least one HIV-related health care appointment. Missed medical appointments by patients using drugs has been given as the reason for poor clinical outcomes such as increased viral load and decreased CD4+ cell counts (Clough et al., 1999; Lucas et al., 1999). Fortunately, Sohler et al. (2007) also show that patients who stopped using drugs did not differ significantly from non-drug users

with respect to health care service utilisation. However, it is not clear from the current literature whether patients who stop consuming alcohol, while on ART, have improved adherence to their health care appointments.

2.5.2.3 Social support

A consistent relationship between social support and non-attendance of ART-related appointments exists across studies. For example, Catz et al. (1999) found a significant relationship between lower perceived social support and non-attendance of appointments among a sample of HIV/AIDS patients in Louisiana. Instrumental support, such as transportation to medical appointments and assistance with home responsibilities have been highlighted as factors of social support that would permit patients to adhere to medical appointments (Catz et al., 1999; Palacio et al., 1999). Medical appointment adherence has also been associated with disclosure, with less disclosure being associated with poor appointment adherence (Mellins et al., 2003). This finding may indicate that without disclosure, and receiving assistance from a social network, appointment adherence may prove difficult for patients on ART.

2.5.3 Clinical aspects

Numerous clinical aspects have been reported in the literature on adherence to medical care and the association with patients missing appointments with their health care providers, including stage of disease, symptoms experienced, the frequency and timing of medical appointments, and treatment duration. The importance of identifying these factors has been highlighted by researchers. According to Palacio et al. (1999), for example, a missed visit equate with failed opportunities for health care providers to perform necessary clinical assessments, to identify early disease progression and/or viral resistance to medications, or to refill prescriptions. Furthermore, Park et al. (2007) argue that missed appointments represent missed opportunities for patients to have their AIDS-defining illnesses (e.g. opportunistic infections) treated prophylactically. An overview of the clinical aspects associated with appointment adherence is given below.

2.5.3.1 Symptoms and disease stage

Adherence to medical appointments appears to be closely related to disease status and the number of symptoms experienced by patients. A study by Palacio et al. (1999) showed how both these factors link to health care visits. They reported that, although a more advanced stage of disease where patients experience AIDS-defining illness, is on the one hand associated with a greater number of primary care visits, appointment adherence, on the other hand, declines with increased number of symptoms experienced. In this regard women may be less adherent than men, as it has been found that women experience a higher incidence of adverse reactions to ARVs (Lucas et al., 1999). However, it has also been found that symptoms decrease with time (Préau et al., 2004), and as CD4 cell counts increase and patient health improves, adherence to appointments declines (McClure et al., 1999). Thus, asymptomatic patients are less likely to adhere to medical appointments. For example, Catz et al. (1999) note that patients who experienced mild or no symptoms reported significantly less medical appointment attendance compared with patients who were more immune compromised. However, missed appointments and, to a larger extent, the number of days that elapse between a missed appointment and the next appointment, have been found to have a direct relationship with disease progression and the development of new AIDS-defining illness (Park et al., 2007).

2.5.3.2 Treatment duration

The literature is limited with respect to the relationship between length of time on treatment and adherence to medical appointments. Nonetheless, length of time on treatment has shown a negative relationship with appointment adherence. A recent study by Gardner (2007), which examined attendance at an HIV primary care provider in relation to time since testing HIV-positive, found that knowing one's status for six months or less has been found to be predictive of being in care after 12 months. This finding may suggest that monitoring of appointment adherence may be necessary among patients who have known their positive HIV status for longer. However, since adherence decreases with increased treatment duration Catz et al. (1999) argues that

findings such as these may be problematic for all HIV/AIDS patients, given the life-long treatment and adherence demands placed upon these patients.

2.5.4 Health-care administration and delivery

Certain aspects of health-care administration and delivery have been found to be of importance for retaining patients in care and adherence to medical appointments. According to Rastegar et al. (2003: 235), for example, “[h]ealth care providers play an important role in selecting optimum regimens, preparing patients for the demands of therapy, and helping them maintain the excellent adherence that is necessary for success”. This ongoing management of ART on the part of health care providers, along with effective service delivery, is crucial for the treatment success of patients.

2.5.4.1 Service delivery

Various service delivery aspects have been associated with poor sustained access to ART, including geographical location of facilities, provision of support services, and appointment waiting times. The geographic locations of health care facilities, especially less accessible locations, have been connected to poor ART access (Cook et al., 2002; Wood et al., 2003). However, for patients already on treatment, where distance implies travel costs, sustained access may become problematic. It is known that if the perceived benefits of treatment outweigh both travel costs and other perceived barriers in getting to a facility, patients may be more inclined to adhere to appointments (Palacio et al., 1999). Housing assistance for patients has also been noted as a particular support service which may assist adherence to treatment. A study by Messeri et al. (2002), exploring the impact of various support services on engagement with medical care among HIV-positive patients in New York, showed that housing assistance facilitated the retention of patients in appropriate HIV-related care. Another service delivery aspect impacting on appointment keeping relates to appointment waiting times. Palacio et al. (1999) reported that shorter waiting times were associated with an increased number of visits with health care providers.

2.5.4.2 Appointment scheduling and monitoring

The frequency and timing of medical appointment are made in accordance with clinical guidelines for the management of ART patients, however, the frequency of visits required of the patient to make at a health care facility, as well as timing of these visits, may be problematic. For example, Palacio et al. (1999) found an association between patients reporting no problems being experienced with appointment times, and an increased number of visits to health care providers. Problems with remembering scheduled appointments among patients on treatment were also associated with missed appointments (Palacio et al., 1999). Missing an appointment and having to reschedule, has been shown to be problematic with respect to the time between a missed appointment and the following appointment. Park et al. (2007: 271) report a significant relationship between the number of days elapsed between a missed appointment and a next appointment. As the number of days increase, so does the incidence of new AIDS-defining illness and death. This finding highlights the need for an effective appointment adherence monitoring system. Record-keeping, as a means of monitoring appointment attendance, combined with an effective method of reminding patients who have missed past appointments, may thus contribute considerably to appointment adherence among ART patients.

2.5.4.3 Patient-provider relationship

Various aspects of the patient-provider relationship have been examined in relation to ART, including patients' quality of life, treatment initiation, and adherence to medications, and treatment initiation (Altice et al., 2001; Murphy et al., 2000; Préau et al., 2004). Aspects relating to how the patient-provider relationship maintains or deters patient adherence to medical appointments have been linked to communication and medical visits with the same health care provider. Communication within the patient-provider relationship has been suggested to be a critical element in treatment adherence. This is evidenced in a study by Beach et al. (2006), who showed that where patients reported that their health care provider knew them "as a person", missed significantly fewer appointments. Beach et al. (2006: 665) add that, although a vague measure, further qualitative work on this concept of patient-centeredness

revealed a range of factors that may improve patient provider relationships, namely, “remembering a patient’s name, establishing good rapport, listening carefully, asking questions to learn about their lives and later remembering and following up on this information with patients”. Irregular physician consistency (regularly visiting the same physician) has been reported to predict medical appointment non-attendance (Catz et al., 1999), however, maintaining a usual source of care has been shown to be more difficult for men (Morales et al., 2004).



2.6 SUMMARY

The success of long-term ART calls for both sustained access to treatment and adherence to ARV medications among patients. Both are necessary for good clinical outcomes and patient survival. It is thus necessary to understand the various factors that impede patient adherence to ARVs and sustained access to ART. A sound understanding of the predictors of poor adherence, as well as the demographic groups most at risk, has important implications for clinical practice, health system management and service delivery. Without appropriate information the development of effective interventions aimed at improving adherence to ARV medications and adherence to health care appointments among susceptible patients, would be problematic.

There are stark similarities between these two aspects of adherence behaviour (adherence to ARV medications and adherence to health care appointments) across demographic, psychosocial and behavioural, clinical, and health-care administration and delivery categories. Firstly, the correlation between demographic characteristics, such as sex, age, and race/ethnicity are highly variable for both adherence to ARV medications and adherence to medical appointments. The same psychosocial or behavioural factors have been reported to impede both the adherence to ARVs and

ART-related appointments, especially with respect to depression and substance abuse. Clinical factors such as disease status and adverse drug reactions negatively affect adherence behaviour. Nevertheless, differences also exist. For instance, while clinical aspects seem to play a more dominant role in adherence to ARV medications, health system factors seem to be more central with respect to factors affecting sustained access to care.

While it may be evident that addressing the factors associated with medication non-adherence would simultaneously improve the likelihood of good sustained access to treatment, it should be noted that there are specific factors which work against one another. In other words, correcting certain factors to improve adherence to ARVs may negatively affect sustained access to care. For example, while expanded access to treatment may result in poor adherence to ARVs, as a result of health care providers and systems of delivery having to accommodate more patients, adherence to scheduled appointments may improve as facilities providing ART become geographically closer to patients.

The main predictors of non-adherence among ART patients in South Africa include younger age, the high dosing frequency of medications and language barriers between patients and health care providers. There is a lack of information in respect of ARV-medication adherence and factors such as race, level of education and long-term, stable housing in South Africa. Furthermore, it is not clear from the existing literature, whether a need for psychological assessment and provision of mental health services exist, or whether drug and alcohol use negatively affects medication adherence. Although the need for further research in this area of ART delivery is evident, even less information exists regarding predictors of appointment non-adherence in the South African context. It is thus difficult to assess whether ART patients can successfully sustain access to treatment.

Furthermore, the factors that are known to affect both medication adherence and adherence to health care appointments also differ significantly between male and

female patients. Although not consistent across studies, it has been reported that while women experience greater difficulties in adhering to ARV-medications than men, men have been found to experience more difficulties with keeping health care appointments. Such findings merit broader attention to the gender dimensions of adherence behaviour among patients on treatment.

CHAPTER 3 – A GENDER PERSPECTIVE FOR
EXPLORING AND EXPLAINING ADHERENCE AND
SUSTAINED ACCESS TO ANTIRETROVIRAL
TREATMENT

3.1 INTRODUCTION

South Africa is still firmly gripped by the HIV/AIDS epidemic. Compared with other southern African countries, South Africa is reported to have the highest prevalence of HIV-infected adults (Muula et al., 2007). Furthermore, AIDS-related deaths after 1996 have appeared to be behind the increase in South Africa's mortality rates (Dorrington et al., 2002; Groenewald et al., 2005). It has been estimated that by 2010 the impact of HIV/AIDS in South Africa will double the total burden of premature mortality (Bradshaw et al., 2003). Effective antiretroviral treatment (ART) is essential to increase patient survival and reduce AIDS-related mortality (Anastos et al., 2002; Coetzee et al., 2004; Cole et al., 2003). However, for ART to be effective, the factors associated with poor treatment outcomes need to be identified and addressed. According to Tolhurst et al. (2002: 139), efforts to address infectious disease mortality can be more effective when the social aspects of the disease are considered, of which "[g]ender is an often neglected but fundamental dimension of these social aspects".

Although gender is an important social aspect of health, "the doing of health" is also a "form of doing gender" (Saltonstall, 1993: 12), which is enacted across individual, organisational, and societal levels (Yoder & Kahn, 2003). It has been shown that men and women manage chronic illnesses, such as asthma and diabetes, in gendered ways (Williams, 2000). An examination of the gendered ways in which men and women manage HIV/AIDS and related treatment is of importance given the increasing feminization of the epidemic in Sub-Saharan Africa, as is reflected by the higher HIV prevalence and AIDS mortality among women (Muula et al., 2007; Shisana & Davids, 2004). Furthermore, in southern Africa more women are reported to be on ARV treatment than men (Muula et al., 2007). Although many studies over the past decade have explored the associations between gender and HIV/AIDS, especially with respect to how gender influences the risk and vulnerability of HIV infection and the implications

for successful prevention (Dunkle et al., 2004; Garg & Sharma, 2006; Giffin & Lowndes, 1999; Pulerwitz et al., 2002), far fewer studies have examined the role of gender in effective treatment, particularly with respect to the role of sustained access to and adherence to antiretroviral treatment.

The purpose of this chapter is to explore and explain how the social construction of gender influences the health-related behaviour and beliefs of HIV/AIDS-infected men and women on treatment. It is argued that taking gender into account – particularly in the context of treatment, care and support for HIV-infected patients – is crucial for effective health services with a view to successful treatment outcomes and ultimately patient survival. This chapter is divided into four parts. The first part focuses on the definitions and understandings of the concepts *sex* and *gender* from a social constructivist perspective, and indicates the way in which these concepts are related to the health, and health-related beliefs and behaviour of men and women. The second part explores why a gender perspective is both relevant to, and necessary for, the effective provision of medical treatment and related care and support services for AIDS patients. This is followed by an overview of how biological sex influences ART, and an exploration of how socially constructed masculinity and femininity influence the health-related behaviour and beliefs of men and women, especially with respect to access and adherence to treatment. Finally, the chapter is concluded with a summary of the implications of sex and gender in ensuring equitable treatment success for men and women.



3.2 SEX AND THE SOCIAL CONSTRUCTION OF GENDER

Since the 1960s, the social sciences have used the term *gender* to describe the social and cultural attributes associated with being male or female (Bird & Rieker, 1999; Risberg et al., 2006). More specifically, it refers to the roles, behaviours, expectations, perceptions, norms and responsibilities that a culture or society views as appropriate

to women and men (Largo-Janssen, 2007; Liguori & Lamas, 2003; Tolhurst et al., 2002). From a social constructivist perspective, Barrett (2001: 78) describes *gender* as “a social organizing principle, a human intervention like language, that organizes life in a culturally patterned way”. The term *gender* differs from the term *sex*, which refers to the biological or inherent sex differences between men and women.

From the same perspective, Lorber (1994) contends that although individuals are borne ‘sexed’ (i.e. male or female), individuals acquire their gender by being taught to be ‘masculine’ or ‘feminine’. Lorber further asserts that gender construction begins with the assignment to a sex category, using biological sex at birth, as the foundation of gender assignment. Through various gender markers, such as one’s name or the way one is dressed, the sex category develops into a gender status, and it is further reinforced through social interaction and the differential treatment of those belonging to one gender or the other. This reinforcement of gender intensifies with age and varies over the life cycle (Arber & Cooper, 1999; Galambos & Almeida, 1990; Macintyre et al., 1996; Risberg et al., 2006). For example, the findings from a study by Galambos & Almeida (1990) on gender intensification among adolescents show that behavioural, attitudinal, and psychological differences increase with age, as a result of the socialisation process which pressures boys and girls to conform to traditional masculine and feminine roles.

With this reinforcement of gender over time, also comes an emphasis on varied health-related beliefs and behaviour for men and women. Summing up the tenets of social constructivism in the context of disease, Petersen et al. (2001: 216) state that “[t]he illness, what the patient is doing about it, and how it is experienced is a product of the patient’s constructions, and these constructions have been derived in large part from the sociocultural context”. It is thus important to recognise that the health-related beliefs and behaviours expected of men and women will vary according to the context in which they are enacted. In this respect, gender, in combination with other determinants such as social class, ethnicity and disability, all act together to influence an individual’s health (Liguori & Lamas, 2003; Tolhurst et al., 2002). Furthermore, the

enactment of health-related beliefs and behaviours is a form of demonstrating one's gender (Courtenay, 2000; Saltonstall, 1993).

The sociology of health and illness has long criticised western medicine for failing to place the body of the individual within its socio-environmental context, and thus repeatedly argues that health and disease are socially patterned and will in consequence vary according to gender (Nettleton, 2006). As one of many social dimensions, "gender ideology prescribes and circumscribes the social behaviour of men and women" so that what is considered "appropriate or supposedly "natural" behaviour for women and men impact on their health and well-being" (Arber & Thomas, 2001: 94). It is, therefore, expected that men and women will react to disease and deal with illness and disease differently; 'disease' referring to "pathological changes in the body" that physicians typically diagnose and treat, and 'illness' referring to "the experience of disease, including the feelings relating to changes in bodily states and the consequences of having to bear that ailment" (Radley, 1994: 3). Men and women will deal with HIV/AIDS and related treatment in accordance with their biological sex and how their gender is socially constructed as is demonstrated in the text below.



3.3 WHY THE NEED FOR A GENDER PERSPECTIVE?

Sex and gender act together to influence men's and women's health and health-related behaviour in different ways. Epidemiological and biomedical research has repeatedly drawn attention to the role of biological sex in influencing vulnerability to infection. For example, women are at increased risk of contracting HIV, compared with men, due to physiological factors which result in the more efficient transmission of the virus from men to women, than from women to men (Garg & Sharma, 2006; Tolhurst et al., 2002). According to Liguori & Lamas (2003: 87), "[g]ender constructions do not

deny the existence of biological differences between the sexes, but go beyond them to emphasize that these differences as such do not justify the imbalance of power and social inequality between men and women". Since sex and gender act together, consideration of the complex links between gender and sex in the context of HIV/AIDS-related treatment is equally important.

The society we live in exposes us to, and reinforces a multitude of images and ideas about appropriate and desirable norms, roles, behaviours and practices for men and women. Yet, it is the endorsement of these very characteristics that produce gender inequalities between men and women (Tiessen, 2005). Tolhurst et al. (2002: 136) maintain that it is the varied "social and economic behaviour, roles, expectations and responsibilities" of men and women that underlie the "social, economic and political inequalities" that exist between men and women. This is particularly evident among women for whom the "almost universally unequal access to social and economic resources", often results in "powerlessness, greater poverty and inequality, and their consequences (e.g. sexual violence, resorting to sex work for income, and so on)" (Dowsett, 2003: 22).

Similarly, the socially constructed masculine and feminine characteristics that form gender identity and establish gender roles, and which simultaneously bring about inequalities between men and women, have also been associated with health inequalities (Bird & Rieker, 1999; Cecile et al., 1996). According to Cecile and colleagues (1996: 707), "[a] major barrier for women to the achievement of the highest attainable standard of health is inequality, both between men and women and among women in different geographical regions, social classes and indigenous and ethnic groups". Thus, in contrast to biological sex, gender inequalities make women more vulnerable to infection as a result of their inferior status and socio-economic power relative to that of men (Amaro et al., 2001; Tolhurst et al., 2002). Bird & Rieker (1999) claim that the inequities in women and men's health cannot be addressed appropriately if sex and gender differences – including the interaction between the two – are not understood.

Such a perspective was lacking early in the HIV/AIDS epidemic. In the past, the gender dimensions of infectious disease were not only under-researched, but also overlooked in disease management approaches, resulting in a lack of evidence on the link between biological differences or gender inequality and infectious diseases (Tolhurst et al., 2002). For example, during the 1980's AIDS was exclusively addressed as a man's disease and, as a result, women were initially not diagnosed, or were misdiagnosed, which led to delayed treatment or treatment not being provided at all (Amaro et al., 2001). Similarly, women's exclusion from early HIV/AIDS clinical trials resulted in little being known about the manifestations of HIV, disease progression, drug efficacy and adverse effects in women (Amaro et al., 2001; Ofotokun & Pomeroy, 2003). These consequences are reflective of how not applying a gender perspective in research and disease management can contribute to gender inequity in health care.

Fortunately, the role of sex and gender has been acknowledged in more recent studies concerned with HIV/AIDS. More specifically, the role of sex and gender is increasingly being researched and highlighted in women's studies, including the different AIDS-related symptoms and infections experienced by men and women, health-related risks and vulnerabilities to infection and how they relate to prevention efforts, the provision of quality health care services, access to and use of health services, and how women are disproportionately affected by the disease (Amaro et al., 2001; Bird & Rieker, 1999; Garg & Sharma, 2006; Tolhurst et al., 2002). However, until recently men's health care concerns and perspectives were also lacking in health research (Cameron & Bernardes, 1998; Courtenay, 2003; Doyal, 2001; Kaplan & Marks, 1995; Largo-Janssen, 2007; Schofield et al., 2000). This new focus on masculinities and men's health, however, threatens to bring about competition between both women's health and men's health perspectives, for already scarce resources (Doyal, 2001).

In South Africa, resources are increasingly being allocated for the expansion of ART into resource-limited settings, and this is being done with insufficient knowledge of how treatment services should best be delivered (Lawn et al., 2005). If limited health

resources are to be distributed equitably, a gender perspective that considers how sex and gender influence the health and health-related beliefs and behaviour of men and women is necessary. The lack of a gender perspective puts appropriate delivery of AIDS-related treatment, care and support services at risk of not meeting the health needs and priorities of men and women, and that may potentially result in inequitable treatment outcomes between men and women. Thus, it is of importance to adopt a gender perspective that acknowledges the role of both sex and gender when examining HIV/AIDS treatment.

The next section provides an overview of how biological sex and social gender affect men's and women's health with respect to AIDS-related treatment. More specifically, it outlines how sex and various gender inequalities may influence successful treatment outcomes by hindering adherence and sustained access to treatment.



3.4 BIOLOGICAL SEX AND SOCIAL GENDER: IMPLICATIONS FOR SUCCESSFUL TREATMENT

Bird & Rieker (1999: 745) maintain that “[a]lthough biological factors such as genetics, prenatal hormone exposure and natural hormonal exposure in adults may contribute to differences in men's and women's health, a wide range of social processes can also create, maintain or exacerbate underlying biological health differences”. They also add that the nature of the disadvantage and its related health consequences will dictate suitable interventions as being either biological or social and either individual or societal. Thus, in order for health services to be both equitable and efficient, sex and gender concerns need to be integrated into research, policy, and practice (Doyal, 2001).

Drawing on current research on men's and women's health-related behaviour, and their experiences of HIV/AIDS-related health care and its impact on their lives, this

section provides an overview of how biological sex and social constructions of gender influence the health of patients on ARV treatment, with specific reference to access and adherence to treatment. For the examination of masculinity and femininity, a framework developed by Tolhurst et al. (2002) that was used for the analysis of gender inequalities in infectious disease in developing countries is used. The framework is adapted to look separately at masculinity and femininity, and is focused on gender inequalities in treatment, rather than vulnerability or general health-seeking behaviour. In this respect, the varied resources that an individual has access to and control over, an individual's decision-making power, the gender norms held by society, and gender roles that men and women are expected to adhere to, are discussed.

3.4.1 Biological sex

It is widely accepted that accounts of differences found between men and women in health outcomes require one to examine not only gender-related factors, but also those relating to biological sex (Payne, 2004). However, it is important first to note that the adoption of the term 'gender difference' has frequently been misapplied in the description of differences observed between men and women's health. According to Bird & Rieker (1999: 752), the adoption of the term 'gender difference' by medical researchers "has frequently been misapplied to describe purely biological differences in sex organs, sex-specific diseases and even male-female differences in animal studies where the biological basis of such differences should be clear". With respect to the biological differences and ARV treatment, the misapplication remains common practice among researchers, particularly in relation to the clinical progression of HIV/AIDS and cellular level differences such as adipose tissue alterations (Anastos et al., 2000; Galli et al., 2003; Prins et al., 1999; Moore et al., 2002; Nicastri et al., 2005; Tollerud et al., 1989).

To be clear about which biological factors affect men's and women's health in relation to ART, this section examines reproductive systems, disease progression and adverse reactions to ART as sex-specific issues that may be responsible for the differences in treatment outcomes between men and women.

3.4.1.1 Reproductive systems

As pointed out by Doyal (2001: 1061), the “differences between male and female reproductive systems have always been an important consideration in healthcare delivery”. In this respect, and in relation to ART, much attention has been drawn to the vertical transmission of the virus from mother to child. Antiretroviral therapy has been successful in drastically reducing the risk of mother-to-child transmission (Dorenbaum et al., 2002; Fiscus et al., 1999). In view of this, attention has been drawn to the reality that women may want to become pregnant or continue their pregnancy despite HIV-infection (Saada et al., 2000). Many studies have examined the implications of pregnancy for treatment, as well as the effect of treatment on pregnancy, including disease progression in the mother, causes of AIDS-related death among pregnant women, changes in the pharmacokinetics of antiretroviral agents and appropriate ARV doses, and regarding the continuation or cessation of ART postpartum (Ahmad et al., 2001; Rodman, 2001; Saada et al., 2000; Tedaldi et al., 2002; Vimercati et al., 2000).

Although there have been many studies examining the effects of administering ARVs to HIV-infected pregnant women, these studies have largely neglected to examine the potential risks and benefits to ARV-experienced HIV-infected mothers. For multiple reasons, the findings of the aforementioned studies cannot be generalised to ARV-experienced HIV-infected pregnant women. For example, the studies above make use of samples that consist solely of treatment-naïve HIV-infected mothers, who have not yet progressed to AIDS or yet required the use of ARVs before pregnancy (Ahmad et al., 2001). Also, HIV-infected pregnant women are compared with non-pregnant HIV-infected women (Saada et al., 2000; Vimercati et al., 2000), neglecting ARV-experienced HIV-infected pregnant women, and HIV-negative pregnant women, as valid groups for comparison. Furthermore, where access to clinical data is reported, including use of ART prior to pregnancy, data are not used in statistical analysis (Saada et al., 2000; Tedaldi et al., 2002). It is thus not clear whether pregnancy has an influence on, for example, perinatal transmission prevention rates, disease progression, and adverse effects among women who have fallen pregnant while

already on ART. Furthermore, it is not known whether specific health and obstetric care is needed, or whether treatment guidelines regarding pregnancy require alteration for ARV-experienced HIV-infected pregnant women.

In this respect, the balancing of preventing perinatal transmission with the therapeutic needs of the mother (Rodman, 2001; Tedaldi et al., 2002) may require some revision. The need for research concerning the risks and benefits of ART during pregnancy for ARV-experienced women is especially important in the South African context. Firstly, although national and provincial treatment guidelines (FSDoH, 2004a; DoH, 2004) outline specific treatment instructions for women who fall pregnant while on ART and call for the monitoring of medication adherence and adverse reactions during antenatal and postpartum care, common adverse reactions that health care providers ought to be looking out for are not explicitly listed. Secondly, the high prevalence of women of child-bearing age on ART (Muula et al., 2007), coupled with socio-cultural factors, such as women's social status being dependent on the number of children born and women's inability to determine the number and timing of children (Kimani, 2008), merits the necessity of further research.

3.4.1.2 Disease progression

Viral load and CD4 cell counts are usually employed as clinical markers of disease stage in studies examining the progression of HIV to AIDS, and from AIDS to AIDS-related death (Anastos et al., 2002; Moore et al., 2002; Prins et al., 1999). Although some studies have reported no difference in disease progression to AIDS or death between men and women (Junghans et al., 1999; Moore et al., 2002; Moore et al., 2003; Murri et al., 2003; Nicastrì et al., 2005), other studies, however, have found significant differences in both virologic and immunological responses between men and women at various stages of infection. Differences have even been reported between HIV-negative men and women, with women exhibiting higher CD4 cell counts than men (Maini et al., 1996; Tollerud et al., 1989). Thus, it would seem that women have a pre-infection immunological advantage over men. However after HIV-infection conflicting data have continuously been reported.

Before the onset of AIDS and initiation of ART, HIV-infected women have been reported to have higher CD4 cell counts than HIV-infected men (Box et al., 2003; Moore et al., 2002; Prins et al., 1999), which suggests a clinical benefit for women. Although some studies have reported no difference in CD4 cell counts at initiation of treatment (Furler et al., 2006), other studies have reported lower CD4 counts in women at treatment initiation, as well as during the initial phases of treatment – which when compared with men – is suggestive of an immunologic disadvantage (Collazos et al., 2007; Moore et al., 2002). At death, however, women have been reported to have higher, although not significant CD4 cell counts (Moore et al., 2003). There is evidence that disease progression in women on ARVs may be influenced by CD4 cell count at treatment initiation. A cohort study, by Anastos et al. (2002) of HIV-infected women starting treatment at different stages of disease, shows that women had significantly more rapid progression when they initiated treatment with a CD4 cell count of less than 200/ μ L. It is not clear whether men who initiate treatment at a CD4 cell count of less than 200/ μ L have similar rates of progression.

Regarding viral load levels, several studies have reported differences in levels between men and women with comparable CD4 cell counts, with lower viral loads in women being reported at seroconversion and during the early stages of HIV infection (Anastos et al., 2000; Farzadegan et al., 1998; Sterling et al., 1999). Furthermore, this difference in viral load levels between men and women is maintained for several years after seroconversion (Sterling et al., 1999). The degree of difference in viral load between men and women has been reported to be approximately 50% lower among women (Anastos et al., 2000; Farzadegan et al., 1998). Despite women having lower viral load levels than men, both men and women have been shown to progress to AIDS at a similar rate, however, the onset of AIDS, again, occurs in women at lower viral load levels than in men (Farzadegan et al., 1998; Napravnik et al., 2002; Sterling et al., 2001). The difference in viral loads persists into the initial months after treatment commencement (Collazos et al., 2007). The lower reported viral load levels among women are suggestive of delayed treatment initiation, and consequently, the need for

considering lower viral load thresholds for treatment initiation in women (Napravnik et al., 2002; Prins et al., 1999).

The need for further investigation into the differences in clinical markers between men and women, and the implications for disease progression have repeatedly been called for, especially with regard to patient management and whether or not the eligibility criteria for the initiation of treatment requires adjustment for sex (Anastos et al., 2000; Moore et al., 2002; Murri et al., 2003; Pinn, 2003; Prins et al., 1999; Sterling et al., 2001). For men and women to benefit equally from treatment, conclusive findings are required concerning how much the viral load threshold levels should be lowered for treatment initiation (Napravnik et al., 2002). Current guidelines for ARV treatment initiation in South Africa's public health sector require a patient to have a CD4 cell count of less than 200 cells/mm² or WHO Stage IV disease (FSDoH, 2004a; DoH, 2004), while no viral load threshold is explicitly mentioned. Besides the implications for treatment initiation, clinical marker differences between men and women also have implications for adherence studies. For instance, studies which make use of adherence measures that are validated based on viral load levels without sex-disaggregating data (Bangsberg et al., 2000), may possibly result in sex-biased adherence measures. Furthermore, it is possible that the necessary medication adherence level of 95% for treatment to be effective may also require sex-disaggregated reevaluation (Paterson et al., 2000).

3.4.1.3 Adverse drug reactions

Disparities between men and women in the incidence, presentation and severity of adverse drug reactions have increasingly been reported. Different classes of ARV drugs have been shown to exhibit different types of adverse reactions. For example, the first antiretroviral drugs to be used in clinical practice – nucleoside reverse transcriptase inhibitors (NRTIs) – have been associated with myelosuppression, pancreatitis, gastrointestinal intolerance, peripheral neuropathy, myopathy, and lactic acidosis (Clark, 2005; Ofotokun & Pomeroy, 2003). Compared with men, studies have shown that women are at higher risk for the development of adverse reactions to

NRTIs. For example, women have been reported to be at an increased risk of lactic acidosis, an often fatal adverse reaction, which in South Africa has a risk ratio of 1:50 women compared with 1:642 men (Arenas-Pinto et al., 2003; Bolhaar & Karstaedt, 2007).

Similarly, women have been found to experience a higher incidence of adverse reactions to non-nucleoside reverse transcriptase inhibitors (NNRTIs) and protease inhibitors (PIs) (Clark, 2005; Lucas et al., 1999; Ofotokun & Pomeroy, 2003). Common NNRTIs reactions include rash and hepatitis, while adverse reactions to PIs include gastrointestinal intolerance (nausea, vomiting, diarrhea, or cramping), abnormal fat distribution, and metabolic disorders (Ammassari et al., 2001; Clark, 2005; Hawkins, 2006; Lucas et al., 1999; Ofotokun & Pomeroy, 2003). These adverse reactions may have implications for medication adherence. For example, Mannheimer et al. (2002) reported lower levels of adherence for patients on PI-containing regimens than for patients on regimens containing an NNRTI.

Although conclusions about the mechanisms resulting in sex differences are largely inconclusive, differences in hormones, weight, metabolic influences, pharmacokinetic parameters, and immunological interactions have been given as possible factors attributing to differences in the adverse events in men and women (Clark, 2005; Doyal, 2001; Lucas et al., 1999; Murri et al., 2003; Ofotokun & Pomeroy, 2003). Since adverse reactions have been associated with non-adherence to ARV medications (Ammassari et al. 2001; Berg et al., 2004), further investigation into the sex-related differences in adverse reactions to treatment and the influence on successful treatment outcomes is required. However, the findings of the aforementioned studies may be subject to gender-bias, particularly where self-reported measures of medication side-effects were employed to assess adherence (Ammassari et al., 2001; Berg et al., 2004). There is evidence of gender differences in general symptom reporting, with women reporting more symptoms than men (Kroenke & Spitzer, 1998). This serves as an additional example of why it is important to consider how gender

differences shape the health and health-related behaviour and beliefs of men and women on treatment, alongside biological factors.

3.4.2 Masculinity: The 'want-to-be' hegemonic man

It has been repeatedly argued that the social constructions of masculinity can be both health promoting and health limiting for men (Annandale & Hunt, 1990; Courtenay, 2000; Schofield et al., 2000; Seymour-Smith et al., 2002; Williams, 2000). However, it is important to note that men do not constitute a homogenous group. Rather, society constructs multiple masculinities, as first articulated by gender theorist Robert Connell (1987). These multiple masculinities are constructed in a relational and hierarchical manner, with the hegemonic form being the dominant construction (Connell & Messerschmidt, 2005; Pyke & Johnson, 2003). As described by Courtenay (2000: 1388), hegemonic masculinity is “the socially dominant gender construction that subordinates femininities as well as other forms of masculinity, and reflects and shapes men’s social relationships with women and other men; it represents power and authority”. This dominant form of masculinity is characterised by relations of domination, which are actively demonstrated through competition, fearlessness, aggression, physical strength, self-reliance, heterosexism, homophobia, and misogyny (Alt, 2001; Gray et al, 2002). The enactment of these attributes represents the various discourses through which hegemonic masculinity may be reproduced, and in continually doing so, making men’s behaviour appear normative, normal, expected, and acceptable (Connell & Messerschmidt, 2005; Stibbe, 2004).

Not all men possess the traits associated with hegemonic masculinity (Connell & Messerschmidt, 2005; Pyke & Johnson, 2003) However, it is the pursuit of the power and privilege associated with this particular form of masculinity which place men’s health at risk (Alt, 2001; Cameron & Bernardes, 1998; Courtenay, 2000; Stibbe, 2004). For the most part, this is because health is viewed as being synonymous with the representation of ‘the perfect man’, with illness implying weakness and loss of bodily control (Gray et al, 2002; Moynihan, 1998). Illness is thus a threat to the enactment of a hegemonic representation of masculinity, and the power and privilege

that it exemplifies, and as a result, men have to renegotiate their social beliefs and behaviours in order to reap the advantages of the health services and available treatments (Courtenay, 2000; Doyal, 2001; Gray et al., 2002).

The following section focuses on the social construction of this dominant form of masculinity and its influence on the health and health-related behaviour and beliefs of men in the context of AIDS and related treatment and care. It does so by looking specifically at access to and control over health-related resources, power to make decisions concerning health matters, and the influence of gender roles and norms.

3.4.2.1 Access to and control over resources

Men have privileged access to a wide variety of valuable resources, which would seemingly be health promoting (Doyal, 2001). However, access to and control over resources such as health-related information and social support have received considerable attention in the literature as potential barriers to men's health. The implications of these two barriers for the health-related behaviour of men and the associations with treatment adherence are outlined below.

- Knowledge and information-seeking behaviour

Having access to reliable information can be viewed a valuable resource for the promotion of health among men. According to McCaughan & McKenna (2007: 2), “[i]nformation is a key tool in their attempt to make sense of their problems and in developing appropriate strategies and responses to minimize discomfort and promote well-being”. Unfortunately, it has been shown that men are less knowledgeable than women concerning their bodies, general health and disease (Cameron & Bernades, 1998; Courtenay, 2003; O’Brian et al., 2005). Men are also less inclined than women to actively seek out or access information relating to their health (McCaughan & McKenna, 2007). The fear of appearing feminine to their peers has been reported as a reason for not actively seeking out information concerning their bodies (O’Brian et al., 2005). Instead of utilising recognised sources of information, such as health care providers or support groups, men seem to rely on partners, relatives and friends to be

their primary information resource (McCaughan & McKenna, 2007). However, this resource may be limited for a number of reasons. Firstly, it is not available to all men, for example, men who live alone (McCaughan & McKenna, 2007), and low levels of literacy among women can also limit men's access to information (Baghdadi, 2005). For those men who do have access to this resource, there is a concern that the information they receive may only be what women consider relevant, thus leaving men with unmet informational needs (McCaughan & McKenna, 2007). A South African study assessing HIV-positive patients' knowledge regarding ART reported no significant gender differences, however, the need for the reinforcement of educational messages around the implications of non-adherence for disease progression and drug resistance was highlighted (Nachega et al., 2005).

- Social support networks

Men have fewer social networks, such as friends and relatives, to draw on for psychosocial support in comparison with women (Arber, 2004; Bird & Rieker, 1999; Courtenay, 2003). Regarding health matters, men tend to rely on their partners or wives for social support, while rejecting the idea of making use of support groups or services (Cameron & Bernades, 1998; McCaughan & McKenna, 2007). Studies on marital status and health have consistently shown that marriage provides married men with social support, especially emotional support, which contributes to their better health in comparison with unmarried, never married, widowed or divorced men (Arber, 2004; Petersen et al., 2001; Ross et al., 1990; Waldron et al., 1996). Married men are often discouraged by their wives from drug use, smoking and drinking (thus reducing risky health behaviours), and are encouraged to eat healthier diets (Ross et al., 1990). According to O'Brian et al. (2005: 504), "women are said to encourage awareness of health issues, to assist men in interpreting symptoms, and to play a key role in persuading men to seek help". Being unmarried and not living with a partner have been significantly associated with AIDS-related mortality (Lieb et al., 2002). Although not disaggregated by sex, research has consistently shown a positive association between social support and adherence to both medications and appointments (Catz et al., 1999; Gifford et al., 2000; Safren et al., 2001). Thus, the presence of a partner or

spouse should be viewed as an important measure of social support for HIV/AIDS-infected men on treatment.

3.4.2.2 Decision-making power

Men are more able to make decisions concerning their ill-health than women. For instance, accessing health services when ill may be easier for men in situations where families allocate pooled income and resources to men and boys within households before women and girls (Garg & Sharma, 2006). Furthermore, men also have more power to make health-related decisions than women given that they are less likely to have to gain consent from household members, and given the increased financial, energy and time resources at their disposal (Backhans et al., 2007; Baghdadi, 2005; Bird & Rieker, 1999). Nonetheless, there is evidence that men's power to make decisions concerning their health also has the potential to undermine their health. Men's health behaviour is influenced by the reinforcement of cultural beliefs that men are less vulnerable, that men's bodies exemplify structural efficiency and superiority, as well as emotional and physical control (Courtenay, 2000). When illness offsets the enactment of these hegemonic ideals, men's decision-making power affords them the ability to take action or to modify action in a desired direction (Wingood & DiClemente, 2000). It is in this respect that men's decision-making abilities may limit their health.

Decisions made by men as a consequence of the fear of stigmatization and lack of confidentiality are discussed below, as examples of how men's decision-making can have negative consequences for their health.

- Fear of stigmatization

HIV/AIDS-related stigma is of concern for all HIV-diagnosed patients irrespective of age, innocence, morality, gender or race (Carr & Gramling 2004). However, there is evidence that the fear of being stigmatized is motivated by the differing social norms about sexuality for men and women, which results in differing health-related behaviour. For example, Muula et al. (2007), in discussing the beliefs around HIV infection and stigma in sub-Saharan Africa, point out how women may be less stigmatized in an

environment where infection is perceived to have been acquired from a spouse, thus allowing women to be forthright in accessing care, while men in the same environment may fear being perceived as having contracted the infection outside of marriage, thus resulting in delayed care. According to Ware et al. (2006), stigma results in competing priorities (i.e. social versus health interests), where treatment adherence takes second place if effective means of avoiding stigma are not possible. They add that non-adherence can be avoided if less stigmatizing options are available to patients, which includes the ability to misrepresent the explanations for medications and/or doctor's visits, and/or disguising medications as something else.

- Confidentiality

Where fear of stigma is high, patients' concerns about confidentiality are also heightened (Ickovics & Meisler, 1997); and, where maintaining social norms of masculinity conflict with the receipt of and adherence to care or treatment, men may make health-related decisions that allow them the opportunity to maintain their masculinity, despite the negative consequences to their health. For instance, in relation to emotional well-being, men may decide to keep silent instead of addressing their health needs (Largo-Janssen, 2007; Seymour-Smith et al., 2002), or they may decide to address the need through the use of alcohol and drugs as a coping strategy (Williams, 2003). Despite the choice made, it is evident that men are more inclined to decide on the option that does not allow any perceived 'masculine weakness' to be publicly disclosed. In this regard, a South African study by Rowe et al. (2005) highlights how the clinic environment can positively influence adherence to tuberculosis preventive therapy (TBPT), namely by the tuberculosis treatment section being private and separate from the general clinic. Thus, confidentiality could possibly be an important factor in allowing men to redefine their masculine identities in accordance with the 'sick-role' which HIV/AIDS and ARV treatment compels men to engage in, while simultaneously allowing men to address their health-related needs. Confidentiality, thus, represents an aspect of treatment delivery which would allow for men to adhere to treatment without compromising their masculinity.

3.4.2.3 Gender roles and activities

Men are socialised to be successful at paid employment and to be good providers for their families, an economic role which is known to have possible negative consequences for men's health (Tolhurst et al., 2002; Williams, 2003). Unfortunately, as pointed out by Mathews & Power (2002: 799), a gender divide seems to exist in health studies, "such that work factors are considered for men and home factors for women". The influence of additional roles, such as men's role in caring for children and the sick, or in domestic tasks, although highlighted in some studies (Ndinda et al. 2007; Sunderland, 2000), has nevertheless been largely neglected with respect to implications for accessing health care and treatment adherence.

The following section outlines implications of the work role for treatment adherence, as well as how this role may shape the way in which men deal with being ill and manage treatment.

- Economic survival and work experiences

Norms emphasizing achievement and competence compel men to ensure economic survival, for themselves as well as their families, through employment (Williams, 2003). However, as stated by Mahalik et al. (2007: 2202): "The man who constructs masculinity as putting work ahead of all other responsibilities may not make time for self-care". In this regard, employment has been shown to have implications for treatment adherence, especially as a result of various necessary treatment aspects (i.e. taking medications, refilling prescriptions and attending medical appointments) that interfere with men's ability to carry out their work-related responsibilities. For example, access to health care may be limited for working men where health care services are unavailable during non-working hours (Courtenay, 2003). Similarly, gaining permission for sick leave from work has been reported as the most frequent reason for missing clinic appointments (Siika et al., 2005). The non-adherence behaviour may result from concerns about the impact of disclosing AIDS-related treatment needs on employment security and career prospects. However, the long-term consequences of this behaviour may have fatal health consequences, as well as

negative economic consequences for the households which these men financially support. The long-term consequence of such behaviour for treatment adherence requires assessment. With respect to ARV adherence, Ammassari et al. (2001) reported unemployment to be significantly associated with non-adherence among a sample of respondents comprising 72% men. Unemployment, more than employment, may be an especially relevant factor contributing to non-adherence in South Africa given the high unemployment rates (Kingdon & Knight, 2004).

- Dealing with illness

There is evidence, especially from studies on prostate cancer, that work experiences may actively shape men's approach to illness and treatment. McCaughan & McKenna (2007), for example, revealed that work was viewed as a means for men to address their need for normalcy (i.e. 'to get on with life'), as apposed to constantly dwelling on their illness. Examining the narratives of men with prostate cancer, Gray et al. (2002), note that hegemonic men may renegotiate the enactment of their masculinity by adopting a proactive 'work' approach to illness, through the use of workplace language, and notions of purchasing services, managing problems, dealing with and delegating tasks to workers, strategizing and comparative shopping. It is not clear whether HIV/AIDS-infected men would adopt a similar approach to dealing with treatment, and whether the inability to adopt such an approach would influence adherence behaviour negatively.

3.4.2.4 Gender norms and identities

Men are socialised from a young age to endorse gender norms and identities that embody physical and emotional strength, fearlessness or risk-taking, and self-reliance, (Alt, 2001; Courtenay, 2000; Stibbe, 2004). Thus, men are socialised to avoid or deny demonstrations of weakness, such as emotion or paying attention to pain. In addition, there is social pressure on men to avoid or reject health-related behaviour which is socially constructed as feminine (Courtenay, 2000; O'Brian et al., 2005), such as eating more vegetables and less red meat, or cooking ("in its unpaid domestic variety") instead of purchasing convenience foods (Stibbe, 2004). According to Williams (2003),

the adoption of these beliefs about masculinity direct men to take one of two types of action with regard to their personal health practices, namely (1) to avoid or dismiss health-protective behaviours, or (2) to harm themselves through the engagement of risky or health-compromising behaviours. Thus, it is through the dismissal or downplaying of their health care needs and the adoption of risky behaviours that men are, in effect, constructing health-related gender norms and identities (Cameron & Bernardes, 1998; Courtenay, 2000). Although such behaviours do not promote health, behaviour change comes at a cost. According to Courtenay (2000: 1389): “To carry out any one positive health behaviour, a man may need to reject multiple constructions of masculinity”.

The next section seeks to give an overview of how the adoption of any of the two aforementioned behaviours has negative implications for ARV treatment access and adherence among male patients who adopt dominant or traditional norms of masculinity.

- Dismissing health care needs

Studies have highlighted particular health-related behaviours in which men are dismissive of health care needs, including the rejection or avoidance of health care, lower engagement in health care services, delaying treatment, refusal to take sick leave from work, non-disclosure of mental and emotional needs, and ignoring or under-reporting of symptoms or pain (Alt, 2001; Cameron & Bernardes, 1998; Courtenay, 2000; O'Brien et al., 2005; Schofield et al., 2000). According to Courtenay (2000: 1390), “[t]he avoidance of health care is another form of social action that allows some men to maintain their status and to avoid being relegated to a subordinated position in relation to physicians and health professionals, as well as other men”. However, there is evidence that once men have sought out care or treatment, and thus link themselves to the health care system, men are more likely than women to monitor meticulously disease symptoms, treatments, bodily function and diet (Cameron & Bernardes, 1998; O'Brien et al., 2005), as well as have discussions with their health care providers concerning advance directives (Box et al.,

2003). This change in perspective – toward health-promoting or health-protective behaviours – thus represents a reconstruction of masculinity to fit the patient’s health context. However, there is evidence that this change may have a temporary nature, for example, patients not taking medications as prescribed because they feel healthy (Murphy et al., 2000), thus resulting in non-adherence.

- Risky behaviour: smoking, drinking and drugs

Risk-taking behaviour, such as smoking, drinking excessively and the use of drugs, which is more prominent among men, have repeatedly been reported as behaviour that undermines men’s health (Cameron & Bernardes, 1998; Courtenay, 2003; Doyal, 2001; Stibbe, 2004). Demonstrations of masculinity through the adoption of such behaviour may have potentially fatal consequences for men on ARV treatment, especially since the use of these substances are known to be associated with poor immunologic and virologic outcomes (Haubrich et al., 1999; Kerr et al., 2004), result in decreased effectiveness of ARV therapy (Haubrich et al., 1999), and may contribute to increased disease transmission as a result of the loss of inhibitions when under the influence (Naar-King et al., 2006). There is evidence that the use of these substances interferes with appointment attendance and adherence to ARV medications (Chesney et al 2000; Haubrich et al., 1999; Kerr et al., 2004; Lucas et al., 1999). Examining the extent and consequences of alcohol consumption and drug use among South African adolescents, Parry et al. (2004) report that levels of substance use are high, demand for substance abuse treatment services is increasing, and that drug markets are expanding. These findings provide cause for concern due to the impact of substance use on treatment adherence.

3.4.3 Femininity: The subordinated woman

Health care is generally socially constructed as the domain of women, in which women are assigned the role of ‘health supervisors’ (Seymour-Smith et al., 2002). As such, women are generally portrayed as being more health conscious, being at ease with using health care services (Seymour-Smith et al., 2002; Smith et al., 2006). However, the ways in which society constructs femininities may have negative implications for

the way illness is managed by women (Williams, 2000: 395). Studies conducted in various contexts have pointed to the coexistence of multiple femininities which cut across race, age, culture and class (Bekker, 2003; Ozkazanc & Sayilan, 2008; Pyke & Johnson, 2003; Sengupta, 2006). These femininities are constructed in relation to masculinities, particularly in relation to hegemonic masculinity (Ozkazanc & Sayilan, 2008; Pyke & Johnson, 2003).

Drawing on the notion of multiple masculinities for the conceptualisation of a plurality of femininities, Pyke & Johnson (2003: 50-51) distinguish between hegemonic femininity and subordinated femininities, equating hegemonic femininity with the image of an empowered white woman; a woman characterised as self-confident, independent, assertive and successful. Pyke & Johnson also point out that although these ruling traits are similar to those of hegemonic masculinity, “hegemonic masculinity is a superstructure of domination”, while “hegemonic femininity is confined to power relations among women”.

There is evidence that different femininities enact different behaviours in various contexts (Ozkazanc & Sayilan, 2008). This includes health, whereby various health-related behaviours can either be problematic or health-promoting (Williams, 2000). However, there is a lack of research examining different forms of femininities (and masculinities) present in South Africa to draw on for a gender analysis in a health context. Thus, for the purposes of this study, subordinate femininities are discussed, in general, in relation to how their social construction has a limiting effect on women’s health, health-related behaviour and beliefs in the context of ARV treatment.

3.4.3.1 Access to and control over resources

Lack of economic freedom and social independence from male figures in their lives, give women little power to freely access and control resources that would have the potential to improve their health substantially. The lack of economic freedom stems from the different and unequal occupations that are assigned to women, compared with men. According to Wingood & DiClemente (2000), the sexual division of labour

that assigns to women “women’s work” (i.e. “unpaid nurturing work” such as child care, caring for the sick and the elderly, and housework), not only limits women’s economic potential, but also confines their career paths. Since “women’s work” is largely uncompensated, an economic imbalance occurs between men and women. Wingood & DiClemente (2000) add that this economic imbalance also occurs in cases where women have income-generating work, as the work they do is often not recognised as work and is generally less valued relative to the work done by men. The result is that women often have to rely on men financially and are thus left with little control over valuable resources, such as the family income, that would benefit their health (Backhans et al., 2007; Garg & Sharma, 2006).

- Financial resources

By not having economic stability or being economically dependent on someone else means that women may find themselves in a situation where they lack the necessary access to and control over financial resources to pay for transportation and/or health care services (Baghdadi, 2005; Garg & Sharma, 2006; Nanda, 2002). In this respect, the lack of financial resources has been linked to women’s inability to sustain access to treatment. For example, transportation has been associated with poor adherence to medical appointments and postponement of care (Catz et al., 1999; Cunningham et al., 1999). Similarly, a South African study, exploring patient and health care worker perspectives on adherence to TBPT among HIV-positive patients, reported lack of money for transport (i.e. public taxis) and food as a significant barrier to treatment access and adherence (Rowe et al., 2005). Since ART also necessitates food requirements and regular appointments at health care clinics, money for transport and food may create similar barriers for access and adherence among ART patients.

- Time as a resource

Time is another resource which is unequally distributed between men and women, and the high cost thereof for women is known to limit their health more than men’s health (Backhans et al., 2007). For example, Baghdadi (2005: 84) claims that women’s “disproportionate share of work within the household, including agricultural tasks,

collecting water and fuel, and caring for the family, limits the time available to seek healthcare services. As a result, they often fail to seek help until their illness is at a critical stage". Likewise, time spent travelling and queuing may amount to the loss of a day's wage, thus further adding to the high opportunity costs of time for women (Nanda, 2002). Consequently, time is a limited resource which is constantly eroded by the multiple gender roles that women are expected to carry out, and thus serves as a barrier to obtaining effective health care. In this regard, operating hours of health care facilities and appointment waiting times may be of particular importance for women's adherence to treatment.

3.4.3.2 Decision-making power

The role of health care provider for the family is generally bestowed upon women (Baghdadi, 2005; Cameron & Bernardes, 1998; Hoffman et al., 1997). However, the gender relations between men and women are defined by a power imbalance, which results in gender differences in decision-making power which extend to decisions regarding health issues (Rao Gupta, 2000). According to Courtenay (2000: 1388), "[g]ender is negotiated in part through relationships of power" and "[t]hese power relationships are located in and constituted in, among other practices, the practice of health behaviour". The differential decision-making power may render some women incapable of making effective health-related decisions concerning their health. Women's limited decision-making power can place their health at risk in two main ways, namely by having to gain permission (from their husbands or household head) or by delaying or putting off care for themselves for the benefit of others in the household or the household as a unit.

- Seeking permission

The lack of financial independence from men also gives women little power to make decisions regarding their health. In such situations, for instance, women "may not be able to decide for themselves when they need to seek healthcare or purchase medicines. In such a setting, they need to ask their husbands or another senior male family member for permission" (Baghdadi, 2005: 83-84). For example, Romero-

Gutiérrez et al. (2007) found that 23.5% of pregnant women reported not having permission from their husbands as the main reason for rejecting HIV testing during pregnancy. Where permission is not granted, and where women feel inadequate to challenge the authority of their partners, the ability to make health care decisions may be hampered, thus jeopardising their health. In the context of ART, opposition from husbands may deter the necessary access and adherence required for treatment to be successful.

- Putting off care

Regardless of having access to such health care, and despite advanced illness, exhaustion and despair, women still tend to delay seeking out health-related services and treatment (Fleshman, 2004; Garg & Sharma, 2006; Muula et al., 2007). This can be explained in relation to the few resources at their disposal. Particularly in cases of poverty and where out-of-pocket expenses are implied, women may be forced to make trade-offs between addressing their own health needs (i.e. seeking health care) and other immediate necessities such as food, education, housing, or medication for children (Cunningham et al., 1999; Fleshman, 2004; Mellins et al., 2003; Nanda, 2002). Thus, the constrained choices that women are expected to make limit their decision-making power with regard to their own health needs (Bird & Rieker, 1999). The need to address the difficult choices that HIV-infected women are often forced to make has been noted as being of importance for interventions aimed at keeping patients adherent to treatment (Mellins et al., 2003).

3.4.3.3 Gender roles and activities

Feminine roles and related activities are socially determined through the processes of gender construction (Liguori & Lamas, 2003). Through this process women are allocated various roles, which include domestic duties, childrearing, and caring for the sick (Cameron & Bernades, 1998; Doyal, 2001; Nanda, 2002; Ndinda et al., 2007). Each of these roles has implications for the health-related beliefs and behaviours of women. However, it is important to also recognise that masculine and feminine attributes and behaviours also vary across other dimensions, including culture, historical period and social class (Dowsett, 2003; Liguori & Lamas, 2003). An example

of how gender roles vary over historical period has been pointed out by Arber & Cooper (1999), who draw attention to how the gender roles of women have shifted over time, with fewer women remaining full-time housewives as women increasingly enter the paid labour force and thus gain more financial independence than in the past. Since women's participation in the labour force also has implications for health and well-being (Bekker, 2003), it is discussed along with domestic duties, childrearing, and caring for the sick as gender roles that have the potential to have a negative effect on treatment access and adherence.

- Domestic responsibilities

Women's domestic responsibilities typically involve tasks such as the preparation of meals, fetching or heating water, and cleaning the house (Shaffer, 1998). These domestic tasks and the amount of energy and time that they require to be carried out, have implications for women's health and health-related behaviour. Using household size as a measure of family demands, Artazcoz et al. (2001) reported a positive relationship between domestic responsibility and ill health, namely, self-perceived health status, limiting longstanding illness⁵ and chronic conditions. Although household size is not a direct measure of family demands, similar findings have been reported with respect to household size and ARV treatment. For example, a relationship between increased household members and missing medical appointments was found in a longitudinal adherence study among HIV-seropositive mothers (Mellins et al., 2003). The same study also cited an increased number of household members as the only significant reason for incomplete participation in the study. There has been little research on the influence of domestic responsibilities on adherence to medications.

- Childrearing

Women have been shown to have significantly more family-related responsibilities, especially being a primary caregiver for children, than men (Box et al., 2003). Childrearing responsibilities, and especially the associated parenting stress, has been

reported to be a barrier to taking ARV medications as prescribed, as well as adhering to medical appointments (Mellins et al., 2003). Pointing out the need to consider the realities of women's daily lives, Roberts & Mann (2000: 384) contend that "women who have young children may be so busy being caregivers that adherence to their own medication regimens may be of only secondary importance". A longitudinal study of both adherence to ARV medications and medical appointments by Mellins et al. (2003), found parenting stress among HIV-infected mothers to be significantly associated with non-adherence, where self-disclosure of HIV-status to children is reported to be of particular importance as a parental stressor. Concerning the relationship between non-disclosure of status to children and non-adherence to ARVs, Roberts & Mann (2000: 380) comment: "If individuals choose to keep their status a secret, then they often had to make up stories to account for their medication-taking behaviours or find a 'safe place' in which to take their pills". Thus, it is expected that the more family-related responsibilities and demands a woman has, the higher the likelihood of non-adherence.

- Care for the sick

The role of caring for the sick – including children, HIV-infected relatives, or partners – disproportionately falls upon women, and in fulfilling this role, women's workload is increased and opportunity costs of time reduced (Nanda, 2002; Stein et al., 2000; Tolhurst et al., 2002). As a result, this care-giving role has been identified as a reason for the variance in access to medical care between men and women, especially in southern Africa (Muula et al., 2007). A study by Stein et al. (2000), which investigated the characteristics of HIV-infected patients who delay their medical care due to care-giving responsibilities, found that HIV-infected women were 1.6 times more likely to put off care than HIV-infected men as a result of caring for others. Caring for the sick has also been attributed to poor adherence to treatment, especially where women are forced to choose between their care-giving responsibilities and adhering to their own treatment (Mellins et al., 2003). Although the role of caring for the sick is largely

⁵ Limiting longstanding illness (LLI) is used in this study as a functional measure of ill health, in which attention is directed toward the consequences of ill health, such as restrictions on daily activities

thought of as the responsibility of women (Cameron & Bernades, 1998), there is evidence that some men do share some responsibility in caring for the sick. A South African study, by Ndinda et al. (2007), described men's role as involving the physical moving of the sick in and out of their houses, and the provision of basic needs like food. However, when women themselves are the ones in need of care they are at a disadvantage, especially older women who may not have a spouse to provide care (Arber & Cooper, 1999).

- Employment

The gender roles and role-related activities ascribed to women, as discussed above, all constrain women's opportunity to participate in "economic work", or work for an income (Arber, 2004; Bird & Rieker, 1999; Lahelma et al., 2002; Nanda, 2002; Ross et al., 1990). Although employment has been shown to have health benefits in terms of the physical and psychological well-being of women (Lahelma et al., 2002; Mead et al., 2001; Ross et al., 1990), these health benefits are afforded women under certain conditions. For example, there is evidence of health benefits for women who combine their family and domestic responsibilities with employment, providing that the work is not full-time and family responsibilities levels are not too high (Schofield et al., 2000). Similarly, Ross et al. (1990) highlight that employment and no children, or employment and day-care for children, or increased participation of husbands in child care, was most beneficial to women's psychological well-being. However, this benefit is not evident among single mothers who combine full-time employment with parental roles (Whitehead et al., 2000; Lahelma et al., 2002). According to Lahelma et al. (2002), the adverse health effects on single mothers may result from the responsibilities and strains of the parental role that cannot be shared. Ross et al. (1990: 1067) refers to this situation as 'role overload', and results "from the sheer amount of effort it takes to perform in both arenas". Thus the relationship between employment and well-being is dependent on the balance between working conditions (e.g. employment vs. non-employment or part-time vs. full-time employment) and multiple gender roles and related activities.

(Artazcoz et al., 2001: 640-641).

3.4.3.4 Gender norms and identities

Gender norms dictating ignorance and passivity concerning sexuality have repeatedly been shown to limit women's health, especially with respect to HIV prevention and the ability to negotiate safer sex (Garg & Sharma, 2006; Tolhurst et al., 2002). However, the ideas and expectations held by society concerning the way in which women should behave also have implications for HIV/AIDS-related stigma and discrimination, which in turn, act as barriers to appropriate treatment. Gender norms concerned with women's sexuality may give rise to preconceived stereotypes of HIV/AIDS-infected women as promiscuous, immoral, or drug-abusing (Carr & Gramling, 2004). In this sense, women were initially viewed as 'vectors of disease' and were consequently blamed by society for the spread of HIV to men and children (Amaro et al., 2001). According to Garg & Sharma (2006), these preconceptions of women with HIV/AIDS provide a basis for HIV-infected women's stigmatization. HIV-infected women are thus viewed as deviating from what is "normal", and are accordingly interpreted as a threat to others (Varas-Diaz et al., 2005). Reported consequences of HIV/AIDS-related stigma include loss of social support, persecution, isolation, loss of employment and employment opportunities, expatriation from one's community, as well as having a negative effect on psychosocial aspects, such as emotional well-being and self-personification (Fife & Wright, 2000; Fleshman, 2004; Varas-Diaz et al., 2005).

Fear of stigma and non-disclosure, and poor mental health as a consequence of stigma are discussed below with respect to the implications for access and adherence to ART.

- Fear of stigma and non-disclosure

Exploring the effects of stigma on HIV/AIDS-infected women's efforts to promote, maintain, and enhance their health, Carr & Gramling (2004: 31) show that "both the terminal nature of the disease and the social implications of sexual deviancy result in the stigmatization that they confront when others discover their diagnosis". The fear of stigma and discrimination results in many women being reluctant to disclose their HIV

status, especially to sexual partners (Amaro et al., 2001; Carr & Gramling, 2004; Nachega et al., 2005). In the treatment context, fear of being stigmatized and the resultant non-disclosure of HIV status result in further 'stigma avoidance behaviours' which have implications for sustaining access to treatment and adherence to medications, namely the hiding of medications, side-effects and the numerous health care appointments (Carr & Gramling 2004; Nachega et al., 2004; Rintamaki et al., 2006). In South Africa, non-disclosure of HIV status among HIV/AIDS patients has repeatedly been highlighted as a consequence of stigma-related fear (Nachega et al., 2005; Rowe et al., 2005).

- Mental health consequences of stigma

Research suggests that the consequences of HIV/AIDS-related stigma, or the fear thereof, can have negative effects on the mental health of patients (Bird et al., 2004; Varas-Diaz et al., 2005). For instance, greater levels of depression and post-traumatic stress have been associated with perceived discrimination (Bird et al., 2004), and non-disclosure has been reported to increase stress as a result of various 'stigma avoidance behaviours' (Carr & Gramling, 2004). Furthermore, the loss of social support as a consequence of stigma has also been related to poor mental health (Varas-Diaz et al., 2005). Poor mental health is of concern for sustained access to treatment. Among HIV-infected mothers, Mellins et al. (2003) found poor mental health status among HIV-infected mothers to be predictive of non-adherence to medical appointments. Similarly, Safren et al. (2001) reported depression and punishment beliefs to be associated with non-adherence to ARV medications, while satisfaction with social support was positively associated with medication adherence.



3.5 SUMMARY

The purpose of this chapter was to provide an overview of the influence and implications of biological sex and socially constructed gender on the health of HIV/AIDS-infected men and women, for whom disease has progressed to a stage where they require treatment. Despite the lack of research around biological sex and ART, the available literature suggests that biological sex results in distinctive patterns, manifestations and progression of HIV and AIDS in women and men. There are, therefore, implications for treatment guidelines and measures of adherence based on clinical indicators. Furthermore, biological sex has direct implications for non-adherence by means of the severity of adverse reactions to medications in men and women.

The overview of socially constructed feminine and masculine characteristics reveals important gender-related barriers that men and women may face in adhering to their treatment. By using the framework to examine the implications of gender on health-related behaviour and beliefs separately for men and women, evidence is provided that men and women face different barriers in adhering to treatment. These barriers are the product of the varied resources to which men and women have access and that they control, the degree to which men and women can freely make decisions regarding their health and required treatment, and the gender norms and roles that society prescribes for men and women.

The analysis shows both similarities and differences in the barriers faced by men and women. Although both men and women have resources to draw on, the examination of the literature reveals that women have fewer economic resources in comparison with men, and men as having fewer social resources compared with women. Furthermore, although both men and women experience HIV/AIDS-related stigma, the stigma is rooted in the differing social norms and roles ascribed to men and women, and this results in men and women reacting in different ways. These findings serve as examples of the importance of sex-disaggregating data, and giving explanations, not only for significant differences, but also for the similarities in research findings.

The sex and gender differences outlined above all have implications for the way services are delivered, the way treatment and adherence information is provided, patient-provider relations, and further research. The adherence barriers should be addressed in the planning, implementation and monitoring of HIV/AIDS-related policies and programmes to ensure equitable treatment outcomes for men and women. Furthermore, a gender perspective ought to be adopted in all research aimed at improving the health of men and women, not just the health of persons infected HIV/AIDS.

**CHAPTER 4 – GENDER DISPARITIES AND SIMILARITIES IN
ADHERENCE AND SUSTAINED ACCESS TO TREATMENT:
DATA ANALYSIS**

4.1 INTRODUCTION

As was indicated in the previous chapters, high levels of adherence to medication regimens and scheduled appointments are both necessary for optimal treatment outcomes and patient survival, while non-adherence increases the risk of drug resistance and AIDS-related mortality. Multiple factors have been reported to be significantly associated with non-adherence to both medications and scheduled appointments. Identification and understanding of these factors are important for the development of effective adherence interventions within the ART programme, as well as to inform policy and treatment guidelines. However, gender-sensitive development of any of the latter is not possible if the gender-related factors affecting adherence-related behaviour and beliefs are not identified.

Gender research offers the means for providing evidence-based information to guide policy-makers and planners in programme and policy development that promote gender equity in health. At the same time, gender analysis has been subject to much debate, especially with respect to how the measurement of the theoretical concept of gender is approached within quantitative research (For example, see: Addis & Mahalik, 2003; Bird & Rieker, 1999; Knaak, 2004; Petersen, 2003). As noted by Knaak (2004: 312), “[s]ociologists ask people what their gender is, not to elicit information about genitals or birth certificates, but to find out how people live and function as gendered [beings - sic] and, as such, how *that* feature of gender interacts with other social phenomena”. Adherence behaviour in relation to ART is the social phenomenon that is to be examined here as a function of gender.

In this chapter, an overview of common methodological biases in the analysis of gender is given to determine how best to avoid these biases within this study and to produce a reliable source of information. This is followed by an outline of the research design and methodology used in the larger study conducted by the Centre for Health Systems Research & Development (CHSR&D) and which is also applicable to this study. Lastly, results are presented and concluding remarks are made concerning the identified gender disparities and similarities in access and adherence among patients in the Free States ART programme.



4.2 METHODOLOGICAL BIASES IN GENDER ANALYSIS

The literature around gender analysis points to three main discernible methodological biases that relate specifically to single sex-studies, differences and similarities between men and women, and the use of the “sex = gender” variable in quantitative research. These concerns are briefly outlined below followed by a description of the efforts employed in this study to avoid these biases.

4.2.1 Single-sex studies

Studies which include only men or only women in their samples (commonly referred to as single-sex studies) have been criticised for the generalisability of the conclusions that are drawn. From as early as the 1970s, it has been pointed out that the findings of single-sex studies have regularly been subject to overgeneralisation, whereby broad-spectrum conclusions are drawn about human behaviour irrespective of sex, despite the sample being limited to one sex (Reardon & Prescott, 1977). Furthermore, Prescott (1978) argues that limiting a sample to one sex for the purposes of comparability with other studies (i.e. studies that have shown preference to a particular sex) may expand on scientific explanation, but it also serves to extend this generalisability bias.

With regard to non-sex-specific diseases, single-sex studies have similarly been criticised. According to Bird & Rieker (1999), limiting treatment studies of non-sex-specific diseases to one sex does not mean that findings are directly generalisable to the opposite sex. They argue that this results in a lack of information on effective treatment and possible beneficial interventions, and fails to reveal any similarities (or differences) in men’s and women’s health. Thus, since HIV/AIDS is a non-sex-specific disease, both men and women ought to be included as research participants. The

inclusion of both men and women would assist in overcoming the generalisability bias when conclusions are drawn about adherence behaviour.

4.2.2 Differences and similarities between men and women

Gender research typically focuses on the differences between men and women (Petersen, 2003; Risberg et al., 2006). According to Addis & Mahalik (2003) this sex-difference approach to gender analysis has several limitations for the interpretation of research findings. They argue that it does not provide sufficient explanation for differences, it neglects within-group variability, and it can result in gender stereotypes that have the potential to constrain men and women in specific contexts. Similarly, Hyde (2005) argues that the costs of exaggerated claims of gender differences have the potential to cause harm rather than good. Nevertheless, examination of differences between men and women still has merit for gender analyses in health. As pointed out by Bekker (2003), gendered daily life factors – which influence men and women differently – result in differences between men and women, which have relevance for health promotion and risk reduction. Thus, the application of a gender perspective would expose differences and/or vulnerable groups, as well as aid our understanding of the differences and inequities between men and women in relation to the socio-cultural context (Risberg et al., 2006).

The predisposition to focus on differences in gender research frequently results in the similarities between men and women being overlooked (Bekker, 2003; Ho et al., 2005; Petersen, 2003). Despite this, similarities in the health of men and women appear to be more common than differences (Arber & Cooper, 1999; Walters et al., 2002). According to Ho et al. (2005: 391), “the very nature of gender almost forces researchers to look for differences – a finding of ‘no difference’ is assumed to be uninteresting, or at the very least, uninterpretable“. Similarly, Bekker (2003) asserts that the extensive focus on differences and ignorance of similarities is a consequence of the importance placed on statistical tests in empirical investigation, particularly the inclination only to select statistically significant results for analysis and discussion. When similarities are not considered in gender analyses it has the potential to

emphasise the dichotomous thinking about gender (Bird & Rieker, 1999). Furthermore, ignorance of the similarities between men and women can also have implications for policy. As pointed out by Ho et al. (2005), over-looking or not presenting similarities in research has the potential to result in the development of policy that does not reflect or justify the actual research. Thus, consideration of the interconnected similarities and differences between men and women is essential if the gender-sensitivity of research and related policies and guidelines is to be maintained.

4.2.3 The 'sex = gender' variable in research

The current standard in gender analysis, as pointed out by Knaak (2004: 302), is “where gender is operationalised (i.e., transformed from a concept into a research measure) as a single variable (“gender”) with two classification possibilities (“male” or “female”)”. This method of differentiating between men and women is what Bekker (2003: 239) refers to as the exploration of sex differences. Although this method of exploring sex differences has proven to be a useful form of analysis, especially with regard to HIV and AIDS (Dowsett, 2003), it has however received much criticism. For instance, this method leads to the assumptions that gender is dichotomous, as well as congruent and immutable (Annandale & Hunt, 1990; Knaak, 2004), where ‘dichotomous’ refers to gender as only having two exclusive male/female categories, where ‘congruent’ implies that social gender naturally arises from one’s biological sex (i.e. sex and gender are viewed as coincidental), and where ‘immutable’ depicts gender as an unchanging or permanent theoretical concept. Knaak (2004) further argues that employing the “gender = male/female” variable sets in motion assumptions of biological foundationalism which oversimplifies the complexities and variability of gender.

Although biological sex contributes to health-relevant characteristics, this is done in conjunction with social gender (Bekker, 2003). Thus, both biological sex and social gender are equally relevant in gender analyses. So, how then, do we capture the multifaceted and multidimensional concept ‘gender’ as a research variable in

quantitative gender analysis, while simultaneously avoiding assumptions of biological foundationalism which the 'sex = gender' variable seems to exemplify?

Sex-disaggregating data would remain the fundamental 'first step' in analysis, allowing for comparisons to be made between the two sexes (Bekker, 2003; O'Brien et al., 2005). However, to move any analysis beyond quantitatively capturing mere 'sex differences' and toward capturing the complex influence and effect of gender on health, studies would need to examine a multitude of intersecting variables - variables that would be used as proxies reflecting the social hierarchies through which gender is socially constructed. According to Knaak (2004: 306), gender has multiple levels of meaning and "cannot be adequately understood in isolation from other social hierarchies". In this respect, variables such as ethnicity/race, socio-economic status, age, class, educational attainment, economic activity, work roles, sexual orientation, gender ideology, reproductive and marital status, personality characteristics, and life experiences, have previously been noted as being representative of lived experience of – and which simultaneously have different meanings and effects upon – men and women (Bekker, 2003; Knaak, 2004; Schaltz, 2003). Lastly, to capture gender as a multidimensional concept in a quantitative evaluation, gender needs to be conceived of and formulated as the dependent variable within the research strategy (Knaak, 2004).

4.2.4 A quantitative gender methodology for the analysis of sustained access and adherence

From the above overview of the common biases in gender analyses, it is evident that both men and women need to be included in samples, both the similarities and differences need to be examined and explained, and the sex variable - in addition to other gender-related variables - needs to be included in the research strategy, and gender must be regarded as the dependent variable for data analysis. Thus, to increase the gender-sensitivity of this research, this study takes cognizance of these biases by:

- including both men and women in the sample;
- performing descriptive statistics between men and women to identify significant differences in the 'lived experiences' of men and women within the sample of patients on treatment;
- comparing the adherence behaviour (i.e., adherence to medications and appointments) of men and women to identify significant differences and/or similarities; and
- conceiving gender as the dependent variable by separately examining predictors of non-adherence to medications and appointments for men and women.



4.3 RESEARCH DESIGN AND RESEARCH MEHODOLOGY

This section describes the strategy and methodology, including the sampling methods, research techniques and instruments, recruitment and training of data gatherers, data gathering and quality control, and analysis of data employed to meet the objectives of this research.

It should, at this point, be reiterated that this study forms part of a larger ongoing study conducted by the Centre for Health Systems Research & Development (CHSR&D) in partnership and collaboration with the Free State Department of Health (FSDoH), to document, monitor and evaluate the implementation of the national ARV treatment plan in the Free State. Using the patient cohort data collected as part of this larger study⁶, this study investigated whether adherence and sustained access to treatment were differentially associated with gender.

4.3.1 Sample

⁶ All analysis and interpretation of data outlined in thus document refers to the work of this researcher.

Stratified by treatment status, the sample consisted of both treatment patients (patients on treatment at date of sample been drawn) and non-treatment patients (patients eligible and certified for treatment but not on treatment at date of sample been drawn) who were randomly sampled from a list of patients who were eligible to start ART in each of the five health districts in the Free State⁷. To qualify for ARV treatment at the inception of the broader CHSR&D study, a patient was required to have either a CD4 count of less than 200 copies/ml, or have reached WHO stage IV AIDS-defining illness, irrespective of CD4 count, and to have communicated willingness and readiness to take ART adherently (Department of Health 2003). In addition to these criteria, patients who presented with tuberculosis (TB) before starting treatment, were first required to complete a proportion of their TB therapy depending on how far advanced their HIV/AIDS had progressed (Department of Health 2003).

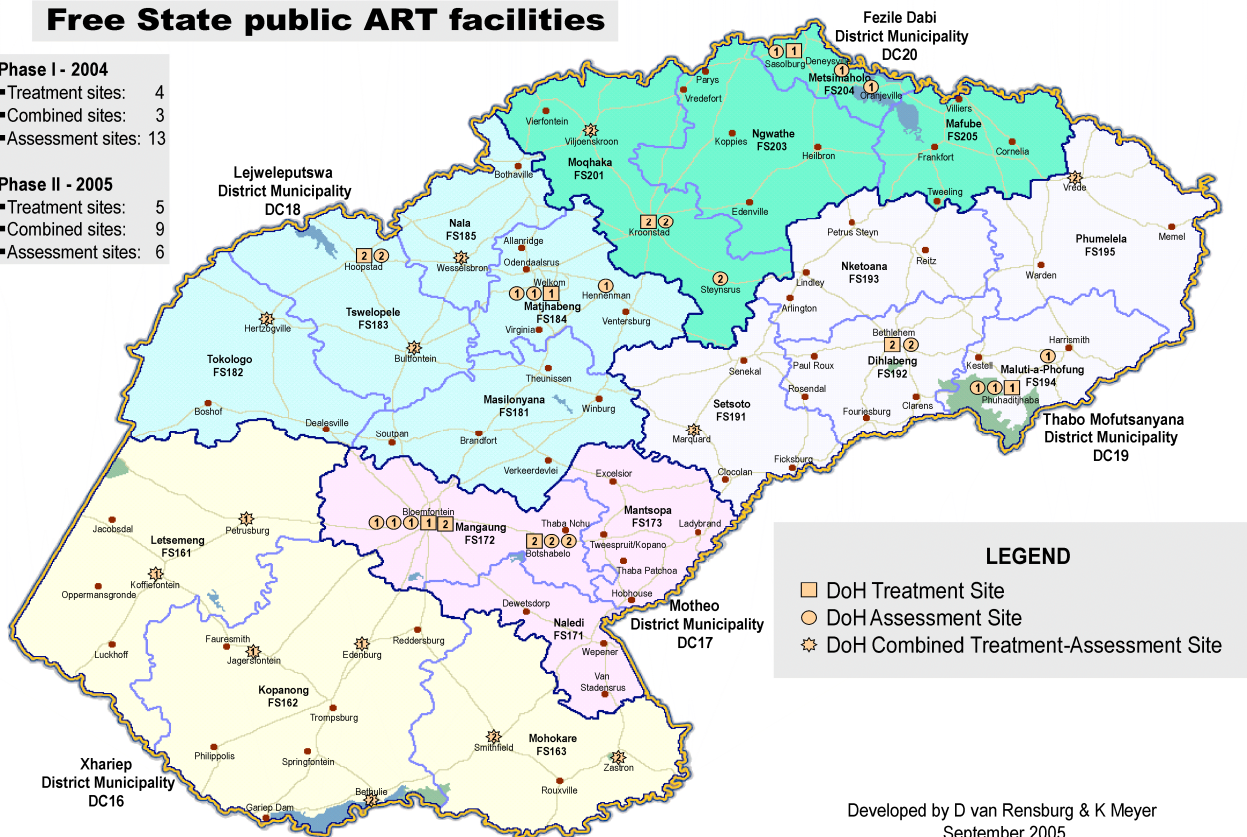
The sample was drawn two months after the first patient had commenced treatment in each particular district. The sample size was estimated at 600 ARV patients with approximately 120 patients per district. These numbers were adjusted after the roll-out of the ARV programme began and clear trends emerged in the proportional uptake of treatment among new patients in each district. Over the span of the project patients were interviewed six times, thus involving an estimated 3600 patient interviews. Map 1 shows the distribution of the first twenty sites to provide ART in the Free State from which patients were sampled in 2004. Written, informed consent for both the study and to access patients' medical files was received from patients prior to the interview, first by nursing staff at the particular facility, and thereafter again by a trained fieldworker.

Map 1: Geographical distribution of ART facilities in the Free State

⁷ Details of the sampling procedure, especially as it relates to the sampling of treatment and non-treatment patients are published elsewhere (Booyesen et al., 2007).

Free State public ART facilities

- Phase I - 2004**
- Treatment sites: 4
 - Combined sites: 3
 - Assessment sites: 13
- Phase II - 2005**
- Treatment sites: 5
 - Combined sites: 9
 - Assessment sites: 6



This study utilised the data collected from the representative cohort of patients on ART (i.e., sampled treatment patients) from all five districts of the Free State public health sector collected as part of the larger CHSR&D study. The cohort of treatment patients also allowed for the observation of any changes in adherence and sustained access to ART among patients, by sex, over six waves (i.e., a thirty-month observation period).

4.3.2 Research instrument

Data were gathered in semi-structured, face-to-face interviews with patients using a newly developed structured questionnaire designed to collect both quantitative and qualitative data. The patient questionnaire covered the following areas relating to ARV adherence and sustained access to treatment: socio-demographics, psychosocial/behavioural characteristics, clinical characteristics, and health-care

administration and delivery⁸. Each interview took approximately 45 minutes to complete and interviews were repeated five times at follow-up visits every six months.

All questions in the questionnaire were phrased in such a way that patients were quickly engaged and their interest maintained throughout the interview session. Each questionnaire also included clear and easy-to-read instructions for field workers to follow while conducting the interview, as well as a letter of consent which was read to each patient (in his or her home language, if necessary) and signed prior to each interview. To test for validity, the questionnaire was piloted with patients on ART and patients awaiting ART within the province and corrections were subsequently made.

4.3.3 Recruitment and training of data gatherers

Given the scale of the research, all interviews with patients were conducted by trained fieldworkers located at the particular facilities or across the sites. According to Babbie & Mouton (2001: 249), “the role of the interviewer is indispensable, as data collection is one of the most crucial phases in the research process. Errors during this phase can render the whole research undertaking futile.” Thus, all fieldworkers were extensively trained over a three-day period. The training included basic information on HIV, AIDS and ARV treatment; interviewing techniques; accurate documentation of information; ethical issues (including patient rights to confidentiality and dignity); and on completing questionnaires and performing a preliminary edit before data were captured.

In addition to the above-mentioned training gender sensitisation training was also provided by this researcher. Since the data were to be collected and recorded by fieldworkers, it was deemed important for reliability purposes of this study that no personal prejudices or biases were brought into the interview. Thus, the purpose of gender sensitisation in the training was to enhance the fieldworkers’ awareness and understanding of how gender and HIV/AIDS are related and to create an awareness of personal gender bias. The objectives of gender sensitisation training were to:

⁸ See Annexure A for patient questionnaire

- clarify/develop an understanding of the concepts 'biological sex' and 'social gender';
- create an understanding of how sex and gender influence an individual's roles, health needs, responsibilities and expectations within society;
- create an awareness that such roles, responsibilities and expectations may be altered in the presence of HIV/AIDS; and
- make clear some of the facts and misconceptions around HIV/AIDS in relation to gender in the South African context.

4.3.4 Data gathering and quality control

According to Babbie & Mouton (2001: 261), "[i]f a high response rate is achieved, there is less chance of significant response bias than in a low rate". In view of this, various mechanisms of quality control were implemented during the data-gathering process with a view to attain the highest possible response rate for this study.

All fieldworkers were required to edit questionnaires immediately after completing each interview (first-level quality control). Various forms of second-level quality control were employed in each district. Some district fieldworker teams were supervised by quality controllers who were responsible for rechecking questionnaires to ensure that they were accurate and complete. In other districts - especially where there are vast distances between the ART sites - fieldworkers were required to edit each other's questionnaires. Where this was not possible, the questionnaires were couriered to the CHSR&D for editing and then returned to the fieldworkers should mistakes have been identified. Final editing (third-level quality control) occurred at the CHSR&D's offices in Bloemfontein, where data-entry staff ensured that there were no mistakes or inconsistencies in the data, while also coding and capturing the data onto the computer statistics programme.

4.3.5 Measures

The two main outcome variables assessed in this study included self-reported adherence to ARV medications and self-reported adherence to scheduled

appointments (as a measure of sustained access to treatment). From the review of treatment adherence literature, a range of factors known to significantly affect adherence to both ARV medication and access to treatment were identified. These factors are assessed in this study according to four main categories, namely, demographic characteristics, psychosocial/behavioural characteristics, clinical aspects, and health-care administration and delivery (Mehta et al., 1997). Measurement of the various variables used for the purposes of this study – including how each variable was defined, created (where required), coded, or recoded – are outlined below.

4.3.5.1 Outcome measures

- *Self-reported adherence to ARV medications*

The first of two outcome variables to be assessed was adherence to ARV medication regimens, determined by using a self-reported measure. According to Godin et al. (2003), a seven-day self-reported measure is a valid method for assessing non-adherence to antiretroviral drug regimens and also correlates with improved immunologic and virologic outcomes or responses. Adherence was assessed by asking patients to indicate: (1) the name of each ARV drug in their treatment regimen; (2) the prescribed dose per day for each ARV medication; and (3) whether each ARV medication was taken as prescribed over the seven days preceding the interview (response options: No, Yes, Cannot remember). Data for patients who reported “yes” to taking their ARVs as prescribed during the week preceding the interview, were coded as being adherent to their prescribed regimen, while data for patients who reported having missed at least one dose of ARV medication in their regimen in the past seven days were coded as being non-adherent. Patients who responded with “cannot remember”, were excluded from the analysis. Thus, a binary variable for ARV medication adherence (adherent vs. non-adherent) was created in accordance with the formal definition of adherence (Bangsberg et al., 2002), whereby patients who reported not taking their ARV medications as prescribed, were defined as non-adherent.

- *Self-reported ART appointment adherence*

Sustained access was defined as being able to attend all scheduled appointments for ARV-related treatment, care and support. To measure sustained access to ART, self-reported data on scheduled appointment adherence were used. This outcome measure was not included in the baseline assessment of patients, but from follow-up 1 (wave 2) through to follow-up 5 (wave 6). In the questionnaire, patients were asked to indicate: (1) the number of scheduled appointments for ARV-related treatment, care and support - excluding non-scheduled appointments - made since commencing the government's ARV Treatment Programme (at baseline), or since the previous interview (six-month period), and (2) the number of scheduled appointments attended. This was asked separately for both treatment and assessment sites⁹. To generate the appointment adherence variable, the number of missed scheduled appointments was first calculated by subtracting the number of scheduled appointments attended from the actual number of scheduled appointments. Next, an appointment adherence variable¹⁰ was generated by coding the data for patients who did not miss any appointments as 'adherent', and data for patients who reported missing at least one scheduled appointment as 'non-adherent'. Lastly, an overall appointment adherence variable was created by combining the appointment adherence variables across assessment and treatment sites. Accordingly, patients who missed at least one scheduled appointment, at either site, were defined as being 'non-adherent', and were therefore viewed as having difficulty in maintaining sustained access to ART.

4.3.5.2 Validity of outcome measures

Validation of self-reported adherence measures are consistently done by comparing the average HIV viral load (HIV RNA copies/ml) between adherent and non-adherent groups of patients (Bangsberg et al., 2002; Godin et al. 2003; Kleeberger et al., 2001). Accordingly, validation of both self-reported outcome measures in this study were tested by comparing patients' HIV viral load collected closest to interview dates between adherent and non-adherent groups of patients. The outcome measures were

⁹ Patients attending combined sites completed both sections.

¹⁰ Formal definition of adherence was applied (Bangsberg et al., 2002: 7).

considered valid if the proportion of adherent patients had significantly lower average HIV viral load than non-adherent patients. The differences between means were determined using the Student's *t*-test.

4.3.5.3 Predictor variables: demographic characteristics

- *Sociodemographics*

All patients were asked to report their age (years), population group (black, coloured, indian/Asian, white, or other), highest formal educational level, and marital status (living together: married, living together: unmarried, spouse/partner living elsewhere, single, or other).

- *Employment status and income*

In addition to personal monthly income - measured in Rands as the sum of salaries, wages and government grants - patients were also asked to report on their employment status and whether or not they were the main income generator (or breadwinner) within their household. In respect of employment, patients were asked to report whether they had worked for pay, profit or family gain in the seven days preceding the interview. For employment status, patients were defined as having employment if they responded 'yes' to having formal registered work (non-farming), to having informal unregistered work (non-farming), to having farming work, to having work, but being temporarily absent, or being a seasonal worker.

- *Housing status and household dynamics*

Patients were asked to report on (1) household size (number of people in the household), (2) household age structure (14 years and younger; 15-59 years, and 60 years and older), and (3) type of housing. Type of housing was recoded as either formal or informal housing.

4.3.5.3 Predictor variables: psychosocial/behavioural characteristics

- *Depression and anxiety*

Various measures of depression have shown a significant relationship with non-adherence (Mugavero et al., 2006; Safren et al., 2001; Simoni et al., 2002).

Unfortunately, the research instrument used for the purposes of this study did not include any such measures. However, it has been shown that elevated levels of depression and anxiety exist among HIV patients (McClure et al., 1999). In the absence of a more sophisticated measure to appropriately determine depression or anxiety among this sample of patients, a self-reported proxy indicator was used to assess the level of depression and anxiety. Patients were asked to indicate which statement best described their state of health on the day on which the interview took place. Responses included “I am not anxious or depressed”, “I am moderately anxious or depressed”, and “I am extremely anxious or depressed”.

- *Substance use*

With respect to substance use, patients reported whether or not they had used the following substances in the last month (30 days): (1) alcohol, (2) tobacco and (3) dagga (marijuana). In addition to assessing each substance separately, a ‘substance use’ variable was coded; defined as having used any alcohol, tobacco or dagga in the last month (30 days).

- *Disclosure*

Patients were asked to report whether they had disclosed their HIV/AIDS status (yes/no). Data were assessed for a significant association between non-adherence and non-disclosure of HIV/AIDS status.

- *Stigma index*

Stigma was assessed by means of a five-item scale whereby patients were asked to report on whether they experienced (1) any unpleasant physical problems related to their HIV infection, (2) being blamed for their HIV status, (3) blaming themselves for their HIV infection, (4) feeling guilty about being HIV-positive, and (5) feeling guilty when needing help and care from others. Response categories included ‘not at all’, ‘sometimes’ and ‘very often’. ‘Do not know’ and ‘not important’ responses were coded as missing for the purposes of analysis. A stigma index was created and assessed to

ascertain whether a high score was significantly associated with non-adherence. The scale items showed good internal consistency (Cronbach's alpha = 0.73).

- *Social support*

Patients were asked to report on the social support that they receive in the public and private spheres. As a measure of public sphere support, whereby patients would seek out and make use of support provided by social organisations (Arber, 2004), patients reported whether they participated in a support group for people living with HIV/AIDS (yes/no). Support in the private sphere was limited to patients reporting whether or not they have someone who supports them emotionally (yes/no). Data were analysed to see whether a relationship existed between either, 'not belonging to a support group', or 'not receiving emotional support' and between non-adherence to medications and to scheduled appointments.

- *Treatment knowledge*

Knowledge of ART was assessed by asking patients to indicate their agreement or disagreement with six statements scored on Likert-type scales ranging from 'definitely true' to 'totally false'. Statements referred to the appropriateness of stopping ARV treatment, the relationship between ARVs and disease progression and further transmission of the virus, as well as the acceptability of missing ARV medications. A treatment knowledge index was created, and compared with adherence to medications and scheduled appointments to see whether a low treatment knowledge index score was related to non-adherence. The scale used yielded an alpha coefficient of 0.54, indicating that the items need refinement to improve the reliability of this scale for measuring treatment knowledge among the current sample of patients. Results should thus be interpreted with caution.

4.3.5.4 Predictor variables: clinical aspects

- *ARV side-effects*

Side-effects of ARV medication were assessed by asking patients whether they experienced any side-effects when taking their ARV medication (yes/no). Experiencing

any side-effects was assessed to see whether a relationship existed with non-adherence.

- *Disease status*

CD4 cell count (CD4+ lymphocytes/ml) is the commonly used clinical indicator of disease status in adherence studies (Catz et al., 1999; Remor et al., 2007). The disease status of each patient was assessed using CD4 cell counts which were collected from patient files. Disease status was coded as a categorical variable for analysis (CD4<200, CD4=200-500 and CD4>500).

- *Treatment duration*

Time on ART (or treatment duration) was defined as the time period (years) between when a patient started ART and when the first interview was conducted. Treatment start dates (month and year) were collected from patient files. Treatment duration was assessed as a continuous variable.

4.3.5.5 Predictor variables: health-care administration and delivery

- *Access barriers*

Patients were asked to report whether they had experienced any difficulty in visiting their assessment or treatment sites (i.e. access barriers) for their ARV-related treatment, care and support as expected according to their schedule (yes/no). This was asked separately for assessment and treatment sites. A relationship between 'experiencing access barriers' and 'non-adherence' was looked for during analysis. Furthermore, patients who reported experiencing difficulties were asked to list their most important difficulties separately for the assessment and treatment sites (open-ended question).

- *Service delivery*

Satisfaction with services was assessed by asking patients to rate their satisfaction with various aspects of service delivery using a seven-point scale. The aspects assessed included: (1) medical care provided, (2) complaint procedure, (3) cleanliness

of facility, (4) privacy during examinations, (5) confidentiality of medical record, (6) health information about HIV/AIDS, (7) opportunity to ask questions, (8) consultation language, (9) facility operating hours, and (10) waiting times before consultations. Non-applicable responses were coded as missing, while 'do not know' responses were recoded as 'neither satisfied nor dissatisfied'. A service-satisfaction index was created and assessed to see whether a low index score was associated with non-adherence. Service satisfaction was assessed separately for clinic (Cronbach's alpha = 0.81) and hospital facilities (Cronbach's alpha = 0.91). To ascertain whether patients require additional HIV/AIDS-related services, patients were asked to report whether they needed any HIV/AIDS-related services that were not currently available to them (yes/no).

- *Adherence strategies*

Drug-readiness training (DRT) is a programme that patients attend before the initiation of treatment. During the interviews, patients were asked to rate the quality of the DRT that they received with respect to (1) clarity of information provided; (2) opportunity to ask questions; (3) information discussed; (4) health information provided in regard to AIDS; (5) health information on ARV medication; and (6) language used. Response options ranged from 'very good' to 'very poor'. A quality-of-DRT index was created and assessed to see whether a low index score predicted non-adherence. Since patients were encouraged to adopt a 'treatment buddy' (or treatment supporter) to assist them while on treatment, their role in aiding patient adherence was also assessed. Not having a treatment buddy was assessed for a relationship with non-adherence.

- *Patient-provider relationship*

Various aspects of the patient-provider relationship were examined. Firstly, having regular health-care providers was assessed. A patient was defined as having regular health-care providers if he or she reported seeing the same health-care staff (e.g. same nurse or doctor) at each visit to either the treatment or assessment sites for their ARV-related treatment, care and support. Secondly, patients were asked to rate their satisfaction with the ARV-related services they received from nurses and doctors at

both the treatment and assessment sites. Response categories included: 'not applicable', 'very good', 'good', 'neither good nor bad', 'poor', 'very good', and 'do not know'. Thirdly, patients specifically evaluated the respect they received, and the information they received about ARV medication from both doctors and nurses, where response categories included: 'not applicable', 'very good', 'good', 'neither good nor bad', 'poor', 'very good', and 'do not know'. High index scores represented poorer ratings of, or satisfaction with, health-care providers.

4.3.6 Statistical analysis

To provide a general profile of the sample of patients, descriptive statistics were used to compare the various adherence-related factors between men and women. Bivariate analyses were used to investigate whether significant associations existed between ARV adherence and demographic, psychosocial/behavioural, clinical, and health-care administration and delivery factors. These bivariate analyses were then performed separately for men and women (split analysis) to provide information regarding gender differences in medication adherence. Appointment adherence was analysed in the same manner to determine whether any significant bivariate associations exist. The Chi-squared test (or the Fisher's exact test when sample sizes were small) was used to compare categorical variables and the Student's *t*-test for comparing the mean values of continuous variables. Findings from a non-sex-disaggregated analysis for both outcome measures are also reported in tables to reveal which adherence factors are masked for men and women¹¹.

Multivariate logistic regression analyses were also performed separately for men and women to determine which variables are predictors of (1) non-adherence to ARV regimens and (2) non-adherence to scheduled appointments. Only factors found to be significant in bivariate analyses were included in the respective adherence models. All statistical analyses were performed using the *Stata10* computer programme.

¹¹ See Annexure C for non-sex-disaggregated analyses of factors associated with non-adherence to ARV medications and scheduled ART appointments.

Statistical significance was set at the level of $P<0.05$ and confidence intervals (CI) were set at 95%.



4.4 RESULTS

In the following sections the results of the statistical analyses, conducted in order to establish whether gender differences exist in respect of predictors of adherence to ARV medications and scheduled appointments, are presented and described.

A total of 1609 patients interviewed over the course of the study. Patients were excluded from analyses if they were not on treatment and thus unable to report on treatment adherence. Patients were also excluded from analyses if data for either outcome variable or the dependent variable were missing. In this respect, a total of 28 patients were excluded from analysis of medication adherence and 231 patients from analysis of appointment adherence. During the study period (2004 to 2008) 404 patients (20%) were lost to follow-up; 115 lost to follow-up due to death, 193 were lost to follow-up for other reasons, and 96 were lost to follow-up for unknown reasons. No statistically significant differences - between men and women in the sample - were found between patients lost to follow-up ($P=0.113$).

4.4.1 Descriptive characteristics of men and women compared

The descriptive statistics comparing the demographic characteristics of men and women are reflected in Table 1. Men were significantly older than women ($P<0.001$), where men had a mean age of 42 years (range 20-73) and women had a mean age of 37 years (range 18-63). The majority of patients on treatment were black, where more women were observed across all population groups except in the white population group ($P<0.001$). However, given the small absolute numbers of patients in all population groups other than black, all significant finding ought to be interpreted with

caution. A comparison of *marital status* between men and women shows that women were significantly more likely to be single than men (54% vs. 31%, respectively; $P<0.001$). The majority of patients were unemployed, however a significantly larger proportion of women (83%; $P<0.001$) were unemployed compared with men (71%). *Mean income* was significantly higher among men than women ($P<0.001$), where men reported an average income of R1180, while women had an average income of R750. Compared with women (57%), a higher proportion of men (74%) reported being the main or primary income generator (“breadwinner”) in their households ($P<0.001$). On average, women resided in households with significantly more people who formed part of the total number of people in the household than men (4.25 vs. 3.8, respectively; $P<0.001$). In respect of *household age structure*, men were significantly more likely to reside in households with no children (42%) compared with women (27%). Although the majority of both men and women reside in households with two or more adults, men (4%) were significantly more likely to reside in households with no other adults than women (2%). No differences by sex were observed in *level of education* ($P=0.205$), and *type of housing* ($P=0.426$).

Table 1: Demographic characteristics of men and women on ART in the Free State public health sector compared

Demographic characteristic	N	Men	Women	P-value *
Mean age (years) [±SD]	(M=598; W=1219)	42.46 [8.85]	37.16 [7.95]	<0.001
Population group (%)	(M=584; W=1213)			<0.001
Black		93.66	95.80	
Coloured		3.25	3.46	
Indian/Asian		0.00	0.25	
White		3.08	0.49	
Level of education (%)	(M=607; W=1246)			=0.205
None		5.11	3.53	
Primary		29.98	27.37	
Some secondary		47.28	48.48	
Matric		14.66	17.74	
Tertiary		2.97	2.89	
Marital status (%)	(M=606; W=1238)			<0.001
Living together: married		35.81	14.86	
Living together: unmarried		12.38	7.59	
Spouse/partner living elsewhere		20.79	23.83	
Single		31.02	53.72	
Employment status (%)	(M=600; W=1233)			<0.001
Employed		29.17	16.87	
Unemployed		70.83	83.13	
Mean income (Rands)	(M=610; W=1248)	1179.62	749.34	<0.001

	[±SD]		[1622.71]	[678.81]	
Breadwinner (%)		(M=599; W=1232)			<0.001
No			26.38	43.10	
Yes			73.62	56.90	
Mean household size (number of persons)		(M=600; W=1233)	3.84	4.25	<0.001
	[±SD]		[1.95]	[4.12]	
Household age structure					
Children		(M=611; W=1248)			<0.001
No children			41.73	27.40	
1 child			28.31	35.10	
2 or more children			29.95	37.50	
Adults		(M=611; W=1248)			=0.030
No adults			3.76	1.76	
1 other adult			19.48	20.27	
2 or more adults			76.76	77.96	
Elderly		(M=611; W=1248)			=0.082
No elderly			81.34	82.21	
1 elderly			11.46	12.98	
2 or more elderly			7.20	4.81	
Type of housing (%)		(M=604; W=1237)			=0.426
Formal			77.98	76.31	
Informal			22.02	23.69	

* *P*-values for test of difference, between men and women, in means or distributions

4.4.2 Validity of outcome measures

To evaluate the validity of both outcome measures, both measures were compared with HIV viral load for significant differences in mean values (Table 2). The group of patients who reported being non-adherent to their ARV medications had a mean viral load that was significantly higher than that of adherent patients ($P<0.001$). This finding suggests that the seven-day self-reported measure is a valid measure for the assessment of non-adherence in this study population. Similarly, patients who reported being non-adherent to their scheduled appointments had a significantly higher average viral load than patients who reported being adherent ($P=0.021$), indicating that this outcome measure was also valid measure.

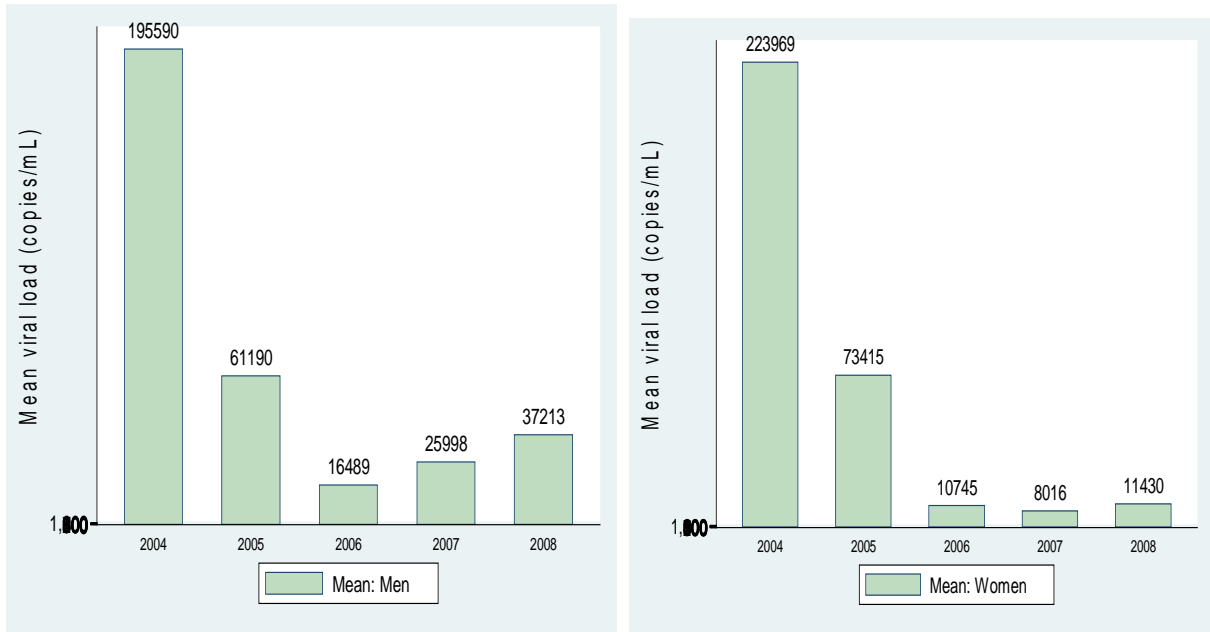
Table 2: Validity of self-reported outcome measures

Adherence to medications	Total N	100% adherence %(n)	<100% adherence %(n)	<i>P</i> -value
Total sample:	1460			<0.001
Mean viral load [±SD]		51371.74 (1430) [195739.4]	170095.60 (30) [466532.9]	
Men:	471			=0.102
Mean viral load		51334.51 (460)	122960.60 (11)	

	[±SD]		[184666.5]	[173640]	
Women:		989			=0.002
Mean viral load			51389.39 (970)	197384.20 (19)	
	[±SD]		[200869.8]	[575993.6]	
Adherence to scheduled appointments		Total N	100% adherence %(n)	<100% adherence %(n)	P-value
Total sample:		1327			=0.021
Mean viral load			15340.31 (1210)	37477.30 (117)	
	[±SD]		[91127.09]	[575993.6]	
Men:		428			=0.538
Mean viral load			19636.86 (389)	18322.56 (39)	
	[±SD]		[84807.22]	[84807.22]	
Women:		896			=0.011
Mean viral load			13353.25 (818)	47054.67 (78)	
	[±SD]		[95035.16]	[288196.2]	

Although both of the self-report measures are valid for assessing non-adherence to ARV medications and scheduled ART appointments in this population, when analysed separately for men and women, both outcome measures proved to be valid for women but not for men. Figure 1 illustrates change in viral load (copies/ml) over time, separately for men and women on ART. Although the average viral load declines rapidly in the initial period of treatment, compared with women, men demonstrate a steady increase in average viral load over time. Since both outcome measures employed for this study were found to be significant for women and not for men, and given the upward trend in mean viral load after initial suppression among men and not women, it is assumed that self-reported outcome measures for men are unsound as a result of this upward trend in viral load. This finding is suggestive of either underlying biological differences in men and women, or of over-reported adherence among men. Thus, in the absence of a valid measure for men, reported findings for medication and appointment adherence need to be interpreted with caution.

Figure 1: Comparison of mean viral load (copies/ml) over time for men and women



4.4.3 Comparison of ARV medication adherence and scheduled appointment adherence

Bivariate analysis of medication adherence and scheduled appointment adherence reveals a highly statistically significant association ($P < 0.001$): 38% of patients who reported being non-adherent to their medications also reported not being adherent to their scheduled ART appointments, while only 7% of patients who reported non-adherence to scheduled ART appointments also reported not being adherent to their ARV medications. This finding suggests that appointment non-adherence is more predictive of medication non-adherence, than reported non-adherence to medications is of missing appointments. When medication adherence was regressed on appointment adherence in a separate regression model, results revealed that the odds of medication non-adherence significantly increased as non-adherence to appointments increases (OR=5.62, 95% CI: 2.28, 13.84; $P < 0.001$).

4.4.4 Factors associated with non-adherence to ARV medications in men and women

In this section, a comparison of ARV-medication adherence between men and women is made, followed by the separate presentation of factors found to be significantly associated with adherence for men and women (i.e. slit analysis). Lastly, findings for the logistic regression models for men and women are presented.

4.4.4.1 Comparison of ARV-medication adherence between men and women

Presented in Table 3 are the results of the bivariate analysis of medication adherence by sex. There was no statistically significant difference in medication adherence between men and women ($P>0.05$). Results show that approximately 98% of the sample self-reported being adherent to their ARV medications.

Table 3: Self-reported ARV-medication adherence by sex

Adherence to medications	Total N	100% adherence %(n)	<100% adherence %(n)	P-value
Men	528	97.54 (515)	2.46 (13)	=0.598
Women	1072	97.95 (1050)	2.05 (22)	

4.4.4.2 Factors associated with medication non-adherence in men

Table 4 presents the results of the bivariate analysis of factors associated with ARV medication adherence among men.

- Demographic characteristics

A marginally statistically significant relationship between *age* and non-adherence was found, with younger patients being more likely to be non-adherent than older patients ($P=0.065$). A statistically significant difference was found with respect to *population group* and adherence ($P=0.009$). The largest proportion of non-adherence was reported among black patients (73%), followed by coloured patients (27%). There were no statistically significant differences in levels of education ($P=0.433$), marital status ($P=0.525$), being a breadwinner ($P=0.347$), type of housing ($P=0.644$), or with respect to the age structure of the household (Children, $P=0.144$; Adults, $P=0.673$; Elderly, $P=0.532$) between adherent and non-adherent men. However, patients who reported a smaller household size (mean, 3.08; $P=0.078$) showed a marginally statistically significant relationship with medication non-adherence. A marginally

significant association was also detected in respect of employment status, where the largest proportion of non-adherent patients were employed (92%; $P=0.091$).

Table 4: Factors associated with non-adherence to ARV medications among men on ART in the Free State public health sector

Demographic characteristics	Total N	100% adherence %(n)	<100% adherence %(n)	P-value ^o
Mean age (years) [±SD]	517	42.23 (504) [8.81]	38.46 (13) [10.06]	=0.065
Population group*	501			=0.009
Black		94.08 (461)	72.73 (8)	
Coloured		2.84 (14)	27.27 (3)	
Indian/Asian		0.00 (0)	0.00 (0)	
White		3.06 (15)	0.00 (0)	
Level of education	524			=0.433
None		5.28 (27)	0.00 (0)	
Primary		30.94 (158)	23.08 (3)	
Some secondary		46.38 (237)	46.15 (6)	
Matric		14.09 (72)	30.77 (4)	
Tertiary		3.33 (17)	0.00 (0)	
Marital status	523			=0.525
Living together: married		36.08 (184)	30.77 (4)	
Living together: unmarried		11.18 (57)	15.38 (2)	
Spouse/partner living elsewhere		20.78 (106)	7.69 (1)	
Single		31.96 (163)	46.15 (6)	
Employment status	517			=0.091
Employed		70.83 (357)	92.31 (12)	
Unemployed		29.17 (147)	7.96 (1)	
Mean income (Rands) [±SD]	527	1138.13 (514) [1515.30]	687.69 (13) [725.48]	=0.143
Breadwinner	518	73.27 (370)	61.54 (8)	=0.347
Mean household size (number of persons) [±SD]	518	3.87 (505) (1.99)	3.08 (13) (1.93)	=0.078
Household age structure				
Children (>14 years)	528			=0.144
No children		41.94 (216)	69.23 (9)	
1 child		27.18 (140)	15.38 (2)	
2 or more children		30.87 (156)	15.38 (2)	
Adults (15-59 years)	528			=0.673
No adults		4.08 (21)	0.00 (0)	
1 other adult		20.00 (103)	15.38 (2)	
2 or more adults		75.92 (391)	84.62 (1)	
Elderly (60 years +)	528			=0.532
No elderly		81.34 (419)	84.62 (11)	
1 elderly		10.87(56)	15.38 (2)	
2 or more elderly		7.77 (40)	0.00 (0)	
Type of housing	521			=0.644
Formal		76.77 (390)	76.92 (10)	
Informal		23.23 (118)	23.08 (3)	
Psychosocial/behavioural characteristics				
Depression/anxiety**	518			=0.803

Not anxious/depressed		70.30 (355)	76.92 (10)	
Moderately anxious/depressed		23.17 (117)	15.38 (2)	
Extremely anxious/depressed		6.53 (33)	7.69 (1)	
Substance use**	517	28.57 (144)	38.46 (5)	=0.309
Non-disclosure	518	10.69 (54)	7.69 (1)	=0.590
Stigma index**	516	1.44 (503)	1.48 (13)	=0.378
[±SD]		[0.48]	[0.59]	
Social support				
No support group membership	518	91.29 (461)	100.00 (13)	=0.266
No emotional support	517	69.25 (349)	92.31 (12)	=0.074
Treatment knowledge index**	517	4.85 (504)	4.63 (13)	=0.032
[±SD]		[0.40]	[0.87]	
Clinical aspects				
Side-effects**	455	19.46 (86)	30.77 (4)	=0.244
Disease status	471			=0.157
<200		37.61 (173)	45.45 (5)	
200-500		56.09 (258)	36.36 (4)	
>500		6.30 (29)	18.18 (2)	
Mean time on ART (years)**	472	1.37 (459)	0.91 (13)	=0.030
[±SD]		[0.87]	[0.86]	
Health-care administration and delivery				
Access barriers				
Clinic*	512	7.62 (38)	15.38 (2)	=0.270
Hospital**	510	9.05 (45)	30.77 (4)	=0.028
Service-satisfaction index				
Clinic**	512	4.22 (499)	3.80 (13)	=0.003
[±SD]		[0.52]	[0.66]	
Hospital**	513	4.46 (500)	3.95 (13)	<0.001
[±SD]		[0.51]	[0.56]	
Service needs	517	25.00 (126)	15.38 (2)	=0.337
Quality-of-DRT index	517	4.54 (504)	4.53 (13)	=0.462
[±SD]		[0.48]	[0.48]	
No treatment buddy	517	58.53 (295)	53.85 (7)	=0.735
No regular health-care providers				
Clinic staff	497	42.77 (207)	46.15 (6)	=0.808
Hospital nurse	505	36.92 (182)	33.33 (4)	=0.799
Hospital doctor	496	39.75 (192)	38.46 (5)	=0.583
Rating of health-care providers				
ARV-related services index	516	1.39 (503)	1.59 (13)	=0.083
[±SD]		[0.49]	[0.55]	
Respect by health-care providers index**	517	1.48 (504)	1.92 (13)	=0.001
[±SD]		[0.52]	[0.56]	
ARV-medication information index*	516	1.47 (503)	1.85 (13)	=0.005
[±SD]		[0.51]	[0.48]	

^o *P*-values for test of difference, between adherent and non-adherent men, in means or distributions.

* Significant at the 10% level ($P \leq 0.10$) in non-sex-disaggregated analysis (See Table 1 in Annexure D).

** Significant at the 5% level ($P \leq 0.05$) in non-sex-disaggregated analysis (See Table 1 in Annexure D).

- Psychosocial/behavioural characteristics

There were no significant differences in self-reported depression/anxiety or disclosure of HIV/AIDS status between adherent and non-adherent men. Although there were no

significant differences in the use of combined substances (i.e., alcohol, cigarette or dagga use) between adherent (29%) and non-adherent (38%) men ($P=0.309$), significant differences appeared when substance use were analysed separately. Substance use by medication adherence for men is shown in Table 5. The proportion of non-adherent men (38%; $P=0.035$) were significantly more likely to report using alcohol in the 30 days preceding their interviews than were adherent men (16%). No statistically significant association was found with respect to stigma or social support and non-adherence to ARV medications. Non-adherent patients showed a significantly lower average score on the treatment knowledge index than adherent patients (4.63 vs. 4.85; $P=0.032$), indicating that non-adherent men are less knowledgeable about ART than adherent men.

Table 5: Reported substance use by ARV medication adherence among men on ART in the Free State public health sector

Substance use	Total N	100% adherence %(n)	<100% adherence %(n)	P-value
Alcohol**	517	16.27 (82)	38.46 (5)	=0.035
Tobacco**	517	20.44 (103)	38.46 (5)	=0.114
Dagga	517	0.60 (3)	0.00 (0)	=0.926

** Significant at the 5% level ($P \leq 0.05$) in non-sex-disaggregated analysis (See Table 3 in Annexure D).

- Clinical aspects

Although experiencing ARV-related side-effects was shown to be significantly associated with medication non-adherence for the combined sample ($P \leq 0.05$)¹², the split analysis showed no significant association with non-adherence for men ($P=0.244$). No association between disease status and non-adherence was found. There was a significant difference in treatment duration, measured as the mean number of years on ART, and medication non-adherence. Adherent men were more likely to have been on treatment for a longer period of time than non-adherent men (mean: 0.91 vs. 1.37; $P=0.030$).

- Health-care administration and delivery

¹² See Annexure C for the statistics on variables used in the non-sex-disaggregated analysis.

While *experiencing difficulties in visiting clinic facilities* showed no significant association with *adherence* ($P>0.05$), *difficulties experienced in visiting hospital facilities* showed a statistically significant association ($P=0.028$). Thirty percent of non-adherent men reported difficulties in visiting their respective hospital facilities compared with 9% of adherent men. Where patients reported difficulties, analysis of an open question concerning the specific difficulties revealed that 90% experienced financial difficulties, 11% experienced transport difficulties, 9% experienced physiological difficulties¹³, and 4% experienced employment-related difficulties in visiting hospital facilities. All (100%) of the non-adherent men cited financial costs as the specific difficulty they experienced. No association was found between medication non-adherence and having service needs, the scores on the quality-of-DRT index, having no treatment buddy, or not having regular health-care providers. With respect to health care providers, statistically significant differences were found in scores on the respect shown by health care providers index ($P<0.001$) and the ARV-medication information index ($P=0.005$) between adherent and non-adherent men. Higher average scores among non-adherent men on both indexes suggests that medication adherence is associated with better ratings of respect received and information received about ARV medication from health-care providers.

4.4.4.3 Factors associated with medication non-adherence in women

Table 6 presents the descriptive statistics for independent variables associated with adherence to ARV medications among women.

Table 6: Factors associated with non-adherence to ARV medications among women on ART in the Free State public health sector

Demographic characteristics	Total N	100% adherence %(n)	<100% adherence %(n)	P-value °
Mean age (years)	1049	36.85 (1027)	36.32 (22)	=0.376

¹³ Included any bodily affliction (i.e., painful or swollen legs, knees or feet) that prevented a patient from accessing a particular facility (e.g. to painful to walk to the clinic or hospital or patient was confined to a bed).

	[±SD]		[7.92]	[8.14]	
Population group*		1037			=0.964
Black			95.87 (975)	95.00 (19)	
Coloured			3.44 (35)	5.00 (1)	
Indian/Asian			0.20 (2)	0.00 (0)	
White			0.49 (5)	0.00 (0)	
Level of education		1070			=0.061
None			3.34 (35)	13.64 (3)	
Primary			27.29 (286)	36.36 (8)	
Some secondary			47.90 (502)	40.91 (9)	
Matric			18.42 (193)	9.09 (2)	
Tertiary			3.05 (32)	0.00 (0)	
Marital status		1066			=0.379
Living together: married			14.94 (156)	4.55 (1)	
Living together: unmarried			7.85 (82)	4.55 (1)	
Spouse/partner living elsewhere			23.37 (244)	36.36 (8)	
Single			53.83 (562)	54.55 (12)	
Employment status		1057			=0.855
Employed			83.29 (173)	81.82 (4)	
Unemployed			16.71 (862)	18.18 (18)	
Mean income (Rands)		1072	727.08 (1050)	647.95 (22)	=0.292
[±SD]			[669.92]	[760.49]	
Breadwinner		1056	56.29 (582)	59.09 (13)	=0.793
Mean household size (number of persons)		1058	4.24 (1036)	4.59 (22)	=0.757
[±SD]			[2.31]	[2.34]	
Household age structure					
Children (>14 years)		1072			=0.297
No children			28.10 (295)	13.64 (3)	
1 child			34.57 (363)	45.45 (10)	
2 or more children			37.33 (392)	40.91 (9)	
Adults (15-59 years)		1072			=0.794
No adults			1.81 (19)	0.00 (0)	
1 other adult			20.29 (213)	22.73 (5)	
2 or more adults			77.90 (818)	77.27 (17)	
Elderly (60 years +)		1072			=0.480
No elderly			81.71 (858)	81.82 (18)	
1 elderly			13.33 (140)	18.18(4)	
2 or more elderly			4.95 (52)	0.00 (0)	
Type of housing		1062			=0.176
Formal			75.38 (784)	86.36 (19)	
Informal			24.62 (256)	13.64 (3)	

Psychosocial/behavioural characteristics

Depression/anxiety**		1056			=0.003
Not anxious/depressed			72.34 (748)	50.00 (11)	
Moderately anxious/depressed			21.86 (226)	27.27 (6)	
Extremely anxious/depressed			5.80 (60)	22.73 (5)	
Substance use**		1057	16.31 (196)	33.33 (7)	=0.038
Non-disclosure		1058	14.29 (148)	9.09 (2)	=0.376
Stigma index**		1053	1.42 (1032)	1.70 (21)	=0.002
[±SD]			[0.45]	[0.67]	
Social support					
No support group membership		1057	82.72 (857)	80.95 (17)	=0.832
No emotional support		1054	59.05 (610)	61.90 (13)	=0.792

Treatment knowledge index** [±SD]	1056	4.86 (1035) [0.38]	4.71 (21) [0.44]	=0.045
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Clinical aspects

Side-effects**	935	21.88 (200)	38.10 (8)	=0.077
Disease status	989			=0.538
<200		33.81 (328)	47.37 (9)	
200-500		50.72 (492)	42.11 (8)	
>500		15.46 (150)	10.53 (2)	
Mean time on ART (years)** [±SD]	967	1.32 (946) [0.86]	1.01 (21) [0.82]	=0.052

Health-care administration and delivery

Access barriers				
Clinic*	1044	6.07 (62)	13.64 (3)	=0.152
Hospital**	1050	6.03 (62)	18.18 (4)	=0.044
Service-satisfaction index				
Clinic**	1045	4.20 (1024) [±SD] [0.51]	4.09 (21) [0.55]	=0.173
Hospital**	1051	4.47 (1030) [±SD] [0.49]	4.49 (21) [0.53]	=0.570
Service needs	1052	25.70 (265)	33.33 (7)	=0.429
Quality-of-DRT index	1048	4.47 (1027) [±SD] [0.45]	4.54 (21) [0.45]	=0.742
No treatment buddy	1054	64.96 (671)	47.62 (10)	=0.100
No regular health care providers				
Clinic staff	1021	40.34 (403)	59.09 (13)	=0.077
Hospital nurse	1024	33.43 (335)	40.91 (9)	=0.463
Hospital doctor	1016	41.65 (414)	36.36 (8)	=0.619
Rating of health care providers				
ARV-related services index	1056	1.40 (1035) [±SD] [0.50]	1.35 (21) [0.56]	=0.671
Respect by health care providers index**	1056	1.49 (1035) [±SD] [0.54]	1.53 (21) [0.56]	=0.372
ARV medication information index*	1055	1.46 (1034) [±SD] [0.50]	1.44 (13) [0.50]	=0.571

° *P*-values for test of difference, between adherent and non-adherent women, in means or distributions.

* Significant at the 10% level ($P \leq 0.10$) in non-sex-disaggregated analysis (See Table 1 in Annexure D).

** Significant at the 5% level ($P \leq 0.05$) in non-sex-disaggregated analysis (See Table 1 in Annexure D).

- Demographic characteristics

None of the demographic characteristics assessed among women showed a statistically significant association with adherence to ARV medications ($P > 0.05$). However, a marginally significant relationship was found between level of education and adherence ($P = 0.061$). A larger proportion of non-adherent women reported no education (14%) or only primary level education (36%) compared with adherent women, who reported no education (3%) or only primary level education (27%).

- Psychosocial/behavioural characteristics

A statistically significant difference was found between medication adherence and self-reported depression or anxiety. Adherent women were more likely to report not being anxious or depressed than non-adherent women (72% vs. 50%; $P=0.003$). Although substance use showed a significant association with non-adherence ($P=0.038$), tobacco use showed the strongest association with non-adherence when substance use was assessed separately ($P=0.005$). Results of reported alcohol, tobacco and dagga use by adherence for women are shown in Table 7.

Table 7: Reported substance use by medication adherence among women on ART in the Free State public health sector

Substance use	Total N	100% adherence %(n)	<100% adherence %(n)	P-value
Alcohol**	1057	5.31 (55)	14.29 (3)	=0.074
Tobacco**	1057	12.64 (131)	33.33 (7)	=0.005
Dagga	1056	0.00 (0)	0.00 (0)	N/A

** Significant at the 5% level ($P \leq 0.05$) in non-sex-disaggregated analysis (See Table 3 in Annexure D).

No differences were found with respect to medication non-adherence and non-disclosure of HIV/AIDS-status, not belonging to a support group for people living with HIV/AIDS, or not having a person who provides emotional support. Higher stigma index scores were significantly associated with non-adherence ($P=0.002$), suggesting that non-adherent women experience more stigma than adherent women. Lower scores on the treatment knowledge index showed a statistically significant association with non-adherence to medications ($P=0.045$), which suggests that non-adherent women have poorer knowledge concerning the appropriateness of stopping ARV treatment, the relationship between ARVs and disease progression and further transmission of the virus, and the acceptability of missing ARV medications.

- Clinical aspects

Mean time on ART showed a borderline significant association with adherence. Adherent women were more likely to have been on treatment for a longer period of time than non-adherent women (1.32 vs. 1.01; $P=0.052$). Although a larger proportion

of non-adherent women (38%) reported experiencing ARV-related side-effects in comparison with adherent women (22%), the difference was not significant. No significant differences were found in respect of disease status.

- Health-care administration and delivery

Except for experiencing access barriers in visiting hospitals, no other significant relationships were found between medication non-adherence and health-care administration and delivery factors. Non-adherent women were significantly more likely to report experiencing difficulty in visiting the hospital for their ARV-related treatment, care and support (18%) than adherent women (6%). Financial costs was the difficulty that all non-adherent women (100%) gave as the difficulty that they experienced in visiting hospital facilities. A marginally significant difference was found regarding medication adherence and regular health care providers at clinics ($P=0.077$). Non-adherent women (41%) were less likely to have regular health-care providers than adherent women (60%).

4.4.4.4 Multivariate analysis of factors associated with ARV medication non-adherence for men and women

Multivariate logistic regression analyses were conducted, separately for men and women, to examine the association between non-adherence to ARV medications and the various demographic, psychosocial or behavioural, clinical, and health-care administration and delivery characteristics found to be significant in the bivariate analyses ($P<0.05$). The results of the logistic regression model for men are presented in Table 8.

Table 8: Logistic regression analysis of factors associated with non-adherence to ARV medications among men (n = 452)

Factor	OR	(95% CI)	P-value
Population group	1.63	(0.68 - 3.91)	=0.268
Treatment knowledge index	0.42	(0.17 - 1.02)	=0.055
Mean time on ART (years)	0.45	(0.18 - 1.12)	=0.086

Access barriers – Hospital	5.03	(1.19 - 21.27)	=0.028
Service satisfaction index - Clinic	0.55	(0.08 - 3.58)	=0.529
Service satisfaction index - Hospital	0.21	(0.03 - 1.33)	=0.097
Respect by health-care providers index	2.16	(0.44 - 10.56)	=0.342
ARV medication information index	0.711	(0.11 - 4.59)	=0.720

Only experiencing difficulties in visiting hospital facilities remained significant in the regression model as a predictor of non-adherence among men ($P<0.005$). The odds ratio for access barriers at hospital facilities was 5.03 ($P=0.028$), suggesting that the odds of non-adherence increases significantly with experiences of access barriers to hospital facilities increases. Treatment knowledge showed a borderline significant association with adherence (OR=0.42, 95% CI: 0.17, 1.02; $P=0.055$), suggesting that as treatment knowledge increases so do the odds of adherence to ARV medications.

Variables that remained significant in the regression analysis for women are presented in Table 9.

Table 9: Logistic regression analysis of factors associated with non-adherence to ARV medications among women (n = 1042)

Factor	OR	95% CI	P-value
Depression/anxiety	1.73	(0.92 - 3.27)	=0.089
Tobacco use	3.04	(1.15 - 8.00)	=0.025
Stigma index	2.60	(1.14 - 5.93)	=0.023
Treatment knowledge index	0.58	(0.27 - 1.25)	=0.166
Access barriers – Hospital	2.15	(0.61 - 7.54)	=0.233

Self-reported depression or anxiety, treatment knowledge, and experiencing access barriers in visiting the hospital were no longer significant predictors of non-adherence to ARV medications ($P>0.05$). The use of tobacco and stigma were the only two factors that remained independently associated with non-adherence among women in the medication adherence model ($P<0.005$). Results show that women who smoked tobacco in the 30 days preceding their interviews (OR=3.04, 95% CI: 1.15, 8.00; $P=0.025$), had a higher odds of non-adherence than women who did not report smoking tobacco. With regard to stigma, the odds of non-adherence increased as scores on the stigma index increased (OR=2.60, 95% CI: 1.14, 5.93; $P=0.023$). Thus,

the more stigma a patient experiences, the higher the odds of not adhering to ARV medications.

4.4.5 Factors associated with non-adherence to scheduled appointments in men and women

This section presents the results from the comparison of adherence to scheduled ART appointments between men and women, for bivariate analyses of predictor factors for men and women, and for logistic regression models for men and women.

4.4.5.1 Comparison of scheduled appointment adherence between men and women

Results of the bivariate analysis of scheduled appointment adherence by sex are reported in Table 10. No statistically significant difference was found between the proportion of adherent and non-adherent men and women ($P>0.05$); both men and women reported approximately 91% adherence to their scheduled appointments.

Table 10: Self-reported scheduled ART appointment adherence by sex

Adherence to scheduled appointments	Total N	100% adherence %(n)	<100% adherence %(n)	P-value
Men	446	90.58 (404)	9.42 (42)	=0.877
Women	928	90.84 (843)	9.16 (85)	

4.4.5.2 Factors associated with scheduled appointment non-adherence in men

The results of descriptive statistics for scheduled appointment adherence among men are presented in Table 11 and described thereafter.

Table 11: Factors associated with non-adherence to scheduled appointments among men on ART in the Free State public health sector

Demographic characteristics	Total N	100% adherence %(n)	<100% adhere %(n)	P-value °
Mean age (years)* [±SD]	441	43.39 (399) [8.84]	40.95 (42) [7.84]	=0.043
Population group**	446			=0.348
Black		93.56 (378)	95.24 (40)	
Coloured		2.72 (11)	4.76 (2)	

Indian/Asian		0.00 (0)	0.00 (0)	
White		3.71 (15)	0.00 (0)	
Level of education	443			=0.033
None		3.99 (16)	14.29 (6)	
Primary		29.18 (117)	16.67 (7)	
Some secondary		49.13 (197)	50.00 (21)	
Matric		14.71 (59)	19.05 (8)	
Tertiary		2.99 (12)	0.00 (0)	
Marital status*	446			=0.086
Living together: married		37.13 (150)	19.05 (8)	
Living together: unmarried		13.86 (56)	16.67 (7)	
Spouse/partner living elsewhere		21.04 (85)	21.43 (9)	
Single		27.97 (113)	42.86 (18)	
Employment status	445			=0.037
Employed		67.74 (130)	83.33 (7)	
Unemployed		32.26 (273)	16.67 (35)	
Mean income (Rands)**	446	1369.95 (404)	956.19 (42)	=0.077
[±SD]		[1857.80]	[899.11]	
Breadwinner	444	76.12 (306)	71.43 (30)	=0.500
Mean household size (number of persons)	445	3.85 (403)	3.88 (42)	=0.539
[±SD]		[1.85]	[2.23]	
Household age structure				
Children (>14 years)	446			=0.927
No children		39.36 (159)	38.10 (16)	
1 child		30.45 (123)	33.33 (14)	
2 or more children		30.20 (122)	28.57 (12)	
Adults (15-59 years)	446			=0.483
No adults		2.72 (11)	0.00 (0)	
1 other adult		19.80 (80)	23.81 (10)	
2 or more adults		77.48 (313)	76.19 (32)	
Elderly (60 years +)	446			=0.847
No elderly		79.95 (323)	76.19 (32)	
1 elderly		12.13 (49)	14.29 (6)	
2 or more elderly		7.92 (32)	9.52 (4)	
Type of housing	444			=0.173
Formal		80.35 (323)	71.43 (30)	
Informal		19.96(79)	28.57 (12)	

Psychosocial/behavioural characteristics

Depression/anxiety**	446			<0.001
Not anxious/depressed		77.23 (312)	50.00 (21)	
Moderately anxious/depressed		20.30 (82)	23.81 (10)	
Extremely anxious/depressed		2.48 (10)	26.19 (11)	
Substance use**	446	28.96 (117)	52.38 (22)	=0.002
Non-disclosure**	446	10.64 (43)	16.67 (7)	=0.239
Stigma index**	444	1.34 (402)	1.44 (42)	=0.094
[±SD]		[0.44]	[0.49]	
Social support				
No support group membership	446	90.59 (366)	92.86 (39)	=0.629
Emotional support	445	71.71 (289)	64.29 (27)	=0.313
Treatment knowledge index**	446	4.86 (404)	4.63 (42)	<0.001
[±SD]		[0.81]	[0.37]	

Clinical aspects

Side-effects	437	10.08 (40)	15.00 (6)	=0.333
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Disease status**	431			=0.538
<200		26.42 (104)	34.21 (13)	
200-500		64.12 (252)	55.26 (21)	
>500		9.41 (37)	10.53 (4)	
Mean time on ART (years)**	441	1.90 (400)	1.79 (41)	=0.221
[±SD]		[0.88]	[0.82]	

Health-care administration and delivery

Access barriers				
Clinic**	442	3.74 (15)	43.90 (18)	<0.001
Hospital**	443	6.22 (25)	41.46 (17)	<0.001
Service-satisfaction index				
Clinic**	443	4.23 (403)	3.82 (40)	<0.001
[±SD]		[0.49]	[0.58]	
Hospital**	444	4.48 (402)	4.28 (42)	=0.008
[±SD]		[0.51]	[0.53]	
Service needs*	446	20.54 (83)	19.05 (8)	=0.819
Quality-of-DRT index	443	4.56 (401)	4.60 (42)	=0.693
[±SD]		[0.46]	[0.47]	
No treatment buddy	445	39.70 (160)	45.24 (19)	=0.486
No regular health care providers				
Clinic staff	432	47.84 (188)	56.41 (22)	=0.307
Hospital nurse	441	39.85 (159)	47.62 (20)	=0.329
Hospital doctor**	433	40.56 (159)	53.66 (22)	=0.106
Rating of health care providers				
ARV-related services index**	445	1.42 (403)	1.72 (42)	<0.001
[±SD]		[0.48]	[0.62]	
Respect by health care providers index**	446	1.47 (404)	1.88 (42)	<0.001
[±SD]		[0.50]	[0.64]	
ARV medication information index*	446	1.46 (404)	1.75 (42)	<0.001
[±SD]		[0.48]	[0.56]	

° *P*-values for test of difference, between adherent and non-adherent men, in means or distributions.

* Significant at the 10% level ($P \leq 0.10$) in non-sex-disaggregated analysis (See Table 2 in Annexure D).

** Significant at the 5% level ($P \leq 0.05$) in non-sex-disaggregated analysis (See Table 2 in Annexure D).

- Demographic characteristics

Of all the demographic variables tested, only age, level of education and employment status were found to be significantly associated with scheduled appointment adherence. On average, non-adherent men were found to be younger (41 years) than adherent men (43 years; $P=0.043$). The proportion of non-adherent men with no education (14%) was significantly larger than the proportion of adherent men (4%; $P=0.033$). Employed men (83%) were more likely than unemployed men (17%) to report non-adherence to their scheduled ART appointments ($P=0.037$).

- Psychosocial/behavioural characteristics

Depression/anxiety was highly associated with scheduled appointment adherence among men ($P<0.001$). The proportion of patients reporting no depression/anxiety was significantly higher among adherent men (77%) compared with non-adherent men (50%), suggesting that patients who perceive themselves to be anxious or depressed were more likely to be non-adherent. Substance use was significantly associated with adherence ($P=0.002$), and the subgroup analysis of the substance use variable (presented in Table 12) showed significantly higher use of alcohol (40% vs. 17%; $P<0.001$), tobacco (38% vs. 20%; $P=0.009$) and dagga (5% vs. 0%; $P<0.001$) among non-adherent men compared with adherent men.

Table 12: Reported substance use by scheduled appointment adherence among men on ART in the Free State public health sector

Substance use	Total N	100% adherence %(n)	<100% adherence %(n)	P-value
Alcohol**	446	17.08 (69)	40.48 (17)	<0.001
Tobacco**	446	20.54 (83)	38.10 (16)	=0.009
Dagga**	446	0.00 (0)	4.76 (2)	=0.009

** Significant at the 5% level ($P \leq 0.05$) in non-sex-disaggregated analysis (See Table 4 in Annexure D).

Treatment knowledge was also significantly associated with adherence ($P<0.001$). On average, adherent men showed a significantly higher average treatment knowledge score than non-adherent men, suggesting that ART knowledge is more limited among non-adherent men than adherent men. No significant differences were found in respect of stigma, social support or non-disclosure of HIV/AIDS-status ($P>0.005$).

- Clinical aspects

No statistically significant results were found when comparing adherent and non-adherent men for side-effects, disease status or treatment duration for differences.

- Health-care administration and delivery

Differences in adherence were found when comparing the accessibility of clinic and hospital facilities across adherent and non-adherent groups of men. Non-adherent men reported experiencing significantly more access barriers in visiting their respective clinics (44% vs. 4%; $P<0.001$). Analysis of the open question regarding the

specific difficulties patients experienced showed that 53% experienced financial difficulties, 30% experienced physiological difficulties (such as painful or swollen legs, knees or feet, which prevent a patient from accessing a particular facility), 9% experienced transportation difficulties and 9% experienced employment-related barriers in visiting clinic facilities. Non-adherent men who reported experiencing difficulties in visiting clinic facilities cited financial (50%) and physiological (44%) difficulties. Similarly, 41% of non-adherent men reported experiencing difficulty in visiting the hospital ($P<0.001$) compared with 6% of adherent men. Service satisfaction at both hospitals ($P<0.001$) and clinics ($P=0.008$) were found to be positively associated with adherence. Adherence was also significantly related to lower satisfaction scores on the ARV-related service satisfaction index, and lower rating scored on the respect by health-care providers index and ARV medication information index (all, $P<0.001$). No differences in service needs, perceived quality of DRT, not having a treatment buddy or not having regular health-care providers and adherence were found.

4.4.5.3 Factors associated with scheduled appointment non-adherence in women

The results of the bivariate analyses of appointment adherence with demographic, psychosocial/behavioural, clinical, and health-care administration and delivery variables are summarised in Table 13 and described below.

- Demographic characteristics

Statistically significant differences were found among women of different population groups in adherence to scheduled ART appointments ($P=0.012$), however, this result needs to be interpreted with caution due to the small number of women in the population groups other than “black”. Although adherence was unrelated to household size or the number of children and adults that women reside with, adherence was significantly associated with residing with elderly persons ($P=0.002$). Adherent women (82%) were more likely to be residing in households with no elderly persons, than non-adherent women (76%). No other demographic variables showed statistically

significant results when scheduled appointment adherence was compared between adherent and non-adherent women ($P>0.05$).

Table 13: Factors associated with non-adherence to scheduled appointments among women on ART in the Free State public health sector

Demographic characteristics	Total N	100% adherence %(n)	<100% adherence %(n)	P-value °
Mean age (years)* [±SD]	910	37.71 (826) [7.88]	36.92 (84) [8.33]	=0.193
Population group**	928			=0.012
Black		96.56 (814)	91.76 (78)	
Coloured		2.73 (23)	5.88 (5)	
Indian/Asian		0.12 (1)	2.35 (2)	
White		0.59 (5)	0.00 (0)	
Level of education	927			=0.602
None		3.56 (30)	3.53 (3)	
Primary		26.01 (219)	32.94 (28)	
Some secondary		49.52 (417)	42.35 (36)	
Matric		18.17(153)	17.65 (15)	
Tertiary		2.73 (23)	3.53 (3)	
Marital status*	921			=0.561
Living together: married		15.55 (130)	10.59 (9)	
Living together: unmarried		7.42 (62)	8.24 (7)	
Spouse/partner living elsewhere		24.52 (205)	22.35 (19)	
Single		52.51 (439)	58.82 (50)	
Employment status	927			=0.904
Employed		81.71 (688)	81.18 (69)	
Unemployed		18.29 (154)	18.82 (16)	
Mean income (Rands)** [±SD]	928	815.78 (843) [681.96]	740.85 (85) [754.81]	=0.170
Breadwinner	926	57.60 (485)	53.57 (45)	=0.477
Mean household size (number of persons) [±SD]	926	4.32 (841) [2.32]	4.19 (85) [2.50]	=0.312
Household age structure				
Children (>14 years)	928			=0.908
No children		25.50 (215)	25.88 (22)	
1 child		35.71 (301)	37.65 (32)	
2 or more children		38.79 (327)	36.47 (31)	
Adults (15-59 years)	928			=0.907
No adults		0.95 (8)	1.18 (1)	
1 other adult		19.45 (164)	21.18 (18)	
2 or more adults		79.60 (671)	77.65 (66)	
Elderly (60 years +)	924			=0.002
No elderly		82.21 (693)	76.47 (65)	
1 elderly		12.10 (102)	23.53 (20)	
2 or more elderly		5.69 (48)	0.00 (0)	
Type of housing	927			=0.472
Formal		77.55 (653)	74.12 (63)	
Informal		22.45 (189)	25.88 (22)	
Psychosocial/behavioural characteristics				
Depression/anxiety** Not anxious/depressed	925	76.93 (647)	52.38 (44)	<0.001

Moderately anxious/depressed		19.02 (160)	30.95 (26)	
Extremely anxious/depressed		4.04 (34)	16.67 (14)	
Substance use**	927	18.53 (156)	24.71 (21)	=0.167
Non-disclosure**	928	16.01 (135)	23.53 (20)	=0.077
Stigma index**	926	1.34 (841)	1.51 (85)	<0.001
[±SD]		[0.43]	[0.43]	
Social support				
No support group membership	928	82.68 (697)	83.53 (71)	=0.844
Emotional support	925	64.05 (538)	69.41 (59)	=0.325
Treatment knowledge index**	927	4.87 (842)	4.89 (85)	=0.679
[±SD]		[0.36]	[0.37]	
Clinical aspects				
Side-effects	909	15.50 (128)	13.25 (11)	=0.588
Disease status**	896			=0.014
<200		21.76 (178)	23.08 (18)	
200-500		58.07 (475)	43.59 (34)	
>500		20.17 (165)	33.33 (26)	
Mean time on ART (years)**	914	1.84 (829)	1.69 (85)	=0.063
[±SD]		[0.91]	[0.77]	
Health-care administration and delivery				
Access barriers				
Clinic**	925	3.69 (31)	31.76 (27)	<0.001
Hospital**	925	3.81 (32)	25.88 (22)	<0.001
Service-satisfaction index				
Clinic**	927	4.21 (843)	3.85 (84)	<0.001
[±SD]		[0.50]	[0.48]	
Hospital**	924	4.50 (839)	4.34 (85)	=0.003
[±SD]		[0.48]	[0.53]	
Service needs*	924	22.95 (193)	13.25 (11)	=0.042
Quality-of-DRT index	915	4.47 (830)	4.49 (85)	=0.683
[±SD]		[0.45]	[0.47]	
No treatment buddy	924	66.83 (561)	69.41 (59)	=0.634
No regular health care providers				
Clinic staff	904	45.38 (373)	50.00 (41)	=0.423
Hospital nurse	923	35.68 (299)	38.82 (33)	=0.565
Hospital doctor**	912	58.77 (341)	55.29 (47)	=0.013
Rating of health care providers				
ARV-related services index**	928	1.40 (843)	1.61 (85)	<0.001
[±SD]		[0.50]	[0.17]	
Respect by health care providers index**	928	1.47 (843)	1.72 (85)	<0.001
[±SD]		[0.55]	[0.55]	
ARV medication information index*	928	1.45 (843)	1.64 (85)	<0.001
[±SD]		[0.49]	[0.49]	

^o *P*-values for test of difference, between adherent and non-adherent women, in means or distributions.

* Significant at the 10% level ($P \leq 0.10$) in non-sex-disaggregated analysis (See Table 2 in Annexure D).

** Significant at the 5% level ($P \leq 0.05$) in non-sex-disaggregated analysis (See Table 2 in Annexure D).

- Psychosocial/behavioural characteristics

Adherence to scheduled appointments was significantly related to self-perceived anxiety or depression among women ($P < 0.001$); while only 23% of adherent women reported either moderate or extreme anxiety or depression, non-adherent were

approximately twice as likely to report either moderate or extreme depression or anxiety (48%). Neither combined substance use, nor any individually assessed substance in the subgroup analysis ($P>0.05$) as presented in Table 14, showed a significant association with appointment adherence. A higher average score on the stigma index among non-adherent patients suggests that experiencing stigma is significantly related to non-adherence of scheduled ART appointments ($P<0.001$). Non-disclosure of status showed a relatively weak association with appointment adherence ($P=0.077$), while social support and the treatment knowledge showed no relationship ($P>0.05$).

Table 14: Reported substance use by scheduled appointment adherence among women on ART in the Free State public health sector

Substance use	Total N	100% adherence %(n)	<100% adherence %(n)	P-value
Alcohol**	927	6.77 (57)	9.41 (8)	=0.363
Tobacco**	926	14.15 (119)	18.82 (16)	=0.245
Dagga**	926	0.00 (0)	0.00 (0)	N/A

** Significant at the 5% level ($P \leq 0.05$) in non-sex-disaggregated analysis (See Table 4 in Annexure D).

- Clinical aspects

Experiencing ARV-related side-effects showed no association with appointment adherence ($P>0.05$). Adherence showed a statistically significant relationship with disease status ($P=0.014$). Furthermore, a weak association was found between treatment duration and adherence ($P<0.063$), where non-adherent women were more likely to be on treatment for a shorter length of time than adherent patients. This suggests that appointment adherence improves with treatment duration.

- Health-care administration and delivery

Significantly more difficulties were reported by non-adherent women compared with adherent women in visiting their clinic (32% vs. 4%; $P<0.001$) and hospital facilities (26% vs. 4%; $P<0.001$). Experiencing financial difficulty was the most reported difficulty visiting both clinic (58%) and hospital facilities (81%). Lower service satisfaction index scores reported for the clinic and hospital facilities were significantly associated with non-adherence to scheduled appointments ($P<0.005$). This finding

suggests that adherence decreases as satisfaction with services at either type of facility declines. Unexpectedly, adherent women reported more service needs than non-adherent women ($P=0.42$); 23% of adherent women reported having HIV/AIDS-related service needs compared with 13% of non-adherent women. Having no regular health-care providers showed a significant association with adherence with regard to hospital doctors ($P=0.013$), while regular clinic staff and having a regular nurse at hospital facilities showed no association ($P>0.05$). An inverse relationship was found, since non-adherent women (55%) were more likely to report having a regular doctor than adherent women (59%). Scheduled appointment adherence was also significantly associated with higher ratings of ARV-related services provided by health care providers ($P<0.001$), and high satisfaction with perceived respect shown ($P<0.001$) and high satisfaction with ARV medication information provided by health care providers ($P<0.001$).

4.4.5.4 Multivariate analyses of factors associated with non-adherence to scheduled appointments

Results of the multivariate regression analysis, examining factors independently associated with adherence to scheduled ART appointments among men, are presented in Table 15. Self-reported depression or anxiety and experiencing difficulty in visiting clinics were inversely associated with adherence. Men who reported depression or anxiety were more likely to be non-adherent (OR=0.38, 95% CI: 0.20, 0.74; $P=0.004$). Likewise, men who reported experiencing difficulties in visiting their respective clinic, showed higher predicted non-adherence to appointments (OR=0.82, 95% CI: 0.03, 0.27; $P<0.001$).

Table 15: Logistic regression analysis of factors associated with non-adherence to scheduled ART appointments among men (n = 428)

Factor	OR	(95% CI)	P-value
Mean age (years)	1.04	(0.99 - 1.10)	=0.125
Level of education	1.19	(0.65 - 2.16)	=0.578
Employment status	2.13	(0.65 - 6.98)	=0.214
Depression/anxiety	0.38	(0.20 - 0.74)	=0.004
Alcohol use	0.43	(0.14 - 1.30)	=0.135
Tobacco use	1.03	(0.34 - 3.06)	=0.963
Treatment knowledge index	1.82	(0.84 - 3.95)	=0.127

Access barriers – Clinic	0.82	(0.03 - 0.27)	<0.001
Access barriers – Hospital	0.76	(0.22 - 2.57)	=0.658
Service satisfaction index - Clinic	2.14	(0.68 - 6.71)	=0.193
Service satisfaction index - Hospital	0.41	(0.10 - 1.63)	=0.208
ARV-related services index	0.58	(0.19 - 1.77)	=0.335
Respect by health care providers index	0.64	(0.16 - 2.53)	=0.521
ARV medication information index	0.97	(0.26 - 3.56)	=0.960

The multivariate logistic regression model for women (Table 16) shows depression or anxiety, access barriers at both clinics and hospitals, satisfaction with services at clinics, and having HIV/AIDS-related service needs as statistically significant predictors of adherence to scheduled ART appointments among women ($P<0.005$). With regard to anxiety or depression, adherent women were less likely to self-report experiences of anxiety or depression than non-adherent women (OR=0.60, 95% CI: 0.38, 0.96; $P<0.031$). Experiencing no difficulty in visiting either the hospital (OR=0.27, 95% CI: 0.09, 0.31; $P=0.020$) or the clinic (OR=0.27, 95% CI: 0.05, 0.31; $P<0.001$), significantly predicted appointment adherence among women. Women who reported lower satisfaction with service provision at clinics showed an increase risk of non-adherence to scheduled appointments (OR=5.19, 95% CI: 2.43, 11.06; $P<0.001$). Lastly, fewer self-reported HIV/AIDS-related service needs were found to significantly increase the odds of non-adherence to scheduled appointments among women (OR=4.21, 95% CI: 1.77, 9.99; $P<0.001$).

Table 16: Logistic regression analysis of factors associated with non-adherence to scheduled ART appointments among women (n = 870)

Factor	OR	95% CI	P-value
Population group	0.88	(0.43 - 1.80)	=0.729
Elderly	0.73	(0.44 - 1.21)	=0.221
Depression/anxiety	0.60	(0.38 - 0.96)	=0.031
Stigma index	0.61	(0.34 - 1.11)	=0.107
Disease status	0.73	(0.47 - 1.13)	=0.158
Access barriers – Clinic	0.13	(0.05 - 0.31)	<0.001
Access barriers – Hospital	0.27	(0.09 - 0.82)	=0.020
Service satisfaction index - Clinic	5.19	(2.43 - 11.06)	<0.001
Service satisfaction index - Hospital	0.61	(0.27 - 1.38)	=0.273
Service needs	4.21	(1.77 - 9.99)	=0.001
No regular health care providers - Hospital	1.07	(0.59 - 1.96)	=0.821
ARV-related services index	0.97	(0.45 - 2.06)	=0.927
Respect by health care providers index	1.07	(0.47 - 2.45)	=0.868
ARV medication information index	0.79	(0.36 - 1.74)	=0.557



4.5 SUMMARY

The main predictors of medication adherence identified by this study are summarised in tables 17 below. From the table it is clear that there are more differences than similarities between men and women, which are indicative of the different gendered daily life factors or lived experiences affecting the medication adherence behaviour of men and women in this study.

Table 17: Synoptic table of identified similarities and differences in medication adherence by sex

Predictor variable	Similarities in medication adherence		
	men	women	Description
Treatment knowledge index ^o	√ *	√	Treatment knowledge increases adherence to medications, especially among men.
Access barriers: Hospital	√	√	Experiencing difficulties in visiting hospital facilities increases medication non-adherence, especially among men.
Predictor variable	Differences in medication adherence		
	men	women	Description
Population group ^o	√	X	Black men more likely than men from all other population groups to non-adherent to medications.
Depression/ anxiety	X	√	Self-reported depression or anxiety among women is associated with medication non-adherence.
Substance use • Tobacco use	X	√	Tobacco use is a strong predictor of medication non-adherence among women.
Stigma index	X	√	Increased perceived stigma results in non-adherence to medication among women.
Mean time on ART (years)	√	X	Medication adherence among men increases over time on treatment.
Service satisfaction index • Clinic • Hospital	√	X	Less satisfaction with services at health care facilities (i.e., provision of medical care, complaint procedure, cleanliness of facility, privacy, confidentiality, information provision, consultation language, operating hours, waiting times) is associated with poor adherence to medications among men.
Rating of health care providers • Respect by healthcare providers index • ARV medication information index	√	X	Patient-provider relationships characterised by respect and good delivery of information predicts better medication adherence among men.

Note: Shaded blocks represent variables found to be significant predictors of non-adherence in logistic regression analysis.

√ Variable found to be a significant predictor of non-adherence in bivariate analysis.

X Variable not associated with adherence in the current sample.

* Borderline significance in logistic regression analysis

° Interpret with caution; See variable description for explanation.

With regard to predictors of non-adherence to scheduled appointments more significant similarities between men and women were identified namely, depression or anxiety and experiencing difficulty in visiting clinic facilities (see Table 18).

Table 18: Synoptic table of identified similarities and differences in scheduled appointment adherence by sex

Predictor variable	Similarities in scheduled appointment adherence		
	men	women	Description
Depression/ anxiety	√	√	Self-reported depression or anxiety among men and women is associated with non-adherence to scheduled appointments.
Access barriers: Clinic	√	√	Experiencing difficulties in visiting health care facilities predicts non-adherence to scheduled appointment for men and women.
Access barriers: Hospital	√	√	
Service satisfaction index: Clinic	√	√	Less satisfaction with services at health care facilities (i.e., provision of medical care, complaint procedure, cleanliness of facility, privacy, confidentiality, information provision, consultation language, operating hours, and waiting times) is equally associated with poor adherence to scheduled appointments among men and women. However, poor satisfaction with services at clinics is a strong predictor of non-adherence among women.
Service satisfaction index: Hospital	√	√	
Rating of health care providers <ul style="list-style-type: none"> • ARV-related services index • Respect by healthcare providers index • ARV medication information index 	√	√	Patient-provider relationships characterised by poor respect, poor delivery of information, and poor delivery of ARV-related services is associated with poor adherence to schedule appointment among both men and women.
Predictor variable	Differences in scheduled appointment adherence		
	men	women	
Population group°	X	√	Black women more likely than women from all other population groups to non-adherent to medications.
Mean age (years)	√	X	Younger men are more likely to be non-adherent to their scheduled appointments.
Level of education	√	X	Non-adherence to appointments is most likely to occur among men with no education; adherence increases as level of education increases.
Employment status	√	X	Employed men are more likely to employed men to be non-adherent to heir scheduled appointments.

Household age structure Elderly (60 years +)	X	√	Women who reside in households with elderly persons are more likely to adhere to their scheduled appointments.
Substance use • Alcohol use • Tobacco use	√	X	The use of alcohol and tobacco is associated with non-adherence to scheduled appointment among men.
Treatment knowledge index [°]	√	X	Treatment knowledge increases adherence to appointments among men.
Service needs	X	√	Fewer self-reported service needs predicts non-adherence to scheduled appointments among women.
No regular healthcare providers • Hospital doctor	X	√	Regular doctors at hospital facilities predicted non-adherence to scheduled appointments among women.

Note: Shaded blocks represent variables found to be significant predictors of non-adherence in logistic regression analysis.

√ Variable found to be a significant predictor of non-adherence in bivariate analysis.

X Variable not associated with adherence in the current sample.

[°] Interpret with caution; See variable description for explanation.

These significant predictors of non-adherence to ARV medications and scheduled ART appointments identified for men and women are discussed in greater detail, drawing on the framework outlined in the previous chapter, in the next chapter.

CHAPTER 5 –DISCUSSION OF FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

Despite the proven success of ART at reducing morbidity and mortality, it is clear from the overview of literature that if patients with AIDS are not in a position to maintain access to treatment and/or are unable to adhere to their ARV regimens, they may not effectively benefit from ART. Although various factors have been identified as being predictive of non-adherence to ARV medications and ART appointments, studies seldom sex-disaggregate data before analysis, thus ignoring any underlying gender dynamics and possibly masking any inequitable treatment outcomes among men and women.

The purpose of this study was to investigate whether demographic, psychosocial/behavioural, clinical, or health-care administration and delivery factors were differently associated with medication adherence and sustained access to treatment among men and women on ART in the Free State public health sector. In the following section research findings are discussed, areas that require further research are indicated, and an outline is provided of the implications of the findings for policy and practice, especially where strategies are necessary to challenge non-adherence to treatment.



5.2 DISCUSSION OF RESEARCH FINDINGS

The focus of this study was to examine whether gender differences exist between men and women in adherence to ARV medications and sustained access to ART (measured as adherence to scheduled appointments), as well as to describe any significant differences or similarities between men and women. Study results show both significant similarities and differences in demographic, psychosocial or behavioural, clinical, health-care administration and delivery factors significantly affecting adherence to both ARV medications and scheduled ART appointments between men and women.

5.2.1 Demographic differences and similarities

Both the women and the men in the sample showed more significant differences than similarities when demographic characteristics were statistically compared. For example, while men and women in the sample were similar regarding *level of education, the number of elderly persons they reside with, and type of housing*, they differed significantly with regard to the following variables, namely *age, population group, marital status, employment status, mean income, being the main income generators within households (or breadwinner), mean household size, and number of children and other adults that a patient resides with*.

- Conclusion: The 'lived experience' of men and women in this sample of ART patients is more different than it is similar.

5.2.2 Medication adherence and sustained access to ART in the Free State

The high self-reported medication adherence reported in this sample is higher than the level of adherence reported by other South African medication adherence studies. For example, in a cross-sectional study of medication adherence in Soweto by Nachege et al. (2004), 88% of patients self-reported an adherence level of more than 95% for the previous month. The present study reveals that medication adherence in the Free State is higher than in other areas of South Africa, although this finding may be a result of over-reporting medication adherence – a known consequence of using self-reported measures of adherence (Arnsten et al., 2001). A cohort study conducted

in Cape Town using clinic-based pill counts and pharmacy refill data (considered the gold standard measure of medication adherence) reported a mean adherence level of 87% (Orrell et al., 2003).

- Conclusion: Self-reported medication adherence in the Free State, although higher than adherence reported in previous South African studies, is likely to be over-reported by patients.

Although no appointment adherence studies have been published in South Africa, appointment adherence in this study is higher than appointment adherence reported in studies among HIV/AIDS patients in America and Korea (Catz et al., 1999; McClure et al., 1999; Park et al., 2007).

- Conclusion: The majority of patients on ART in the Free State public health sector are able to successfully maintain access to their required treatment, care and support.

5.2.3 Sustained access is positively related to medication adherence

Self-reported adherence to ARV medications (98%) was higher than self-reported adherence to ART appointments (91%), a difference that was previously reported in a study examining both types of adherence outcomes (Mellins et al., 2003). When medication adherence and appointment adherence were compared it was revealed that non-adherence to appointments was positively associated with non-adherence to ARV medications. This finding supports arguments that adherence to drug regimens is not possible without first attending medical appointments (Catz et al., 1999; McClure et al., 1999). Furthermore, this finding suggests that improving appointment adherence will sequentially improve adherence to ARV medications, which emphasises the need of future research to identify predictors of both appointment adherence and medication adherence, rather than only examining predictors of medication adherence.

- Conclusion: Appointment adherence predicts medication adherence.

5.2.4 Predictors of ARV medication non-adherence

While no significant differences were found between men and women with regard to medication adherence or appointment adherence, significant differences were found in respect of predictors of non-adherence in men and women.

5.2.4.1 Access barriers

Sex-disaggregated analysis of data showed *difficulties in visiting hospital facilities* to be the strongest predictor of non-adherence to ARV medications among. Experiencing financial difficulties was reported by all non-adherent men. However, it is not clear whether these financial difficulties are directly or indirectly related to visiting the hospital facility. In other words, it is not clear whether such financial difficulties result in a patient not being able to pay transportation costs involved in visiting the hospital, or whether the reported financial difficulties require a patient to choose between working for income and visiting the hospital. Since experiencing difficulties in visiting hospital facilities for ARV-related treatment, care and support was found to be a significant predictor, while difficulties in visiting clinic facilities was not, it is believed that there are geographical implications to the reported difficulties.

- Conclusion: This finding is indicative of the need for future research to examine how the lack of this particular resource – to which men are believed to have privileged access (Doyal, 2001) – contributes to medication non-adherence among men in the Free State.

5.2.4.2 Treatment knowledge

Treatment knowledge was moderately associated with adherence to ARV medications for men. This finding indicates that the more knowledgeable men are regarding their treatment - especially with regard to stopping ARV treatment, missing doses of medication, and the relationship between ARVs and disease progression and further transmission of the virus - the more likely they are to be adherent to their medications. A similar finding has been reported among a sample of ART patients in California. Using a newly created scale to measure HIV knowledge, Gifford et al. (2000) found that patients who believed that non-adherence leads to drug resistance were more likely to be adherent.

Conclusion: Findings of this nature are indicative of the importance of instilling an accurate understanding about ART and the dangers of non-adherence, especially among men.

5.2.4.2 Tobacco use

The *use of tobacco* and increased *perceived stigma* were found to be significant predictors of medication non-adherence among women in the sex-disaggregated multivariate analysis. Women who smoked tobacco were significantly more likely to be non-adherent to their ARV medications than women who reported no tobacco use. While a considerable body of research exists with regard to the relationship between medication adherence and alcohol use and/or illicit drug use (Haubrich et al., 1999; Kerr et al., 2004; Lucas et al., 1999; Wagner et al., 2004), studies seldom include tobacco use as a possible predictor of adherence. Although tobacco use has not been associated with medication adherence in studies that included tobacco use as a possible predictor (Gebo et al., 2003), the significant association in this study is of concern. Substance use, such as smoking tobacco, is a form of coping response to high levels of stressors (Williams, 2003) and there is a lack of information pertaining to such stressors in relation to treatment adherence. There is evidence that smoking among men is associated with gender role-related stressors, such as unemployment, job insecurity, homelessness (Williams, 2003). Similarly there is evidence that smoking is associated among both employed men and women experiencing high job strain (Lallukka et al., 2004). This provides evidence that 'risky behaviour' is a consequence of gender roles being under threat. In the context of AIDS and ART, women's ability to carry out gender role-related activities – including domestic duties, childrearing, caring for the sick, and economic work – may be under threat due to being physically ill and/or the requirements of treatment.

- Conclusion: Since smoking was predictive of medication non-adherence among women and not among men, these findings warrant further study of possible stressors relating to women's gender roles.

5.2.4.4 Stigma

Among women in this study, increased stigma was also strongly associated with non-adherence to ARV medications. A significant correlation between *fear of stigmatisation* and *reduced medication adherence* was previously reported among South African ART patients (Nachega et al., 2004). These findings give credibility to the position that non-adherence to ARV medications is a form of ‘stigma avoidance behaviour’, and as such, adherence to medications takes second place if no means of avoiding stigma are possible (Nachega et al., 2004; Ware et al. 2006). Women in this study may endorse non-adherent behaviour as a means of maintaining confidentiality (concerning their HIV/AIDS status and treatment thereof) and, by doing so, also reducing any perceived risk of experiencing stigma (Ickovics & Meisler, 1997). Accordingly, appropriate adherence interventions would need to consider less stigmatising alternatives for the way in which women take their medications. These alternatives would ideally allow women the opportunity to take their ARV medications discreetly, thereby avoiding the negative consequences associated with non-adherence and simultaneously reducing any fears and/or experiences of stigma.

- Conclusion: Less stigmatising alternatives for taking ARV medications, especially among women, are required if medication adherence is to be maintained in environments where stigma is prevalent or perceived to be prevalent.

5.2.5 Predictors of poor sustained access to ART

A sex-disaggregated analysis revealed similar predictors of poor sustained access to ART for men and women, namely experiencing *difficulty in visiting clinic facilities* and *self-reported depression and anxiety*. While only these two factors were significant for men, the results demonstrated that experiencing *difficulty in visiting hospital facilities*, *satisfaction with services at clinics*, and *reduced service needs* were additional predictors of appointment non-adherence among women.

5.2.5.1 Depression or anxiety

Self-reported depression or anxiety was found to be significantly associated with non-adherence to scheduled appointments for both men and women in this study. Although there is a lack of research on depression and anxiety and the relationship

with appointment adherence, the presence of depression and anxiety has been negatively associated with adherence to medical appointments among HIV-seropositive mothers (Mellins et al., 2003). Owing to the fact that higher rates of internalising disorders - such as anxiety and depression - are more commonly reported among women than men (Bekker, 2003; Williams, 2003), depression as a predictor of non-adherence was expected among women, but not among men. However, Williams (2003) explains that differences in reported depression and anxiety can be reversed when the traditional roles of men and women are altered. For men, treatment may impose considerable interference with their ability to carry out traditional roles, such as being good providers for their families (an economic role), and simultaneously force men to accept a 'sick-role', thus resulting in increased depression and anxiety.

- Conclusion: This finding, although in need of further investigation, is indicative of the need for psychological assessment and mental health services to be made available to patients on ARV treatment.

5.2.5.2 Access barriers

Financial difficulties in visiting either clinic or hospital facilities was the most reported difficulty experienced by both men and women as deterring their sustained access to treatment. This finding is comparable to the findings of a South African study on adherence to tuberculosis preventive therapy (TBPT), where patients reported lack of money for transport (public taxis) and food as a significant barrier to maintaining access to treatment (Rowe et al., 2005). Significant demographic differences found between men and women in this sample may explain why *financial difficulties in visiting clinic and hospital facilities* significantly deterred sustained access to treatment among women, while for men only *difficulties in visiting hospital facilities* was found to deter sustained access. Women were found to be less likely than men to be employed and were more likely to be receiving an average income significantly lower than that of men. Where accessing facilities implies a financial cost, it is thus expected that women would be more disadvantaged than men. Increased distance to a facility may also imply increased cost, thereby further contributing to the differences

in difficulty visiting hospital facilities between men and women. Geographical location has previously been associated with poor sustained access to ART (Cook et al., 2002; Wood et al., 2003).

- Conclusion: The financial costs involved in visiting clinic and hospital facilities among men and women require further investigation, which considers the geographical location of facilities, men and women's access to financial resources, and other indirect costs such as money for transport.

5.2.5.3 Service satisfaction

Sustained access was significantly reduced among women who reported lower satisfaction with service provision at clinics. More specifically, *being less satisfied with the provision of care, the complaint procedure, cleanliness of the facility, privacy during examination, confidentiality of medical records, provision of HIV/AIDS information, opportunity to ask questions, language used in consultations, waiting times before consultations, and operating hours of the clinic facility*, were all found to contribute towards poor sustained access among women. Language has previously also been reported as a factor affecting medication adherence among South African patients (Orrell et al., 2003). Such findings suggest that grasping the importance of adhering to all aspects of treatment (medications and scheduled appointments) may be more difficult for patients whose home language differs from that of the health-care staff of a particular ART facility. A study analysing issues of particular concern to women regarding satisfaction with primary care visits, found similar factors to be associated with poor satisfaction. Weisman et al. (2000) reported women to be less satisfied than men with *the length of time between scheduling an appointment and the day of the actual appointment, waiting times before consultations with doctors*, as well as *parking*.

- Conclusion: Overall, these findings suggest that various aspects of service delivery may require quality improvement efforts in order to improve overall satisfaction with services delivered at clinic facilities, and thus, promote sustained access to treatment among women.

5.2.5.4 Service needs

It has been recognised that the support needs of men and women will differ as a result of their different physiology and especially in relation to how gender has been constructed within a particular context, thus resulting in varied responses to initiatives designed to meet the needs of both men and women (WHO, 2003). Needing additional HIV/AIDS-related services (or unmet support needs) were found to be a highly significant predictor of non-adherence to scheduled appointment among women in this study. Unexpectedly, however, non-adherent women reported that they required significantly less HIV/AIDS-related services than adherent women. A study by Whetten et al. (2004) examining gender differences in knowledge and perceptions of HIV resources, found women to be less knowledgeable about HIV/AIDS resources. They claim that where available services are not targeted toward women's specific needs and concerns, women may be less aware of services or less inclined to want to access services perceived to be irrelevant.

- Conclusion: A strategy for meeting the specific HIV/AIDS-related service needs of women, and especially women who are non-adherent to their scheduled ART appointments would possibly improve sustained access.



5.3 RECOMMENDATIONS FOR FUTURE RESEARCH

As allude to above, additional research efforts are required regarding the specific outcome measures employed and some of the factors predicting non-adherence to ARVs and poor sustained access identified by this study. These efforts would provide clarity and relevant information on how best to improve assessment of non-adherence and poor sustained access among this population. Furthermore, these efforts would

promote adherence and sustained access through appropriate interventions among this population of ART patients, and patients awaiting treatment.

5.3.1 Gender sensitive outcome measures

The results of this study reveal that self-reported measures of ARV medication and scheduled appointment adherence are not valid for determining predictors of non-adherence among men in this population of ART patients. Further research is needed to uncover whether or not the reported difference in validity of outcome measures between men and women is the result of one or more of three factors.

Firstly, over-reporting medication and appointment adherence among men may be a result of the self-reported adherence measures employed in this study. In this respect, a more accurate measurement method, such as MEMS, could enhance the validity of future medication adherence studies (Arnsten et al., 2001; Berg et al., 2004). However, it should be noted that this 'gold standard' method for the assessment of medication adherence is not without its deficiencies (Howard et al., 2002; Ickovics & Meisler, 1997; Mannheimer et al., 2002). Regarding appointment adherence, accuracy of data may be improved by collecting data from patients' medical files.

Secondly, an underlying biological difference between men and women may have resulted in differences in viral loads; the variable used to test the validity of both self-reported outcome measures. For example, future studies may want to control for CD4 cell counts, since immunological differences have been reported between men and women in previous studies (Collazos et al., 2007; Moore et al., 2002).

Lastly, the small number of non-adherent men, in comparison to the number of men reporting 100% adherence, may have contributed to a lack of statistical power to detect a statistically significant difference in viral loads between these two groups of men. In this respect, a larger sample of non-adherent men would be required in future studies.

5.3.2 Improving treatment knowledge

In respect of improving treatment knowledge, especially among men, there is a lack of research on how men would prefer to receive information or how they actively seek out information pertaining to their health and treatment. It has been reported that men are less inclined than women actively to seek out or access health-related information that could benefit their health (McCaughan & McKenna, 2007). It has also been argued that this lack of health knowledge is a result of prevailing norms of masculinity that dictate that men be self-reliant (Mane & Aggleton, 2001). Therefore, future research ought to examine the perceived barriers men experience in seeking out information relating to ART, as well as how men would prefer to be informed about various aspects of treatment. Both of these aspects are relevant to the design of treatment knowledge interventions aimed at improving medication adherence among men. Given that smaller scale studies, employing qualitative research, would allow exploration of the meanings that men attach to accessing information, and how men understand the information that they are currently receiving (Walters et al., 2002), qualitative investigations are required to establish the context for intervention among men.

5.3.3 Risky behaviour among women: smoking tobacco

As was indicated, future medication adherence studies examining the relationship between substance use and adherence among HIV/AIDS patients ought to include tobacco use, in addition to the use of alcohol and/or illicit drugs, as a possible predictor of adherence. Since smoking is a form of coping response to stressors (Williams, 2003), further research is required to reveal what these exact stressors are among women in this population, for smoking of tobacco to be addressed as part of an adherence intervention. Examination of possible stressors should include those pertaining to the gender roles and activities that are socially allocated to women in this study population (i.e., domestic duties, childrearing, caring for the sick, and economic work). This study also highlights the need for assessment of risky or health-compromising behaviours, which are said to be more prominent among men (Cameron & Bernardes, 1998; Courtenay, 2003; Doyal, 2001; Stibbe, 2004), to be extended upon to include how such behaviour also undermines women's health.

5.3.4 Stigma avoiding alternatives

As mentioned previously, less stigmatising alternatives to medication-taking among women are required to improve adherence and to reduce the fear and experience of stigma. Research among adherent women regarding the stigma-avoiding techniques they employ when they need to take medications discreetly in various situations would be beneficial for informing intervention.

5.3.5 Difficulties experienced in visiting health care facilities

The particular difficulties experienced by men and women in visiting clinic and hospital facilities require further analysis. These difficulties were assessed in this study with the use of an open-ended question. In future studies, a more objective fixed-choice measure would more accurately assess the specific difficulties that contribute to both poor medication and appointment adherence. Such a measure would have to include factors such as difficulties relating to, for example, employment conditions, transport needs and geographical location of facilities.

5.3.6 Comprehensive study of depression and anxiety

A more statistically reliable measure for the assessment of self-reported depression and anxiety is also required. Statistically reliable measures - such as the Beck Depression Inventory (BDI), the Hospital Anxiety and Depression Scale (HADS), and the Center for Epidemiological Studies Depression Scale (CES-D) - have repeatedly been employed in studies among HIV-infected patients, given their proven validity and reliability (Berg et al., 2004; Campos et al., 2006; Safren et al., 2001). A more in-depth study, employing reliable measures of depression and anxiety among this population of patients on ARVs, would serve to validate the findings of this study, as well as allow for identification of how best to structure any necessary mental health services and any involved processes of psychological assessment (i.e., screening of patients for depression and anxiety) in this study population.

5.3.7 Closer examination of service needs

This study, unfortunately, only assessed whether or not patients required any additional HIV/AIDS-related services that were not currently available. Additional investigation into the specific services required, especially those reported by non-adherent women, is thus necessary. Moreover, Whetten et al. (2004) assert that HIV-related stigma can add to women's perceptions of and/or willingness to seek out services. Thus, since both unmet service needs and stigma predicted poor sustained access, an in-depth study of patient's unmet service needs, knowledge and perceptions of currently available services may be beneficial.

5.3.8 Quality assessment of services rendered

Service satisfaction proved to be the strongest predictor of appointment adherence among women. In view of this finding, it may be necessary to conduct a quality assessment of the following aspects of service delivery at clinic facilities, namely the provision of care, the complaint procedure, cleanliness of the facility, privacy during examination, confidentiality of medical records, provision of HIV/AIDS information, opportunity to ask questions, language used in consultations, waiting times before consultations, and operating hours of the clinic facility.



5.4 IMPLICATIONS FOR POLICY AND PRACTICE

The findings of this study have various implications for policy and practice. In terms of the intervention areas requiring the integration of gender in order to facilitate better adherence behaviour among this population of patients, the following comments can be made.

5.4.1 Monitoring adherence among patients

The findings of this study suggest that adherence to scheduled appointments is as important as medication adherence for successful treatment outcomes. Thus, both

adherence-related behavioural components would require monitoring among men and women on treatment in the Free State public health sector to maintain the current high level of adherence and sustained access to ART. Since sustained access predicts ARV non-adherence, attention ought to be given to improving those aspects that discourage sustained access, and especially those factors that discourage sustained access and simultaneously predict ARV non-adherence. Furthermore, systematic monitoring of appointment adherence represents an inexpensive means of indirectly monitoring non-adherence to ARV medication. This monitoring system, if extended to patients awaiting treatment, could also serve as a reliable means of judging future adherence to medications, thus allowing appropriate interventions to be commenced before ARV medication initiation.

5.4.2 Improving access to treatment information

Increasing men's knowledge in respect of both their treatment and the importance of medication adherence - as stated above - requires further research. The literature on men's access to information as a valuable resource for health promotion does however reveal a potential direction for intervention. A possible means of indirectly improving treatment knowledge among men would be by targeting women, especially women who indicate that they are in current relationships. Men are known to rely more on partners, relatives and friends to be their primary information resource, than to make use of recognised sources of information, such as health-care providers or support groups (McCaughan & McKenna, 2007). Given that more than 70% of the men in this study reported being in a relationship (i.e., having access to an informal source of information) and that 100% of the non-adherent men reported not making use of support groups (a formal source of information), this indirect approach may be applicable to this population of men.

5.4.3 Reducing HIV/AIDS-related stigma

Interventions aimed at reducing HIV/AIDS-related stigma need to be sensitive of stigma's multiple and hierarchical nature (Ware et al., 2006), in addition to preconceived stereotypes of women with HIV/AIDS held by society which provide a basis for their

stigmatisation (Garg & Sharma, 2006). It is the fear of stigma that contributes to medication non-adherence because patients attempt to avoid potential or perceived HIV/AIDS-related stigma (Nachega et al., 2004; Ware et al. 2006). Since HIV/AIDS-related stigma predicted non-adherence to ARV medication among women in this study, intervention would require less stigmatising alternatives for taking medications among women. These alternatives, according to Ware et al. (2006) may include, for example, a means of disguising medications (i.e., medication containers), or misrepresenting ARV medications (i.e., medication for depression as opposed to ARV medication). These types of alternatives would not only serve to reduce HIV/AIDS-related stigma and the fear thereof, as well as potential consequences (e.g., isolation, loss of employment, loss of social support, poor emotional well-being, etc.), but also help improve medication adherence.

5.4.4 Improving mental health

Any mental health interventions aimed at addressing depression and anxiety need to take cognisance of the differing needs of men and women in terms of the screening process and treatment. With regard to diagnosis among women, for example, tobacco use ought to be a major indicator for the need to be screened for depression and anxiety. Treatment of depression and anxiety among men, as a further example, would require health-care professionals to be aware of the relationship between increased depression and anxiety and the 'sick role' that men are expected to endorse as a consequence of HIV/AIDS treatment and related treatment. Patients may require effective means of adjusting to this new role without overly compromising their masculinity. This may imply empowering men to deal with employers when various aspects of treatment become a priority (e.g., attending appointments or refilling ARV prescriptions).

5.4.5 Addressing unmet service needs

'Case management' is a strategy employed within health care systems to reduce unmet support service needs of patients in addition to improving other aspects of service delivery (Katz et al., 2001). This study provides evidence for the need of such a

programme to be implemented, especially among patients identified as being non-adherent to scheduled appointments. Katz et al. (2001) point out that case management for HIV/AIDS patients appears to decrease unmet needs by linking patients to relevant services. Since patients can not access and thus benefit from services that they are unaware of (Whetten et al., 2004), such a strategy may be of benefit to the improvement of sustained access among ART patients and especially women.

5.4.6 Monitoring quality of services

Addressing dissatisfaction with various aspects of services may require implementation of a patient satisfaction monitoring system at each clinic facility. This system would allow each facility to identify key areas of service delivery that patients are dissatisfied with. However, any monitoring system would need to be as uncomplicated as possible, so as to not overly contribute to staff's existing workload, but should still be able to accurately identify relevant areas for quality improvement.



5.5 STRENGTHS AND LIMITATIONS OF THE STUDY

Several limitations to this study need to be noted. Firstly, the analyses conducted to determine which factors are predictive of non-adherence are based on a small number of patients reporting non-adherence to either medications and/or scheduled appointments. These small numbers may have limited the ability to detect additional significant associations between non-adherence and other potential predictors, especially predictors found to be highly significant in the non-sex-disaggregated analysis, and among demographic characteristics, such as population group. Secondly, since this study makes use of data collected from patients who were randomly selected based on treatment status, rather than a gender-stratified sample of ART patients, the study may be prone to selection bias. However, the higher number of women in the sample, compared with men, is reflective of the consistently

higher numbers of women on ART in the Free State (FSDoH, 2004b). Thirdly, although the outcome measures used were validated for the sample as a whole and for women, the measures did not prove to be valid among men. Whether this finding is as a result of underlying biological difference or over-reporting of actual adherence requires further investigation. As a result, cautious interpretation of data pertaining to men in this study is required. Lastly, this study employed self-reported measures of adherence to ARV medication and scheduled appointments. Self-reported measures of adherence are known to over-estimate the actual level of adherence within a study population (Arnsten et al., 2001). Based on the findings of this study, it is believed that over-estimation of actual adherence when employing self-reported measures is higher among men than women.

In spite of these limitations, the main strength of this study is that the findings from the sex-disaggregated analyses reveal considerable differences in adherence to ARV medications and sustained access to treatment between men and women, as well as many similarities. These identified differences and similarities in predictors suggest that adherence-related behaviour and beliefs are constructed differently for men and women. Thus, interventions to improve adherence and treatment guidelines may require re-evaluation to be gender-sensitive and accordingly meet the adherence and access needs of men and women in an appropriate and equitable manner.

This study also contributes to further discussion around the factors affecting appointment adherence, especially in the South African context where appointment adherence has not been researched previously. Furthermore, this study serves as a contribution to the Department of Health's (2003) call for investigation into the gender dimensions of HIV/AIDS treatment, care and support by the local research community. The findings of differences and similarities between men and women in medication adherence and sustained access to treatment in this study reveal that standardised treatment, care and support to men and women as though they constitute one homogenous group may not be appropriate. Therefore, further sex-

disaggregated research to highlight gender-specific concerns and needs of women and men is required in relation to other aspects of the delivery of ART.



5.6 CONCLUDING REMARKS

In this prospective cohort study of ART patients in the Free State public health sector, sex-disaggregated analysis provided evidence that different demographic, psychosocial/behavioural, clinical, or health-care administration and delivery characteristics are associated with ARV medication adherence and sustained access to ART in men and women. The results of this study suggest that in future studies examining adherence-related behaviour among ART patients, such behaviour ought to be examined separately for men and women by sex-disaggregating the data. Moreover, the findings should be interpreted from a gender perspective which takes into consideration the fact that men and women face different gender-related barriers in the pursuit of health. Factors predictive of medication non-adherence among men include experiencing difficulty in visiting hospital facilities and being less knowledgeable about when to stop ARV treatment, and the relationship between the dangers of missing doses of medication and disease progression and further transmission of the virus. Among women, tobacco use and experiencing stigma are factors that predict medication non-adherence. Sustained access is similarly deterred by financial difficulties in visiting ART-related facilities and perceived depression or anxiety. The long-term success of ART among patients on the treatment programme in the Free State public health sector requires gender-specific intervention to equitably improve adherence and sustained access.



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SYNOPSIS

Sustained access to ART and adherence to ARV medications remain crucial for reducing AIDS-related mortality and morbidity, minimising the development of drug resistance, and for appropriate treatment decision-making by health care providers. Thus, the factors associated with non-adherence to ARV medication and poor sustained access need to be identified and addressed. Although there is a preponderance of treatment adherence research, in which social aspects that affect the way patients manage HIV/AIDS and related treatment have been identified, far less attention has been paid to the relevant gender dimensions of treatment, care and support.

The aim of this study was to examine how gender influences adherence to ARV medications and sustained access to treatment among patients on ART in the Free State public health sector. To achieve this aim, several methods were deemed necessary. First, current literature was reviewed to identify factors that predict non-adherence to ARV medications and impede sustained access to ART. Second, a framework was adapted to focus on inequalities in treatment from a gender perspective, and to take cognisance of both biological sex and socially constructed gender influences on the health of patients on ARV treatment, with specific reference to access and adherence to treatment. Masculinity and femininity is discussed in respect of the varied resources that an individual has access to and control over, an individual's decision-making power, the gender norms held by society, and gender roles that men and women are expected to adhere to.

Third, an empirical investigation of data from a prospective cohort study was conducted to identify similarities and differences in factors associated with non-adherence to ARV medications and to poor sustained access among men and women on ART in the Free State's public health sector. A total of 1609 patients were interviewed in face-to-face interviews using semi-structured questionnaires. Patients were interviewed six times during the course of this study with an average six-month interval between interviews. The outcome variables assessed included self-reported seven-day adherence to ARV medication regimens and self-reported adherence to

scheduled appointments over a six-month period as a measure of sustained access to treatment. Sex was used as the dependent variable in all analyses. Demographic, psychosocial/behavioural, clinical, and service delivery variables were all tested for a statistically significant association with non-adherence to medications and appointments in separate sex-disaggregated multivariate regression analyses ($P \leq 0.05$).

Logistic regression models showed that the strongest predictors of medication non-adherence among men included financial difficulties in visiting hospital facilities and poor treatment knowledge. Among women, tobacco use and perceived stigma were identified as the strongest predictors of medication non-adherence. Self-reported depression or anxiety and experiencing difficulties in visiting clinic and hospital facilities were similarly associated with non-adherence to appointments for men and women. Service satisfaction at clinics and having few self-reported service needs were also independently associated with appointment non-adherence among women, but not among men. Findings for men do however need to be interpreted with caution, as both outcomes, despite being valid measures for the combined sample and among women, were not valid for men.

Marked differences and similarities in the factors influencing medication adherence and sustained access to treatment between men and women were identified, reflecting the different lived experiences of men and women on ART in the Free State. Gender-sensitive interventions - as opposed to standardised ones - are thus required to improve adherence and sustained access in this population. Further research and possible interventions are required in respect of gender-sensitive outcome measures for adherence, improving treatment knowledge among men, coping responses to gender role stressors among women, less stigmatising means for taking medications, improving mental health and improving the quality of services rendered at health care facilities.

OPSOMMING

Volgehoue toegang tot teenretrovirale behandeling en die nakoming van voorskrifte vir die gebruik van teenretrovirale medikasie bly deurslaggewend vir die vermindering van Vigsverwante mortaliteit en morbiditeit, die minimalisering van die ontwikkeling van middelweerstandigheid en vir toepaslike besluitneming aangaande behandeling deur gesondheidsorgvoorsieners. Dus moet die faktore wat verband hou met nie-nakoming van teenretrovirale medikasievoorskrifte en swak volgehoue toeganklikheid geïdentifiseer en hanteer word. Alhoewel heelwat navorsing gedoen is ten opsigte van behandelingsnakoming - waarin die sosiale aspekte van die wyse waarop pasiënte MIV/Vigs en verbandhoudende behandeling hanteer geïdentifiseer is - is veel minder aandag egter geskenk aan die relevante genderdimensies van behandeling, sorg en ondersteuning.

Die doel van hierdie studie was om die invloed van gender op die nakoming van teenretrovirale medikasievoorskrifte en ook op die volgehoue toeganklikheid tot behandeling onder pasiënte in die openbare gesondheidssektor in die Vrystaat te ondersoek. Verskeie metodes is nodig geag om hierdie doel te bereik. Eerstens is die huidige literatuur hersien met die oog op identifikasie van die faktore wat nie-nakoming van teenretrovirale medikasievoorskrifte voorspel en volgehoue toeganklikheid tot teenretrovirale behandeling belemmer. Tweedens is 'n raamwerk aangepas om vanuit 'n genderperspektief op ongelykhede ten opsigte van behandeling te fokus, asook om kennis te neem van die wyse waarop sowel biologiese geslag as sosiaal-gekonstrueerde gender die gesondheid van pasiënte op teenretrovirale behandeling beïnvloed, met spesifieke verwysing na toeganklikheid en nakoming van behandeling. Manlikheid en vroulikheid word bespreek in terme van die uiteenlopende hulpbronne waartoe 'n individu toegang toe en beheer oor het, 'n individu se besluitnemingsmag, die gendernorme wat die samelewing huldig, asook die genderrolle waaraan mans en vroue verwag word om te voldoen.

Derdens is 'n empiriese ondersoek uitgevoer op die data van 'n voortgesette kohortstudie ten einde ooreenkomste en verskille te identifiseer met betrekking tot die faktore wat verband hou met nie-nakoming van die voorskrifte van teenretrovirale medikasie en met swak volgehoue toeganklikheid vir mans en vroue op teenretrovirale behandeling in die Vrystaat se openbare gesondheidsektor. Aan die hand van semi-gestruktureerde vraelyste is persoonlike onderhoude met 1609 pasiënte gevoer. Ses onderhoude is tydens die verloop van die studie met pasiënte gevoer, met gemiddelde tussenposes van ses maande tussen onderhoude. Die uitkomsveranderlikes wat geassesseer is, het ingesluit: selfgerapporteerde sewedaagse nakoming van teenretrovirale medikasievoorskrifte en selfgerapporteerde nakoming van geskeduleerde afspraak oor 'n periode van ses maande as 'n maatstaf van volgehoue toegang tot behandeling. In alle ontledings is geslag as die afhanklike veranderlike gebruik. Demografiese, psigo-sosiale/gedrags-, kliniese, en dienslewingsveranderlikes is almal getoets vir 'n statisties-beduidende verband met nie-nakoming van medisynevoorskrifte, asook afspraak in afsonderlike geslagsgedisaggregeerde meervoudige regressie-analises ($P \leq 0.05$).

Logistiese regressiemodelle het aangetoon dat die sterkste voorspellers van medikasie nie-nakoming by mans finansiële probleme in verband met besoeke aan hospitaalfasiliteite en swak behandelingskennis was. By vroue is tabakgebruik en waargenome stigma geïdentifiseer as die sterkste voorspellers van medikasie nie-nakoming. Selfgerapporteerde depressie of angs, probleme ten opsigte van besoeke aan kliniek- en hospitaalfasiliteite het vir mans en vroue op dieselfde wyse verband gehou met nie-nakoming van afspraak. Dienstevredenheid by klinieke en enkele selfgerapporteerde diensbehoefte het ook onafhanklik verband gehou met afspraak nie-nakoming. Daar dien op gelet te word dat die bevindinge ten opsigte van mans met omsigtigheid geïnterpreteer moet word, aangesien albei uitkomsmaatstawwe in die geval van mans nie geldig was nie, ten spyte daarvan dat hulle wel geldig was vir die gekombineerde steekproef en vir vroue.

Beduidende verskille en ooreenkomste is geïdentifiseer in die faktore wat medikasienakoming en volgehoue toegang tot behandeling by mans en vroue beïnvloed. Dit reflekteer die uiteenlopende geleefde ervaringe van mans en vroue op teenretrovirale behandeling in die Vrystaat. Derhalwe is gender-sensitiewe en nie-gestandaardiseerde intervensies nodig om nakoming en volgehoue toegang in hierdie populasie te verbeter. Verdere navorsing en moontlike intervensies word benodig ten opsigte van gender-sensitiewe uitkomsmaatstawwe vir nakoming, ten opsigte van die bevordering van mans se kennis omtrent behandeling, ten opsigte van vroue se vermoëns om geslagsrolstressors te hanteer, ten opsigte van minder stigmatiserende wyses waarop medikasie geneem kan word, ten opsigte van die verbetering van geestesgesondheid en ten opsigte van die verbetering van die gehalte van dienste by gesondheidsorgfasiliteite gelewer.

KEY TERMS

- Acquired immunodeficiency syndrome
- Human immunodeficiency virus
- Antiretroviral treatment
- Adherence
- Sustained access
- Gender
- Sex
- Social construction
- Masculinity
- Femininity

Annexure A:

LETTERS OF AUTHORISATION

- Annexure A (i): Approval letter from the Free State Department of Health, 2004
- Annexure A (ii): Approval letter from the Free State Department of Health, 2006
- Annexure A (iii): Approval letter from the Free State Department of Health, 2007
- Annexure A (iv): Letter of ethical clearance

Annexure A (i): Approval letter from the Free State Department of Health, 2004

FREE STATE PROVINCE



Prof HCJ (Dingie) van Rensburg
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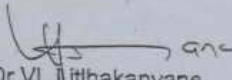
DOCUMENTING, MONITORING, EVALUATING AND FACILITATING THE IMPLEMENTATION OF THE NATIONAL TREATMENT PLAN IN THE FREE STATE PROVINCE – SOUTH AFRICA

Approval is hereby granted to the CENTRE FOR HEALTH SYSTEMS RESEARCH & DEVELOPMENT (UFS) to undertake the above-mentioned research project in facilities of the Free State Department of Health.

It is a long-term project that will run over a period of three years. The research will entail six-monthly surveys at all ARV Service Sites in the province, and the surveys will be conducted among selected staff and patients at these facilities.

The Department appreciates this initiative and is looking forward to receiving regular feedback, to ensure that we successfully implement the ARV Program.

Kind regards


Dr VL Lithakanyane
HEAD : HEALTH

20 March 2004



Department of Health • Departement van Gesondheid • Lefapha La Bophelo Bo Botie

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Annexure A (ii): Approval letter from the Free State Department of Health, 2006

FREE STATE PROVINCE



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RESEARCH PROJECT: DOCUMENTING, MONITORING, EVALUATING AND FACILITATING THE IMPLEMENTATION OF THE NATIONAL TREATMENT PLAN IN THE FREE STATE PROVINCE

Renewed approval is hereby granted to the **Centre For Health Systems Research & Development** (University of the Free State) to proceed with the above-mentioned research project in facilities of the Free State Department of Health.

It is a long-term project that runs over several years and is conducted at all ARV service sites in the province. The research entails two components, firstly, **annual facilities appraisals** among selected staff of ARV service sites and, secondly, **six-monthly surveys** among patients/clients on ARV treatment at these facilities.

The Department appreciates this initiative and is looking forward to receiving regular feedback, to ensure that we successfully implement the ARV Programme.

Kind regards

Mr Mosioua Shuping
ACTING HEAD: HEALTH

Date: 23/2/008



Department of Health ◀ Departement van Gesondheid ◀ Lefapha La Bophelo Bo Botle

Evangelina Momoze Health Services, De PD, Chapman - PO Box 337, Bloemfontein 9300 - Tel. 07 51 3401117



Annexure A (iii): Approval letter from the Free State Department of Health, 2007

FREE STATE PROVINCE



17 October 2007

To whom it may concern,

APPROVAL: Research project on *Effective AIDS Treatment and Support in the Free State province (FEATS)*

The Centre for Health Systems Research & Development has been successful in obtaining a research grant from the World Bank to conduct the above research over the next four years (2007-10). This study builds on and expands the ART research project in the Free State province that the Centre has already been engaged in since early 2004.

The principal contact at the Centre for Health Systems Research & Development for this research project is the following person:

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This study has three main objectives, namely to:

- Present a broader view of treatment success
- Develop a more complete model of the determinants of treatment success
- Understand the nature of links between treatment and prevention

More specifically, the research is aimed at enhancing our understanding of treatment success in situations where access to antiretroviral treatment is being scaled up, in other words, in phase I-ARV facilities where treatment already has been available for two to three years and where the numbers of patients on treatment are relatively large.

The following twelve phase I-assessment (combined) sites in the Free State province have been selected to partake in the study.

Batho clinic (Bloemfontein)
 Heidedal community health centre (Bloemfontein)
 Itumeleng community health centre (Jagersfontein)
 Maljhabeng clinic (Welkom)
 MUCOM community health centre (Bloemfontein)
 Namaheli clinic (Fhuthedjithsba)



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Phomolong clinic (Hennenman)
 Refengkgotso clinic (Deneysville)
 Tseki clinic (Phuthaditjhaba)
 Tshame clinic (Harrismith)
 Welkom clinic (Welkom)
 Zamdela community health centre (Sasolburg)

The study comprises a patient and household survey. It is envisaged that patient recruitment will commence in October 2007 and that the recruitment phase will last for two/three months. Patients visiting the above clinics or community health care centres and who have initiated antiretroviral treatment in the month prior to this facility visit will be considered eligible for recruitment into the study. During the visit, nursing personnel working at the facility will introduce the study to the patient and will obtain written, informed consent from study participants. At each facility, approximately sixty patients will be recruited into the study (total sample ~650). However, due to low patient numbers at smaller health care facilities, recruitment numbers at smaller facilities may be less than fifty, while numbers at larger facilities may exceed fifty. Following the recruitment phase of the study, trained enumerators will conduct semi-structured face-to-face interviews with patients and with their households. Importantly, consent for the household interviews will be obtained from the patient, while the identity of patients will not be divulged to household respondents during the household interview, for which written, informed consent will also be obtained from all respondents. Furthermore, interviews will also be conducted with a small number (~180) of randomly sampled (comparison) households at each study site, using the same survey instrument. Baseline interviews will be conducted with patients and households during the period October to December 2007, while three more follow-up interviews will be conducted with patients and households over the next twelve to eighteen months.

In addition, the research team will be collecting selected clinical information from the patient files of study participants, with written informed consent to do so being obtained from study participants during the patient interview. These data will be collected at baseline and following the completion of the last round of follow-up interviews with study participants. Patient files kept at treatment (combined) sites will be used for this purpose, which means that the research team, in addition to the above facilities, will also be visiting the following phase I-treatment sites in the Free State province:

Bongani regional hospital (Welkom)
 National district hospital (Bloemfontein)
 Mofumahadi Mahapo Mopeli regional hospital (Phuthaditjhaba)
 Metsimaholo district hospital (Sasolburg)

The research team will also be conducting brief interviews with selected health care professionals employed at the above health care facilities in order to obtain key information on provider- and facility-level factors that may influence patient outcomes. Similar to the patient and household survey, these interviews will be conducted at baseline (October/November 2007) and at two more six-monthly intervals over the next twelve to eighteen months.

The study also comprises two interventions (this in addition to the support already provided to patients as part of the ART programme) aimed at improving treatment success, namely a nutritional intervention [a random sample of patients at each study site will be receiving a weekly supply of two cans of pilchards (high in iron content) in tomato sauce] and an adherence support intervention [treatment-experienced patients (or treatment for at least 12



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months) will be provided with basic training on adherence support and on how to refer patients to other health care workers in cases where they need other services, and will visit randomly selected patients at each study site on a frequent basis to provide them with adherence support). The two Interventions will run for a period of approximately twelve months and will be implemented approximately three to four months after the baseline interviews with study participants. There will be three groups of study participants: those patients receiving the current support and interventions provided as part of the ART programme (~216), those patients receiving only the peer adherence support intervention provided by trained, experienced ART patients (~216), and those patients receiving both the nutritional and peer adherence support intervention (~216).

Physicians at treatment/combined sites will moreover be required to request an Hb test for study participants during routine three- or six-month visits to treatment/combined sites for clinical assessment, when blood are drawn for the purpose of routine CD4 and viral load tests, using a prescribed form. Currently, Hb tests are not requested routinely for all ART. It is necessary however to do so for all study participants, given that Hb represents the principal outcome of the nutritional intervention. These tests are being paid for by the project and an arrangement to this effect has already been made with NHI S representatives in the province.

The Free State Department of Health offers its full cooperation and assistance to the research team in carrying out this important research once the research team has obtained the necessary ethical approval for the research project from the Ethics Committee of the Faculty of Medicine at the University of the Free State. In addition, the Executive Manager Strategic Health Programs and the Senior Management of the ART programme will prior to the submission of research outputs for conferencing or publication purposes have the opportunity to comment on outputs emanating from the research project.

Yours sincerely



PROF P.L. RAMELA
HEAD: HEALTH

DATE: 1 NOVEMBER 2007



Department of Health • Departement van Gesondheid • Lefapha La Bophelo Bo Botle

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Annexure A (iv): Letter of ethical clearance

PUBLIC SECTOR ANTI-RETROVIRAL TREATMENT

Documenting, monitoring, evaluating and facilitating implementation of the national treatment plan in the Free State province, South Africa.

Component 6: Client/patient survey

Component 7: Health services/systems appraisal

Component 8: Macro context, process and policy analysis

Ethical evaluation of the three proposed Component Projects to be conducted by the Centre for Health Systems Research & Development, UFS

The evaluation of this project is based on ethical guidelines that can be summarised in the following three questions:

- Is the research really necessary?
- Is the research scientifically and economically properly planned?
- Is there a balance between the potential risks and potential value of this research?

Is the research really necessary?

The obvious reality of HIV and AIDS substantiates research of the nature stipulated in this proposal. As stated in the proposal, prospects for enhanced access to anti-retroviral treatment (ART) have greatly improved. This emphasises the pronounced necessity for recommendations and guidelines as how to deliver this treatment effectively.

The necessity of this study is further supported by the aim to facilitate the application of the research and research results. It is therefore not only limited to the documentation, monitoring and evaluation of the roll-out of the ART programme in the Free State. This is consistent with the overall aim of the study.

Further justification is finally supported by the comprehensiveness in scope of the research as outlined in the proposal.

Is the research economically and scientifically properly planned?

The detailed proposal is a good indication that this is not merely a case of research for the sake of research. The proposed project is well elucidated with particular attention to economic and scientific justification.

Concerning the economic aspect of this proposed research project, it is evident that planning was not only performed in a detailed fashion, but realistically as well. This is illustrated by the detailed budget given in the proposal.

Regarding scientific planning it is evident that the proposed research project is thoroughly analysed and outlined in terms of general purpose and aims, specific objectives, research strategy and methodology as well as project management. The scientific approach of this research project, which is of utmost importance, is underlined by a continuous systematic procedure.

Structures are in place to administer the research. The CHSR&D, based in the Free State, have conducted many survey research projects over the past ten years and is therefore able to draw on a cadre of experienced interviewers. The project teams for each of the three Component Projects, have been carefully assembled and consists of experts in the relevant fields. Based on this and the reputable history of years of experience, the CHSR&D is well placed to conduct a project of this nature.

Is there a balance between the potential risks and potential value?

It is evident that the researchers are conscious of the sensitive nature of this research as well as the potential ethical dilemmas involved. They have therefore identified certain ethical considerations that need to be taken into account. This is relevant to all respondent categories, including health managers/workers and clients/patients. It has been dealt with comprehensively in the proposal, with specific attention to the following issues:

- No deceiving of subjects and informed written consent
- Confidentiality of information
- No harm to research subjects
- Beneficence

The ethical principle of respect for human dignity (of all the people involved) is of utmost importance and this is captured throughout the proposal.

- Special care is taken with regard to the careful selection of experienced interviewers that will be specifically trained for the client/patient surveys and the health services/system appraisal. Training will be ongoing during fieldwork as stipulated in the proposal.
- Questions about sexuality will be formulated in a non-threatening manner and great care will be given with the preparation of the interview schedules (especially regarding Component Project 6).

Another ethical principle relevant to this research is sensitivity for worldviews. Cultural differences relating to health care has been taken into account. For example:

- the recognition that the focus should not only be on women but also on the importance of men's access to ART and their role in the transmission of AIDS.

- the intended involvement and participation of alternative medicine and traditional healers in the ART programme.
- face-to-face interviewing in the home language of respondents in the case of client/patient surveys.

The interview itself might be a traumatic experience for some of the respondents (despite the various precautionary measures taken) and therefore counselling should be available for those respondents who might have the need.

Beneficiaries of this research is not limited to a few individuals or a single institution, but include the Free State Department of Health, involved communities, clients/patients served by the health care system, health service staff and researchers. This accentuates the value of the research.

Conclusion

Research of this nature is more often than not characterised by the probability of certain ethical dilemmas. This is not always predictable, but the advantages of this proposed research project outweighs the possible risks by far. Based on the submitted research proposal, no evident ethical dilemmas appear. However, in order to ensure that the research is done ethically and responsibly, ethical guidelines should be followed consistently throughout the research process.

It is thus our conclusion that this proposed research project is well motivated and from an ethical point of view there seems to be no obvious reason why this project should not be recommended.

Our best wishes accompany those involved in the execution of this research project.

_____ Date: _____
Prof GW de Klerk
Dean: Faculty of the Humanities, University of the Free State

_____ Date: _____
Prof L Cilliers
Chairperson: Research Committee, Faculty of the Humanities

_____ Date: _____
JC van der Merwe
Department of Philosophy, University of the Free State

Annexure B:

PATIENT QUESTIONNAIRE

1. INTERVIEW PARTICULARS

1.1 Questionnaire number:

.....

1.2 Survey wave:

.....

1.3 Sample group:

Treatment	1
Non-treatment	2

1.4 Treatment group

Receiving treatment	1
Not yet receiving treatment	2
Treatment stopped	3

1.5 Analysis group:

Cohort (follow-up interviewee)	1
Cross section (once-off interviewee)	2

1.6 Date of interview:

Day	Month	Year
		200

1.7 Health district:

Lejweleputswa	1
Motheo	2
Fezile Dabi (NFS)	3
Thabo Mofutsanyana	4
Xhariep	5

2. DRUG ADHERENCE

2.1 [ARV NAME]	2.2 During the past week (7 days) did you take [ARV NAME] as you just explained?		
	No	Yes	Cannot remember
1 st ARV:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dosage:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2 nd ARV:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dosage:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3 rd ARV:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dosage:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4 th ARV:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dosage:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5 th ARV:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dosage:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

3. APPOINTMENT ADHERENCE

3.1 Since [commencing the government's ARV Treatment Programme/the previous interview], how many scheduled appointments did you have at the **assessment site** for ARV-related treatment, care and support?

.....time(s)

3.2 Since [commencing the government's ARV Treatment Programme/the previous interview], how many scheduled visits did you actually make to the assessment site for ARV-related treatment, care and support?

.....time(s)

3.3 Since [commencing the government's ARV Treatment Programme/the previous interview], did you miss any of your scheduled appointments at the assessment site for ARV-related treatment, care and support?

No	0
Yes	1

3.4 Since [commencing the government's ARV Treatment Programme/the previous interview], how many scheduled appointments did you have at the **treatment site** for ARV-related treatment, care and support?

.....time(s)

3.5 Since [commencing the government's ARV Treatment Programme/the previous interview], how many scheduled visits did you actually make to the treatment site for ARV-related treatment, care and support?

.....time(s)

3.6 Since [commencing the government's ARV Treatment Programme/the previous interview], did you miss any of your scheduled appointments at the treatment site for ARV-related treatment, care and support?

No	0
Yes	1

4. DEMOGRAPHIC CHARACTERISTICS

4.1 What is your sex?

Male	1
Female	2

4.2 Which population group do you consider yourself part of?

Black (African)	1
Coloured	2
Indian/Asian	3
White	4
Other (specify)	

4.3 What is your date of birth?

Day	Month	Year
		19

4.4 What is your marital status at present?

Living together: married	1
Living together: unmarried	2
Spouse/partner living elsewhere	3
Single	4
Other (specify)	

4.5 What is the highest formal educational level that you have completed?

No formal education	0
Grade 1/Sub A	1
Grade 2/Sub B	2
Grade 3/Standard 1	3
Grade 4/Standard 2/ABET L1	4
Grade 5/Standard 3	5
Grade 6/Standard 4/ABET L2	6
Grade 7/Standard 5	7
Grade 8/Standard 6/ABET L3	8
Grade 9/Standard 7	9
Grade 10/Standard 8/ABET L4	10
Grade 11/Standard 9	11
Grade 12/Standard 10/ABET L5	12
Diploma	13
Degree	14
Other (specify)	

4.6 Indicate the type of dwelling that you currently live in?

House or brick structure on a separate stand or yard	1
Town/cluster/semi-detached house (simplex, duplex or triplex)	2
Flat or apartment in a block of flats	3
Unit in a retirement village	4
Workers' hostel	5
House/flat/room in back yard	6
Traditional dwelling/hut/structure made of traditional materials, e.g. mud, grass, etc.	7
Informal dwelling/shack in informal/squatter settlement	8
Informal dwelling/shack in backyard	9
Caravan or tent	10
Informal dwelling/shack in township/suburb	11
Other (specify)	

4.7 How many people are part of your household, i.e., live together at least four nights a week and share resources?

people

4.8 How many people in each of the following categories live in your household?

Age category	
14 years and younger	
15-59 years	
60 years and older	

4.9 In the seven (7) days preceding this interview did you have a work for pay (in cash or in kind), profit or family gain, for one hour or more?

Yes: formal registered (non-farming)	1
Yes: informal unregistered (non-farming)	2
Yes: farming	3
Yes: had work but was temporarily absent	4
No: did not have work	5
Other (specify)	

4.10 What is your total personal monthly income from the following:

Category		Total monthly Amount
Refused	0	
Salary	1	R
Wage	2	R
Remittance(s)	6	R
Work pension	7	R
Stipend	10	R
Unemployment fund	16	R
Other (specify)		R
		R

4.11 Are you the main income generator (breadwinner) in your household?

No	0
Yes	1

5. PSYCHOSOCIAL/BEHAVIOURAL CHARACTERISTICS

5.1 Anxiety/depression. [The following question is about your general health. Please indicate which statements best describe your own state of health today]

I am not anxious or depressed	1
I am moderately anxious or depressed	2
I am extremely anxious or depressed	3

5.2 During the past month (30 days), did you drink alcohol?

No	0
Yes	1

5.3 During the past (30 days), did you smoke tobacco?

No	0
Yes	1

:

5.4 During the past month (30 days), did you smoke dagga?

No	0
Yes	1

5.5 Please indicate how much you experience the following:

Sub-question	Not at all	A moderate amount	An extreme amount	Do not know
1 Unpleasant physical problems related to your HIV infection	1	2	3	0
2 People blaming you for your HIV status	1	2	3	0
3 You blame yourself for your HIV infection	1	2	3	0
4 You feel guilty about being HIV-positive	1	2	3	0
5 How guilty you feel when you need help and care from others	1	2	3	0

5.6 Do you have someone who supports you emotionally, excluding a treatment buddy or health worker?

No	0
Yes	1

5.7 Do you participate in a support group for people living with HIV/AIDS (e.g. where PLWA meet to discuss issues/problems related to living with HIV and AIDS)?

No	0
Yes	1

5.8 Please indicate to what extent you agree or disagree with each of the following statements.

Sub-question	Definitely true	Partly true	Uncertain	Partly false	Totally false
1 One should continue to take ARV treatment after gaining weight	1	2	3	4	5
2 It is correct to stop ARV treatment when one no longer suffers from opportunistic infections	1	2	3	4	5
3 ARV medication cures HIV	1	2	3	4	5
4 After a couple of years one can stop taking ARV medication	1	2	3	4	5
5 Missing a few doses of ARV medication is acceptable	1	2	3	4	5

6. CLINICAL ASPECTS

6.1 Do you experience any side effects when taking ARV medication?

No	0
Yes	1

7. HEALTH CARE ADMINISTRATION AND DELIVERY

7.1 Do you experience any difficulty to visit the assessment site for your ARV-related treatment, care and support as expected according to your schedule?

No	0
Yes	1

If YES:

7.2 What are the most important difficulties to visit the assessment site for ARV-related treatment, care and support as expected?

7.3 Do the same health care staff (e.g. same nurse) see you every time you visit the assessment site for ARV-related treatment, care and support?

No	0
Yes	1

7.4 Please rate the ARV-related services you received at the assessment site in terms of the following:

		Not applicable	Very satisfied	Satisfied	Neither satisfied nor dis-satisfied	Dis-satisfied	Very dis-satisfied	Do not know
Sub-question								
1	Medical care provided at [ASSESSMENT SITE]		1	2	3	4	5	0
2	Complaint procedure at [ASSESSMENT SITE]		1	2	3	4	5	0
3	Cleanliness of [ASSESSMENT SITE]		1	2	3	4	5	0
4	Privacy during examinations at [ASSESSMENT SITE]		1	2	3	4	5	0
5	Confidentiality of your medical record at [ASSESSMENT SITE]		1	2	3	4	5	0
6	Respect shown by nurses at [ASSESSMENT SITE]	-1	1	2	3	4	5	0
7	Respect shown by doctor(s) at [ASSESSMENT SITE]	-1	1	2	3	4	5	0
8	Health information about HIV/AIDS at [ASSESSMENT SITE]	-1	1	2	3	4	5	0
9	Information about ARV medication provided by nurse(s)	-1	1	2	3	4	5	0
10	Information about ARV medication provided by doctor(s)	-1	1	2	3	4	5	0
11	Opportunity to ask questions	-1	1	2	3	4	5	0
12	Language used during consultations at [ASSESSMENT SITE]		1	2	3	4	5	0
13	Hours that [ASSESSMENT SITE] is open		1	2	3	4	5	0
14	Waiting time before consultations at [ASSESSMENT SITE]		1	2	3	4	5	0

7.5 Please rate the ARV-related services you receive from the following staff at the assessment site:

Sub-question	Not applicable	Very good	Good	Neither good nor bad	Poor	Very poor	Do not know
1 Nurse	-1	1	2	3	4	5	0
2 Doctor	-1	1	2	3	4	5	0

7.6 Do you experience any difficulty to visit the treatment site for your ARV-related treatment, care and support as expected according to your schedule?

No	0
Yes	1

7.7 What are the most important difficulties to visit the treatment site for ARV-related treatment, care and support as expected?

.....

.....

.....

.....

7.8 Do the same health care staff see you every time you visit the treatment site for ARV-related treatment, care and support?

Staff category	No, different staff	Yes, same staff
Nurse	0	1
Doctor	0	1

7.9 Please rate the ARV-related services you received at the treatment site in terms of the following:

<i>Sub-question</i>	Not applicable	Very satisfied	Satisfied	Neither satisfied nor dis-satisfied	Dis-satisfied	Very dis-satisfied	Do not know
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1	Medical care provided at [TREATMENT SITE]		1	2	3	4	5	0
2	Complaint procedure at [TREATMENT SITE]		1	2	3	4	5	0
3	Cleanliness of [TREATMENT SITE]		1	2	3	4	5	0
4	Privacy during examinations at [TREATMENT SITE]		1	2	3	4	5	0
5	Confidentiality of your medical record at [TREATMENT SITE]		1	2	3	4	5	0
6	Respect shown by nurses at [TREATMENT SITE]	-1	1	2	3	4	5	0
7	Respect shown by doctor(s) at [TREATMENT SITE]	-1	1	2	3	4	5	0
8	Health information about HIV/AIDS at [TREATMENT SITE]	-1	1	2	3	4	5	0
9	Information about ARV medication provided by nurse(s)	-1	1	2	3	4	5	0
10	Information about ARV medication provided by doctor(s)	-1	1	2	3	4	5	0
11	Opportunity to ask questions	-1	1	2	3	4	5	0
12	Language used during consultations at [TREATMENT SITE]		1	2	3	4	5	0
13	Hours that [TREATMENT SITE] is open		1	2	3	4	5	0
14	Waiting time before consultation at [TREATMENT SITE]		1	2	3	4	5	0

7.10 Please rate the ARV-related services you receive from the following staff at the treatment site:

Sub-question	Not applicable	Very good	Good	Neither good nor bad	Poor	Very poor	Do not know
1 Nurse	1	1	2	3	4	5	0
2 Doctor	1	1	2	3	4	5	0

7.11 Please rate the drug readiness training you received in terms of the following:

Sub-question	Very good	Good	Neither good nor poor	Poor	Very poor	Do not know
1 Clarity of information provided	1	2	3	4	5	0
2 Opportunity to ask questions	1	2	3	4	5	0
3 Information thoroughly discussed	1	2	3	4	5	0
4 Health information provided to you in regard to AIDS	1	2	3	4	5	0
5 Health information on ARV medication	1	2	3	4	5	0
6 Language used	1	2	3	4	5	0

7.12 Do you have a treatment buddy?

No	0
Yes	1

7.13 Do you need any HIV/AIDS-related services that are not available to you?

No	0
Yes	1

CLINICAL DATA COLLECTION INSTRUMENT

1. DATA COLLECTION PARTICULARS

1.1 Date of clinical data collection:

Day	Month	Year
		200

1.2 Questionnaire number:

1.3 Health district:

1.4 Assessment site:

1.5 Treatment site:

2. PATIENT PARTICULARS

2.1 Patient RSA ID no:

2.2 Patient sex:

Male	1
Female	2

2.1 Patient date of birth:

Day	Month	Year
		200

2.2 Patient ZU number:

3. TREATMENT PARTICULARS

3.1 Public sector ARV therapy ever started?

No	0
Yes	1

3.2 Date ARV therapy started:

Day	Month	Year
		200

3.3 Is patient indicated as lost to follow-up from clinical file?

No	0	↓
Yes	1	→

If YES:

3.4 Reason for loss to follow-up?

Moved outside Free State	2
Moved to another Free State district	6
Untraceable	3
Cannot determine from file	99
Died	4
Other (specify)	

3. CLINICAL DATA

	Date	ARV1	ARV2	ARV3	ARV4	CD4 date	CD4 result	VL date	VL result
1.	200 / /					0 /20		0 /20	
2.	200 / /					0 /20		0 /20	
3.	200 / /				z	0 /20		0 /20	
4.	200 / /					0 /20		0 /20	
5.	200 / /					0 /20		0 /20	
6.	200 / /					0 /20		0 /20	
7.	200 / /					0 /20		0 /20	
8.	200 / /					0 /20		0 /20	
9.	200 / /					0 /20		0 /20	

	Date	ARV1	ARV2	ARV3	ARV4	CD4 date	CD4 result	VL date	VL result
10.	200					0	/20	0	/20
11.	200					0	/20	0	/20
12.	200					0	/20	0	/20
13.	200					0	/20	0	/20
14.	200					0	/20	0	/20
15.	200					0	/20	0	/20
16.	200					0	/20	0	/20
17.	200					0	/20	0	/20
18.	200					0	/20	0	/20
19.	200					0	/20	0	/20

Annexure D:

NON-SEX-DISAGGREGATED ANALYSES

Table 1. Factors associated with non-adherence to ARV medications among patients on ART in the Free State public health sector

Demographic characteristics	Total N	100% adherence (%)	<100% adherence (%)	p-value ^o
Mean age (years) (±SD)	1566	38.62 (8.60)	37.11 (8.82)	=0.152
Population group	1585			=0.077*
Black		95.30	87.10	
Coloured		3.28	12.90	
Indian/Asian		0.13	0.00	

White		1.29	0.00	
Level of education	1595			=0.536
None		3.97	8.57	
Primary		28.46	31.43	
Some secondary		47.44	42.86	
Matric		16.99	17.14	
Tertiary		3.14	0.00	
Marital status	1590			=0.751
Living together: married		21.86	14.29	
Living together: unmarried		8.94	8.57	
Spouse/partner living elsewhere		22.51	25.71	
Single		46.69	51.43	
Employment status	1574			=0.342
Employed		79.21	85.71	
Unemployed		20.79	14.29	
Mean income (Rands)	1658	830.83	662.71	=0.171
(±SD)		(1038.48)	(737.12)	
Breadwinner	1574	61.86	60.00	=0.823
Mean household size (number of persons)	1576	4.12	4.03	=0.403
(±SD)		(2.21)	(2.29)	
Household age structure				
Children	1659			=0.909
No children		35.10	34.29	
1 child		30.97	34.29	
2 or more children		33.93	31.43	
Adults				
No adults	1659	6.10	0.00	=0.320
1 other adult		19.46	20.00	
2 or more adults		74.45	80.00	
Elderly	1659			=0.258
No elderly		82.27	82.86	
1 elderly		12.07	17.14	
2 or more elderly		5.67	0.00	
Type of housing	1583			=0.336
Formal		75.84	82.86	
Informal		24.16	17.14	

Psychosocial/behavioural characteristics

Depression/anxiety	1574			=0.025**
Not anxious/depressed		71.67	60.00	
Moderately anxious/depressed		22.29	22.86	
Extremely anxious/depressed		6.04	17.14	
Substance use	1574	20.32	35.29	=0.033**
Non-disclosure	1576	13.11	8.57	=0.313
Stigma index	1569	1.43	1.62	=0.008**
(±SD)		(0.46)	(0.64)	
Social support				
No support group membership	1575	85.53	88.24	=0.657
No emotional support	1571	62.39	73.53	=0.184
Treatment knowledge index	1573	4.85	4.68	=0.006**
(±SD)		(0.38)	(0.63)	

Clinical aspects

Side-effects	1390	21.09	35.29	=0.046**
Disease status	1460			=0.358
<200		35.03	46.67	
200-500		52.45	40.00	

>500		12.52	13.33	
Mean time on ART (years)	1439	1.34	0.97	=0.008**
(±SD)		(0.86)	(0.82)	
Health care administration and delivery				
Access barriers				
Clinic	1556	6.57	14.29	=0.082*
Hospital	1560	7.02	22.86	<0.001**
Service satisfaction index				
Clinic	1557	4.20	3.98	=0.007**
(±SD)		(0.51)	(0.60)	
Hospital	1564	4.47	4.28	=0.016**
(±SD)		(0.49)	(0.60)	
Service needs	1569	25.47	26.47	=0.895
Drug readiness training index	1565	4.49	4.53	=0.682
(±SD)		(0.46)	(0.46)	
No treatment buddy	1571	62.85	50.00	=0.126
No regular health care providers				
Clinic staff	1518	41.13	54.29	=0.118
Hospital nurse	1529	34.58	38.24	=0.658
Hospital doctor	1512	41.03	37.14	=0.619
Rating of health care providers				
ARV-related services index	1572	1.40	1.44	=0.308
(±SD)		(0.50)	(0.56)	
Respect by health care providers index	1573	1.48	1.67	=0.018**
(±SD)		(0.53)	(0.59)	
ARV medication information index	1571	1.47	1.60	=0.068*
(±SD)		(0.50)	(0.53)	

^o *P*-values for test of difference, between adherent and non-adherent ART patients, in means or distributions.

* Significant at the 10% level ($P \leq 0.10$).

** Significant at the 5% level ($P \leq 0.05$).

Table 2. Factors associated with non-adherence to scheduled appointments among patients on ART in the Free State public health sector

Demographic characteristics	Total <i>N</i>	100% adherence (%)	<100% adherence (%)	<i>p</i> -value ^o
Mean age (years)	1355	39.56	38.27	=0.055*
(±SD)		(8.61)	(8.36)	
Population group	1378			=0.006**
Black		95.60	92.91	
Coloured		2.72	5.51	
Indian/Asian		0.08	1.57	
White		1.60	0.00	
Level of education	1374			=0.408
None		3.69	7.09	
Primary		27.02	27.56	
Some secondary		49.32	44.88	
Matric		17.08	18.11	
Tertiary		2.89	2.36	
Marital status	1371			=0.074*
Living together: married		22.59	13.39	
Living together: unmarried		9.49	11.02	

Spouse/partner living elsewhere		23.39	22.05	
Single		44.53	53.54	
Employment status	1376			=0.218
Employed		77.10	81.89	
Unemployed		22.90	18.11	
Mean income (Rands)	1378	996.41	812.06	=0.048**
(±SD)		(1223.36)	(808.22)	
Breadwinner	1374	63.62	59.52	=0.363
Mean household size (number of persons)	1375	4.16	4.08	=0.354
(±SD)		(2.19)	(2.41)	
Household age structure				
Children	1378			=0.854
No children		30.06	29.92	
1 child		33.97	36.22	
2 or more children		35.97	33.86	
Adults	1378			=0.672
No adults		1.52	0.79	
1 other adult		19.66	22.05	
2 or more adults		78.82	77.17	
Elderly	1378			=0.017**
No elderly		81.45	76.38	
1 elderly		12.07	20.47	
2 or more elderly		6.47	3.15	
Type of housing	1375			=0.177
Formal		78.45	73.23	
Informal		21.55	26.77	
Psychosocial/behavioural characteristics				
Depression/anxiety	1375			<0.001**
Not anxious/depressed		77.10	51.59	
Moderately anxious/depressed		19.38	28.57	
Extremely anxious/depressed		3.52	19.84	
Substance use	1377	21.92	33.86	=0.002**
Non-disclosure	1378	14.31	21.26	=0.036**
Stigma index	1374	1.34	1.49	<0.001
(±SD)		(0.44)	(0.45)	
Social support				
No support group membership	1378	85.29	86.61	=0.687
No emotional support	1374	66.48	67.72	=0.778
Treatment knowledge index	1377	4.87	4.80	=0.033**
(±SD)		(0.36)	(0.57)	
Clinical aspects				
Side-effects	1350	13.69	13.82	=0.968
Disease status	1330			=0.015**
<200		23.23	26.72	
200-500		60.05	47.41	
>500		16.72	25.86	
Mean time on ART (years)	1359	1.87	1.72	=0.040**
(±SD)		(0.90)	(0.79)	
Health care administration and delivery				
Access barriers				
Clinic	1371	3.69	35.71	<0.001**
Hospital	1372	4.57	30.95	<0.001**
Service satisfaction index				
Clinic	1374	4.22	3.84	<0.001**

(±SD)		(0.50)	(0.52)	
Hospital	1372	4.48	4.32	<0.001**
(±SD)		(0.49)	(0.53)	
Service needs	1374	22.18	15.20	=0.070*
Drug readiness training index	1362	4.50	4.53	=0.760
(±SD)		(0.46)	(0.47)	
No treatment buddy	1373	64.85	64.57	=0.950
No regular health care providers				
Clinic staff	1340	53.98	47.93	=0.204
Hospital nurse	1368	63.09	58.27	=0.284
Hospital doctor	1349	58.95	45.24	=0.003**
Rating of health care providers				
ARV-related services index	1377	1.41	1.65	<0.001**
(±SD)		(0.49)	(0.57)	
Respect by health care providers index	1378	1.47	1.77	<0.001**
(±SD)		(0.53)	(0.58)	
ARV medication information index	1378	1.45	1.67	<0.001**
(±SD)		(0.49)	(0.51)	

^o *P*-values for test of difference, between adherent and non-adherent ART patients, in means or distributions.

* Significant at the 10% level ($P \leq 0.10$).

** Significant at the 5% level ($P \leq 0.05$).

Table 3 Reported substance use by medication adherence among women on ART in the Free State public health sector

Substance use	Total <i>N</i>	100% adherence (%)	<100% adherence (%)	<i>p</i> -value
Alcohol	1574	8.90	23.53	=0.004**
Tobacco	1574	15.19	35.29	=0.001**
Dagga	1573	0.19	0.00	=0.938

** Significant at the 5% level ($P \leq 0.05$).

Table 4 Reported substance use by scheduled appointment adherence among patients on ART in the Free State public health sector

Substance use	Total <i>N</i>	100% adherence (%)	<100% adherence (%)	<i>p</i> -value
Alcohol	1377	10.16	19.69	=0.001**
Tobacco	1376	16.25	25.20	=0.011**
Dagga	1376	0.00	1.59	=0.008**

** Significant at the 5% level ($P \leq 0.05$).