

**EVALUATION OF THE IMPACT OF THE INFORMATION-MOTIVATION-  
BEHAVIOURAL SKILLS MODEL OF ADHERENCE TO ANTIRETROVIRAL  
THERAPY IN ETHIOPIA**

by

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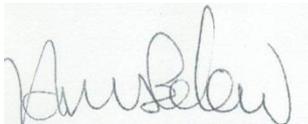
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June 2015

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### **DECLARATION**

I declare that this thesis entitled **EVALUATION OF THE IMPACT OF THE INFORMATION-MOTIVATION-BEHAVIOURAL SKILLS MODEL OF ADHERENCE TO ANTIRETROVIRAL THERAPY IN ETHIOPIA** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.



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1 June 2015

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# **EVALUATION OF THE IMPACT OF THE INFORMATION-MOTIVATION-BEHAVIOURAL SKILLS MODEL OF ADHERENCE TO ANTIRETROVIRAL THERAPY IN ETHIOPIA**

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## **ABSTRACT**

The purpose of the study was to evaluate the IMB skills model for its relevance to the Ethiopian context. According to the model, adherence-related information and motivation work through adherence-related behavioural skills to affect adherence to ART. Quantitative, analytical, observational, cross-sectional, institution-based study was conducted to evaluate the model by assessing those patients who have and do not have the right information, motivation, and behavioural skills whether they have or do not have good adherence to ART. Data was collected using structured questionnaires where a total of 400 randomly selected participants provided data on adherence-related information, motivation and behavioral skills as well as adherence behavior per se. Data was analysed using the Statistical Package for Social Sciences (SPSS) version 20.0.

Both descriptive and inferential statistics used in the study. Only 90.75 % of the total sample population reported ART adherence rate of more than or equal to 95% in this study. Free and restricted model tests, through bivariate and multivariate analyses, used to assess the propositions of the IMB model of ART adherence and provided support for the interrelations between the elements proposed by the model. The study has supported the applicability of the IMB model of adherence to the Ethiopian context highlighting its application in adherence-promotion intervention efforts. The findings revealed the need for on-going educational, informational and other interventions to address the knowledge, motivation and adherence behavioural skills of patients in order to improve the current levels of ART adherence behaviour.

## **KEY CONCEPTS**

HIV/AIDS; antiretroviral drugs; adherence to ART; Information-Motivation-Behaviour Skills Model; self-reported adherence; optimal adherence; sub-optimal adherence.

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- A special “thank you” to my supervisor, Prof GB Thupayagale-Tshweneagae, for her guidance, support and unending encouragement without her I would never succeed in my studies.
- Last but not least, I would like to convey my heartfelt thanks to the study participants for their willingness to spend their precious time to give their responses, the data collectors and the staff of Felege Hiwot Hospital ART unit for their cooperation and support during data collection.

## *Dedication*

*This work is dedicated to people living with  
HIV and those affected by it.*

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## List of abbreviations

AIDS	Acquired Immuno-Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Anti-Retroviral
CD4	Cluster Differentiation T-lymphocyte
CEO	Chief Executive Officer
CI	Confidence Interval
COPD	Chronic Obstructive Pulmonary Disease
CSA	Central Statistics Agency
CVD	Cardio Vascular Disease
EDHS	Ethiopian Demographic and Health Survey
FDC	Fixed Dose Combination
HAPCO	HIV/AIDS Prevention and Control Office
HBC	Health Behaviour Change
HCP	Health Care Provider
HIV	Human Immunodeficiency Virus
IMB	Information-Motivation-Behavioural skills
LW-IMB-AAQ	LifeWindows Information-Motivation-Behavioural Skills ART Adherence Questionnaire
MOH	Ministry of Health
OR	Odds Ratio
PEP	Post-Exposure Prophylaxis
PITC	Provider Initiated Testing and Counselling
PLWH	People Living with HIV
PMTCT	Prevention of Mother-to-Child Transmission of HIV
RLS	Resource Limited Setting
RRS	Resource Rich Setting
SES	Socio-Economic Status
SPSS	Statistical Package for Social Sciences
SSA	Sub-Saharan Africa
TB	Tuberculosis
USA	United States of America
VCT	Voluntary Counselling and Testing
VL	Viral Load
WHO	World Health Organization

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Annexure A

Ethical clearance certificate from Health Studies Higher Degrees Committee,  
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Letter seeking consent from Amhara National Regional Health Bureau research and technology transfer process

## Annexure C

Letter of approval from Amhara National Regional Health Bureau research and technology transfer process

Annexure D

Informed consent

Annexure E

Questionnaires

# CHAPTER 1

## ORIENTATION TO THE STUDY

### 1.1 INTRODUCTION

Adherence is the backbone of antiretroviral therapy. Studies of the first antiretroviral therapy (ART) showed that almost perfect adherence, classically greater than 95% was required to obtain maximal effectiveness (Paterson, Swindells, Mohr, Brester, Vergis, Squier, Wagener & Singh 2000:21-30). Never before in medical history has a therapeutic regimen required such strict lifetime adherence with serious consequences for non-adherence. Sustaining consistent and nearly perfect adherence is required to optimise the outcomes of ART, such as minimised drug resistance, slowed disease progression, decreased hospitalisation and delayed death and general health, longevity, and, quality of life (World Health Organization (WHO) 2013:90).

The success of ART is compromised by failure to maintain optimal levels of adherence over the long term and inadequate adherence is the major cause for sub-therapeutic drug levels and drug resistance that is transmissible to un-infected or infected others. Thus, adherence to therapy has become central and a major concern which requires continuous attention to prevent or delay resistance (Ramadhani, Thielman, Landman, Ndosi, Gao, Kirchherr, Shah, Shao, Morpeth, McNeill, Shao, Bartlett & Crump 2007:1492).

Recent reviews suggest that behavioural interventions to promote ART adherence can have significant effects. The intervention strategies are various, including one-on-one individual or group counselling and education sessions delivered by a clinician or a pharmacist, peer group and individual counselling, social and emotional support, telephone support such as phone-based counselling, and mobile text messaging, and internet-based computerised methods such as electronic pill monitoring as an intervention tool (Simoni, Pantalone, Frick & Turner 2010:72).

Some use theoretical approaches to guide the development of intervention content, mainly drawing from well-known theories of health behaviour changes (such as Information, Motivation, Behavioural Skills Model, Trans-theoretical Model, Health Belief Model, and others).

In the light of the complexity, dynamicity of human behaviour and a growing urgency in understanding the challenges to medication adherence confronting the people with Human Immunodeficiency Virus (HIV) in clinical care, developing theory-based interventions is essential in promoting an understanding of adherence behaviour. It can be used as a framework for providers of care in facilitating transferability from one geographical area or health care setting to another.

One potentially relevant model, the Information-motivation-behavioural skills (IMB) model, was first developed in 2001 as a general health model and subsequently was tested as a model for ART adherence. Since then it has been repeatedly evaluated and finally developed in 2009 as a three-pronged strategy in the United States of America (USA) for ART adherence from a meta-analysis perspective. It is comprehensive and addresses the cognitive, motivational, and behavioural aspects of change (Medical Express 2011; McHorney [S.a.]). The model, however, is characterised by a more individualistic approach. The advantage of IMB model is its simplicity and has been shown to be moderately effective in promoting behaviour change for ART adherence. The model views adherence behaviour as a function of the interrelations between adherence-related information, motivation, and behavioural skills. It hypothesises that adherence-related information and motivation work through adherence-related behavioural skills to affect the initiation and maintenance of optimal ART adherence (Munro, Lewin, Swart & Volmink 2007:104). The researcher has selected the model because it is the only health model tested and being implemented for intervention for ART adherence (Munro et al 2007:104), hence, it has a well-developed tool (questionnaire) which can be used for evaluation.

The proposed study aims to evaluate the IMB model and to explore its potential application and adaptability on ART adherence in order to determine whether its constructs incorporate the patients' perceived familial and social responsibilities in Ethiopian context, where the culture is more collectivist.

The proposal presents the following sections: Background to the research problem, statement of the research problem, the study framework of the research, purpose of the research, research objectives, the research design, significance of the study, limitations of the study, and ends with a conclusion.

## **1.2 BACKGROUND**

If the current progress in universal access and scaling up of ART is sustained, the world can achieve the global target of 15 million people receiving ART by the end of 2015. Most countries with a high burden of HIV infection are potentially on track to achieve the universal access based on the 2010 WHO criteria for treatment eligibility (WHO 2010:19-24; WHO 2013:13). The number of people receiving HIV treatment has tripled in the last five years – and reached 9.7 million in low- and middle-income countries in 2012. That total represents 65% of the global target of 15 million people set for 2015, up from 54% at the end of 2011 (WHO 2013:13).

Although the goal of ART is to achieve and sustain viral suppression, drug resistance is an inevitable condition which is mainly aggravated by poor adherence to the prescribed pills (WHO 2013:11, 90). Multiple factors related to health care delivery systems, the medication and the person taking ARV drugs may affect adherence to ART. The individual factors include forgetting doses; being away from home; changes in daily routines; depression or other illness; a lack of interest or desire to take the medicines; and substance or alcohol use. Adherence to ART may also be challenging in the absence of supportive environments for people living with HIV and due to HIV-related stigma and discrimination (WHO 2013: 80-82).

No single adherence intervention or package of interventions is effective for all populations and all settings. People's needs and circumstances may also change over time, and programmes and care providers therefore need to tailor a combination of feasible interventions to maximise adherence to ART based on individual barriers and opportunities.

Patient education and counselling are an essential package of adherence support both when ART is initiated and throughout the course of treatment. Studies (Zeleeke &

Thupayagale-Tshweneagae 2013:154; WHO 2013:82) show that counselling improves adherence to ART. Informing and encouraging or motivating people receiving ART and their families and peers, are essential components of chronic HIV care (WHO 2013:82).

### **1.3 RESEARCH PROBLEM**

Perfect adherence to demanding ART is now recognised as essential for HIV-positive patients in order to realise its life sustaining benefits. Adherence success depends on a well-established medication taking routine, including health care provider support and adequate education on medication changes. Adherence to HIV ART among people living with HIV (PLHIV) in developing settings is poorly understood. While many factors influence adherence, the literature is dominated by studies on only one or a small set of them. Although substantial progress has been made in recent years in better understanding why individuals fail to adhere to ART and have proposed conceptual models of ART adherence in resource-rich settings, it is questionable if these social cognitive models are well-tested in resource limited settings. This has created a critical need to identify factors influencing ART adherence and to develop interventions that target such factors. Multivariate, theory-based models of adherence behaviour are of greater interest and could help in designing more effective interventions to promote treatment adherence (Munro et al 2007:104).

Hence, the evaluation of the transferability of such models is critical in the development of effective interventions in resource-poor settings. The current study aims to evaluate one such model, which offers a dynamic, multivariate account of ART adherence which assumes that adherence-related information, motivation, and behavioural skills are fundamental determinants of adherence to ART for its applicability to the Ethiopian context where the setting is resource constrained, the culture is collectivist, and the health seeking is inclined more to spiritual than biomedical services (Amico, Toro-Alfonso & Fisher 2005:665). The problem under investigation is that even though the IBM model is used its effectiveness is not known within the Ethiopian context.

### **1.4 RESEARCH PURPOSE**

The purpose of the study is to evaluate the IMB skills model for its relevance to the Ethiopian context. According to the model, adherence-related information and

motivation work through adherence-related behavioural skills to affect adherence to ART. Empirical evaluation for the IMB model of adherence will be presented, and if the evaluation supports its applicability to the Ethiopian context its application in adherence-promotion intervention efforts will be discussed.

## **1.5 RESEARCH OBJECTIVE**

### **1.5.1 General aim**

The general aim of this study is to evaluate the Information, Motivation and Behavioural Skills (IMB) model of ART adherence in the Ethiopian context, i.e., to determine if the assumed or theorised associations between IMB model constructs and adherence in resource-rich settings would be applicable for ART patients in the Ethiopian setting.

### **1.5.2 Specific objectives**

In order to achieve the general aim of this study, the following specific objectives were set:

- To assess the levels of ART adherence behaviour in patients taking ARV drugs at Felege Hiwot hospital which located in Bahir Dar town of the Amhara region of Ethiopia.
- To explore the impact of information about ART and adherence on ART adherence behaviour among patients receiving ARV drugs from Felege Hiwot hospital.
- To explore the motivation on ART adherence behaviour among patients receiving ARV drugs from Felege Hiwot hospital.
- To determine behavioural skills needed to practice strict ART adherence on their self-reported adherence behaviour of patients at Felege Hiwot hospital ART clinic.
- To assess the benefits of the integration of information, motivation and behavioural skills needed to practise strict ART adherence in patients receiving ARV drugs from Felege Hiwot hospital.

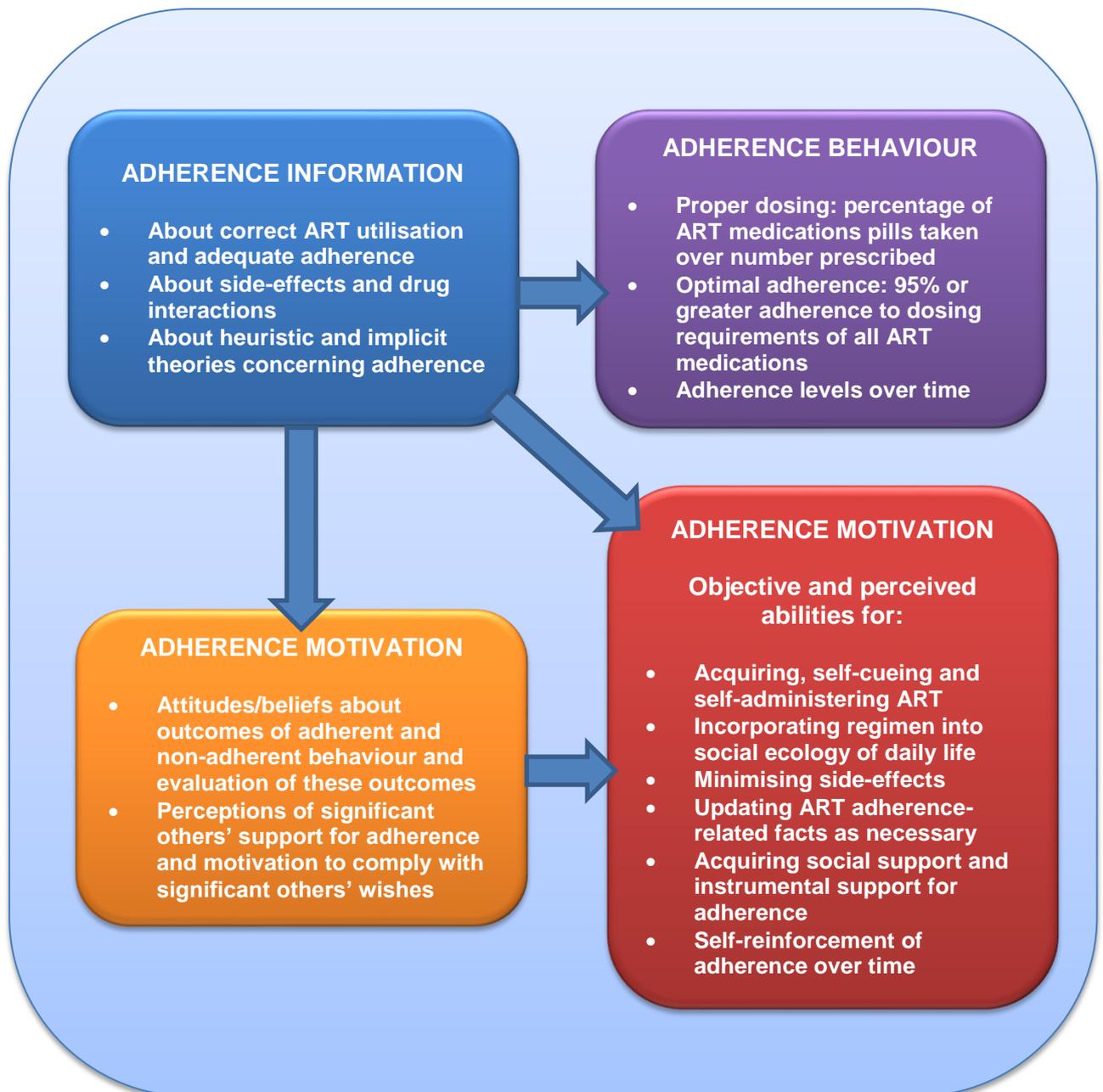
### **1.5.3 Research questions**

Based on the objectives above the study aims to answer the following questions:

- What are the levels of ART adherence behaviour in patients taking ARV drugs?
- What is the impact of information about ART and ART adherence behaviour among patients taking ARV drugs
- What are the behavioural skills needed to practice strict ART adherence
- Are there any benefits of the integration of information, motivation and behavioural skills needed to practice strict ART adherence?

### **1.6 FOUNDATIONS OF THE STUDY**

The researcher has used the following IMB skills model of ART adherence adopted from previous research to analyse its applicability to the Ethiopian setting.



**Figure 1.1 IMB model of ART adherence**

(Adopted from Amico et al 2005:662)

### 1.6.1 IBM Model

The IBM model includes three main constructs which are information and knowledge about the behaviour; the individual motivation to perform the behaviour and the behavioural skills necessary to perform the behaviour (Amico et al 2005:662). Adherence information includes relevant knowledge on antiretroviral medications such as correct doses, side-effects and drug interactions (Fisher, Fisher, Amico & Harman 2006b:463). The manner in which information is given can either impede or facilitate adherence. On the other hand adherence motivation includes both personal and social spheres of motivation. Personal motivations refers to the willingness or non-willingness of an individual towards taking ARV drugs, it also means the individual perceptions on the benefits of taking drugs. Social support makes for social motivations. For those patients that believe they have enough social support for adherence will probably adhere to drugs. The last construct refers to the individual's ability and willingness to do all the necessary skills that would improve adherence (Amico et al 2005:666-669).

### 1.7 DEFINITION OF KEY CONCEPTS

**Information:** The *Oxford Advanced Learner's Dictionary* (1995:611) defines *information* as "facts told, heard or discovered about something/somebody".

In this study, *information* refers to the facts about antiretroviral (ARV) drugs adherence and their relative importance for the purposes of this study.

**Motivation:** The *Oxford Advanced Learner's Dictionary* (1995:758) defines *motivation* as "the reason for somebody's action" or the reason why someone acts as they do.

In this study, *motivation* refers to the personal and social driver that some people have to adhere to the dosage requirements of ART.

**Behaviour:** The *Oxford Advanced Learner's Dictionary* (1995:96) defines *behaviour* as a way in which someone acts or reacts "in the specified way".

**ART** is the regimen that is made up of, at least, three antiretroviral drugs (ARV) that is potent enough to suppress viral replication and prevent the emergence of resistance for a significant period of time. Such regimens have been associated with immunologic

restoration, slower HIV clinical progression, durable therapeutic responses, improvements in quality of life, and reduction in the emergence of drug resistance (African Network for the Care of Children Affected by HIV/AIDS (ANECCA) 2011:155-156).

**ART adherence** means the ability of the person living with HIV to be involved in choosing, starting, managing and maintaining a given ART regimen to control HIV (Human Immunodeficiency Virus) replication and improve the immune function. It means taking the correct doses of drugs at the correct time and in the correct way (such as with the right type of food or fluid) and sticking to the treatment plan. It also means looking after drugs to make sure they are safe and effective to use. Adherence is different from compliance in that the latter is not based upon shared decision-making between the patient and provider (Horizons ... 2004:16).

**Non-adherence to ART** includes the following: Missing a dose or doses of ARVs; stopping medicine for a day or days; taking the medicines at the wrong time, and taking the medicines without dietary instructions (Horizons ... 2004:17).

**Level of adherence/Adherence behaviour** means the percentage of prescribed doses swallowed by the patient following instructions given by the provider (conceptual definition) (Horizons ... 2004:17).

## **1.8 SIGNIFICANCE OF THE STUDY**

Studies in South Africa and Thailand favour the IMB model with complementary recommendation of psychosocial support and with modification of the motivation construct of the IMB respectively (Peltzer, Preez, Ramlagan & Anderson 2010:3; Rongkavilit, Naar-King, Kaljee, Panthong, Koken, Bunupuradah & Parsons 2010:787). However, studies conducted to assess the transferability and adaptability of the health behaviour models including the model of interest to resource-poor settings are still scarce. It remains to be seen whether this model has general applicability to resource constrained settings where health care service and culture is more spiritual than biomedical and social, economic and logistical factors, including the accessibility and quality of health care services may primarily impact adherence, rather than individual client-centred factors. Results from the study will help policy-makers and health

managers to make decisions on whether to adopt and apply, modify or adapt the model as framework for enhanced adherence intervention. The results of this study will also influence curriculum development in training institutions and also stimulate further research by researchers.

## **1.9 ETHICAL CONSIDERATIONS**

Researchers, contends that there are important ethical issues which should be taken cognisance of while undertaking research (Parahoo 2006:111 & Streubert-Speziale & Carpenter 2007:62). Researchers are indebted to observe certain ethics, in order to generally safeguard participants' rights.

### **1.9.1 Institutional Review Board**

The study was carried out after obtaining ethical clearance from the UNISA Higher Degrees Committee (Annexure A).

### **1.9.2 Permissions**

Research Ethics Committees were set up to assess the ethical implications of studies which can otherwise be unknowingly detrimental to the lives of research participants. The code of ethics and its guidelines are concerned with the protection of human rights violations in research involving human subjects. For this study a letter of cooperation from Amhara Regional Health Bureau Research and Technology Transfer Process was requested and data was collected after receiving written authority from the office of the Chief Executive Officer (CEO) of the study hospital (Annexures B and C). The hospital CEO was assured that the study would not pose any risk to the participants and that the result of the study would be disseminated to the hospital for utilisation.

### **1.9.3 Informed consent**

Informed verbal consent of participants was sought, granted and recorded in writing (Annexure D). The objectives of the study were discussed with each participant who were briefed that participation in the study has no incentive but has benefits in the long run and also that it does not carry any risk. Participants were also informed that they

have full right to discontinue the questioning at any time during the session. All those who participated in the study signed a consent form (Annexure D).

#### **1.9.4 Privacy and confidentiality**

The right to respect of individuals privacy is an international norm that is strongly emphasised in research. It is the foundation for building appropriate interpersonal relationships among people (Gastmans 1998:26). Confidentiality is used synonymously with concealment or secrecy and in research it is understood to mean that any identity of a participant should not be exposed. Any information collected from participants should exclude their names and only shared anonymously with other researchers or significant others such as policy makers.

Confidentiality and the protection from invasion of privacy were key in this study. The interviews were conducted in a private room to ensure privacy and confidentiality. No names were used in the interviewing forms and codes were used instead of names. All forms with information about the participants are stored separately from the completed questionnaires and in secure storage.

Privacy and confidentiality will be maintained during and after the interview. The cell phone address of the researcher was given to the participants for in case they need clarity on any issue regarding the study. The researcher never received any calls from participants.

#### **1.10 OPERATIONAL DEFINITIONS**

For the purpose of this study **adherence behaviour/level of adherence** will be defined as follows:

- Asking the patient skipped doses or delayed doses for more than two hours over the last 3 days, and calculating the adherence rate by the following formula:  $\text{Number of doses taken} / \text{Number of doses supposed to be taken for 3 days} \times 100\%$  ART adherence level is said to be “ Good” if  $\geq 95\%$ . Patients will be asked about missed doses in the last 72 hours. Assessment will be done by counting

how many dose/s s/he missed (taking also delayed doses for  $\geq 2$  hours as missed) in the previous 3 days.

- A patient will be labelled as adherent if she or he took all doses in the previous 3 days, and non-adherent if s/he skipped or took with delay of  $\geq 2$  hours even a single dose in the previous 3 days. This is based on the above formula and considering GOOD ( $\geq 95\%$ ) or near to perfect adherence necessary for ART.

**Adherence behavioural skill** in this study refers to the act of taking of ARV drugs in compliance with the prescription of the health care worker who administers them. It is the perceived as well as objective ability to self-administer ARV medications as noted in the conceptual model of the study (operational definition).

## **1.11 ORGANISATION OF THE THESIS**

The thesis is divided into the following chapters:

**Chapter 1:** Introduction and background information

**Chapter 2:** Literature review

**Chapter 3:** Research methodology

**Chapter 4:** Results and discussion

**Chapter 5:** Conclusions, strategies, limitations and recommendations

## **1.12 CONCLUSION**

This introductory chapter provided an overview of the study. It includes an introduction to the chapter, background information on adherence and ART as used in Ethiopia. The chapter also gave an overview of the research problem, significance of the study, purpose of the study and objectives of the study. Research questions were also included. The chapter concludes by providing the structure for the study.

## CHAPTER 2

### LITERATURE REVIEW

#### 2.1 INTRODUCTION

Chapter 2 begins with the background, and then provides an overview of the range of social-psychological models, theories and principles. In addition, the chapter provides a detailed discussion of the key considerations, limitations and strengths when using behavioural models to design interventions. The chapter ends with conclusion.

#### 2.2 BACKGROUND

The current standard of HIV-clinical care in Ethiopia recommends one clinical examination every two months and CD4 determination every six months for asymptomatic patients responding to treatment (Federal HIV/AIDS Prevention and Control Office 2008:6-18). However, gaining an in-depth understanding of the core facilitators and barriers to self-sustained retention in HIV care is desperately needed to inform effective intervention efforts.

There is an urgent demand in health education and health behaviour science to facilitate behaviour changes. According to the Position Paper on Health Education prepared jointly by the International Union for Health Education and the Division of the Health Education, WHO, Geneva, with the support from the Centres for Disease Control, USA (WHO 1992:3) health education is a "combination of planned social actions and learning experiences designed to enable people to gain control over the determinants of health and health behaviours, and the conditions that affect their health status and the health status of others. Health education is therefore, "any combination of learning experiences designed to facilitate voluntary actions conducive to health. The word "*combination*" in the definition of health education emphasises the importance of matching the multiple determinants of behaviour with multiple learning experiences or education interventions; while "*designed*" distinguishes health education from incidental learning experiences as a systematically planned activity. The word "*facilitate*" means

predispose, enable, and reinforce. “*Voluntary*” means without coercion and with full understanding and acceptance of the purposes of the action; and “*actions*” means behavioural steps taken by an individual, group, or community to achieve an intended health effect or to build their capacity for health” (Green & Kreuter 1999:190; WHO 2012:16).

Very often, *health promotion* as a term is associated with *health education*. In 1984, the WHO defined health promotion as “a process of enabling people to increase control over and to improve their health” (WHO 1984:65). Labont’e and Little (Donev, Pavlekovic & Kragelj 2007:8-9) defined health promotion as “any activity or programme designed to improve social and environmental living conditions such that people’s experience of well-being is increased” Therefore, health promotion is not just the responsibility of the individual or the health sector, but goes beyond healthy life-styles to well-being and demands coordinated action and inter-sectoral collaboration.

Historically, there has been a shift from health education to health promotion. The aim of health education in its early days was to make people aware of the health consequences of their behaviour. People were considered as “empty vessels” that process information in a logical manner and subsequently act accordingly. Changes in individual opinion attitudes and behaviours were seen to result from information and knowledge. The line of thought was that if you provide people with knowledge, they could make good decisions regarding their health. In the 1970s the insight grew that providing knowledge alone was not enough. To be able to live a healthy life, individual motivation, skills and the influence of the social environment were recognised as very important determinants as well. People also have to be encouraged, educated, trained and facilitated to be able to improve their health and change the environment they live in. In addition it has become recognised that individuals cannot be isolated from their social environment and that a single behaviour cannot be isolated from the context. The approach of the health professionals changed from an educational into a more health promotional one (Donev et al 2007:6).

*Health behaviour has been defined* as “those personal attributes such as beliefs, expectations, motives, values, perceptions, and other cognitive elements; personality characteristics, including affective and emotional states and traits; and overt behaviour

patterns, actions, and habits that relate to health maintenance, to health restoration, and to health improvement” (Gochman1997:5).

In the broadest sense, *health behaviour* refers to the actions of individuals, groups, and organisations, as well as their determinants, correlates, and consequences, including social change, policy development and implementation, improved coping skills, and enhanced quality of life (Glanz, Rimer & Viswanath 2008:12). There are specific categories of overt health behaviour embraced in the broader definition of health behaviour (Glanz et al 2008:12) including:

- (i) Preventive health behaviour: any activity undertaken by an individual who believes him/herself to be healthy, for the purpose of preventing or detecting illness in an asymptomatic state.
- (ii) Illness behaviour: any activity undertaken by an individual who perceives herself or himself to be ill, to define the state of health, and to discover a suitable remedy.
- (iii) Sick-role behaviour: any activity undertaken by an individual who considers being ill, for the purpose of getting well. It includes receiving treatment from medical providers. Generally, it involves a whole range of dependent behaviours, and leads to some degree of exemption from one’s usual responsibilities.

“Health Behavioural Science” is an interdisciplinary science which aims to (Pan 2014):

- Understand and describe the nature of human behaviour
- Investigate the relationship between behaviour and health
- Find out the barriers and facilitators which influence behaviour
- Strengthen the theoretical background of health behaviour
- Develop the behavioural modification techniques
- Formulate the health intervention or education plan
- Evaluate the effectiveness of intervention strategies

Where professionals once might have seen their roles as working at a particular level of intervention or employing a specific type of behaviour change strategy, there is now

increased recognition that multiple interventions at multiple levels are often needed to initiate and sustain behaviour change more effectively (Glanz et al 2008:4).

There are many tools and strategies developed to address behaviour change. Systematic reviews have shown that designing interventions grounded in theory can lead to more fruitful effects than interventions developed without theory. A better understanding of the role theories play in producing effective, sustained behaviour change is necessary because the theories transform the tools and strategies from one that is primarily local and country-specific to one that is both global and local, in a way that we increasingly see the world as interconnected (Glanz et al 2008:4).

In the twentieth century, theoretical and practical advances in psychology have helped lay the foundation for contemporary important and areas of interest in personality, social, clinical, and health psychology. As a microcosm of both psychology and the interdisciplinary endeavour of behavioural medicine, these developments have taken the position that biological, psychological, and social factors are implicated in all stages of health and illness, and the bio-psycho-social model is a guiding framework for the application of both psychological theory and research to health, illness, and health care.

Much of the strongest work involved provides theoretical and conceptual frameworks that constitute major contributions inasmuch as they are often lacking in traditional medicine and medical practice. In this context, it becomes essential to consider such distinct theoretical ideas and models as (Donev et al 2007:488).

#### **(a) Psychodynamic conceptions**

Psychodynamic theories have gained widespread acceptance and are deeply entrenched in the public view of human behaviour. These conceptions of human nature commonly view human behaviour as motivated from within by various needs, drives, impulses, and instincts. Thought refers to acts of reasoning, reflection, imagining, and other personal activities. Psychological methods are evaluated in terms of their effectiveness in changing actual psychological functioning (Donev et al 2007:489).

## **(b) Trait theory**

Trait theorists are concerned with how dispositions generate behaviour, motivate and guide it as well as with assessing personality traits and testing their predictive utility. Recent research developments suggest specific models of personality-disease relationships. Among these are the investigating the role of Type A behaviour syndrome in the aetiology of coronary heart disease, and the potentially protective role of positive emotional states and coping styles in the development of illness (Donev et al 2007:490).

## **(c) Rotter's social learning theory**

The theory infers that behaviour is a function of expectancy and reinforcement value in a specific situation. Training in mature decision making, healthy behaviour, coping with stress and other life skills is of great importance (Donev et al 2007:490-495).

## **(d) Bandura's social cognitive theory**

The theory accords a central role to the mechanisms through which the individual operates: cognitive processes, motivational processes, affective processes, selection processes, and the power of forethought to override feedback control. Self-monitoring, self-regulation, including appropriate goal-setting, self-efficacy, and self-control mechanisms are described as effective and productive cognitive coping strategies (Bandura 1997:126; Bandura 2000:11-27; Donev et al 2007:489).

## **(e) Creativity in everyday life**

Recent research suggests that individuals that use to understand and control events in their lives include the creation of new original ways to act upon the environment and their life conditions. They engage in the creative process as they construe their world, plan their activities, and regulate their behaviour within some reality constraints. Creativity involves awareness of context and the flexibility of thinking that can lead a person to the creation of multiple perspectives and new ways of looking at things (Donev et al 2007:490).

The most frequent causes of mortality and morbidity globally are chronic diseases, including HIV, heart disease, cancer, lung diseases, and diabetes. Behavioural factors, such as sexual behaviour, medication non-adherence, tobacco use, diet and activity patterns, alcohol consumption, and avoidable injuries are among the most prominent contributors to mortality. Projections of the global burden of disease for the next two decades include among others a dramatic rise in deaths from HIV. Worldwide, the major causes of death by 2030 are expected to be HIV, depressive disorders, and heart disease (Glanz et al 2008:6).

In the advent of ART, the reason why mortality continues from HIV is mainly due to non-adherence behaviour to prescribed medication which results in treatment failure because when patients take their medications irregularly the virus is exposed to inadequate (sub-inhibitory) concentrations of antiretroviral medication. This in turn leads to on-going viral replication and to the development of resistance to antiretroviral medication which accounts for a large portion of treatment failures. Hence, there is a critical need to design interventions to improve adherence rate.

Despite the recognised need for targeted need interventions to improve retention in care, the literature exploring factors influencing retention in HIV care is largely dominated by the identification of demographic correlates of retention. Such correlates suggest poorer retention is more likely to occur in people living with HIV (PLWH) who are: younger, single, female, those with history of substance use or active current use and those with lower socio economic status (SES) (e.g. lower educational attainment, lower income, and lack of insurance). Poor retention is also associated with structural factors (e.g. unstable housing, greater distances to health facilities) (Volberding, Sande, Greene, Lange, Gallant & Walsh 2008:209).

More recent efforts have sought to identify individual-level factors that may be more amenable to behavioural change efforts (e.g. health beliefs, acceptance of HIV status and abilities to overcome practical barriers to care. Identification of discrete correlates, particularly those that are in fact malleable, is critical in building behavioural models that more comprehensively attend to the underlying dynamics of sustained retention in HIV care, which can be understood as self-directed health promotion behaviour. Even if not fundamentally causal, changes in health knowledge and attitudes can contribute to individual and population behaviour changes over time (Fishbein 1998:175). There is

evidence that health-behaviour change (HBC) interventions in fields such as smoking cessation, exercise, diet and HIV risk control have reduced mortality and morbidity from conditions such as lung cancer, chronic obstructive pulmonary disease (COPD), cardiovascular disease (CVD) and acquired-immune deficiency syndrome (AIDS) (Fishbein 1998:176; Fishbein & Pequegnat 2000:101). But the specific part played by psychological model use in achieving such health outcomes is uncertain.

Several comprehensive models of health behaviour adoption and maintenance have been applied individually and as a system level approach to accessing HIV care, including: Anderson's Behavioural Model of Health Service Utilization, the Chronic Care Disease Model, the Health Belief Model, and the Socio-ecological Framework. However, models that provide both a good characterisation of underlying determinants of retention in HIV care and lead to actionable intervention approaches are lacking. There are still relatively few rigorous evaluations of interventions to promote adherence to ART and tuberculosis (TB) treatment (Simoni, Frick, Pantalone & Turner 2003:3; Volmink & Garner 2006:16); even fewer have explicitly utilised behaviour change theories. For example, a systematic review of interventions to promote adherence to TB treatment (Volmink & Garner 2006:16) included ten trials, none of which used an explicit theoretical framework. A similar review identified seven different randomised controlled trials of interventions to promote adherence to ART (Simoni et al 2010), of which only one employed an explicit theoretical framework. The researcher cannot therefore suggest that these theories be used routinely to design adherence promoting interventions. However, since these theories may well have practical behaviour change potential, and since the problem of medication adherence remains significant for both clinical medicine and public health, further exploratory and explanatory research is needed (Munro et al 2007:104).

Given the insufficient amount of evidence to support any particular health behaviour theory and partly in response to this gap in literature, Amico and colleagues (Amico et al 2005:1210) proposed an application and extension of the Information, Motivation, Behavioural Skills (IMB) model as an explanatory model of initiation and maintenance in clinical care for chronic medical conditions that has immediate application for retention-related intervention approaches. Thus, the current study uses the IMB model, to test its constructs for predicting ART adherence.

## **2.3 THE INFORMATION-MOTIVATION-BEHAVIOURAL SKILLS MODEL**

According to Munro et al (2007:104), health behaviour theories may be useful for assessing adherence and for developing practical interventions that will promote an optimal adherence to ART. From the various health behaviour theories that were available, the researcher selected the Information-Motivation-Behavioural skill (IMB) model of adherence in order to assess rates of adherence in a particular sample prior to designing and implementing a remedial intervention (Fisher et al 2006b:462; Amico, Barta, Konkle-Parker, Fisher, Cornman, Shuper & Fisher 2009:73).

### **2.3.1 The origin and development of IMB model of adherence to ART**

The IMB model was initially used in efforts that were targeted at reducing the incidence of AIDS-risk behaviour, and the study undertaken by Fisher, Fisher, Misovich, Kimble and Malloy (1996:120) showed that after an intervention that made use of the IMB model, participants showed significant increments in their personal AIDS-risk preventive behaviour. With antecedents in both the health sciences and in social psychology, the IMB model conceptualises adherence to ART as a health-related behaviour. The IMB model is determined mainly by the extent of an individual's knowledge of ART, the serious consequences of non-adherence, by personal attitudes toward the taking of ARV medications (personal motivation), and by the ability to perform whatever adherence-related tasks are necessary, together with a strong sense of self-efficacy (behavioural skills) (Ware, Wyatt & Bangsberg 2006:19). According to the model, information and motivation make a direct as well as an indirect impact on adherence behaviour; directly information and motivation can help the individual to acquire an optimal adherence behaviour and indirectly they impact on adherence behaviour through adherence behavioural skills because information and motivation are determinant factors for one to develop and use behavioural skills (Ware et al 2006:19) (see figure 1.1). In the light of this, the following three points are considered to be of primary importance in the IMB model:

- Information about adherence
- Motivations for adherence
- Behavioural skills that facilitate adherence

### **2.3.2 Core assumptions of and statements about the IMB model**

The IMB model assumes that adherence-related information, motivation, and behavioural skills are fundamental determinants of adherence to ART as well as a wide range of useful health-related behaviours. The model asserts that people who are well-informed and motivated to act and those who possess the behavioural skills to do so, are far more likely to adhere to the ART regimen than those who lack these qualities and skills. The reverse is also true. A poorly informed person who lacks the motivation to act and those who lack the behavioural skills to act effectively, will be less likely to adhere to the requirements of the ART regimen (Fisher et al 2006b:463).

The univariate characteristics of the IMB model consider that a direct relation exists between adherence behaviour and adherence information, adherence motivation and adherence behavioural skills while the multivariate assumptions of the IMB model assert that ART adherence information and motivation generally manifest themselves in ART adherence behavioural skills in a way that affects adherence behaviour. This is especially true if sophisticated skills are a precondition for taking the ARV medications (Fisher et al 2006b:466).

The present practice is for patients who are involved with ART to take one fixed-dose combination (FDC). This simplifies their lives because they are required to take only one tablet in the morning and one tablet in the evening (Federal HIV/AIDS Prevention and Control Office (HAPCO) 2008:61). This in itself reveals that no complex behavioural skills are required for patients who wish to adhere optimally to their medication. In such cases, adherence information and motivation will mainly exert a direct effect on adherence behaviour in addition to an indirect effect on behavioural skills (Amico et al 2005:664; Fisher et al 2006b:464; Starace, Massa, Mariniello, Amico & Fisher 2006:155; Amico et al 2009:67). It is for this reason that this study assessed the univariate correlation of the IMB model constructs (ART adherence-related information and motivation and behavioural skill elements) to the levels of adherence for prescribed ARV medications.

### **2.3.3 Applications of the IMB model**

The IMB model of adherence to ART can be used to understand, predict and promote adherence to ARV regimens and to propose a set of operations for designing, implementing and evaluating ART adherence promotion interventions. The IMB model can also be used to assess a wide range of health-related behaviours with information, motivation and behavioural skills as fundamental determinants of behaviour (Fisher et al 2006b:463).

### **2.3.4 Components of the IMB model when it is applied to adherence to ART**

The components of the IMB model which are displayed in the conceptual framework of the current study in chapter 1 (refer to figure 1.1) are information, motivation, behavioural skills, and adherence behaviour. Each component is discussed below in detail in light of evidence from previous quantitative and qualitative works on the IMB model of adherence behaviour to HIV medication as well as retention in HIV care. Accordingly, the following concepts are identified and discussed:

- Adherence-relevant information and heuristics
- Adherence-relevant motivation which refers to a personal and social motivation to follow one's ART regimen as prescribed
- Adherence-relevant behavioural skills which comprise an individual's objective abilities and perceived self-efficacy to enact a series of coordinated behaviours involved in the execution of the adherence behaviour
- Adherence behaviour *per se*

#### **(i) Information**

The first determinant of an IMB model, information, reflects objective information (and misinformation) held by an individual regarding the specific health behaviour in question. The information construct also contains cognitive heuristic or implicit theories held by an individual such as health beliefs specific to HIV that are often used to guide health behaviours (e.g. absence of AIDS symptoms means one does not need medical care). The heuristic process is used as a simple decision rule permitting the individual to make decisions (often incorrect ones) about engaging or not engaging in the specific

health behaviour. The use of inaccurate heuristics typically occurs without recognition of the cognitive process associated with the behavioural decision in question (Fisher, Cornman, Osborn, Amico, Fisher & Friedland 2004:S78; Fisher & Fisher 1992:455).

The specific kinds of objective information (and misinformation) relevant to adherence include basic accurate information about the regimen, requirements of adherence, drug interactions and side-effects, information on the disease itself (HIV/AIDS), including the process of adjusting life with HIV and changes in the disease course; and information about the available system(s) of care and support such as information about available treatment(s), their purpose and typical procedures, including interrelated ancillary services available to facilitate access to and use of HIV treatment (e.g. case management) and patients' rights to receive the services (Fisher et al 2006b:462; Fisher, Amico, Fisher & Harman 2008:193; Amico 2011:1071).

## **(ii) Motivation**

Motivation to engage in the health behaviour is the second component in the IMB model, impacting on individuals' inclination to act on what they know about the behaviour. Motivation is comprised of an individual's personal motivation (i.e., attitudes and beliefs about engaging or not engaging in the behaviour), as well as his or her social motivation (i.e., perceptions of social norms regarding the appropriateness of the behaviour and of the social support or social consequences for engaging in the behaviour; Fisher & Fisher 1992:457; Fisher et al 2004:S80).

Amico (2011:1072) states that the specific kinds of personal motivation identified in the situated application of the IMB model as critical to adherence to HIV medication (and retention in HIV care) include the attitudes and beliefs about the positive and negative consequences of adherence to HIV medication in terms of (1) prioritising self-care in the face of competing priorities, (2) obtaining results of viral load, CD4 monitoring and disease progression, (3) managing negative feelings related to living with HIV such as HIV stigma, acceptance of diagnosis or the long term effects of HIV, and HIV treatment). Social norms and degree of support for navigating care are reflected in social motivation in terms of (1) degree of perceived social support for adhering to medication from important others (including navigating HIV stigma or cultural beliefs about the relevance of adherence to HIV medication); (2) perceptions of patient-provider

interactions including anticipated consequences of disclosing substance use or non-adherence to HIV medication; (3) resilience against social pressures and norms to prioritise adherence to HIV medication.

Motivation-related correlates identified in the literature and anticipated to be of relevance to patients' experiences of adherence behaviour in the current study reflect: personal motivation which includes one's attitudes and beliefs about outcomes of adherent and non-adherent behaviour and evaluation of these outcomes (Beer, Fagan, Valverde & Bertolli 2009:785-792), perceived vulnerability (including subjective health status) to the positive consequences of adherence or negative consequences of non-adherence (Gordon, McGinnis, Conigliaro, RodriguezBarradas, Rabeneck & Justice 2006:S37), trust in one's provider and the health care system (Beer et al 2009), and attitudes towards living with HIV (e.g., HIV-stigma and acceptance of diagnosis; Beer et al 2009:790).

In addition to personal motivation, social motivation refers to factors such as perceived social norms and social support for adherence as well as one's motivation to comply with their wishes, perceived engagement of one's provider in patient-provider interactions (Bakken, Holzemer & Brown 2000:189; Cunningham, Sohler, Korin, Gao & Anastos 2007:226), and the presence of personal external support systems (e.g., family, friends, mental health treatment, transportation and other support services (Bodenlos, Grothe, Whitehead, Konkle-Parker, Jones & Brantley 2007:65; Cunningham, et al 2007:228; Rajabiun, Mallinson, McCoy, Coleman, Drainoni, Rebholz & Holbert 2007:S20) for accessing care and adhering to HIV medication over time.

### **(iii) Behavioural skills**

Behavioural skills for engaging in the health behaviour is the third critical component of the IMB model, and comprises an individual's objective abilities and perceived self-efficacy to enact a series of coordinated behaviours involved in the execution of the health behaviour, *per se* (Fisher et al 2004; Fisher & Fisher 1992). The specific kinds of behavioural skills identified in the situated application of the IMB model as critical to adherence to HIV medication (Amico 2011:1078) include objective skills and perceived self-efficacy across three distinct skill sets for systems navigation, overcoming practical

barriers to adherence to HIV medication, and enhancing sustained optimal adherence to medication over time.

**Systems navigation skills:** These set of skills reflect perceived and actual abilities to access available HIV care and arrange resources for adherence to medication (including navigation of ancillary care services to aid in adherence to HIV medication).

**Functional skills (organising/planning):** Are used to overcome practical barriers to medication adherence, such as skills to integrate HIV medication in regular part of one's daily life when one is too busy to take the medication or when the daily routine deviates, such as long distance travel (including use of reminder strategies) and arranging to attend care visits to refill medication (including transportation) in the context of competing demands and barriers, such as employment, child care, and more pressing comorbidities, such as active substance use or depression.

**Activation skills:** Reflect intend to minimise perceived negative consequences of medication adherence and maximise perceived positive consequences of medication adherence and refill important for sustaining adherence over time (i.e., skills to increase/maintain HIV health literacy, invest in affective adjustment to HIV diagnosis and long term outcomes, seek instrumental and emotional social support for medication adherence and medication refill appointments regularly, and sustain prioritisation of self-care in the face of competing demands and barriers such as mental health issues, substance use, and housing instability).

Correlates reflecting such behavioural skills noted in previous work and anticipated to be present across patients' experiences of adherence to HIV medication in the current study include: perceived and objective ability to overcome perceived and practical barriers to adherence to medication and appointment (e.g. transportation, competing priorities, and mental health issues) (Rajabuin et al 2007:S22), ability to access support services (e.g., case management, mental health treatment) (Cunningham et al 2007:226; Tobias, Cunningham, Cunningham & Pounds 2007:8), as well as the ability to negotiate care in the context of living with HIV (e.g., coping with diagnosis, maintaining a sense of 'normalcy', HIV stigma) and other comorbidities (e.g., substance use, depression) (Rajabuin et al 2007:S24).

**Adherence behaviour:** Adherence behaviour is the cumulative percent of medication that a patient has taken from the number of drugs that have been prescribed for that patient. This can be calculated as the number of doses that a patient has taken over the total number that were prescribed during a specific time period (Amico et al 2005:665). The adherent behaviour of individuals to ART can be divided into two modes: *optimal adherence* is practised by those who took 95% or more of their dosing requirements while *sub-optimal adherence* is practised by those who took less than 95% of the dosages that were prescribed for them during the prescribed period (Fisher et al 2006b:468; Glass, Geest, Weber, Vernazza, Rickenbach, Furrer, Bernasconi, Cavassini, Hirschel, Battegay & Bucher 2006:386; Amico et al 2009:67; Amberbir, Woldemichael, Getachew, Girma & Deribe 2008:4).

### **2.3.5 Modifying factors of the IMB model relationship**

Practical adherence barriers such as inadequate or difficult access to medical care can affect the relationship between information, motivation and behavioural skills and adherence behaviour (Fisher et al 2006b:463; Amico et al 2009:67). This means that patients with no perceptual adherence barriers may not adhere if they have barriers related to capacity and resources. Fisher et al (2006b:462) suggests that in such cases the moderator variables can operate through the core IMB model constructs and the intervention would address information regarding the interaction of ARVs and for instance hazardous drinking, and motivational barriers and behavioural skills specific to unintentional non-adherence which is related to practical barriers. Some of the moderating factors affecting adherence without the intention of the patient are (Fisher et al 2006b:268):

- Poor access to medical care and services( e.g. shortage of medication supplies, distance, and lack of insurance coverage)
- Unstable living situation
- Substance use or addiction
- Psychological health( e.g. depression)

### **2.3.6 Summary of the components of the IMB model**

The IMB model of adherence addresses information about adherence and the motivation to maintain adherence that includes personal and social motivations and the necessary behavioural skills for adhering to ART. It also considers situational and individual characteristics such as the ease or difficulty of access to medical care that can affect the relationship between IMB model constructs and adherence behaviour (Amico et al 2009:67).

### **2.3.7 Critique of the IMB model**

The Information-Motivation-Behavioural Skills (IMB) model of ART adherence offers a systematic framework for theory-based interventions (Fisher et al 2006b:3; Fisher et al 2008:193). The model has received support from previous research with other populations on ART and has been the basis for a number of different adherence interventions (Amico, Konkle-Parker, Cornman, Barta, Ferrer, Norton, Fisher 2007:1210; Amico et al 2009:66; Amico et al 2005:661; Fisher et al 2008, Smith 2011). It has been previously used in risk behaviour interventions in young people (Fisher et al 1996), in investigating challenges of ART adherence in HIV-positive youth (Rongkavilit et al 2010), and ART-related views in youth at risk of HIV infection (Simon, Altice, Moll, Shange & Friedland 2010:464).

The Information-Motivation-Behavioural Skills (IMB) model of ART adherence offers a systematic framework for theory-based interventions (Fisher et al 2006b:4; Fisher et al 2008:195). The model has received support from previous research with other populations on ART and has been the basis for a number of different adherence interventions (Amico et al 2005:662; Amico et al 2007:1212; Amico et al 2009:67; Fisher et al 2008:194; Smith 2011:S205). It has been previously used in risk behaviour interventions in young people (Fisher et al 1996:), in investigating challenges of ART adherence in HIV-positive youth (Rongkavilit et al 2010:790), and ART-related views in youth at risk of HIV infection (Simon et al 2010:463).

However, the model is not without limitations and it has specific limitations when it is applied to ART adherence as well as general limitations that it shares with any health behaviour model. According to Darnton (2008:19-20), the IMB model has the following

limitations which are generally shared by other behavioural models used as frameworks for developing interventions:

- Models are concepts, not representations of behaviour: they show the factors influencing behaviour, but do not explain the processes for changing behaviour.
- Behaviour is complex, but models are deliberately simple: they are concepts to aid understanding – they are deliberately simplistic and do not capture all the factors that account for behavioural outcomes.
- There is a limit to how far models will stretch: they are developed in the context of a specific behaviour, and tend to work best in that context – although some do have wider applicability.
- Models don't tend to differentiate between people: they tend to show the behaviour of a statistical 'everyman' – and need to be adapted in order to cover different audience groups.
- Factors don't always precede behaviour: most behavioural models present social-psychological factors as preceding behaviour but there are instances where people are compelled to change their behaviour first, which then lead to change in the social-psychological variables.
- Factors are not barriers: behavioural models can appear to present factors as buttons to be pressed, in the expectation that the behavioural outcome shown will result. This is a misleading interpretation, not only because other factors which are 'off the model' may also need to be accounted for, but because the mechanistic assumptions underpinning such a view are inadequate to explain the nature of change, and to support individuals in that process.
- The review of theories of change also identifies a number of procedural limits to using behavioural models in aiming to bring about behaviour change. At a basic level, theories of change stress that interventions must look beyond the individual to address the context within which they function (their 'social field', or 'system of interest'). Procedurally, the principles of action research as deployed in diverse methods show that engaging actors in the process is the best way to bring about change amongst them. In addition, systems thinking approaches have put forward fundamental objections to interventions based on models. Systems thinking can best be understood as a discipline for understanding complex problems; the process of analysing the problem itself reveals opportunities for

interventions. Systems thinking thus offer an approach based on modelling complex behaviours, rather than advocating the use of existing models.

While the above generic limitations hold true in varied degree to the IMB model, it also has a few specific limitations when it is applied to ART adherence which are directly related to the questionnaire and not to the model as such. The suggested LW-IMB-AAQ contains sets of ART adherence information, motivation, and behavioural skills items which remain the same despite they are being used in different settings and cultures. For example, the behavioural skills that are required to take on time and store drugs may not be difficult for those living at home, while they may be difficult for those who live in prison; individuals who are in prison may need to exercise highly sophisticated behavioural skills to cope with the stigma and discrimination that emanate from the institution. This then represents a challenge to use the proposed questionnaire unanimously (Fisher et al 2006b:465). It is, however, important to note that the measure is not intended for use as a comprehensive or generic measure of the IMB model of adherence constructs. According to Fisher et al (2006a:4), that the Life Windows Project Team preliminary analyses suggest that the LW-IMB-AAQ does provide an overview of adherence related barriers that generally fall within information, motivation, and behavioural skills areas, and can be used as a tool to quickly identify potential adherence related deficits in practical or real-world settings. The measure and its psychometric properties will be evaluated over the course of the Life Windows Project.

### **2.3.8 Summary of the components of the IMB model**

The IMB model of adherence addresses information about adherence and the motivation to maintain adherence that includes personal and social motivations and the necessary behavioural skills for adhering to ART. It also considers situational and individual characteristics such as the ease or difficult access to medical care that can affect the relationship between IMB model constructs and adherence behaviour (Amico et al 2009:67).

## 2.4 CONCLUSION

There is currently an emerging understanding of attitudes and norms in shaping adherence behaviour to HIV medication. Policy makers and health managers have recognised that poor adherence has dire consequences and that though many factors contribute to poor adherence, changing individual adherence behaviour is often central to the solution. However, there is no simple solution to the subject of behaviour change required for adherence. Health behaviour theories may throw light on the processes underlying behaviour change to improve ART adherence. However, a 'single-variable', predictive approach is not always effective for a successful intervention and further examination is needed to determine whether theory based interventions in health care are more effective than those without an explicit theoretical foundation. To understand and overcome the barriers to treatment adherence, considerable further research is needed.

The current review contributes to advancing the field of HIV medication adherence behaviour by paying a special attention on the information, motivation, and behavioural skills model of ART adherence which is the focus of the study. The review gives an intensive description of the IMB model of ART adherence, presenting the evidence and critique for it and discussing applicability of the model to ART adherence behaviour in the study setting. In doing so, the review aims to evaluate the utility and validity of applying the IMB model to a new behavioural and sociocultural setting (i.e., PLWH on ART in chronic HIV care clinic at Felege Hiwot referral hospital located in Bahir Dar town, Ethiopia); identifying the types of theoretical content (i.e., types of information, motivation, and behavioural skills) underlying adherence to ART to address in future intervention development for this target population.

## CHAPTER 3

### RESEARCH DESIGN AND METHODOLOGY

#### 3.1 INTRODUCTION

This chapter outlines and elaborates on the methodological aspects and processes which were used to evaluation of the impact of information-motivation-behavioural skills model of adherence to antiretroviral therapy in Ethiopia.Aspects of the methodological issues such as research design, sampling, data collection methods and analysis used, validity of the data and ethical considerations undertaken during the research will be discussed.

Four main topics are discussed:

- research design
- sampling
- methods of data collection
- methods of data analysis

As part of data analysis, issues around internal and external validity of data were considered. Lastly, the summary of the chapter is given.

#### 3.2 RESEARCH DESIGN

A research design is a blueprint for conducting the study that maximises control over factors that could interfere with the validity of the findings (Burns & Grove 2013:195). Quantitative design will be adopted for this study. Stommel and Wills (2004:3) refers to quantitative research as “the systematic development of new knowledge via a process of assembling empirical evidence”, and Burns and Grove (2013:54) point out that quantitative studies seek to describe variables, investigate relationships among variables, and determine cause and effect relationships between variables.

### **3.2.1 Rationale for choosing a quantitative cross-sectional design**

Study design refers to the structured approach followed by researchers to answer a particular research question (Joubert & Ehrlich 2007:77). This study will be a quantitative, analytical, observational, cross-sectional, institution-based study. A cross-sectional study is the simplest variety of descriptive or observational epidemiology that can be conducted on representative samples of a population. It is used as a useful way to gather information. Like cohort and case-control studies, the goal of analytical cross-sectional study is to examine the relationship between an exposure and an outcome. Unlike cohort and case-control studies, however, a cross-sectional study does not assess and compare occurrence of incident cases in two groups, rather, it assesses and compares the prevalence of exposure or outcome across the two groups (Joubert & Ehrlich 2007:84). This characteristic of cross-sectional study makes it a preferable design for conducting this study because the researcher has time pressure, and resources and financial constraints to conduct a study.

### **3.3 RESEARCH METHODOLOGY**

Research methodology refers to the practices and techniques use to sample the population size and how data was processed and analysed (Vaus 2001:143). According to Khothari (2004:7), a research methodology may be defined as academia's established framework for the collection and evaluation of existent knowledge for the purpose of arriving at, and validating new knowledge. Also the importance of research methodology emanates from its definition of activities of a specified research, its procedural methods, strategies for project measurements and criteria for research success (Kothari 2004:7).

#### **3.3.1 Study setting and period**

Ethiopia is a low-income country in East Africa, with a total population of 73.8 million according to the 2007 population and housing census (Central Statistical Agency (CSA) 2012:3). The overall adult HIV prevalence in Ethiopia has remained low and according to the 2011 Ethiopian Demographic and Health Survey (EDHS 2011), the HIV prevalence among adults aged 15 to 49 is 1.5% and women have a higher HIV prevalence (1.9%) as compared to 1.0% among men. For both women and men the

HIV prevalence increases substantially as the number of lifetime sexual partners increases (CSA 2012:234).

This study was conducted at one of the public referral hospitals in Amhara regional state, located in Bahir Dar town. The hospital is 55 years old with a catchment population of 7 million people in 2014. The hospital has a total of 800 staff including 14 general practitioners, 10 general surgeons, 4 gynaecologists, 4 internists, 3 paediatricians, 1 orthopaedic surgeon, 1 ophthalmologist, 1 urologist, 4 radiologist, 1 dermatologist, and 4 psychiatric specialists. It has an outpatient department and, obstetrics and gynaecology, chronic care, surgery, ophthalmologic, psychiatric, orthopaedic, ICU, pharmacy, emergency, inpatient serving, paediatrics, physiotherapy unit, and central laboratory units, and a blood bank. The hospital has its own ART team and a clinic led by a physician, nurses, health officers, laboratory technicians, data clerks, case managers and adherence counsellors.

The hospital provides general outpatient and in-patient services, including surgical and obstetric emergency care. Infectious diseases account for most of the inpatient and outpatient visits. The hospital has been providing voluntary counselling and testing (VCT) services for more than a decade and provider initiated testing and counselling (PITC) services for the past 8 years. Free ART services were started in January 2006. According to the 2011 EDHS (CSA 2012:235), the adult HIV prevalence among women and men aged 15 to 49 who were tested in the Amhara region was 1.6%. The study period was six weeks between 1<sup>st</sup> September and 12 October 2014.

Below is the map of Ethiopia and the study site, Felege Hiwot hospital is located in Bahir Dar town.

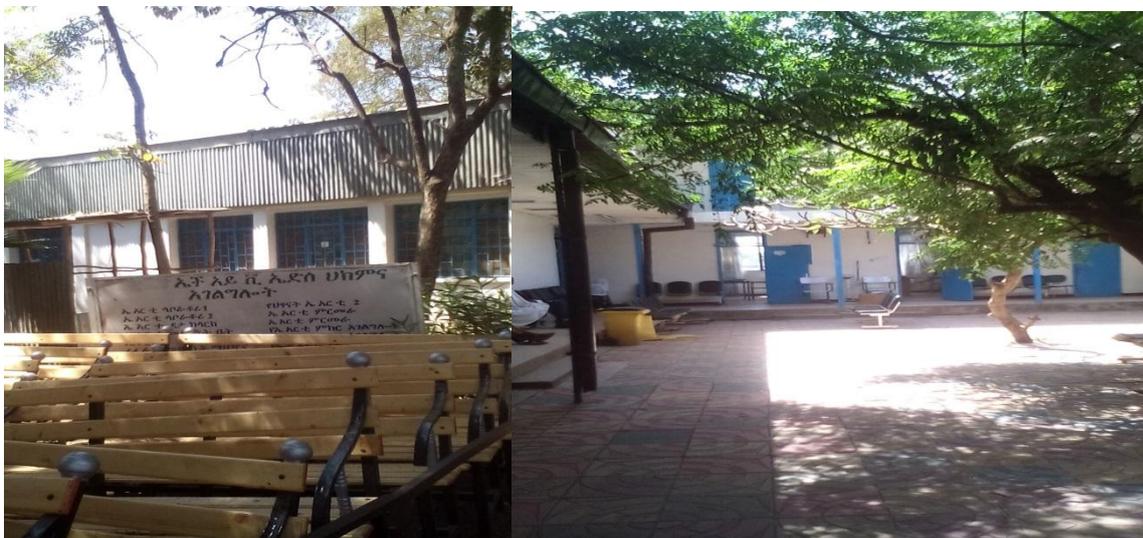


(Bahir Dar)

**Figure 3.1 Map of Ethiopia**

(Source World Atlas)

Below are the pictures of the ART clinic at Felege Hiwot hospital. The pictures show the hind and front views of the ART clinic located inside the hospital compound.



**Figure 3.2 Felege Hiwot hospital ART clinic**

### **3.3.2 Sampling, sampling procedure, sample size and the population and sample selection**

#### **3.3.2.1 Sampling**

Sampling involves selecting a group of people, events, behaviours or other elements from a larger population or universe, with which to conduct a study. The objective of sampling is to determine mathematically the most effective way of acquiring a group of participants that would accurately reflect the population under study. A probability sampling plan better ensures precision in the accurate estimation of the population parameters, thus reducing sampling errors (Burns & Grove 2013:357). For the current study, a sampling procedure was designed to ensure representation of the study population.

#### **3.3.2.2 Sampling procedure**

The concept of systematic sampling was applied in this study when selecting participants for the structured interviews. Systematic sampling refers to selecting, from a population list or “sampling frame,” every  $k^{\text{th}}$  individual, using a starting point selected randomly. The population size is divided by the desired sample size, giving  $k$ , the size of the gap between elements selected from the list. For this study, Felege Hiwot referral hospital was selected conveniently as it is the most nearby hospital with adequate population size. The participants were only included if they fulfilled the criteria, i.e. patients who are 15 years of age and older and who have been on ART for a period of 12 months or more. These participants were recruited when they came into the clinic to collect their medication or had doctors’ appointments by using systematic random sampling.

The sampling frame (adult appointment calendar/logbook) contains names of patients on ART who were expected to attend the health facility in the time period decided to collect data. The sampling frame contains all the patients on ART and each patient is given an appointment for follow-ups every month.

Using systematic random sampling, the first participant was selected randomly. Then, each 6<sup>th</sup> individual attending an appointment at the ART clinic was included in the study.

### 3.3.2.3 Sample size

Patients meeting the inclusion criteria were selected until the required sample size was obtained. The sampling interval is:  $K = \text{Sampling frame (N) / Sample size (n)} = 5785 / 400 = 14.4 \approx 14$ . The starting participant was selected randomly and every 14<sup>th</sup> person on the list was included in the sample. The health facility, Felege Hiwot referral hospital, where the study was carried out, at the time of the data collection had 5785 registered patients who were on ART.

The sample was determined using the single population proportion formula as described by Le (2003:452). The assumptions are that the sample is representative; the sampling error is small, the sample is viable in the context of funds available for the research study, systematic bias is controlled in a better way and results from the sample study will be generalisable.

Assuming a random sampling and a normal distribution, a response rate of 90%, 50% for anticipated proportion and a significance level of 0.05, the sample size needed was calculated using the formula below:

$$n_o = \frac{z^2 p(1-p)}{d^2}$$

Where,

$p$  = anticipated population proportion (50%, since there is no previous study done)

$d$  = the precision required on either side of the proportion (=0.05)

$z$  = the cut-off value of the Normal distribution (=1.96 at level of significance of 0.05)

$n_o = \frac{z^2 p(1-p)}{d^2} = \frac{1.96^2 0.5(1-0.5)}{(0.05)^2} = 384.16 = 384$ , since sampling is from a finite population of  $N = 5785$  (Adults > 14 years of age currently on ART in the hospital ART clinic).

$$n = \frac{n_o}{1 + \frac{n_o}{N}} = \frac{384}{1 + \frac{384}{5785}} = 360.09 = 360$$

For a response rate of 90%,  $n_f = \frac{360}{0.9} = \underline{\underline{400}}$ , where  $n_f$  = the final sample size.

#### **3.3.2.4 Population and sample selection**

The study/target population in this study included all PLWH who are currently on ART at the HIV care clinic, Felege Hiwot hospital in Bahir Dar. PLWH aged 15 years and above who were started on and receiving ART for at least 12 months at the time of data collection were included in the study.

##### **3.3.2.4.1 Inclusion criteria**

The participants had to be outpatients at least 15 years of age, able to give informed consent, and not seriously sick, and had been taking ART for a minimum of one year because studying a trend of an individual's ART adherence requires to set adequate time period in which the researcher can capture both the immediate issues or barriers of adherence like pills side-effects as well as maintenance challenges in adherence behaviour.

##### **3.3.2.4.2 Exclusion criteria**

Those patients on 2<sup>nd</sup> line regimen after treatment failure, and those on short-course ART for prophylaxis (PEP (Post-Exposure-Prophylaxis) and PMTCT (Prevention of Mother-to-Child Transmission of HIV)) were excluded from the study because the purpose of the study was to investigate adherence in chronic care, those clients receiving ART for life long and the study was not intended to evaluate short-term adherence.

#### **3.3.3 Ethical issues related to sampling**

The age of consent in Ethiopia is 15 years old and above. The study complied with national requirements (Federal MOH and Federal HAPCO 2007:4) which require that study participants can consent from the age of 15. The ethical protection of the respondents was maintained throughout this study. The following ethical principles were adhered to:

### **3.3.3.1 Informed consent**

Informed consent is viewed as a process by which the researcher and a potential study participant communicate about the goals, benefits, and risks of the research. Informing is the transmission of essential ideas and content from the investigator to the prospective subject. Consent is the prospective subject's agreement to participate in a study or subject, which is reached after assimilation of essential information.

The goal of informed consent is to allow the person to make an informed decision about whether to participate in the research. Procedures about informed consent should support the intent of the three key ethical principles (beneficence, respect of persons, justice). Informed consent is an important mechanism to ensure that people have the rights to:

- Remain free from harm and undue exploitation
- Receive any benefits to which they are entitled as a result of research participation
- Receive fair treatment that ensures the protection of personal privacy
- Be fully informed of the risks associated with research participation
- Freely decide whether to participate or to continue to participate in research at any time, without forfeiture of benefits to which they would otherwise be entitled (Stommel & Wills 2004:387-388).

Informed consent requires the researcher to disclose specific information to each prospective subject. The following information has been identified as essential content for informed consent in research:

- Introduction of research activities
- Description of risks and discomforts
- Description of benefits
- Disclosure of alternatives
- Assurance of anonymity and confidentiality
- Compensation for participation in research
- Offer to answer questions

- Non-coercive disclaimer
- Option to withdraw
- Consent to incomplete disclosure

Informed consent implies not only the imparting of information by the researcher but also the comprehension of that information by the subject. Thus, the consent information must be written and verbalised in lay terminology, not professional jargon, and must be presented without the use of loaded or biased terms that might coerce a subject into participating in a study. Most studies require a written consent form, although in some studies, the consent form is waived. The documentation of informed consent depends on (i) the level of risk involved in the study and (ii) the discretion of the researcher and those reviewing the study for institutional approval (Burns & Grove 2005:195-196).

Informed verbal consent of participants was sought and recorded in writing. The objectives of the study were discussed with each participant. The cell phone number of the principal investigator will be given to the participants for any queries. All this information will be given both orally and in written leaflet to each participant.

### **3.3.3.2 Risk and discomfort**

The participants were told that the study had no risks or discomfort except that answering questions would take a maximum of 30 minutes to avoid participants feeling like their time is being wasted and that they had full right to discontinue the questioning at any time during the session.

### **3.3.3.3 Benefits**

Participants were told that their participation in the study might not give them direct benefits or incentives, but that it would enable the researcher to identify barriers and facilitators of adherence to ART, which subsequently could be utilised by the relevant health care workers to provide evidence-informed and appropriate ART adherence counselling and support based on the study.

#### **3.3.3.4 *Anonymity and confidentiality***

Anonymous data collection means that the researchers have no way to link the identifying information for study participants with the data provided. In contrast, confidential data collection means that the researcher potentially or actually can link the identifying information for study participants with the data. In this situation, the researcher must provide assurances, including specific information about the methods used to safeguard confidentiality, to the study participants (Stommel & Wills 2004:382-383).

The information that we collected from this research project was kept both anonymous and confidential. Information was stored in a file, which does not have names of respondents on it, but a code number assigned to it. Which number belongs to which name is kept secret.

#### **3.3.3.5 *Right to refuse or withdraw***

Participants were told that they had full right to refuse to participate in the research (they could choose not to respond to some or all questions). It was further explained to the participants that if they did not wish to participate in the study it would not affect the treatment or health care that they get from the health facility in any way. Participants were also told that they had the full right to withdraw from the interview at any time they wished to, without losing any of their rights as clients in this health institution.

#### **3.3.4 *Data collection***

The most important purpose of any research is to collect information the researcher can use to synthesise and analyse in order to find meaning from large raw information which can be generalised into a summary of a phenomenon. Burns and Grove (2011:52) explain that data gathering is the precise, systematic collection of information relevant to research problems using appropriate design and methods. In this study data was collected in line with the objectives of the study.

### **3.3.4.1 Data collection approach and method**

**Quantitative** data were collected by asking questions (self-report). Face-to-face exit interview was selected as the preferred mode of administration of the written questionnaire as it is personal (one-on-one) setting. ART outpatients at point-of-HIV-care services were the sources of data.

### **3.3.4.2 Development and testing of the data collection instrument**

The Life Windows version of Information-Motivation-Behavioural Skills ART Adherence Questionnaire (LW-IMB-AAQ) adopted from the University of Connecticut, Centre for Health, Intervention, and Prevention (Fisher, Amico, Cornman & Fisher 2006a) was used to collect data from the participants. A short questionnaire was also prepared by the researcher to assess level of adherence (Annexure E).

The questionnaire was translated into Amharic, a local language used in the city. The items were translated by the principal investigator and back-translated by another skilful interpreter. The translation and back translation was done to ensure that participants would understand and comprehend the purpose, methods, and risks and benefits related to the study before consenting to participate in the study.

### **3.3.4.3 Characteristics of the data collection instrument**

*The LW-IMB-AAQ* contains sets of ART adherence information, motivation, and behavioural skills items. It is a structured questionnaire composed of closed-ended questions that have options with five response categories with response choices addressing agreement. The agreement options include statements such as *I strongly disagree, I somewhat disagree, I neither agree nor disagree, I somewhat agree, and I strongly agree*. It is the recognised standard questionnaire to collect quantitative data to evaluate the validity and utility of the IMB model in a specific setting; it contains sets of ART adherence information, motivation, and behavioural skills items that assess the impact or applicability of the IMB model to address the information needs as well as the motivation and the behavioural skills that are necessary for investigating adherence to ART (Fisher et al 2006a).

The LW-IMB-AAQ was developed within the Life Windows adherence intervention software programme, a computer-delivered ART adherence intervention for the purpose of assessing barriers to antiretroviral therapy (ART) adherence among HIV+ patients in clinical care (Fisher, Fisher, Amico & Harman 2006b).

The LW-IMB-AAQ provides the Life Windows intervention programme with critical information about users' ART adherence-related strengths and weaknesses. The software programme uses that information to determine which specific intervention activities would be most relevant to a user given his or her specific constellation of adherence-related barriers. The user is then offered this targeted set of intervention activities and asked to select an activity that would be most helpful in improving or maintaining his or her ART adherence. Thus, each LW-IMB-AAQ item serves a dual purpose: quantifying information, motivation, and/or behavioural skills strengths and weaknesses, and signalling which specific IMB adherence-related deficits should be addressed in order for adherence to improve or most effectively be maintained.

In developing the LW-IMB-AAQ items, item content was a target specifically to reflect barriers within the information, motivation, and behavioural skills constructs pertinent to the population involved. It is likely; however, that the barriers reflected in the LW-IMB-AAQ would generalise across many HIV+ populations. Nonetheless, any application of this measure outside of the Life Windows project should take into consideration

- (a) The purpose for which the measure was developed — quantification of IMB based adherence-related deficits so as to direct participants to available intervention activities and
- (b) The target population for whom it was developed — HIV+ men and women in clinical care. It is also important to note that the measure is not intended for use as a comprehensive or generic measure of the IMB model of adherence constructs. Preliminary analyses suggest that the LW-IMB-AAQ does provide an overview of adherence related barriers that generally fall within information, motivation, and behavioural skills areas, and can be used as a tool to quickly identify potential adherence related deficits in practical or real-world settings. The measure and its psychometric properties will be evaluated over the course of the Life Windows project.

#### **3.3.4.4 Data collection process**

Data were collected by one medical doctor (who was the supervisor) and four trained nurses on basic ART. The nurses were not employees of the hospital. This was done in order to free participants from possible fear of judgment by the staff during subsequent visits. Training was given on data collection techniques, and there was close supervision during data collection process. All collected data was assessed daily by the supervisor for its completeness for implementation of early correctional measures for the following day activities.

Data were collected for six weeks in order to obtain the desired population according to the sampling method selected, as every ART patient is appointed every one month for refill and reassessment. The daily patient flow according to appointment was found to range from 120 (over the weekends) to 260 clients (in week days). Assuming this and participating every 14<sup>th</sup> client seven days a week (as the ART clinic is open in the weekends though the client is less by half) attains the calculated sample size. The two weeks were added to capture those who came days after the appointment date because of different reasons.

#### **3.3.4.5 Data measurement**

Adherence-related information was measured by nine behaviourally relevant knowledge items using a five point Likert scale as '*I strongly disagree*', '*I somewhat disagree*', '*I neither agree nor disagree*', '*I somewhat agree*' or '*I strongly agree*' to show the effect on the dependent construct were rated by the participants. These items are presented in the information construct of the IMB model (figure 1.1).

##### *(i) Knowledge of information*

The responses to the nine items on the knowledge about what to do if one misses a dose of any of HIV medications (e.g., whether or not to take the pill(s) later); how substance use (Khat, marijuana) could affect the way HIV pills work and what the side-effects of the combination therapy medication might be were scored as correct response "2 =strongly agree and "1"=/unsure and/incorrect responses.

From the responses, the researcher then created two groups to represent participants who were well-informed and those who were not. Since the median in the sample falls between four and five points, the researcher defined those well-informed as having scored five or more, and those less well-informed as having scored four or less than four.

*(ii) Adherence related motivation*

Adherence-related motivation was also measured according to the IMB model (figure 1.1). Participants used a five point Likert scale to respond to each of the ten items designed to assess aspects of adherence related motivation (M1, M2, M3, M4, M5, M6, M7, M8, M9, M10). Similarly, 'attitudes about ART and ART adherence' (e.g., It upsets me that the HIV medications I have been prescribed can cause side-effects) were assessed and rated very good or "1" if the response was 'I strongly disagree'. The responses were rated very bad or "0" if the response was 'I somewhat disagree'. In addition, the 'perceptions of significant others' support for ART adherence' (e.g., 'Most people who are important to me who know I am HIV positive support me in taking my HIV medications') was assessed. The responses were rated "1" for ('I strongly agree' and 'I somewhat agree'). Item responses were then summed and compared with the median after the item reflecting success (M4) was reverse scored. Total motivation scores ranged from zero to ten, where ten represents higher motivation. Whether the patient has good motivation or not was decided by taking the median as a cut-off point. Those respondents with six and above out of ten were decided to have good motivation and those with five and below were decided to have poor motivation.

*(iii) Behavioural skills*

In the IMB model, adherence related behavioural skills are represented by fourteen behaviourally relevant items that represent the diverse set of skills required for adequate ART adherence. The Items include assessments of the participants' skills for taking medication as prescribed in the presence of a number of barriers including ('How hard or easy is it for you to stay informed about HIV treatment?', 'How hard or easy is it for you to get the support you need from others for taking your HIV medications (e.g., from friends, family, doctor, or pharmacist)?' 'How hard or easy is it for you to take your

HIV medications when you are wrapped up in what you are doing?', 'How hard or easy is it for you to manage the side-effects of your HIV medications?', 'How hard or easy is it for you to make your HIV medications part of your daily life?', 'How hard or easy is it for you to take your HIV medications when your usual routine changes( e.g., when you travel or when you go out with your friends? ').

Participants were rated according to the extent to which they agree or disagree with each statement on a five-point scale. The scoring gave "1" for 'easy' and 'very easy' and "0" for the 'very hard', 'hard', 'sometimes hard, and sometimes easy' responses. All B labelled items were summed to represent a total behavioural skills score. Out of 14 items or responses, if a respondent scored 8 and above 'easy'/ 'very easy' responses or 'somewhat agree' / 'strongly agree' in the case of B1 they were considered having good behavioural skills and those with 7 and below easy/very easy responses were decided as having poor or inadequate behavioural skills important to adhere to ART.

B1 appears to behave differently and does not share significant variability with the other behavioural skills items. B1 may be more valuable as an indicator of a barrier and need for intervention, but may also prove to be useful in explaining adherence for individuals who specifically use alcohol or drugs ( Refer to the study questionnaire: Annexe D).

#### **3.3.4.6 Ethical considerations related to data collection**

In order to respect the rights of the institutions where the study was carried out, the researcher assured the following before commencement of the study:

- Permission to carry out the research study was obtained from the Higher Degrees Committee of the Department of Health Studies at UNISA for ethical clearance (Annexure A).
- Letter of cooperation from Amhara Regional Health Bureau, Research and Technology Transfer Process, was requested and data was collected after receiving written authority from the office of the Medical Director of the study hospital. The hospital management was assured that the study would not pose any risk to the participants and that the result of the study would be disseminated to the hospital and to the bureau for information and possible utilisation.

### **3.3.5 Data analysis**

Data were sorted, coded, and entered into the computer using a Statistical Package for Social Sciences (SPSS) software version 20.0. Data was presented using charts, graphs and frequency tables.

The IMB model's critical constructs and assumptions were evaluated for its applicability in an Ethiopian ART clinic with the following analytical steps:

The analysis of the evaluation of the IMB model constructs' association with each other and with treatment adherence was carried out in two steps:

1. The first step applied binary logistic regression to explore the relation between the three constructs and the dependent variable, ART adherence.
2. The second step applied binary logistic regression to explore the relation between each of the three constructs.
3. The third step involved evaluation of the association between the interaction of variables of the three independent constructs (information, motivation, and adherence behavioural skills) with ART adherence. The step applied multivariate analysis and binary logistic regression.

The magnitude of the association between the variables of the independent constructs, in relation to a dependent variable was measured through odds ratios (OR) and their 95% confidence interval (CI). For comparisons  $P < 0.05$  values were considered statistically significant.

### **3.4 INTERNAL AND EXTERNAL VALIDITY OF THE STUDY**

Bowling (1997:180) had suggested that the reliability of data collected during research should be tested using internal consistency; a process that usually involves ensuring that the questions presented in the questionnaires and interviews could be classified in one category. According to Van der Riet and Durrheim (2008:90), a study is said to have external validity if the findings can be generalised beyond the confines of the design and the study settings.

### 3.4.1 Validity

Polit and Beck (2012:236) state that validity is the approximate truth of an inference and it is always a matter of degree, not an absolute; validity is a property of an inference, not of a research design, but design elements profoundly affect the inferences that can be made. Validity refers to the conceptual and scientific soundness of a research study. There are four distinct types of validity: internal validity, external validity, construct validity, and statistical conclusion validity. Internal validity refers to the ability of a research design to rule out or make implausible alternative explanations of the results, or plausible rival hypotheses. External validity is concerned with the generalisability of the results of a research study. In the context of research design and methodology, the term construct validity relates to interpreting the basis of the causal relationship, and it refers to the congruence between the study's results and the theoretical underpinnings guiding the research. Statistical conclusion validity refers to aspects of quantitative evaluation that affect the accuracy of the conclusions drawn from the results of a study (Polit & Beck 2012:236; Marczyk, DeMatteo & Festinger 2005:158-197).

In this study validity was assured through the following processes:

- (i) The questionnaire: pre-tested questionnaire was adopted from a standardised questionnaire
- (ii) Translation of the questionnaire: The questionnaire was applied after translating into local language to suit the language ability of participants.
- (iii) Sample size determination: Adequate sample size was determined and used for data collection.
- (iv) Inclusion and exclusion criteria: Strong inclusion and exclusion criteria were used
- (v) Reducing bias: By using random selection of study subjects from the study population, and making the participants/sample population representative of the study population, selection bias was prevented in this study. To minimise information bias, the study ensured that all variables were measured in the same way on all participants. In this cross-sectional study design, unlike in a case-control study, the data collectors knew little about the participants which would help to additionally prevent information bias in the study. By using rigorous inclusion and exclusion criteria and using random selection of study subjects from the study population, and making the participants/sample population

representative of the study population, selection bias will be prevented in this study. Social desirability bias was minimised by being non-judgmental. In addition, social desirability and recall biases with reference to medication swallowing were avoided by assuming that those participants with optimal behavioural skills would have optimal ART adherence.

- (vi) External validity: The source of data is a primary source (at point of service) and external validity was maintained.

### **3.4.2 Reliability**

Reliability is concerned with the consistency or stability of the score obtained from a measure or assessment over time and across settings or conditions. If the measurement is reliable, then there is less chance that the obtained score is due to random factors and measurement error (Polit & Beck 2012:231-336; Marczyk et al 2005:103).

By using an adequate sample size and standard questionnaire, the researcher optimised precision of the measurement instruments. Self-report data is the most commonly used method for measuring adherence in routine clinic settings because it is easy and inexpensive to collect data and can distinguish between the two forms of non-adherence, that is, intentional and unintentional. However, the approach has some drawbacks including tendency to over-estimate adherence, lack of sensitivity and specificity and it typically only reflects short-term adherence. Hence, the researcher has preferred to use self-report to measure adherence.

### **3.5 CONCLUSION**

Chapter 3 outlined the research methods used to solicit information from participants, hence answer the research questions. The population sampling, data collection, instrument, ethical considerations, and data analysis were also discussed. Most of the topics were defined; the study methodology was viewed and discussed in line with the definition given and in line with the objective of the study. Advantages and challenges of selected study methods and designs were discussed.

## CHAPTER 4

### PRESENTATION AND DESCRIPTION OF THE RESEARCH FINDINGS

#### 4.1 INTRODUCTION

Chapter 3 presented and discussed the research design and the research methods that were used in this study. This chapter presents the results that emerged from the data analysis. The purpose of this study was to assess levels of adherence to ART and the factors that affect it using the IMB model's proposed set of factors in a randomly selected sample of HIV infected patients who were on a regimen of ART at Felege Hiwot hospital of the Amhara region of Ethiopia.

In order to meet the purposes of the study the data collection and analysis was guided by the following five objectives of the study:

- To assess the levels of ART adherence behaviour in patients taking ARV drugs at Felege Hiwot hospital which is located in Bahir Dar town of the Amhara region of Ethiopia.
- To explore the impact of information about ART and adherence on ART adherence behaviour among patients receiving ARV drugs from Felege Hiwot hospital.
- To explore the impact of motivation on ART adherence behaviour among patients receiving ARV drugs from Felege Hiwot hospital.
- To determine the impact of adherence behavioural skills needed to practice strict ART adherence on their self-reported adherence behaviour of patients at Felege hiwot hospital ART clinic.
- To assess the benefits of the integration of information, motivation and behavioural skills needed to practise strict ART adherence in patients receiving ARV drugs from Felege Hiwot hospital.

## 4.2 DATA MANAGEMENT AND ANALYSIS

In this study, the data were collected by means of a structured questionnaire that consisted of the following four sections:

1. Adherence information
2. Adherence motivation
3. Adherence behavioural skills
4. Adherence behaviour

The population consisted of HIV/AIDS patients on ART who had been taking ARV medication for at least twelve months and who were at least 15 years old at the commencement of the study. A sample of 400 respondents was determined from a total population of 5785 registered patients who were on ART at the time of data collection. The sample was determined using the single population proportion formula.

The data were at all times kept safely and stored in a place to which no one other than the researcher had access, and the data was saved and protected on by a secret password.

A statistician analysed the data that were collected from all 400 respondents by using a Microsoft software package called the Statistical Package for the Social Science (SPSS) (version 20). The findings of the study aimed at meeting the study objectives and are presented according to the sequence in the questionnaire and are presented according to the following sub-headings:

- Information factors
- Motivation factors
- Behavioural skills
- Summary of findings from descriptive statistics
- Patients reported rates of adherence
- Overview of research finding findings from inferential statistics

Various tables, graphs and descriptions as well as percentages, p-values, and other tests are used to present the findings and ends up with a conclusion.

## 4.3 RESEARCH RESULTS

### 4.3.1 Information factors

This section assessed how much the respondents knew about adherence to ART.

#### 4.3.1.1 Knowledge of prescription advice

A total of 325 patients claimed that they know how each of their current HIV medication is supposed to be taken (for example whether or not their current medication can be taken with food, herbal supplements, or other prescription medication) whereas 46 patients reported that they did not know how each of their HIV medication is supposed to be taken.

These figures suggest that the majority knew how to take their ARV medication. In contrast to the findings in this study, Starace et al (2006:156) indicated that only 51% of their samples were adequately informed about how to adhere to the ART dosage schedule, and that 49% demonstrated that they were inadequately informed about how to adhere to their ART dosage schedule. In a study carried out by Wang and Wu (2007:151), only 75.4% of their patients were able to demonstrate the correct dosage schedules for their HIV-prescribed medication.

**Table 4.1 Know HIV medicine are supposed to be taken**

<b>Description</b>	<b>Frequency</b>	<b>Percent</b>
Strongly disagree	45	11.3
Somewhat disagree	1	0.3
Neither agree nor disagree	2	0.5
Somewhat agree	27	6.8
Strongly agree	325	81.3
<b>Total</b>	<b>400</b>	<b>100.0</b>

#### 4.3.1.2 Knowledge of measures to take for missed doses

A total of 140 patients claimed that they know what to do when they miss a dose of any of their HIV medication while 255 patients reported that they don't know what to do if they miss a dose of their HIV medication. These results show that more than 63.8% of the respondents were of the opinion that they didn't know what they should do if they had missed a dose(s) of their ARV medication.

**Table 4.2 Know what to do if I miss a dose of medication**

Description	Frequency	Percent
Strongly disagree	241	60.3
Somewhat disagree	14	3.5
Neither agree nor disagree	5	1.3
Somewhat agree	52	13.0
Strongly agree	88	22.0
<b>Total</b>	<b>400</b>	<b>100.0</b>

#### 4.3.1.3 Consequence of skipping a dose

A total of 372 patients agreed that skipping a few of their HIV medication from time to time would not really hurt their health, while only 26 patients disagreed. Two patients neither agreed nor disagreed. This shows that the majority of patients said it was a serious problem to miss doses provided that they felt healthy. A study carried out by Golin, Liu, Hays, Miller, Beck, Ickovics, Kaplan & Wenger (2002:759) reported that 77% of their respondents did not agree with the statement, "You could fight off HIV without medication."

**Table 4.3 Skipping few of my HIV medication will not really hurt my health**

Description	Frequency	Percent
Strongly disagree	18	4.5
Somewhat disagree	8	2.0
Neither agree nor disagree	2	0.5
Somewhat agree	5	1.3
Strongly agree	367	91.8
<b>Total</b>	<b>400</b>	<b>100.0</b>

#### **4.3.1.4 Knowledge of side-effects**

Three hundred and twenty two patients claim that they know the possible side-effects of each of their HIV medicines, while 73 patients reported the opposite. This shows that only 18.3% of the population were ignorant of the possible side-effects of their HIV medication.

**Table 4.4 Know the possible side-effects of my HIV medication**

<b>Description</b>	<b>Frequency</b>	<b>Percent</b>
Strongly disagree	59	14.8
Somewhat disagree	14	3.5
Neither agree nor disagree	4	1.0
Somewhat agree	79	19.8
Strongly agree	243	60.8
<b>Total respondents</b>	<b>399</b>	<b>99.8</b>
Missing	1	0.3
<b>Total</b>	<b>400</b>	<b>100.0</b>

#### **4.3.1.5 Knowledge for lifelong medication adherence**

Altogether, 373 patients strongly believe that as long as they are feeling healthy, missing their HIV medication from time to time is acceptable and only 24 patients reported that missing their medication was dangerous.

**Table 4.5 As long as feeling healthy missing HIV medication is acceptable**

<b>Description</b>	<b>Frequency</b>	<b>Percent</b>
Strongly disagree	19	4.8
Somewhat disagree	5	1.3
Neither agree nor disagree	3	.8
Strongly agree	373	93.3
<b>Total</b>	<b>400</b>	<b>100.0</b>

#### **4.3.1.6 Knowledge on medication mechanisms of action**

A total of 369 patients reported that they understand how each of their HIV >medicines works in their bodies to fight HIV while 27 of them said they did not understand the mechanism of action of their HIV medication.

**Table 4.6 Understand HIV medication works to fight HIV**

<b>Description</b>	<b>Frequency</b>	<b>Percent</b>
Strongly disagree	20	5.0
Somewhat disagree	7	1.8
Neither agree nor disagree	3	0.8
Somewhat agree	25	6.3
Strongly agree	344	86.0
Total respondents	399	99.8
Missing	1	0.3
<b>Total</b>	<b>400</b>	<b>100.0</b>

**4.3.1.7 Knowledge of consequences of interruption of medication**

A total of 180 patients agreed that if they did not take their HIV medication as prescribed, the medicines may not work for them in the future whereas, 214 patients disagreed on this. This means out of the total number of respondents, 45% of the respondents said that the medication would not work properly in the future if they missed doses from time to time while 53.5% of the respondents said the drugs would work properly in the future if they did not take their medication as prescribed. This is a lower rate than that reported in the study by Golin et al (2002:759), who reported that 85% patients agreed that if they did not take their HIV drugs as prescribed; their HIV would become resistant to treatment in the future. This rate of responses is also higher than that reported in the study undertaken by Wang and Wu (2007:151), who reported that 66.3% of their patients believed that non-adherence to ART could lead to the failure of the treatment in the future.

**Table 4.7 If I do not take my HIV medication, the medicine may not work for the future**

Description	Frequency	Percent
Strongly disagree	196	49.0
Somewhat disagree	18	4.5
Neither agree nor disagree	5	1.3
Somewhat agree	80	20.0
Strongly agree	100	25.0
Total	399	99.8
Missing	1	0.3
<b>Total</b>	<b>400</b>	<b>100.0</b>

#### **4.3.1.8 Knowledge of the benefits of medication adherence**

There were 387 patients who believe that if they take their HIV medication as prescribed, they will live longer while only 8 patients believe the opposite of this. Two patients did not give their answers. This means that 96.8% of respondents have the knowledge and belief that the HIV medication will help them fight and control their HIV infection to let them live longer.

**Table 4.8 If I take my HIV medication, I can live longer**

Description	Frequency	Percent
Strongly disagree	6	1.5
Somewhat disagree	2	0.5
Neither agree nor disagree	3	0.8
Somewhat agree	12	3.0
Strongly agree	375	93.8
Total	398	99.5
Missing	2	0.5
<b>Total</b>	<b>400</b>	<b>100.0</b>

#### **4.3.1.9 Knowledge of drug interactions with alcohol and substances**

A total of 85.5% of the respondents claimed that they know how their HIV medicines interact with alcohol and other substances and 13% of patients reported that they did not agree with this idea. Only five respondents said that they neither agree nor disagree with interaction of HIV medication with alcohol and other substances.

**Table 4.9 Know HIV medication interact with alcohol and other substances**

Description	Frequency	Percent
Strongly disagree	48	12.0
Somewhat disagree	4	1.0
Neither agree nor disagree	5	1.3
Somewhat agree	30	7.5
Strongly agree	312	78.0
Total	399	99.8
Missing	1	0.3
<b>Total</b>	<b>400</b>	<b>100.0</b>

**4.3.2 Motivation factors**

This section assessed both the personal and social motivation of respondents to adhere to their ARV medication.

**4.3.2.1 Secrecy to swallow pills**

Out of the total number of respondents, 56.8% strongly agreed, 4% agreed, 0.8% were undecided, 19.5% disagreed, and 18.8% strongly disagreed with statement that they are worried that other people might realise that they are HIV+ if they see them taking their HIV. In a study conducted by Wang and Wu (2007:152), 43.8% claimed that they had been treated differently by their neighbours and friends after their neighbours and friends knew that they were taking ART.

**Table 4.10 Worried HIV+, if people see me taking my HIV medication**

Description	Frequency	Percent
Strongly disagree	75	18.8
Somewhat disagree	78	19.5
Neither agree nor disagree	3	0.8
Somewhat agree	16	4.0
Strongly agree	227	56.8
Total respondents	399	99.8
Missing	1	0.3
<b>Total</b>	<b>400</b>	<b>100.0</b>

### 4.3.2.2 Frustration to plan to take medication

Out of the total number of respondents, 70.5% strongly agreed, 2.5% agreed, 0.5% were undecided, 13% disagreed, and 13.5% strongly disagreed with the idea that it frustrated them to have to plan their lives around their HIV medication. The results obtained from the survey showed that more than 88% of the respondents were not frustrated by having to plan their lives in such a way that they could accommodate their HIV medication in their schedules.

**Table 4.11 Frustrated taking HIV medication around my life**

Description	Frequency	Percent
Strongly disagree	54	13.5
Somewhat disagree	52	13.0
Neither agree nor disagree	2	0.5
Somewhat agree	10	2.5
Strongly agree	282	70.5
<b>Total</b>	<b>400</b>	<b>100.0</b>

### 4.3.2.3 Dislike taking HIV medication because of how it reminds of HIV status

Out of the total number of respondents, 88.8% strongly agreed, 0.5% agreed, 2.3% disagreed, and 8.5% strongly disagreed with the statement that they did not like to take their HIV medication because it reminded them that they were HIV-positive. The result shows that more than 89% of the respondents agreed with the statement that they did not like to take their HIV medication because it reminded them that they were HIV-positive. This shows that acceptance of the diagnosis and resolution to live positively with the infection is achieved only by a small proportion of patients.

**Table 4.12 Don't like taking my HIV medication, reminds me that I am HIV+**

Description	Frequency	Percent
Strongly disagree	34	8.5
Somewhat disagree	9	2.3
Somewhat agree	2	0.5
Strongly agree	355	88.8
<b>Total</b>	<b>400</b>	<b>100.0</b>

#### 4.3.2.4 My HCP takes account of needs while selecting ART regimen

Out of the total number of respondents, 65% strongly agreed with the statement, 21.5% agreed, 0.5% remained undecided, 4.8% disagreed and 7.8% strongly disagreed with the statement that their HCPs take their needs into account when making recommendations about which HIV medicine to take.

**Table 4.13 Feel that health care provider’s recommendations are client-need-based**

Description	Frequency	Percent
Strongly disagree	31	7.8
Somewhat disagree	19	4.8
Neither agree nor disagree	2	0.5
Somewhat agree	86	21.5
Strongly agree	260	65.0
<b>Total respondents</b>	<b>398</b>	<b>99.5</b>
Missing	2	0.5
<b>Total</b>	<b>400</b>	<b>100.0</b>

#### 4.3.2.5 People support to take medication

Out of the total number of respondents, 75.3% strongly agreed with the statement, 12.5% agreed, 0.5% remained undecided, 1.3% disagreed and 10.3% strongly disagreed with the statement that most people who are important to them who know they are positive support them in taking their HIV.

**Table 4.14 People are important for taking HIV medication**

Description	Frequency	Percent
Strongly disagree	41	10.3
Somewhat disagree	5	1.3
Neither agree nor disagree	2	0.5
Somewhat agree	50	12.5
Strongly agree	301	75.3
Total respondents	399	99.8
Missing	1	0.3
<b>Total</b>	<b>400</b>	<b>100.0</b>

#### **4.3.2.6 HCP gives inadequate support to take medication**

Out of the total number of respondents, 83.3% strongly agreed with the statement, 2.8% agreed, 0.5% remained undecided, 6% disagreed and 7.5% strongly disagreed with the statement that their health care providers don't give them enough support when it comes to taking their medication as prescribed.

**Table 4.15 Health care provider doesn't give enough support**

<b>Description</b>	<b>Frequency</b>	<b>Percent</b>
Strongly disagree	30	7.5
Somewhat disagree	24	6.0
Neither agree nor disagree	2	0.5
Somewhat agree	11	2.8
Strongly agree	333	83.3
<b>Total</b>	<b>400</b>	<b>100.0</b>

#### **4.3.2.7 Frustration of the thought of taking medication for lifelong**

Out of the total number of respondents, 79.5% strongly agreed with the statement, 3.8% agreed, 0.5% remained undecided, 6.8% disagreed and 9.5% strongly disagreed with the statement that it would frustrate them to think that they would have to take HIV medication daily for the rest of their lives. The result shows that the vast majority of the respondents said that it frustrates them to think that they will have to take these HIV medicines every day for the rest of their lives.

**Table 4.16 Frustrating to take HIV medication for life**

<b>Description</b>	<b>Frequency</b>	<b>Percent</b>
Strongly disagree	38	9.5
Somewhat disagree	27	6.8
Neither agree nor disagree	2	0.5
Somewhat agree	15	3.8
Strongly agree	318	79.5
<b>Total</b>	<b>400</b>	<b>100.0</b>

#### **4.3.2.8 Worry that the medication hurts health**

Out of the total number of respondents, 78.5% strongly agreed with the statement, 3% agreed, 0.5% remained undecided, 10.3% disagreed and 7.8% strongly disagreed with the statement that they would be worried by the knowledge that the HIV medication that were prescribed for them could harm their health. These results indicate that more than 80% of the respondents were worried about the fact that the HIV medicines that were prescribed for them could harm their health.

**Table 4.17 Worried HIV medication hurts my health**

<b>Description</b>	<b>Frequency</b>	<b>Percent</b>
Strongly disagree	31	7.8
Somewhat disagree	41	10.3
Neither agree nor disagree	2	0.5
Somewhat agree	12	3.0
Strongly agree	314	78.5
<b>Total</b>	<b>400</b>	<b>100.0</b>

#### **4.3.2.9 Concerns that the medication change one's look**

Out of the total number of respondents, 64% strongly agreed with the statement, 1.8% agreed, 1.8% remained undecided, 21.5% disagreed, and 11% strongly disagreed with the statement that its went upset them think that the HIV medication that had been prescribed for them could affect the way they looked. The results shows that at least 65% of the respondents were upset by the fact that the HIV medication could affect the way that they looked.

**Table 4.18 I am upset by HIV medication, it affects the way I look**

<b>Description</b>	<b>Frequency</b>	<b>Percent</b>
Strongly disagree	44	11.0
Somewhat disagree	86	21.5
Neither agree nor disagree	7	1.8
Somewhat agree	7	1.8
Strongly agree	256	64.0
<b>Total</b>	<b>400</b>	<b>100.0</b>

#### **4.3.2.10 Fear of side-effects**

Out of the total number of respondents, 62.3% strongly agreed with the statement, 4% agreed, 0.8% remained undecided, 20.5% disagreed, and 12.3% strongly disagreed with the statement that they would be upset to think that the prescribed HIV medicine could cause side-effects. These responses show that more than 66% of the respondents were upset about the side-effects that can be caused by HIV medication.

**Table 4.19 I am up upset by HIV medicine, they cause side-effects**

<b>Description</b>	<b>Frequency</b>	<b>Percent</b>
Strongly disagree	49	12.3
Somewhat disagree	82	20.5
Neither agree nor disagree	3	0.8
Somewhat agree	16	4.0
Strongly agree	249	62.3
Total respondents	399	99.8
Missing	1	0.3
<b>Total</b>	<b>400</b>	<b>100.0</b>

#### **4.3.3 Behavioural skills**

This section assessed the behavioural skills of respondents with regard to ART adherence.

##### **4.3.3.1 Difficulty of taking medication with alcohol and substance use**

Out of the total number of respondents, 50.5% strongly agreed with the statement, 1% agreed, 1.3% remained undecided, 8% disagreed, and 39.3% strongly disagreed with the statement that there are times when it is hard for them to take their HIV medication when they drink alcohol or use drugs. The data show that more than 50% of the respondents witnessed their experience that alcohol and other substances are barriers to adherence.

**Table 4.20 Difficulty in taking HIV medication, while drinking alcohol or using drugs**

Description	Frequency	Percent
Strongly disagree	157	39.3
Somewhat disagree	32	8.0
Neither agree nor disagree	5	1.3
Somewhat agree	4	1.0
Strongly agree	202	50.5
<b>Total</b>	<b>400</b>	<b>100.0</b>

**4.3.3.2 Difficulty of getting information on HIV treatment**

Out of the total number of respondents, 3.8% maintained that it was very hard for them to remain well-informed about HIV treatment, 3% reported it was hard, 12.3% were undecided, 80.3% said that it was easy for them to remain well-informed, and 0.8% said it was very easy for them to remain well-informed about HIV treatment. This means that more than 80% of the respondents have the perception that they are able to remain well-informed about their HIV treatment.

**Table 4.21 Informing about HIV treatment**

Description	Frequency	Percent
Very hard	15	3.8
Hard	12	3.0
Sometimes hard	28	7.0
Sometimes easy	21	5.3
Easy	321	80.3
Very Easy	3	0.8
<b>Total</b>	<b>400</b>	<b>100.0</b>

**4.3.3.3 Difficulty in getting support from others**

Out of the total number of respondents, 3.5% said it was very hard for them to get the support they needed from others in order to take their HIV medication, 1% said that it was hard, 12.3% said that it was difficult to decide, 81.8% said it was easy for them to get support, and 1.5% said that it was very easy for them to get the support they needed from others in order to take their HIV medication. This study therefore showed that

83.3% of the participants felt that they could get the support they needed from others in order to take their HIV medication.

**Table 4.22 Get support from others for taking HIV medication**

Description	Frequency	Percent
Very hard	14	3.5
Hard	4	1.0
Sometimes hard	35	8.8
Sometimes easy	14	3.5
Easy	327	81.8
Very Easy	6	1.5
<b>Total</b>	<b>400</b>	<b>100.0</b>

**4.3.3.4 Difficulty of refilling of medicine**

Out of the total number of respondents, 6.3% said that it was difficult for them to obtain refills on time, 2.3% said they did was hard, 10.3% said that it was sometimes difficult and sometimes easy, 80.8% said it was easy, and 0.5% said it was very easy for obtain their HIV medication refills on time. Of the respondents in this study, 81.3% of the population therefore felt that they were able to obtain the refills of their HIV medication on time.

**Table 4.23 Get your HIV medication refill on time**

Description	Frequency	Percent
Very hard	25	6.3
Hard	9	2.3
Sometimes hard	34	8.5
Sometimes easy	7	1.8
Easy	323	80.8
Very Easy	2	0.5
<b>Total</b>	<b>400</b>	<b>100.0</b>

**4.3.3.5 Becoming too busy to take medication**

Out of the total number of respondents, 8.8% said it was very hard for them to take their HIV medication when they were wrapped up in what they were doing, 4.5% said that it

was hard, 26.1% said that it was sometimes hard and sometimes easy, 60.5% said it was easy for them to take their HIV medication even though they were wrapped up in what they were doing. This study shows that 60.5% of the respondents said they were able to take their HIV medication even when they were wrapped up in what they were doing.

**Table 4.24 Take HIV medication, during working time**

<b>Description</b>	<b>Frequency</b>	<b>Percent</b>
Very hard	35	8.8
Hard	18	4.5
Sometimes hard	81	20.3
Sometimes easy	23	5.8
Easy	242	60.5
Total respondents	399	99.8
Missing	1	0.3
<b>Total</b>	<b>400</b>	<b>100.0</b>

**4.3.3.6 Difficulty of managing medication side-effects**

Out of the total number of respondents, 5.3% said it was very hard for them to manage the side-effects of the HIV medication, 5% said that it was hard, 16.3% said that it was sometimes hard and sometimes easy, 72.3% said it was easy, and 1.3% said it was very easy to manage the side-effects of their HIV medication. The result of the survey showed that 73.6% of the respondents were of the opinion that they were able to manage the side-effects of their HIV medication.

**Table 4.25 Manage side-effects of HIV medication**

<b>Description</b>	<b>Frequency</b>	<b>Percent</b>
Very hard	21	5.3
Hard	20	5.0
Sometimes hard	45	11.3
Sometimes easy	20	5.0
Easy	289	72.3
Very Easy	5	1.3
<b>Total</b>	<b>400</b>	<b>100.0</b>

#### **4.3.3.7 Forgetfulness to take medication**

Out of the total number of respondents, 1.5% said it was very hard for them to remember to take their HIV medication, 2.3% said that it was hard for them to remember, 15.8% said that it was sometimes hard and sometimes easy for them to remember, 80.5% said it was easy for them to remember to take their prescribed HIV medication. These results indicate that 80.5% of the respondents were of the opinion that they were able to take their HIV medication on time.

**Table 4.26 Remember to take HIV medication**

<b>Description</b>	<b>Frequency</b>	<b>Percent</b>
Very hard	6	1.5
Hard	9	2.3
Sometimes hard	46	11.5
Sometimes easy	17	4.3
Easy	322	80.5
<b>Total</b>	<b>400</b>	<b>100.0</b>

#### **4.3.3.8 The pills are too inconvenient to swallow**

Out of the total number of respondents, 4% said it was very hard for them to take the medication, 3% said it was hard for them to take the medication, 16.5% said that it was sometimes hard and sometimes easy, and 76.3% said that it was easy for them to take their HIV medication despite the fact that the pills were hard to swallow, that they tasted bad and that they made one feel sick in one's stomach. These results show that 76.3% of the respondents felt that they could take their HIV medication even though the pills were hard to swallow, even though they tasted bad and even though they made them feel sick in their stomachs.

**Table 4.27 HIV medication is hard to swallow because they taste bad or irritate stomach**

<b>Description</b>	<b>Frequency</b>	<b>Percent</b>
Very hard	16	4.0
Hard	12	3.0
Sometimes hard	44	11.0
Sometimes easy	23	5.8
Easy	305	76.3
<b>Total</b>	<b>400</b>	<b>100.0</b>

**4.3.3.9 Difficulty of making medication part of daily life**

Out of the total number of respondents, 1.3% said it was hard to incorporate the taking of HIV medication a regular part of daily life, 2.3% said it was hard, 10% said it was sometimes hard and sometimes easy, 85.8% said it was easy, and 8% said it was very easy to make HIV medication a regular part of their daily lives. The result show that 93.8% of the respondents felt that they could incorporate the taking of HIV medication into the routine of their daily lives.

**Table 4.28 Make HIV medication part of daily life**

<b>Description</b>	<b>Frequency</b>	<b>Percent</b>
Very hard	5	1.3
Hard	9	2.3
Sometimes hard	26	6.5
Sometimes easy	14	3.5
Easy	343	85.8
Very easy	3	0.8
<b>Total</b>	<b>400</b>	<b>100.0</b>

**4.3.3.10 A change in daily routine**

Out of the total number of respondents, 5.5% said that it was very hard to for them to stick to their treatment plan, 4.3% said it was hard, 15.8% said that it was sometimes hard and sometimes easy, 74% said it was easy, and 0.5% said it was very easy to stick to treatment plan when their daily routine changes. The study shows that 94% of

the respondents were committed to stick to the treatment plan even when their daily routine changes for example, when they travel or when they go out with their friends.

**Table 4.29 Take HIV medication when usual routine changes**

Description	Frequency	Percent
Very hard	22	5.5
Hard	17	4.3
Sometimes hard	56	14.0
Sometimes easy	7	1.8
Easy	296	74.0
Very easy	2	0.5
<b>Total</b>	<b>400</b>	<b>100.0</b>

**4.3.3.11 Feel depressed or overwhelmed to take medication**

Out of the total number of respondents, 7.5% said it was very hard for them to take their HIV medications when they were not feeling emotionally well, 4.3% said it was hard, 24.8% said it was sometimes hard and sometimes easy, 63.3% said it was easy, and 0.3% said that it was very easy. The results show that 63.6% of the respondents are able to take their HIV medication even when they are not feeling emotionally well.

**Table 4.30 Take HIV medication, when I don't feel good emotionally**

Description	Frequency	Percent
Very hard	30	7.5
Hard	17	4.3
Sometimes hard	72	18.0
Sometimes easy	27	6.8
Easy	253	63.3
Very easy	1	0.3
<b>Total</b>	<b>400</b>	<b>100.0</b>

**4.3.3.12 Felt well**

Out of the total number of respondents, 11.8% said it was very hard for them to take their HIV medication when they were feeling physically good and did not show any symptoms of their HIV disease, 3.8% said it was hard, 10.5% said it was sometimes hard and sometimes easy, 73.3% said it was easy, and 0.5% said it was very easy. The

results show that 73.8% of the respondents said that they were able to take their HIV medication even when they were feeling physically good and did not show any symptoms of their of their HIV disease.

**Table 4.31 Take HIV medication when I am good physically and don't feel symptoms of HIV**

<b>Description</b>	<b>Frequency</b>	<b>Percent</b>
Very hard	47	11.8
Hard	15	3.8
Sometimes hard	34	8.5
Sometimes easy	8	2.0
Easy	293	73.3
Very Easy	2	0.5
Total respondents	399	99.8
Missing	1	0.3
<b>Total</b>	<b>400</b>	<b>100.0</b>

#### **4.3.3.13 Felt sick**

Out of the total number of respondents, 5.8% said that it was very hard for them to take their HIV medication when they were not feeling physically well, 3.8% said that it was hard, 20.8% said that it was sometimes hard and sometimes easy, 68.8% said that it was easy, and 0.8% said it was very easy. The result shows that 69.6% of the respondents maintained that they were able to take their HIV medication even when they were not feeling physically good.

**Table 4.32 Take HIV medication, I don't feel good physically**

<b>Description</b>	<b>Frequency</b>	<b>Percent</b>
Very hard	23	5.8
Hard	15	3.8
Sometimes hard	66	16.5
Sometimes easy	17	4.3
Easy	275	68.8
Very easy	3	0.8
Total respondents	399	99.8
Missing	1	0.3
<b>Total</b>	<b>400</b>	<b>100.0</b>

#### 4.3.3.14 Ability to talk to the HCP about the medication

Out of the total number of respondents, 2.3% said it was very hard to talk to their health care providers about HIV medication and their side-effects and symptoms, 1.5% said it was hard, 10% said that it was sometimes hard and sometimes easy, 85.3% said it was easy, and 1% said that it was very easy. These results show that 86.3% of the respondents are unable to talk to their health care providers about HIV medication and their side-effects and symptoms.

**Table 4.33 Talk to health care provider about HIV medication**

Description	Frequency	Percent
Very hard	9	2.3
Hard	6	1.5
Sometimes hard	28	7.0
Sometimes easy	12	3.0
Easy	341	85.3
Very easy	4	1.0
<b>Total</b>	<b>400</b>	<b>100.0</b>

## 4.4 OVERVIEW OF RESEARCH FINDINGS

### 4.4.1 Information status of patients

The data were managed first by reversing and changing the five **Likert** Scale into two or dichotomised groups. *Strongly disagree, disagree and neutral* responses were grouped as having poor information and the rest of the responses, i.e., *strongly agree and agree* as good information. There is a total of nine items under information construct and responses such as *strongly agree* and *agree* were counted and summed for each respondent. The respondents with five and more than five strongly agree/agree out of the nine responses were decided as 'good information' and if four and below will be decided as having 'poor information'. The median was used for deciding the cut-off point as good and poor information.

Out of the total 400 respondents, 389 had good information and there were only eleven patients with poor information about adherence to ART.

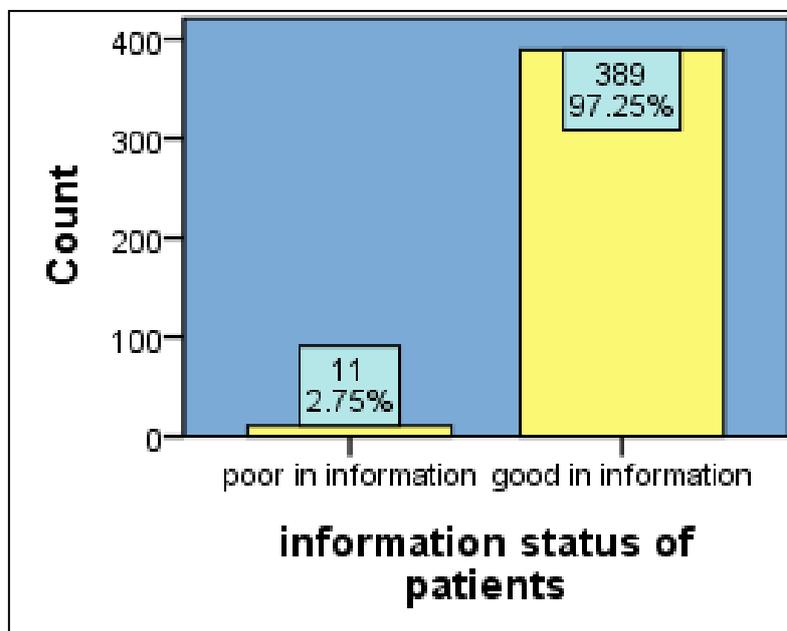
**Table 4.34a Information status of patients**

Information items	Perceptions of patients					Total
	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	
Know HIV medication is supposed to be taken	45 (11.3)	1 (0.3)	2 (0.5)	27 (6.8)	325 (81.3)	400 (100.0)
Know what to do if I miss a dose of medication	241 (60.3)	14 (3.5)	5 (1.3)	52 (13.0)	88 (22.0)	400 (100.0)
Skipping few of my HIV medication will not really hurt my health	18 (4.5)	8 (0.5)	2 (2.0)	5 (1.3)	367 (91.8)	400 (100.0)
Know the possible side-effect of my HIV medication	59 (14.8)	14 (1.0)	4 (3.5)	79 (19.8)	243 (60.8)	399 (99.8)
As long as feeling health missing HIV medication is ok	19 (4.8)	5 (1.3)	3 (0.8)		373 (93.3)	400 (100.0)
Understand HIV medication works to fight HIV	20(5.0)	7(1.8)	3 (0.8)	25 (6.3)	344 (86.0)	399 (99.8)
If don't take my HIV medication, may not work for the future	196 (49.0)	18 (4.5)	5 (1.3)	80 (20.0)	100 (25.0)	399 (99.8)

Information items	Perceptions of patients					Total
	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	
If take my HIV medication, live longer	6 (1.5)	2 (0.5)	3 (0.8)	12 (3.0)	375 (93.8)	398 (99.5)
Know HIV medication interact with Alcohol and other substances	48 (12.0)	4 (1.0)	5 (1.3)	30 (7.5)	312 (78.0)	399 (99.8)

**Table 4.34b Information status of patients**

Information status of patients		Frequency	Percent	Valid percent	Cumulative percent
Valid	Poor in information	11	2.8	2.8	2.8
	Good in information	389	97.3	97.3	100.0
	<b>Total</b>	<b>400</b>	<b>100.0</b>	<b>100.0</b>	



**Figure 4.1 Information status of patients**

#### 4.4.2 Motivation of patients towards ART adherence

With the same data management, whether the patients have good motivation or not were decided by taking the median as a cut-off point. Those respondents with six and above out of ten were decided to have good motivation and those with five and below were decided to have poor motivation.

Out of the total 400 respondents, 351 had good motivation and there were 49 patients with poor motivation to adhere to ART medication.

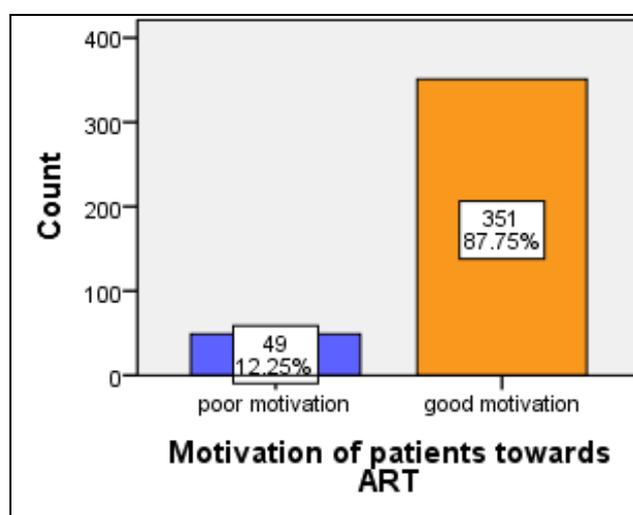
**Table 4.35a Motivation status of patients**

Motivation items	Perceptions of patients					Total
	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	
Worried HIV+, if people see me taking my HIV medication	75 (18.8)	78 (19.5)	3 (0.8)	16 (4.0)	227 (56.8)	399 (99.8)
Frustrated taking HIV medication around my life	54 (13.5)	52 (13.0)	2 (0.5)	10 (2.5)	282 (70.5)	400 (100.0)
Don't like taking my HIV medication, reminds me that I am HIV+	34 (8.5)	9 (2.3)		2 (0.5)	355 (88.8)	400 (100.0)
Feel that health care provider recommendations	31 (7.8)	19 (4.8)	2 (0.5)	86 (21.5)	260 (65.0)	398 (99.5)
People are important for taking HIV medication	41 (10.3)	5 (1.3)	2 (0.5)	50 (12.5)	301 (75.3)	399 (99.8)
Health care provider doesn't give enough	30 (7.5)	24 (6.0)	2 (0.5)	11 (2.8)	333 (83.3)	400 (100.0)

Motivation items	Perceptions of patients					Total
	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree	
support						
Frustrate to take HIV medication for life long	38 (9.5)	27 (6.8)	2 (0.5)	15 (3.8)	318 (79.5)	400 (100.0)
Worried HIV medication hurt my health	31 (7.8)	41 (10.3)	2 (0.5)	12 (3.0)	314 (78.5)	400 (100.0)
Upsets HIV medication, Affect the way I look	44 (11.0)	86 (21.5)	7 (1.8)	7 (1.8)	256 (64.0)	400 (100.0)
I am up upset by HIV medication, they cause side-effects	49 (12.3)	82 (20.5)	3 (0.8)	16 (4.0)	249 (62.3)	399 (99.8)

**Table 4.35b Motivation status of patients towards ART**

Motivation of patients towards ART		Frequency	Percent	Valid percent	Cumulative percent
Valid	Poor motivation	49	12.3	12.3	12.3
	Good motivation	351	87.8	87.8	100.0
	<b>Total</b>	<b>400</b>	<b>100.0</b>	<b>100.0</b>	



**Figure 4.2 Motivation of patients towards ART**

#### 4.4.3 Behavioural skills of patients relevant to ART adherence

Out of the total of 14 behavioural skills items in the study questionnaire, if a respondent scored 8 and above easy/very easy responses they will be decided as having good behavioural skills and those with 7 and below easy/very easy responses were decided as having poor or inadequate behavioural skills important to adhere to ART.

Out of the total of 400 respondents, 328 had adequate behavioural skills and 72 had inadequate behavioural skills.

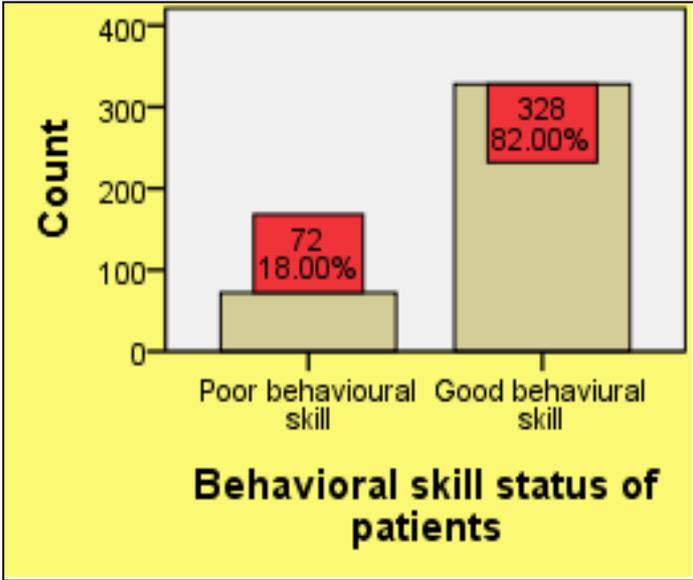
**Table 4.36a Behavioural skills status of patients relevant for ART adherence**

Behavioural skill items	Perceptions of patients						Total
	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree		
It is hard taking HIV medication, while drinking alcohol or using drugs	157 32 5 4 202 400	39.3 8.0 1.3 1.0 50.5 100.0					
Behavioural skill items continued	Very hard	Hard	Sometimes hard	Sometimes easy	Easy	Very easy	Total
Informing about HIV treatment	15 (3.8)	12 (3.0)	28 (7.0)	21 (5.3)	321 (80.3)	3 (0.8)	400 (100.0)
Get support from others for taking HIV medication	14 (3.5)	4 (8.8)	35 (1.0)	14 (3.5)	327 (81.8)	6 (1.5)	400 (100.0)
Get your HIV medication refill on time	25 (6.3)	9 (2.3)	34 (8.5)	7 (1.8)	323 (80.8)	2 (0.5)	400 (100.0)
Take HIV medication, during working time	35 (8.8)	18 (20.3)	81 (4.5)	23 (5.8)	242 (60.5)		399 (99.8)

Behavioural skill items	Perceptions of patients						Total
	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree		
Manage side-effect of HIV medication	21 (5.3)	20 (5.0)	45 (11.3)	20 (5.0)	289 (72.3)	5 (1.3)	400 (100.0)
Remember to take HIV medication	6 (1.5)	9 (2.3)	46 (11.5)	17 (4.3)	322 (80.5)		400 (100.0)
HIV medication hard to swallow taste bad or sick stomach	16 (4.0)	12 (3.0)	44 (11.0)	23 (5.8)	305 (76.3)		400 (100.0)
Make HIV medication part of daily life	5 (1.3)	9 (2.3)	26 (6.5)	14 (3.5)	343 (85.8)	3 (0.8)	400 (100.0)
Take HIV medication. usual routine changes	22 (5.5)	17 (4.3)	56 (14.0)	7 (1.8)	296 (74.0)	2 (0.5)	400 (100.0)
Take HIV medication. don't feel good emotional	30 (7.5)	17 (4.3)	72 (18.0)	27 (6.8)	253 (63.3)	1 (0.3)	400 (100.0)
Take HIV medication when good physically and don't feel symptoms of HIV take HIV medication. don't feel good physically	47 (11.8)	15 (3.8)	34 (8.5)	8 (2.0)	293 (73.3)	2 (0.5)	399 (99.8)
Talk to health care provider about HIV medication	23 (5.8)	15 (3.8)	66 (16.5)	17 (4.3)	275 (68.8)	3 (0.8)	399 (99.8)

**Table 4.36b Behavioural skills status of patients relevant for ART adherence**

Behavioural skill status of patients	Frequency	Percent	Valid percent	Cumulative percent
Poor behavioural skill	72	18.0	18.0	18.0
Good behavioural skill	328	82.0	82.0	100.0
<b>Total</b>	<b>400</b>	<b>100.0</b>	<b>100.0</b>	



**Figure 4.3 Behavioural skill status of patients**

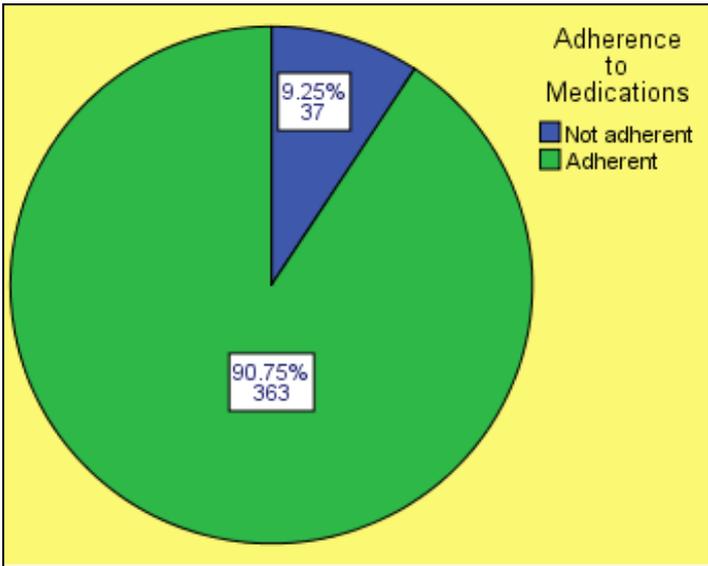
**4.4.4 Patients reported rates of adherence**

Respondents were asked how many doses they had missed in the previous three days. Their replies were used to calculate the percentage of those who took <95% or >95% of the ARV medication prescribed. Table 4.37 shows the results of the question about how many doses each patient had missed during the previous three days.

**Table 4.37 The percentage of ARV doses taken by the respondents in the three days preceding the study (N=400)**

Description	Frequency	Percent
Not adhere	37	9.3
Adhere	363	90.8
<b>Total</b>	<b>400</b>	<b>100.0</b>

Complete adherence data were provided by 400 participants. Three hundred and sixty-three participants (90.75%) reported optimal adherence (95% or greater rates of adherence) and 37 participants (9.25%) reported sub-optimal adherence (less than 95% rates of adherence). This dichotomous variable, with optimal adherence scored as one and sub-optimal adherence scored as zero, served as the outcome variable in the analyses. This study found a better adherence level than previously reported from Ethiopia (Awel 2007:40; Tadios & Davey 2006:41) except studies by Amberbir et al (2008:7) and Zeleke and Thupayagale-Tshweneagae (2013).



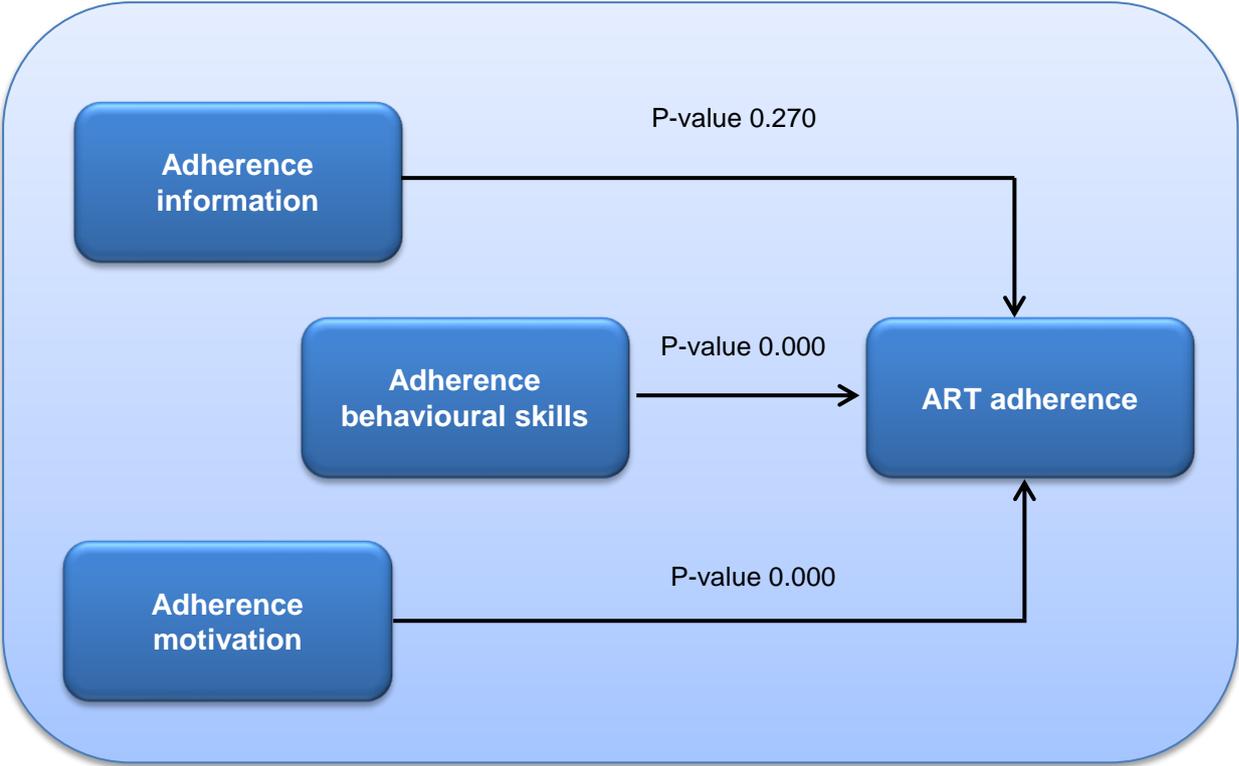
**Figure 4.4 Self-reported adherence score among respondents**

**4.4.5 Overview of research findings from inferential statistics**

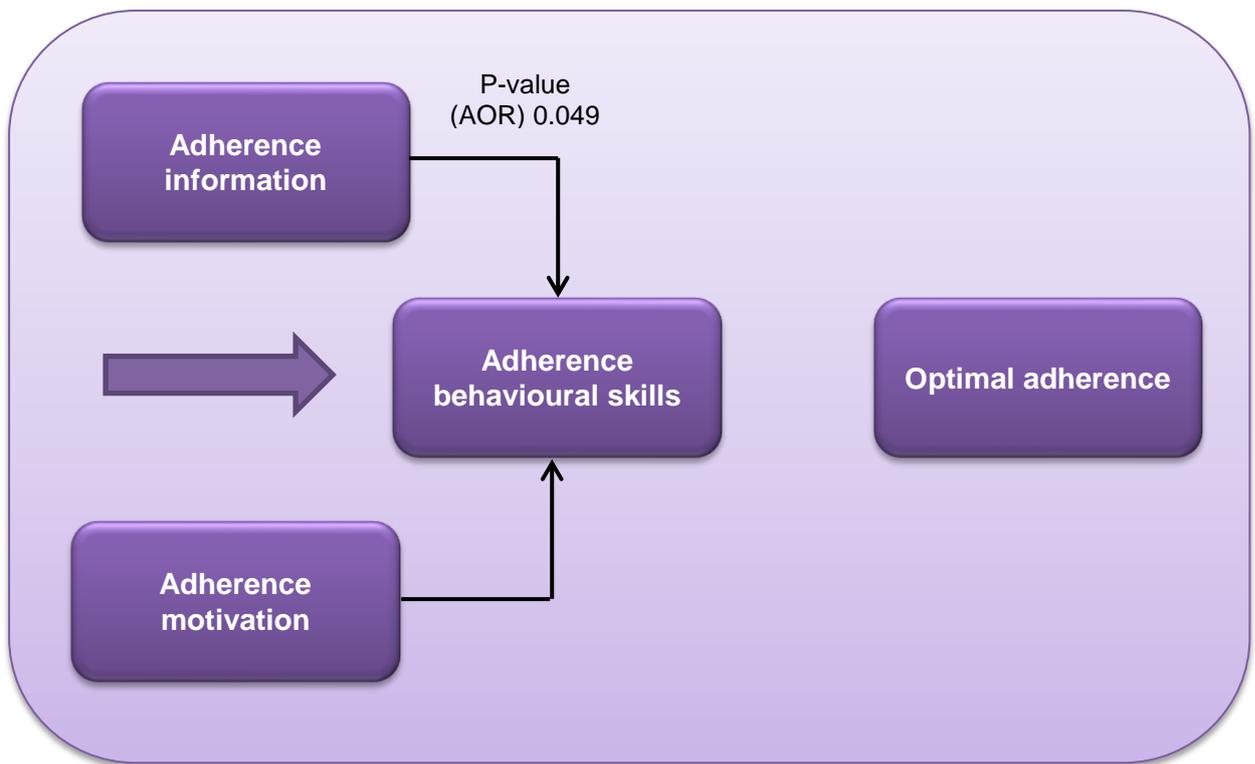
The IMB model of ART adherence was assessed as free and restricted models using variables from the three constructs and the dichotomous dependent variable: adherence-related information, motivation, and behavioural skills are the covariates while adherence per se (defined as optimal versus sub-optimal adherence) is the outcome or dependent variable. In the first free model, each variable from each construct was tested for adherence without adjusting values; the variables were then tested collectively for adherence behaviour. The p-values shown on the free models are the overall p-value for each path as a construct. From the analysis, it was found that motivation and adherence behavioural skills were significantly associated with adherence while information was not significantly associated with adherence.

Further, in the second free model, information was tested univariately first with motivation and then with adherence behavioural skills; motivation was also tested univariately with adherence behavioural skills. The results show that although information was not directly associated with motivation or behavioural skills, motivation was found to be directly and strongly associated with behavioural skills with a p-value of 0.00. This shows an association between motivation and behavioural skills in the second free model analysis and an association between motivation and adherence behaviour in the first free model analysis.

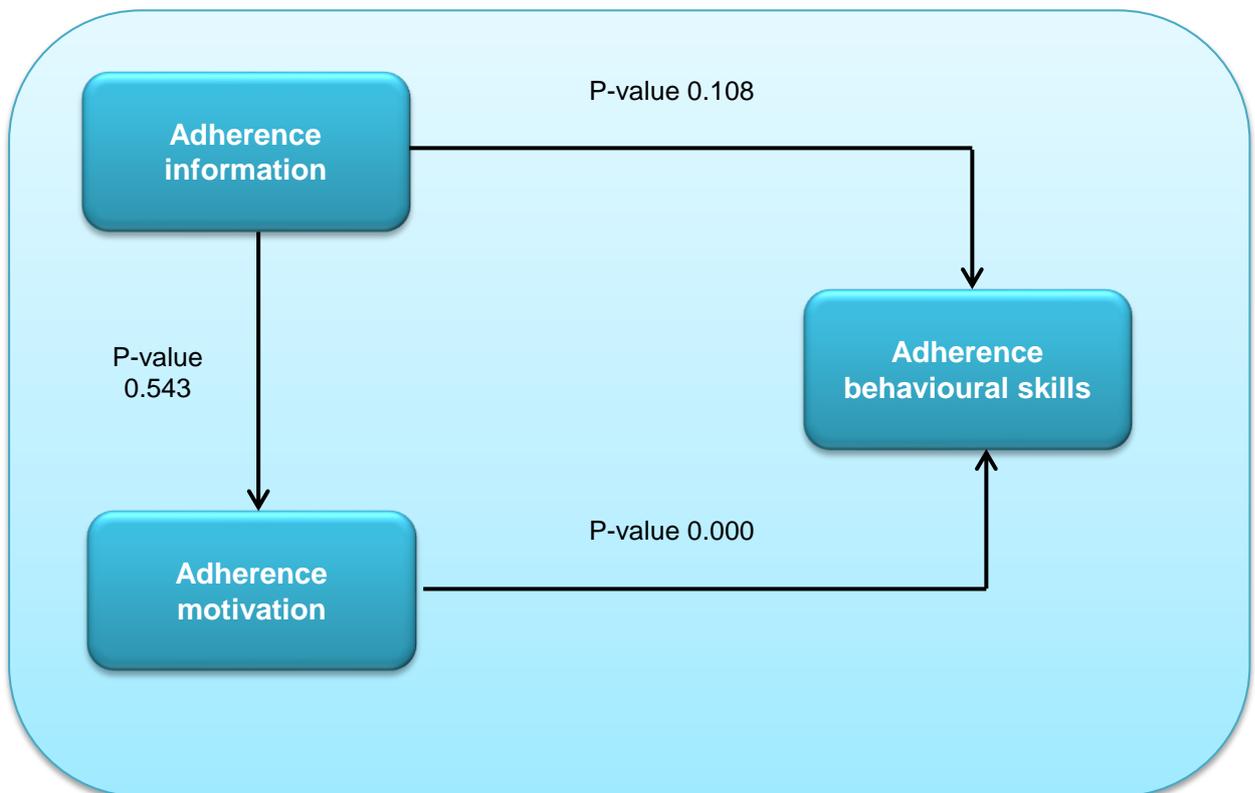
In the restricted model, every variable from each construct was screened with a p-value of 0.25 and later tested with adjusted odds ratio with a p-value of 0.05. One variable, i.e., the first variable from the information construct was found to be significantly but negatively associated with adherence behaviour while four variables from behavioural skills were significantly and positively associated with adherence behaviour. There were no significant associations between motivation variables and adherence behaviour.



**Figure 4.5 Free Model 1**



**Figure 4.6 A Restricted Model**



**Figure 4.7 Free Model 2**

#### 4.4.5.1 The impact of information on ART adherence behaviour

From 2x2 chi square analysis between information and adherence to medication, no significant association was found between the information variables and adherence behaviour when the information variables were tested individually as well as collectively. The tables show that the p-values are greater than 0.05 in both cases.

**Table 4.38a Assessment of the direct association between information and adherence behaviour**

Information items		Adherence to medication		Chi-square value	P-value
		Not adherent	Adherent		
Know HIV medication is supposed to be taken	Not well-informed	2 (0.5%)	46 (11.5%)	1.679	0.195
	Well-informed	35 (8.8%)	317 (79.2%)		
Know what to do if I miss a dose of medication	Not well-informed	26 (6.5%)	234 (58.5%)	0.498	0.48
	Well-informed	11 (2.8%)	129 (32.2%)		
Skipping few of my HIV medication will not really hurt my health	Not well-informed	32 (8%)	340 (85%)	2.657	0.103
	Well-informed	5 (1.2%)	23 (5.8%)		
Know the possible side-effect of my HIV medication	Not well-informed	10 (2.5%)	67 (16.8%)	1.586	0.271
	Well-informed	27 (6.8)	296 (74%)		
As long as feeling health missing HIV medication is ok	Not well-informed	33 (8.2%)	343 (85.8)	1.673	0.262
	Well-informed	4 (1%)	20 (5%)		
Understand HIV medication works to fight HIV	Not well-informed	2 (0.5%)	28 (7%)	0.258	1.000
	Well-informed	35(8.8%)	335 (83.8)		
If don't take my HIV medication, it may not work for the future	Not well-informed	18 (4.5%)	20 (50.2%)	0.613	0.490
	Well-informed	19 (4.8%)	162 (40.5%)		
If I take my HIV medication, I live longer	Not well-informed	1 (0.2%)	10 (2.5%)	0.000	1.000
	Well-informed	36 (9%)	353 (88.2%)		
Know HIV medication interact with alcohol and street drugs	Not well-informed	8 (2%)	49 (12.2%)	1.813	0.213
	Well-informed	29 (7.2%)	314 (78.5%)		

**Table 4.38b Assessment of the direct association between information and adherence behaviour**

Information status of patients	Adherence to medication		Chi-square value	P-value
	Not adherent	Adherent		
Poor information	2 (0.5%)	9 (2.2%)	1.075	0.270
Good information	35 (8.8%)	354 (88.5%)		

#### **4.4.5.2 The impact of motivation on ART adherence behaviour**

From 2x2 chi square analysis between motivation and adherence to medication, with the exception of item 6 there is significant association between the motivation variables and adherence behaviour when the motivation variables were tested individually as well as collectively. The tables show that the p-values are less than 0.05 in both cases.

**Table 4.39a Assessment of the direct association between motivation and ART adherence behaviour**

Motivation items		Adherence to medication		Chi-square value	P-value
		Not adherent	Adherent		
Worried HIV+, if people see me taking my HIV medication	Not well-motivated	13 (3.2%)	234 (58.5%)	12.227	0.000
	Well-motivated	24 (6%)	129 (32.2%)		
Frustrated taking HIV medication around my life	Not well-motivated	22 (5.5%)	272 (68.0%)	4.127	0.051
	Well-motivated	15 (3.8%)	91 (22.8%)		
Don't like taking HIV my HIV medication, HIV+	Not well-motivated	27 (6.8%)	330 (82.5%)	11.259	0.003
	Well-motivated	10 (2.5%)	33 (8.2%)		
Feel that health care provider recommendations	Not well-motivated	11 (2.8%)	41 (10.2%)	10.090	0.004
	Well-motivated	26 (6.5%)	322 (80.5%)		

Motivation items		Adherence to medication		Chi-square value	P-value
		Not adherent	Adherent		
People are important for taking HIV medication	Not well-motivated	9 (2.2%)	39 (9.8%)	5.864	0.029
	Well-motivated	28 (7.0%)	324(81.0%)		
Health care provider doesn't give enough support	Not well-motivated	34 (8.5%)	312 (78.0%)	1.015	0.449
	Well-motivated	3 (0.8%)	51 (12.8%)		
Frustrate to take HIV medication for life long	Not well-motivated	21 (5.2%)	314 (78.5%)	21.829	0.000
	Well-motivated	16 (4.0%)	49 (12.2%)		
Worried HIV medication, hurt my health	Not well-motivated	21 (5.2%)	307 (76.8%)	17.602	0.000
	Well-motivated	16 (4.0%)	56 (14.0%)		
Upsets HIV medication, affect the way I took	Not well-motivated	15 (3.8%)	255 (63.8%)	13.508	0.001
	Well-motivated	22 (5.5%)	108 (27.0%)		
Upsets HIV medication , cause side-effects	Not well-motivated	18 (4.5%)	251 (62.8%)	6.405	0.016
	Well-motivated	19 (4.8%)	112 (28.0%)		

**Table 4.39b Assessment of the direct association between motivation and ART adherence behaviour**

Information status of patients towards ART	Adherence to medication		Chi-square value	P-value
	Not adherent	Adherent		
Poor information	13 (3.2%)	36 (9.0%)	19.865	0.000
Good information	24 (6.0%)	327 (81.8%)		

#### **4.4.5.3 The impact of behavioural skills on ART adherence behaviour**

From 2x2 chi square analysis between motivation and adherence to medication, with the exception of the first item there is significant association between the behavioural skills variables and adherence behaviour when the behavioural skills variables were tested individually as well as collectively. The tables show that the p-values are less than 0.05 in both cases.

**Table 4: 40a Assessment of the association between behavioural skills and adherence behaviour**

Behavioural skills items		Adherence to medication		Chi-square value	P-value
		Not adherent	Adherent		
Hard taking HIV medication, drinking alcohol or use street drugs	Inadequate skill	22 (5.5%)	189 (47.2%)	0.736	0.391
	Adequate skill	15 (3.8%)	174 (43.5%)		
Informing about HIV treatment	Inadequate skill	18 (4.5%)	58 (14.5%)	23.288	0.000
	Adequate skill	19 (4.8%)	305 (46.2%)		
Get support from others for taking HIV medication	Inadequate skill	18 (4.5%)	49 (12.2%)	29.751	0.000
	Adequate skill	19 (4.8%)	314 (78.5%)		
Get your HIV medication refill on time	Inadequate skill	22 (5.5%)	53 (13.2%)	44.353	0.000
	Adequate skill	15 (3.8%)	310 (77.5%)		
Wrap HIV medication, during working time	Inadequate skill	27 (6.8%)	130 (32.5%)	19.446	0.000
	Adequate skill	10 (2.5%)	233 (58.2%)		
Manage side-effect of HIV medication	Inadequate skill	26 (6.5%)	80 (20.0%)	40.103	0.000
	Adequate skill	11 (2.8%)	283 (70.8%)		
Remember to take HIV medication	Inadequate skill	20 (5.0%)	58 (14.5%)	31.011	0.000
	Adequate skill	17 (4.2%)	305 (76.2%)		
HIV medication hard to swallow taste bad or sick stomach	Inadequate skill	22 (5.5%)	73 (18.2%)	28.709	0.000
	Adequate skill	15 (3.8%)	290 (72.5%)		
Make HIV medication part of daily life	Inadequate skill	16 (4.0%)	38 (9.5%)	30.887	0.000
	Adequate skill	21 (5.2%)	32 (81.2%)		
Take HIV medication. usual routine changes	Inadequate skill	25 (6.2%)	77 (19.2%)	37.980	0.000
	Adequate skill	12 (3.0%)	286 (71.5%)		
Take HIV medication. don't feel good emotional	Inadequate skill	32 (8.0%)	114 (28.5%)	43.954	0.000
	Adequate skill	5 (1.2%)	249 (62.2%)		
Take HIV medication, good physically	Inadequate skill	25	79	36.615	0.000

Behavioural skills items		Adherence to medication		Chi-square value	P-value
		Not adherent	Adherent		
and don't feel symptoms of HIV		(6.2%)	(19.8%)		
	Adequate skill	12 (3.0%)	284 (71.0%)		
Take HIV medication. don't feel good physically	Inadequate skill	27 (6.8%)	94 (23.5%)	35.270	0.000
	Adequate skill	10 (2.5%)	269 (67.2%)		
Talk to health care provider about HIV medication	Inadequate skill	13 (3.2%)	42 (10.5%)	15.722	0.000
	Adequate skill	24 (6.0%)	321 (80.2%)		

**Table 4:40b Assessment of the association between behavioural skills and adherence behaviour**

Behavioural skill status of patients	Adherence to medication		Chi-square value	P-value
	Not adherent	Adherent		
Poor skill	27 (6.8%)	45 (11.2%)	83.477	0.000
Good skill	10 (2.5%)	318 (79.5%)		

#### **4.4.5.4 The impact of the integration of information, motivation and behavioural skills which were found to be associated with adherence behaviour**

From the adjusted value, from information variables “Know HIV medication is supposed to be taken” is statistically significant and the odds ratio is greater than one. Therefore, well-informed patients are more likely to have adherent than those of non-informed patients. The other results can be interpreted similarly. The other variables found to be associated are the following and they are positively associated:

*Get your HIV Medication refill on time*

*Manage side-effect of HIV Medication*

*Take HIV Medication. Don't feel good emotionally*

*Take HIV Medication. Good physically and don't feel symptoms of HIV*

**Table 4.41 Assessment of the association between information and motivation with behavioural skills assumed to bring the required adherence behaviour (the Bivariate and multivariate analysis results of adherence)**

Independent variables	Information variables		COR (95%)	P-value COR	AOR (95%)	P-value AOR
Information	Know HIV medication is supposed to be taken	Well-informed	2.39 (0.591, 10.914)	0.210	8.391 (1.04, 71.54)	0.049
		Not well-informed	1		1	
	Know what to do if I miss a dose of medication	Well-informed	1.3 (0.624, 2.72)	0.481	2.784 (0.25, 8.17)	0.902
		Not well-informed	1		1	
	Skipping few of my HIV medication will not really hurt my health	Well-informed	0.532 (0.173, 1.637)	0.271	1.469 (1.02, 4.95)	0.513
		Not well-informed	1		1	
	Know the possible side-effect of my HIV medication	Well-informed	1.64 (0.756, 3.54)	0.212	1.34 (0.423, 4.23)	0.621
		Not well-informed	1		1	
	As long as feeling health missing HIV medication is ok	Well-informed	0.481 (0.155, 1.491)	0.205	0.797 (0.121, 5.262)	0.579
		Not well-informed	1		1	
	Understand HIV medication works to fight HIV	Well-informed	0.684 (0.156, 2.992)	0.614	2.96 (1.02, 7.88)	0.774
		Not well-informed	1		1	
	If don't take my HIV medication, it may not work for the future	Well-informed	1.31 (0.665, 2.58)	0.435	3.55 (1.27, 7.99)	0.758
		Not well-informed	1		1	
	If I take my HIV medication, I live longer	Well-informed	1.02 (0.127, 8.2)	0.985	2.5 (0.66, 7.9)	0.66
		Not well-informed	1		1	

Independent variables	Information variables		COR (95%)	P-value COR	AOR (95%)	P-value AOR
	Know HIV medication interact with alcohol and street drugs	Well-informed	0.566 (0.245, 1.31)	0.183	1.48 (0.369, 5.95)	0.579
		Not well-informed	1		1	
Motivation	Worried HIV+, if people see me taking my HIV medication	Well-motivated	3.35 (1.45, 6.8)	0.001	2.3 (0.79, 6.8)	0.126
		Not well-motivated	1		1	
	Frustrated taking HIV medication around my life	Well-motivated	2.34 (1.01, 4.095)	0.046	1.32 (0.46, 3.75)	0.61
		Not well-motivated	1		1	
	Don't like taking HIV my HIV medication, HIV+	Well-motivated	3.704 (1.65, 8.32)	0.002	2.97 (0.88, 10.10)	0.08
		Not well-motivated	1		1	
	Feel that health care provider recommendations	Well-motivated	0.301 (0.138, 0.654)	0.002	0.344 (0.102, 0.17)	0.087
		Not well-motivated	1		1	
	People are important for taking HIV medication	Well-motivated	0.374 (0.165, 0.851)	0.019	0.74 (0.21, 0.27)	0.67
		Not well-motivated	1		1	
	Health care provider doesn't give enough support	Well-motivated	0.54 (0.16, 1.823)	0.321	2.4 (1.55, 8.93)	0.33
		Not well-motivated	1		1	
	Frustrate to take HIV medication for life long	Well-motivated	4.882 (2.39, 9.99)	0.000	1.5 (0.48,4.7)	0.489
		Not well-motivated	1		1	
	Worried HIV medication, hurt my health	Well-motivated	4.18 (2.053, 8.496)	0.000	1.1 (0.323,8)	0.891
		Not well-motivated	1		1	
	Upsets HIV medication, affect the way I took	Well-motivated	3.46 (1.73, 6.93)	0.000	1.4 (0.42, 4.43)	0.612

Independent variables	Information variables		COR (95%)	P-value COR	AOR (95%)	P-value AOR
	Upsets HIV medication, cause side-effects	Not well-motivated	1	0.013	1	0.831
		Well-motivated	2.37 (1.196, 4.68)		0.88 (0.28, 2.75)	
		Not well-motivated	1		1	
Behavioural skill	Hard taking HIV medication, drinking alcohol or use street drugs	Adequate skill	0.741 (0.372, 1.47)	0.392	1.42 (0.19, 7.55)	0.564
		Inadequate skill	1		1	
	Informing about HIV treatment	Adequate skill	0.201 (0.099, 0.405)	0.000	1.1 (0.36, 3.3)	0.886
		Inadequate skill	1		1	
	Get support from others for taking HIV medication	Adequate skill	0.165(0.081, 0.336)	0.000	0.63 (0.1.94, 2.03)	0.436
		Inadequate skill	1		1	
	Get your HIV medication refill on time	Adequate skill	1.117 (0.057, 3.239)	0.000	0.304 (0.104, 0.89)	0.030
		Inadequate skill	1		1	
	Wrap HIV medication, during working time	Adequate skill	0.207 (0.097, 0.440)	0.000	1.2 (0.39, 3.6)	0.78
		Inadequate skill	1		1	
	Manage side-effect of HIV medication	Adequate skill	1.12 (0.057, 2.253)	0.000	0.254 (0.083, 0.776)	0.016
		Inadequate skill	1		1	
	Remember to take HIV medication	Adequate skill	0.162 (0.08, 0.327)	0.000	1.5 (0.41, 5.51)	0.544
		Inadequate skill	1		1	
	HIV medication hard to swallow taste bad or sick stomach	Adequate skill	0.172 (0.085, 0.347)	0.000	0.82 (0.29, 2.29)	0.706
		Inadequate skill	1		1	

Independent variables	Information variables		COR (95%)	P-value COR	AOR (95%)	P-value AOR
	Make HIV medication part of daily life	Adequate skill	0.153 (0.074, 0.319)	0.000	1.63 (0.43, 6.20)	0.472
		Inadequate skill	1		1	
	Take HIV medication. usual routine changes	Adequate skill	0.129 (0.062, 0.269)	0.000	0.98 (0.284, 3.39)	0.975
		Inadequate skill	1		1	
	Take HIV medication - don't feel good emotional	Adequate skill	2.072 (0.027, 6.188)	0.000	0.15 (0.043, 0.521)	0.003
		Inadequate skill	1		1	
	Take HIV medication. good physically and don't feel symptoms of HIV	Adequate skill	1.134 (0.064, 2.178)	0.000	0.24 (0.083, 0.704)	0.009
		Inadequate skill	1		1	
	Take HIV medication. don't feel good physically	Adequate skill	0.129 (0.06, 0.277)	0.000	0.383 (0.13, 1.14)	0.084
		Inadequate skill	1		1	
	Talk to health care provider about HIV medication	Adequate skill	0.242 (0.114, 0.510)	0.000	1.2 (0.35, 3.37)	0.889
		Inadequate skill	1		1	

## **4.5 CONCLUSION**

The main content included in this chapter are: Information factors, motivation factors, behavioural skills, patient reported rate of adherence, overview of research findings, and finally, a conclusion with respect to the chapter.

This chapter discussed the results and interpretation of data analysis with reference to the literature review. The results were presented in the form of tables and figures.

Chapter 5 concludes the study by drawing conclusions, discussing limitations and making certain recommendations for further research and practice in this field.

## CHAPTER 5

### CONCLUSIONS AND RECOMMENDATIONS

#### 5.1 INTRODUCTION

The purpose of this study was to assess the level of adherence to ART at the Felege Hiwot hospital among adult HIV-infected patients and to identify the major factors that affect adherence to ART. It is expected that the result of the study will be used to address the challenges that patients experience and to encourage them to adhere strictly to ART so that it can be optimally efficacious.

Although strict adherence to the dosage regimen of ARV drugs is critical for the success of ART, no study has been done at the Felege Hiwot hospital to identify and assess the factors that affect the level of patient adherence to the ART dosage regimen. Since the long term success of ART is totally dependent on strict long-term adherence to the dosage schedules, the researcher used theoretical constructs derived from the IMB model, which worked well in the developed countries, to identify and assess factors affecting drug adherence among HIV-positive patients. By using the predictors associated with the IMB model, the researcher was able in this study to identify those factors that affect adherence.

In this chapter, the researcher makes various recommendations for practice and further research in the field and identifies the limitations of the study. The chapter also presented conclusions based on results of a study to answer objectives formulated in Chapter 1 as follows:

- To assess the levels of ART adherence behaviour in patients taking ARV drugs at Felege Hiwot hospital which located in Bahir Dar town of the Amhara region of Ethiopia.
- To explore the impact of information about ART and adherence on ART adherence behaviour among patients receiving ARV drugs from Felege Hiwot hospital.

- To explore the impact of motivation on ART adherence behaviour among patients receiving ARV drugs from Felege Hiwot hospital.
- To determine the impact of adherence behavioural skills needed to practice strict ART adherence on their self-reported adherence behaviour of patients at Felege hiwot hospital ART clinic.
- To assess the benefits of the integration of information, motivation and behavioural skills needed to practise strict ART adherence in patients receiving ARV drugs from Felege Hiwot hospital.

## **5.2 SUMMARY AND INTERPRETATION OF THE RESEARCH FINDINGS**

The findings from this study are discussed below in the same sequence in which the objectives of the study were listed above.

**Objective 1:** To assess the level of adherence behaviour among ART patients who receive ARV drugs at the Felege Hiwot hospital.

### **5.2.1 Level of adherence behaviour**

Out of the total number of respondents, 9.25% respondents took their HIV medications <95% of the time, while 90.75% of the respondents took their ART medications for >95% within the 3 days preceding the study.

Although this represents a good adherence rate, it still indicates that a significant number of the population is sub-optimally adherent to ART. This poses a serious threat because when ARV medications are taken intermittently, they develop an increasing inability to combat the HIV virus therefore, negates the efficacy of the ART regimen in the future. This obviously poses an enormous threat to the overall health status of individuals and of the community as a whole because the selection of ARV drugs that are available to patients in developing countries such as Ethiopia, are very limited indeed. Health care professionals who administer ARV therefore need to take urgent action in order to improve the level of optimal adherence among those who are currently receiving ARV medications.

The researcher measured ART adherence by self-report using structured interview questions that can be subject to overestimation, as patients tend to overstate their

adherence to treatment. Other measures of adherence, such as pill counts, pharmacy records, electronic devices, or therapeutic drug monitoring were not available for the study. Even so, measuring adherence using patients' self-report can be easily replicated in most resource-limited settings including Ethiopia making it a good measure for comparison (Amberbir et al 2008:5-7; Reda & Biadgilign 2012:2).

**Objective 2:** To explore the impact of information about ART and adherence on ART adherence behaviour among patients receiving ARV drugs from Felege Hiwot hospital.

### **5.2.2 The impact of information on ART adherence behaviour**

The study was able to show that information is an important determinant factor for adherence behaviour. Non-adherence is understood in terms of characteristics of the patient (personality traits, socio-demographic background), and patient factors are seen as the targets of efforts to improve adherence. This approach has helped to elucidate the relationships between disease and treatment characteristics on the one hand, and adherence on the other. Technological innovations (e.g. assessing levels of adherence using biochemical measures, developing new devices to administer medications) have had this as their impetus. Other important factors, such as patients' views about their symptoms or their medications have been largely ignored. Behavioural (learning) theory emphasises the importance of positive and negative reinforcement as a mechanism for influencing behaviour, and this has immediate relevance for adherence.

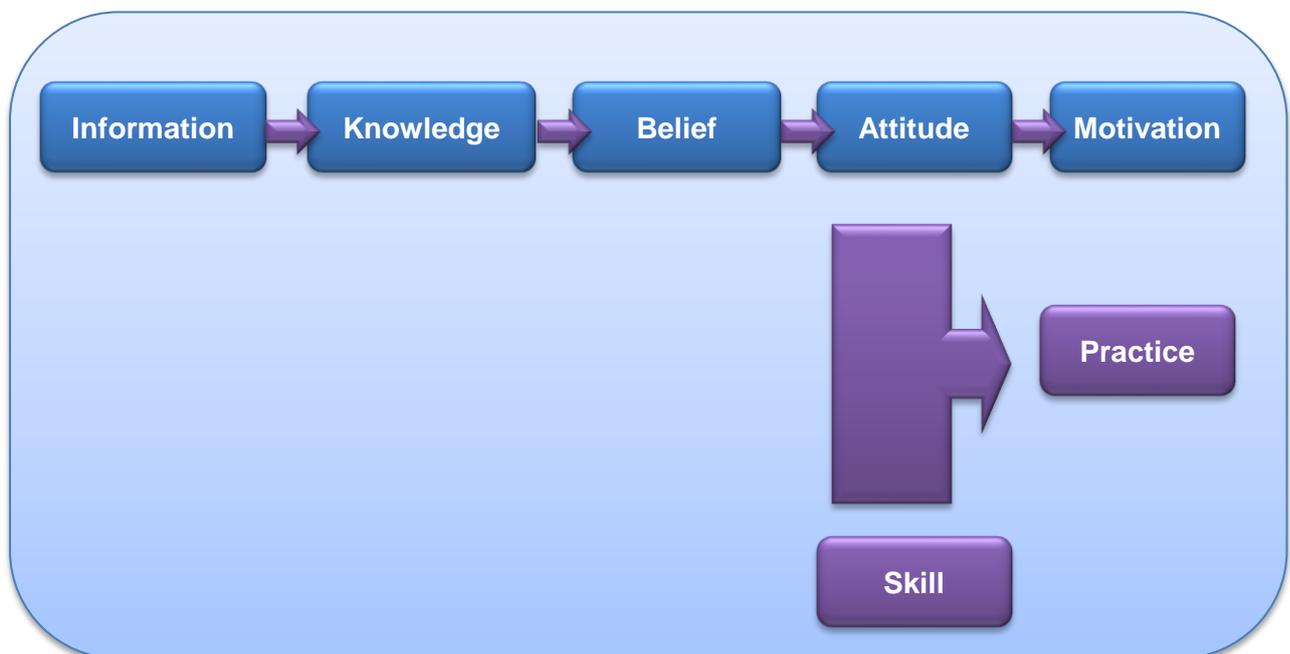
Clinicians need to communicate information effectively to patients. They need to:

- Build trust and encourage patients to participate in decision-making and to be partners in their own health care.
- Ask patients to share why and how they will carry out their treatment recommendations. Listen to patients' concerns and give them full attention.
- Be aware of and sensitive to patient's cultural beliefs and practices, and view treatment through a cultural lens to make sure that recommendations do not conflict with cultural norms.

**Objective 3:** To explore the impact of motivation on ART adherence behaviour among patients receiving ARV drugs from Felege Hiwot hospital.

### 5.2.3 The impact of motivation on ART adherence behaviour

The study analysis has shown that motivation and adherence behaviour are significantly and strongly associated. Negative attitudes toward treatment and demotivation to follow treatment recommendations come from lack of optimal knowledge about the efficacy of the treatment. Motivation, beliefs and actions come from knowledge, therefore, delivering specific information pertaining to the desired behavioural outcome is the basic tool which brings about the knowledge about a medical condition that might include how the disease develops, its expected course and effective strategies for its management. Therefore, teaching patients until they are fully aware of the benefits of strictly adhering to treatment is very important because patients become motivated to follow only treatments they are convinced of. This means that even if the patient has acquired knowledge from the information given and gets training on relevant skills, he or she may not use the knowledge and skill until he or she has the conviction and belief on the knowledge processed from the given information, which means they should be convinced of the subject matter in order to move to action or targeted practice.



**Figure 5.1 The information-motivation cascade diagramme**

(Source: self-created)

**Objective 4:** To determine the impact of adherence behavioural skills needed to practice strict ART adherence.

#### **5.2.4 The impact of behavioural skills on ART adherence behaviour**

Patients need behavioural skills which ensure that the patient has the specific behavioural tools or strategies necessary to perform the adherence behaviour such as enlisting social support and other self-regulation strategies, to achieve this, HCPs need to improve their skills in communicating with their patients which is very important to guide and help their patients to create not only knowledge and motivation but also behavioural skills.

This leads to emphasis being placed on the importance of developing rapport, educating patients, employing good communication skills and stressing the desirability of a more equal relationship between patient and health professional. With regard to communication interventions per se, recent developments have foregrounded the need to move beyond top-down communication towards horizontal and participatory approaches. Such approaches incorporate the concept of addressing enabling environments and contextual factors and are framed by the concept of 'communication for social change'. Elements of this framework include: moving away from people as objects for change, towards people and communities as agents for change; moving away from delivering messages, towards supporting dialogue and debate on key issues; moving away from a focus on individual behaviour, towards a focus on social norms, policies, culture and supportive environments; moving away from persuasion, towards negotiation and partnership; moving away from external technical expertise, towards integrating communities in assessing issues of concern at local level.

Adopting a warm and kind style of interaction with a patient is necessary, but is insufficient in itself to effect changes in the adherence behaviours of patients. Tailored interventions provide individualised information based upon a specific theoretical framework, demographic characteristics or a combination of variables. There is evidence that tailored communications are more effective for influencing health behaviours than non-tailored materials, and comparisons of stage-tailored versus non-tailored interventions have shown that tailoring resulted in increased efficacy in influencing health behaviours. Identification of stage of change can help determine the

most relevant intervention components for each person, thus eliminating the need to deliver all intervention components to all patients. The skill of valid measurement to assess stage of change provides a foundation for the development of stage-matched interventions for the promotion of adherence to medication.

It is important to consider holistic skills that tackle both psychological and physical or concrete adherence barriers. Concrete barriers represent a common set of obstacles to adherence, such as the cost of medications, unreliable transportation to make appointments, mental health issues and complex treatment regimens. Patients need a workable skill or strategy to follow treatment recommendations. HCPs need to:

- Help overcome practical barriers that make it difficult for patients to effectively carry out a course of action.
- Identify individuals who can provide concrete assistance. Identify resources to provide financial aid or discounts.
- Provide written instructions/reminders. Sign a behavioural contract. Offer links to support groups.
- Provide electronic reminders or follow-up phone calls.

**Objective 5:** To assess the benefits of the integration of information, motivation and behavioural skills needed to practise strict ART adherence in patients receiving ARV drugs from Felege Hiwot hospital.

### **5.2.5 The impact of the integration of information, motivation and behavioural skills which were found to be associated with adherence behaviour**

The right information when communicated in the right way can bring about the appropriate knowledge which results in belief and attitude change which are important processes to create the desired motivation. However, information and motivation on their own are not enough to achieve perfect adherence. The IMB model posits that information and motivation can bring about new behaviour through new skills, i.e., knowledge and skill are not enough to result in acceptable practice. Knowledge should further grow to belief and belief is the basis for attitude change. Attitude change, in turn, results in new and desired practices. The new and desired practices must be shaped through the right skills by:

- Counselling, educating and training patients
- Providing regular or continuous training for HCPs

We can achieve the following milestones which are crucial to addressing the information, motivation, and behavioural skills mandatory to bring about ART adherence behaviour:

- Increase awareness of patients' need near-perfect adherence level.
- Assist patients to develop skills to sustain their ART adherence over time for life long.
- Convince the patients that they need to have higher level of adherence to medication.
- Support providers to assess and address adherence barriers: Equip them with patient-centred communication skills which facilitate the process of converting information to knowledge and knowledge to belief system and attitude change, and avail materials integrated into the workflow of provider-patient interaction.

### **5.3 CONCLUSIONS**

Overall the inferential analyses depicted in the figures and tables in chapter 4 show that the mediated structural hypothesis of the IMB model of ART adherence is supported because the free models analysed together show that motivation and behavioural skills are significantly associated with one another and with adherence behaviour as well whereas the restricted model analysis shows that one important variable from information is strongly and positively associated with adherence behaviour.

Predominantly, adherence-related motivation related significantly and positively to behavioural skills, and significantly related positively to optimal adherence. Moreover, as predicted by the model, adherence-related behavioural skills were significantly and positively associated with optimal adherence.

Though it is not possible to detect strict and direct cause and effect relationships, the research showed that information, motivation and behavioural skills are interrelated.

Thus, support was provided for the IMB model's major assertions that adherence-related information, motivation and behavioural skills are important determinants of adherence behaviour and that ART adherence behaviour is influenced by information and motivation primarily through their effects on behavioural skills.

Experiences with ART suggest that adherence is arguably the most important issue in successfully managing HIV/AIDS. A multifaceted approach to improve adherence is the most likely to be beneficial, particularly a combination of actively involving patients in their own health care decisions, provision of appropriate supports, multidimensional educational programmes that teach behavioural skills to the patient to enhance his or her adherence, and tailoring of the regimen to fit the patient.

Furthermore, it is essential that the patient adequately understands the importance of adherence and the serious consequences of non-adherence (i.e. treatment failure, or in some cases, disease progression, drug-resistance or death). Especially for a condition such as HIV, where poor adherence can cause resistance, it may prove wise to delay active treatment until the patient understands the demands of the regimen and feels truly committed to it. One way in which to gauge a person's readiness to adhere to a regimen, identify specific barriers to adherence, and to simultaneously strengthen the patient-provider relationship is to ask the patient an idea of a trial run of the regimen. This may be done using vitamin pills or jelly beans, with different tablets or different-coloured beans representing the various medications. Such a trial can give patients a perspective on how dosing schedules and other complexities, such as food restrictions or requirements will fit into their daily routine. A trial lasting a few weeks is usually sufficient for assessing a patient's ability to stick to the regimen and overcome the barriers. However, such a trial run is unable to mimic possible side-effects.

Ideally, the health practitioner should work together with the patient to select a regimen that will fit with his or her lifestyle. If more than one regimen may be appropriate for a given patient, providers may want to discuss the regimen, the number of pills, the dosing schedule, instructions and potential side effects with the patient. The discussion will foster a more collaborative and positive relationship between the practitioner and the patient, which is likely to enhance adherence. Once the regimen is decided upon, practitioners must make certain that patients fully understand the dosing schedules and instructions.

Rather than associating doses of medication with times of the day, fitting the regimen to the patient's lifestyle calls for working with the patient to associate medication doses with routine activities performed at the times that the medication should be taken. For example, morning doses can be associated with morning rituals (e.g. brushing teeth or reading the newspaper), and evening doses can be associated with evening routines (e.g. children's homework or watching television news programmes). In general it is likely that accomplishing this "fit" will be easier with regimens that require infrequent dosing (i.e. once or twice a day). However, the principle of associating medications with daily activities can also accommodate more frequent and complex regimens.

The simplest, effective and potent regimen will fail if patients experience side-effects that they perceive as problematic and they end up terminating their medications. At the time that the regimen is prescribed, health professionals should be proactive and provide strategies to help patients manage any side-effects that may occur. Given that experiencing side-effects is associated with non-adherence, the provider must accurately assess both the patient's willingness to adhere in the context of possible side-effects, and his or her willingness to overcome potential barriers to taking the medications as prescribed.

Furthermore, providers and their team members should remain in close contact with the patient during early treatment with a new regimen to allow for the timely identification and management of all side-effects and toxicities. A further advantage of this approach is that it provides an opportunity for reinforcing adherence behaviour. A powerful reinforcer of adherence behaviour is positive feedback regarding medication efficacy. Consequently, laboratory and other tests should be conducted soon after the initiation of treatment to show the extent to which it has been effective.

Health care providers and their teams should address the patient-related factors and psychosocial issues associated with non-adherence. While these may vary across conditions, screening for active substance abuse and depressed mood would be appropriate in many patient groups. Finally, enlisting the support of family members and "significant others", or employing "treatment buddies" (trained community health workers) to administer medications can greatly enhance adherence. A comprehensive approach to AIDS care, which includes access to free voluntary tests and counselling,

the provision of ART for the prevention of mother-to-child transmission, diagnosis and referral of opportunistic infections, social assistance and directly observed provision of ART (DOT-ART) can be implemented by using trained health extension workers (HEWs) in Ethiopia.

#### **5.4 RECOMMENDATIONS**

A number of recommendations emerge from this study, and these are closely linked with the conclusions drawn from the data:

- (i) Firstly, future research should focus not on the development of new theories but rather on the further examination of those already elaborated. Several key attributes that should be encompassed by theories explaining behaviour change have been suggested, including demonstrated effectiveness in predicting and explaining changes in behaviour across a range of domains; an ability to explain behaviour using modifiable factors; and an ability to generate clear, testable hypotheses. The theories should include non-volitional components (i.e. issues over which individuals do not have complete control) for instance, system factors, and take into account the influence of external factors, as perceived by individuals.
- (ii) Secondly, further work is required to identify or develop theories of health behaviour that are most applicable to improving adherence to long-term medication. Existing health behaviour theories should be tested systematically to establish which best predict effects on different kinds of behaviour for different groups of people in different contexts. For example, does a particular theory predict changes in adherence behaviour for both men and women with HIV in both Ethiopia and South Africa? Experimental research and increased clarity in theories and methods could assist in the identification of effective behaviour change techniques, thereby contributing to the development of evidence-based practice in health psychology and implementation research. Similar efforts need to be made regarding the use of theories as applied to adherence behaviour.
- (iii) Thirdly, the abundance of theories and their poor evidence base highlights the need to develop and trial interventions that utilise these theories appropriately

(i.e. in concordance with the theory), with well-defined and operationalised variables. This will help to advance the study of human adherence behaviour and allow for better informed decisions related to how these theories could be more widely applied in practice for guidance on developing theoretically informed interventions.

- (iv) Fourthly, reports of interventions to promote adherence to long-term medications for other health issues, such as diabetes, asthma and hypertension, should be reviewed to determine how many have drawn on theory in the design and testing of these interventions; the range of theories utilised and the ways in which this was done; and the ways in which the use of theory contributed to understanding the effects of these interventions.
- (v) Finally, it is worth mentioning that a recent review found that interventions to improve adherence to medication were more effective when they included multiple components such as more convenient care, patient education, information, counselling, reminders, self-monitoring, self-rewards, reinforcement, behavioural skills, social support and telephone follow up. Patients create personal representations of health threats and models of the illness and its treatment, and it is these that guide their decision-making and behaviour. Thus, adherence requires an appropriate model and the right knowledge of the benefits of the new targeted behaviour and a belief that the issue requires one's attention and the modification of one's behaviour. Adherence also requires specific coping skills, in addition to behaviour and more convenient care necessary to perform the adherence behaviour (WHO 2003:143-146). With this regard, providers may use the 5 A's Behaviour Change Model (Assess, Advise, Agree, Assist, Arrange) which is intended to use for improving chronic illness care (Federal HIV/AIDS Prevention and Control Office 2008:64-66; Horizons ... 2004:20-104; WHO 2003:96-103).

*Assess: Beliefs, behaviour and knowledge*

*Advise: Provide specific Information about Health risks and Benefits of change*

*Agree: Collaboratively set goals based on patient's interest and confidence in their ability to change the behaviour.*

*Assist: Identify personal barriers, strategies, problem-solving techniques and social/ environmental support*

*Arrange: Specify plan for follow-up (e.g., visits, phone calls, mailed reminders)*

Specific Interventions after assessment:

- Select strategy: Based on their specific IMB deficits, patients are provided with a tailored list of adherence-promoting strategies and asked to select a specific strategy to work on.
  - After selecting a strategy, clients are given a list of strategy- specific interventions and are asked to select the one that would help them most with taking their HIV medications.
  - Clients are encouraged to explore the intervention they choose at their own pace.
  - There are different interventions that address adherence-related IMB deficits.
- i. How ARVs work: Explain CD4 cells, viral load (VL), how HIV medication help fighting HIV in the body and resistance.
  - ii. Explain ARV medication: Discuss dosage, side effects, drugs interactions and dietary restrictions for each drugs:
    - a. Side-effects and solutions: Explain ARVs side effects and their management by patient and providers.
    - b. Long-term medication side-effects: Discuss long-term side-effect management such as lipodystrophy.
    - c. Focus on the fight: Promote positive attitudes towards one's HIV treatment and share experience of treatment outcomes with other PLHIV.
    - d. Positive voices: Share experience with other PLHIV about HIV treatment and strategies for overcoming barriers to adherence.
    - e. Bill the pill: Adapt strategies for taking pills that hard to swallow, taste bad or nauseous.
    - f. Pharmacist education: Discuss about prescriptions and use written instructions.

- g. Match-up-cue for taking medications: Cues daily routines with medication taking such as meals. Use calendars, diary and check doses.
- h. Information station: Describe support services available to clients, information about counselling and support groups for PLHIV, mental health, substance abuse and housing assistance.
- i. Medication reminders: Provide information about use of adherence support tools (e.g. alarm, pillbox).
- j. Doctor talk: Discuss with physician about ARVs side effects and resistance.
- k. Helping hand: Involve PLHIV in adherence counselling and support for other PLHIV.
- l. Medication taking: Fitting medication taking with daily routines. Taking medication when one's routine changes. Taking medication when others are around.
- m. Provider-patient communication: Address communication skills with a focus on the provider-patient relationship. Present skills of successful provider-patient interaction.
- n. Discuss the effect or interaction of street drugs and alcohol with ARVs in the body, and give tips for staying healthy and taking ARVs even when using drugs or alcohol.
- o. Stress management: Learn about stress and its management.
- p. Battle for health-use tools: Fight off infection, take ARVs at specific time by using reminder tools in challenging situations.
- q. Learning from missed doses: Identify reasons for missing doses and address accordingly.
- r. Celebrate success: Offered to patients with consistently perfect adherence over time. Provide patients a reward certificate and then encourage them to learn about maintaining adherence over time.

## **5.5 CONTRIBUTIONS OF THE STUDY**

Findings in this study suggest implications for research and practice. The contributions of the study are the following:

- Its findings could sensitise programme managers and policy makers to evaluate currently practiced strategies and to update them or even change them with new ones.
- The study leaves a room for further research as it has new questions arising from the discussion of the findings and that the findings can confidently be generalisable to the entire country only if future studies are conducted in different districts of the country.

## **5.6 LIMITATIONS OF THE STUDY**

The researcher feels that this study has the following limitations that warrant mention:

- (i) First, as the study used cross-sectional design, it did not allow the researcher to establish a causal relationship between significantly associated variables and treatment adherence, as both variables were measured at the same time. Since the study is also a cross-sectional study, it addressed the adherence during only the three days prior to the time when the study took place. One therefore needs to consider that adherence behaviour might vary among different patients at different times and on different days. Another limitation is that a cross sectional study of this kind that addresses adherence behaviour in the three days prior to the collection of data, may be problematic because it is accepted that adherence can vary considerably for different people at different times. Adherence is a dynamic process that changes over time with changing beliefs, attitudes, emotions, and daily and larger life events. Patients' adherence decisions are continuously renegotiated because changes made to their present medication, or introduction of new medicines 'upset the balance'. Therefore, a more accurate set of figures about adherence would be more likely to emerge from a longitudinal prospective study than from any cross-sectional studies. The study has, however, vigorously strived to show the first clue about the validity for potential utility of the IMB model of ART adherence in the ART clients of the study health facility. The study findings also afford additional insights and extensions in previously reported relationships in the IMB model of ART adherence literature.

- (ii) Secondly, “gold standard” for assessment of adherence does not exist, in this study adherence was measured using self-report; studies suggest that self-report tends to overestimate adherence and self-reported adherence measurements are known to increase adherence rates( Horizons ... 2004:20). This might be one of the limitations of this study because the study did not make use of objective measures of adherence. The problem with self-reports of health behaviour is that they may be influenced by a subject's reluctance to report non-adherence to treatment recommendations. Social desirability (projection of a positive image) could have induced an overestimation of adherence. Objective measures of health behaviour may be reliable if they involve a single observable action such as attending a health screening programme but this type of measure becomes more difficult, when long-term behaviours are of interest as in a treatment regimen for chronic illness. Given the shortcomings of sampling, design and measurement related to the IMB already described above, these additional problems of measuring behavioural outcome serve only to compound the difficulty in assessing the utility and validity of the model. Even when a researcher collects data by using a structured questionnaire, there is still the possibility that a social desirability bias and recall bias will affect the answers of the respondents. This means that the actual adherence rate that the respondents have reported might be different if they were to fill the questionnaire by themselves while in this case they were asked by their health care providers. However, the researcher tried to minimise that by explaining to each patient that it was not always easy to adhere to medical treatments in general (Joubert & Ehrlich 2007:163). The patients were also informed that their answers would not interfere with the care they received. Furthermore, the patients were asked about the most recent days. Generally, structured self-report has been reliably associated with both objective measures of adherence and viral load (Horizons ... 2004:9). The study, therefore, supplies important information about the current status of the level of optimal adherence behaviour of PLHIV receiving ART care at Felege Hiwot hospital.
- (iii) Thirdly, the study did not segregate patients into cohorts of treatment (at least yearly cohort batches) according to the date of initiation of ART to see issues specific to every cohort. For example, forgetfulness to take pills, which was given by the majority of the respondents as a reason for missing pills, might be a

problem of beginners of treatment until a certain period of time, which can improve later as patients stay more on treatment. This could have been unreasonably concluded as a main reason if the majority of the participants were by chance those who started ART later than the rest. On the other hand, if again only a smaller number of the participants were by chance from those who were chronically on ART, they could develop “treatment fatigue”, which is not usually mentioned and appropriately addressed as a barrier both in the literature as well as by the HIV clinicians. As a result, patients were not tightly adherent to their medication but this variable, which can be more significant in them, could have been masked by other variables predominantly cited by those newer patients (Federal MOH and Federal HAPCO 2007:75). However, the researcher believes that this was handled by applying random sampling procedure, which provides reassurance that the sample is representative of the population of interest so that inclusion of every year of cohort of patients in the study can be safely assumed.

- (iv) Fourthly, since the study was performed only in one public hospital in Amhara and since it was not a longitudinal or a follow-up study, the generalisability of our findings may be limited. Whether the study findings would differ in other subpopulations of PLWH remains to be determined. As adherence and combination therapy are dynamic and continuous process there is a need for more research. The study needs to be replicated with a more diverse sample and different settings to see if the issues related to adherence are similar across the HIV patient population.
- (v) Finally, it should also be noted that any understanding of individual health behaviour, and interventions to change this, must be located within the relevant social, psychological, economic and physical environments. It is clear that poor adherence is also the result of factors outside the individual's control, including clinic and health care organisation factors. Any focus on changing the behaviours of individuals with HIV should not result in the neglect of these other dimensions. Interventions that focus on providers, the provider-patient relationship, health system and contextual factors therefore also need to be developed and evaluated.

## 5.7 CONCLUDING REMARKS

Non-adherence to treatment is a problem of increasing concern to all stakeholders in the health system; the extent and consequences of poor adherence have been well documented in terms of impact on population health and health expenditure. Poor adherence limits the potential of efficacious treatments to improve patients' health and quality of life. This is a particular problem in the context of the chronic conditions that currently dominate the burden of illness in today's society. Across health disciplines, providers experience considerable frustration over the high proportion of their patients who fail to follow treatment recommendations.

Adherence is a behavioural problem observed in patients, but with causes beyond the patient. It occurs in the context of treatment-related demands that the patient must attempt to cope with. These demands are characterised by the requirement to learn new behaviours, alter daily routines, tolerance in discomforts and inconveniences, and persistence in doing so while trying to function effectively in their various life-roles. While there is no behavioural magic bullet, there is substantial evidence identifying effective strategies for changing behaviour.

Providers often assume that the patient is, or should be, motivated by his or her illness to follow a treatment protocol. This means that treatments are frequently offered to patients who are not ready to follow them. This reflects an understandable bias towards treating the biomedical problem and an under-emphasis on addressing the behavioural requirements of the treatment protocol. However, recent research in the behavioural sciences reveals this assumption to be erroneous.

First-line interventions to optimise adherence can go beyond the provision of advice. Building on a patient's intrinsic motivation by increasing the perceived importance of adherence, and strengthening confidence by intervening at the level of self-management skills are behavioural treatment targets that must be addressed concurrently with biomedical ones if overall effectiveness of treatment is to be improved.

In every situation in which patients are required to administer their own treatment, non-adherence is likely. Consequently, the risk for non-adherence for all patients should be assessed as part of the treatment-planning process and their adherence should be

monitored as part of treatment follow-up. The traditional approach has been to wait to identify those patients who demonstrate non-adherence and then try to “fix” the problem. The risk for non-adherence is ever present. Interventions based on non-adherence risk-stratification should be offered from the start, as opposed to using a stepped-care approach. This approach offers a way of increasing the sophistication of the adherence interventions offered to patients. Pharmacists, case managers, health educators and others involved in patient care should become familiar with these basic concepts. Providers have an important role to play and an opportunity to dramatically improve health by specifically targeting issues of patient adherence.

As such, non-adherence is not simply a “patient “problem. At the points of initial contact and follow-up, providers can have a significant impact by assessing risk and delivering interventions to optimise adherence. Poor adherence persists largely because it is a complex problem and is resistant to generic approaches to dealing with it. Adherence-promoting interventions are not consistently implemented in practice because of lack of knowledge, lack of incentives, lack of feedback on performance as barriers and practitioners report lack of time. To make this way of practice a reality, practitioners must have access to specific training in adherence management, and the systems in which they work must design and support delivery systems that respect this objective. Health care providers can learn to assess the potential for non-adherence, and to detect in their patients. They can then use this information to implement brief interventions to encourage and support progress towards adherence. Interventions aimed at particular diseases need to target the most influential and core determinants among the various factors. Given available resources, these targets will invariably be the patient and provider, at least in the immediate term. Disease-specific protocols for patients can be tailored to their needs. Practitioner protocols can convey the key requirements for the creation of optimal treatment relationships and behaviour assessment and management skills.

Beyond this, the systems in which providers work must be organised in such a way as to enable a consistent and systematic focus on adherence. A major focus for future research should be the clarification of the best mode, or modes, of delivering adherence interventions. There are many points of contact with patients and times at which such interventions are required, and delivering them outside the traditional health system may enhance their overall effectiveness.

The study findings indicate a need to attend to multiple determinants of ART adherence, including information, motivation, and behavioural skills, as critical to sustaining perfect adherence over time. An understanding of the dynamics of ART adherence behaviour is critical to promote the development, implementation, and evaluation of effective behavioural interventions that enhance self-sustained adherence to HIV treatment. The current research is a step in that direction, presenting the quantitative test of the Information, Motivation, Behavioural Skills model of care initiation and maintenance for HIV treatment. In providing the first quantitative evaluation of the IMB model to adherence to ART in the current study, the researcher utilised data collected from the patient's perspective to assess the degree to which the IMB model's core theoretical determinants are represented in participant's response. Specifically, the determinants of ART adherence identified by the IMB model of ART adherence (adherence-related information, motivation and behavioural skills) were used in a series of structural equation model tests to evaluate the fit of the IMB model of adherence to the sample data. In doing so, the current study has aimed to evaluate the utility and validity of applying the IMB model to a new behavioural and sociocultural setting (i.e., PLWH on ART in chronic HIV care clinic at Felege Hiwot referral hospital located in Bahir Dar town); identifying the types of theoretical content (i.e., types of information, motivation, behavioural skills, which address important cognitive, affective, socio-cultural, and environmental contextual factors) underlying adherence to ART to address in future intervention development for this target population.

The findings of the current work support the validity and utility of this theoretical model in explicating the behavioural factors underlying perfect adherence in HIV treatment for the population of PLWH in Bahir Dar town and its surroundings. Specifically, core information, motivation, and behavioural skills factors in the model were well represented across participants' experiences.

While multivariate, theory-based models of adherence behaviour are of great interest, behaviour change theories and interventions are clearly constrained by a range of conceptual and contextual factors. Research is dominated in understanding why individuals fail to adhere, Thus far, exploration of the determinants of ART adherence has been dominated by the 'single-variable', predictive approach in studying only one or a small set of them. In many instances there has been an over-reliance and over-

investment in such studies with little parallel investment or strategic support being given to the development of well-tested, multivariate, conceptual models of ART adherence and hence the evaluation of such models is critical in the development of effective interventions. In recognition to as a response of this gap, the current study tested one such model, the Information, Motivation and Behavioural Skills (IMB) model of ART adherence. To this end, the current study findings afford additional insights and extensions in previously reported relationships in the IMB model of ART adherence literature. For example, information and motivation are not independent entities but are interrelated, and the right information when communicated in the right way can bring about the appropriate knowledge which results in belief and attitude change which are important processes to create the desired motivation.

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**UNIVERSITY OF SOUTH AFRICA  
Health Studies Higher Degrees Committee  
College of Human Sciences  
ETHICAL CLEARANCE CERTIFICATE**

**HS HDC/235/2013**

Date: 9 October 2013 Student No: 4325-293-1  
Project Title: Evaluation of the information-motivation-behavioural skills model of adherence to antiretroviral therapy in Ethiopia.  
Researcher: Dr Amsalu Belew Zeleke  
Degree: D Litt et Phil Code: DPCHS04  
Supervisor: Prof GB Thupayagale-Tshweneagae  
Qualification: D Tech  
Joint Supervisor: Prof YJS Mashalla

**DECISION OF COMMITTEE**

Approved

Conditionally Approved



**Prof L Roets  
CHAIRPERSON: HEALTH STUDIES HIGHER DEGREES COMMITTEE**

*For*   
**Prof MM Moleki**

**ACADEMIC CHAIRPERSON: DEPARTMENT OF HEALTH STUDIES**

PLEASE QUOTE THE PROJECT NUMBER IN ALL ENQUIRES

Date: 13-04-2014

To

The core processor

Amhara National Regional Health Bureau

Research and technology transfer process

Bahir Dar

Ethiopia,

***Subject: Applying for ethical review and clearance to conduct a study at FelegeHiwot referral hospital***

Dear Sir/Madam,

I am a public health student from UNISA currently working my thesis after I got ethical clearance for my proposal from the university last year, the ethical clearance certificate is attached with this letter.

My research topic is adherence to HIV medications. It is a quantitative study with an observational and cross-sectional study design and my data collection tool are two structured questionnaires. The study has no risks on the participants except that they give about thirty minutes to go through the structured interview or filling the questionnaires, neither does it have a direct benefit to them, but it will contribute for better knowledge of adherence issues and for designing a strategy to promote adherence to ART (Anti-Retroviral Treatment). The selected study site is FelegeHiwot referral hospital ART unit. The participants will be clients of fifteen years and above in chronic care and receiving ARVs( Antiretrovirals) from the hospital in regular basis.

This is all about the study information and you are welcome to ask me for further clarification. Thanking you in advance for the permission, I am

Dr AmsaluBelewZelege



Principal investigator

(With regards)



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Amhara National Regional State  
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Health Bureau

#T.C. me/9/ta/11/269  
Ref.No. 22/9/06  
ቀን 22/9/06  
Date.....

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ዶ/ር አምሳሉ በለው የደቡብ አፍሪካ ዩኒቨርሲቲ የ3ኛ ዲግሪ ትምህርት /ጤናና ሊትሬቸር/ ተማሪ ሲሆኑ " Evaluation of The Information-Motivation-Behavioural skills Model of Adherence to Antiretroviral Therapy in Ethiopia, " በሚል ርዕስ ላይ በጤና ድርጅቶች ላይ ጥናት ለማድረግ እንዲችሉ ጥናቱ ለሚከናወነበት መ/ቤት የትብብር ደብዳቤ እንድንጽፍላቸው በተጠየቅነው መሠረት ሥራ ሂደቱ የጥናቱን ሀጋዊነትና አስፈላጊነቱን በመመልከት አስፈላጊውን ድጋፍ ያገኙ ዘንድ ይህን የትብብር ደብዳቤ የጻፍንላቸው መሆኑ ታውቆ ለጥናቱ መሳካት የበኩላችሁን እገዛ እንድታደርጉላቸው እናስታውቃለን።

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ግልባጭ፡

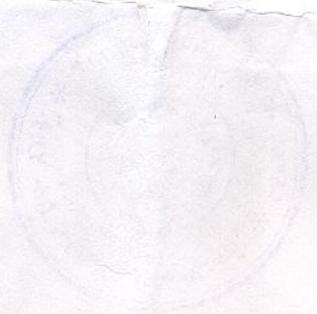
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CEO of FPHR, Inc. 2011



~~I have been thinking  
 about you a lot  
 and hope you are  
 well. I love you  
 and miss you.  
 Love,  
 [Signature]~~

**Consent form**

**Client Exit Interview/ Self- administered Questionnaire on Adherence to care for HIV/AIDS patients at Felege Hiwot referral hospital in Bahir Dar town**

*Questionnaire Identification* \_\_\_\_\_

*Date of interview* \_\_\_\_\_

*Time at the beginning of the interview* \_\_\_\_\_

**Introduction:** Hello, Madam/ Sir .My name is (\_\_\_\_\_).I work for (\_\_\_\_\_).We are conducting a study among clients who come to the health facility of Felege Hiwot referral hospital about factors that influence adherence to ART. The information collected will help the health institution to improve the quality of ART adherence counselling it provides to this health institution and elsewhere.

**Confidentiality and informed consent statement:** I am going to give a questionnaire/ask you questions about your adherence to ART. Your name will not appear on this questionnaire and all the information you provide to me will remain strictly confidential. You are not obliged to answer any questions that you feel uncomfortable with and you can put an end to this interview at any time, if you wish to do so. Your participation in this study does not involve any direct risk or benefit to you but is very important because your answers, as well as those of other participants will help to improve the services offered to you in this health sector and elsewhere. Would you like to participate in the study? [YES] [NO]

**Data collector:** If the answer is “Yes”, please let the participant sign below to certify that the client gave his/her consent to take part in the survey. Otherwise, thank the client, conclude the conversation and file the questionnaire.

\_\_\_\_\_

Signature of the participant

Result Code \_\_\_\_\_

1=Completed 2=Partially Completed 3=Refused 4= Others

Time at end of Interview/ completing questionnaire \_\_\_\_\_

Checked by -Supervisor Name \_\_\_\_\_



When using this measure, please cite it as: The LifeWindows Project Team. *The LifeWindows Information Motivation Behavioral Skills ART Adherence Questionnaire (LW-IMB-AAQ)*. 2006. Center for Health, Intervention, and Prevention. University of Connecticut.

### ***The LifeWindows Information-- Motivation -- Behavioral Skills ART Adherence Questionnaire (LW-IMB-AAQ)***

The LW-IMB-AAQ was developed as a measure of barriers to antiretroviral therapy (ART) adherence among HIV+ patients in clinical care, following the constructs identified in the Information--Motivation--Behavioral Skills (IMB) model of adherence (Fisher, Fisher, Amico, & Harman, 2006). The LW-IMB-AAQ was created for use within the LifeWindows adherence intervention software program, a computer-delivered ART adherence intervention that is currently being evaluated in a multi-site randomized clinical trial<sup>1</sup>. As such, it is important to note that the LW-IMB-AAQ will undergo continued evaluation and revision over the course of the LifeWindows project.

The LW-IMB-AAQ provides the LifeWindows intervention program with critical information about users' ART adherence-related strengths and weaknesses. The software program then uses that information to determine which specific intervention activities would be most relevant to a user given his or her specific constellation of adherence-related barriers. The user is then offered this targeted set of intervention activities and asked to select an activity that would be most helpful in improving or maintaining his or her ART adherence. Thus, each LW-IMB-AAQ item serves a dual purpose: quantifying information, motivation, and/or behavioral skills strengths and weaknesses, and signaling which specific IMB adherence-related deficits should be addressed in order for adherence to improve or most effectively be maintained.

In developing the LW-IMB-AAQ items, item content was targeted specifically to reflect barriers within the information, motivation, and behavioral skills constructs pertinent to the population involved in the LifeWindows project. It is likely, however, that the barriers reflected in the LW-IMB-AAQ will generalize across many HIV+ populations. Nonetheless, any applications of this measure outside of the LifeWindows project should take into consideration (a) the purpose for which the measure was developed— quantification of IMB based adherence-related deficits so as to direct participants to available intervention activities and (b) the target population for whom it was developed—HIV+ men and women in clinical care. It is also important to note that the measure is not intended for use as a comprehensive or generic measure of the IMB model of adherence constructs. Our preliminary analyses suggest that the LW-IMB-AAQ does provide an overview of adherence related barriers that generally fall within information, motivation, and behavioral skills areas, and can be used as a tool to quickly identify potential adherence related deficits in practical or real-world settings. The measure and its psychometric properties will be evaluated over the course of the LifeWindows project.

## **The LifeWindows Information-- Motivation -- Behavioral Skills ART Adherence Questionnaire (LW-IMB-AAQ) ITEMS**

**Note:** Each LW-IMB-AAQ item represents a barrier primarily falling within the I (Information), M (Motivation), or B (Behavioral Skills) constructs. When used with the LifeWindows ART adherence intervention software program, a 'critical zone' is superimposed for a range of response options for each item (reflected here as shaded and in red text). Responses within the critical zone are interpreted as signaling the presence of a deficit or potential deficit that then triggers the offering of intervention activities specifically developed to address the barrier reflected in the content of the item.

**I1** I know how each of my current HIV medications is supposed to be taken (for example whether or not my current medications can be taken with food, herbal supplements, or other prescription medications).

I strongly disagree

I somewhat disagree

I neither agree nor disagree

I somewhat agree

I strongly agree

**I2** I know what to do if I miss a dose of any of my HIV medications (for example, whether or not to take the pill(s) later).

I strongly disagree

I somewhat disagree

I neither agree nor disagree

I somewhat agree

I strongly agree

**I3** Skipping a few of my HIV medications from time to time would not really hurt my health.

I strongly disagree

I somewhat disagree

I neither agree nor disagree

I somewhat agree

I strongly agree

**I4** I know what the possible side effects of each of my HIV medications are.

I strongly disagree

I somewhat disagree

I neither agree nor disagree

I somewhat agree

I strongly agree

**I5** As long as I am feeling healthy, missing my HIV medications from time to time is OK.

I strongly disagree

I somewhat disagree

I neither agree nor disagree

I somewhat agree

I strongly agree

**I6** I understand how each of my HIV medications works in my body to fight HIV.

I strongly disagree

I somewhat disagree

I neither agree nor disagree

I somewhat agree

I strongly agree

**I7** If I don't take my HIV medications as prescribed, these kinds of medications may not work for me in the future.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I strongly disagree	I somewhat disagree	I neither agree nor disagree	I somewhat agree	I strongly agree

**I8** I believe that if I take my HIV medications as prescribed, I will live longer.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I strongly disagree	I somewhat disagree	I neither agree nor disagree	I somewhat agree	I strongly agree

**I9** I know how my HIV medications interact with alcohol and street drugs.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I strongly disagree	I somewhat disagree	I neither agree nor disagree	I somewhat agree	I strongly agree

**M1** I am worried that other people might realize that I am HIV+ if they see me taking my HIV medications.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I strongly disagree	I somewhat disagree	I neither agree nor disagree	I somewhat agree	I strongly agree

**M2** I get frustrated taking my HIV medications because I have to plan my life around them.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I strongly disagree	I somewhat disagree	I neither agree nor disagree	I somewhat agree	I strongly agree

**M3** I don't like taking my HIV medications because they remind me that I am HIV+.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I strongly disagree	I somewhat disagree	I neither agree nor disagree	I somewhat agree	I strongly agree

**M4** I feel that my healthcare provider takes my needs into account when making recommendations about which HIV medications to take.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I strongly disagree	I somewhat disagree	I neither agree nor disagree	I somewhat agree	I strongly agree

**M5** Most people who are important to me who know I'm HIV positive support me in taking my HIV medications.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I strongly disagree	I somewhat disagree	I neither agree nor disagree	I somewhat agree	I strongly Agree	No one that I care about knows I am positive

**M6** My healthcare provider doesn't give me enough support when it comes to taking my

medications as prescribed.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I strongly disagree	I somewhat disagree	I neither agree nor disagree	I somewhat agree	I strongly agree

**M7** It frustrates me to think that I will have to take these HIV medications every day for the rest of my life.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I strongly disagree	I somewhat disagree	I neither agree nor disagree	I somewhat agree	I strongly agree

**M8** I am worried that the HIV medications I have been prescribed will hurt my health.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I strongly disagree	I somewhat disagree	I neither agree nor disagree	I somewhat agree	I strongly agree

**M9** It upsets me that the HIV medications I have been prescribed can affect the way I look.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I strongly disagree	I somewhat disagree	I neither agree nor disagree	I somewhat agree	I strongly agree

**M10** It upsets me that the HIV medications I have been prescribed can cause side effects.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I strongly disagree	I somewhat disagree	I neither agree nor disagree	I somewhat agree	I strongly agree

**B1** There are times when it is hard for me to take my HIV medications when I drink alcohol or use street drugs.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I strongly disagree	I somewhat disagree	I neither agree nor disagree	I somewhat agree	I strongly agree	I don't drink alcohol or use street drugs

**B2** How hard or easy is it for you to stay informed about HIV treatment?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very hard	Hard	Sometimes hard, sometimes easy	Easy	Very easy

**B3** How hard or easy is it for you to get the support you need from others for taking your HIV medications (for example, from friends, family, doctor, or pharmacist)?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Very hard	Hard	Sometimes hard, sometimes easy	Easy	Very easy

**B4** How hard or easy is it for you to get your HIV medication refills on time?

Very hard

Hard

Sometimes hard,  
sometimes easy

Easy

Very easy

**B5** How hard or easy is it for you to take your HIV medications when you are wrapped up in what you are doing?

Very hard

Hard

Sometimes hard,  
sometimes easy

Easy

Very easy

**B6** How hard or easy is it for you to manage the side effects of your HIV medications?

Very hard

Hard

Sometimes hard,  
sometimes easy

Easy

Very easy

**B7** How hard or easy is it for you to remember to take your HIV medications?

Very hard

Hard

Sometimes hard,  
sometimes easy

Easy

Very easy

**B8** How hard or easy is it for you to take your HIV medications because the pills are hard to swallow, taste bad, or make you sick to your stomach?

Very hard

Hard

Sometimes hard,  
sometimes easy

Easy

Very easy

**B9** How hard or easy is it for you to make your HIV medications part of your daily life?

Very hard

Hard

Sometimes hard,  
sometimes easy

Easy

Very easy

**B10** How hard or easy is it for you to take your HIV medications when your usual routine changes (for example, when you travel or when you go out with your friends)?

Very hard

Hard

Sometimes hard,  
sometimes easy

Easy

Very easy

**B11** How hard or easy is it for you to take your HIV medications when you do not feel good emotionally (for example, when you are depressed, sad, angry, or stressed out)?

Very hard

Hard

Sometimes hard,  
sometimes easy

Easy

Very easy

**B12** How hard or easy is it for you to take your HIV medications when you feel good physically and don't have any symptoms of your HIV disease?

Very hard

Hard

Sometimes hard,  
sometimes easy

Easy

Very easy

**B13** How hard or easy is it for you to take your HIV medications when you do NOT feel good physically?

Very hard

Hard

Sometimes hard,  
sometimes easy

Easy

Very easy

**B14** How hard or easy is it for you to talk to your health care provider about your HIV medications?

Very hard

Hard

Sometimes hard,  
sometimes easy

Easy

Very easy

## SCORING LW-IMB-AAQ

### IMPORTANT NOTE

The scoring suggestions provided here are based on our preliminary work with the LW-IMB-AAQ. It must be emphasized that the measure is under continued evaluation in the LifeWindows project<sup>1</sup> and may be revised during the course of this multi-site randomized clinical trial. We provide suggestions for scale and sub-scale scoring, but strongly encourage all research utilizing this measure to carefully explore item covariances, scale structure, reliability, and validity when computing scale or sub-scale scores for their specific study populations.

### NOT APPLICABLE RESPONSE OPTIONS

Prior to scoring the LW-IMB-AAQ, M5 and B1's "not applicable" options must be reviewed. Depending on your sample, an M5 response of "No one that I care about knows I am positive" may represent a potential barrier (e.g., within the target population HIV disclosure to friends/family is common and nondisclosure could impede medication adherence) or may not indicate a potential problem (e.g., in the target population disclosure is uncommon and privacy regarding HIV status is the 'cultural norm'). Thus, based on the specific sample targeted, M5's n/a response might be appropriated rescored as 'strongly disagree' or 'strongly agree'. When such determinations are not possible, an alternative strategy is to use average scores for motivation and allow this item to be missing for those who responded n/a. For B1, participants may indicate n/a because they do not use drugs or alcohol. In practice, not applicable responses for B1 may represent the absence of a barrier and may be reset to the "strongly disagree" category without consequence.

### USE OF EACH INDIVIDUAL ITEM'S CRITICAL ZONES

Responses within the critical region indicate information, motivation, and/or behavioral skills deficits in the content captured by the individual item. Each item can be used individually as an indicator for the need for remediation of the deficit specified by the item. This strategy can have clinical utility, but it should be noted that because of high inter-item consistency in some of the subscales, multicollinearity will pose problems in statistical models that attempt to include certain sets of items as independent variables. Researchers should carefully evaluate that potential when assessing models that use individual LW-IMB-AAQ items. Additionally, while the adherence-related deficits represented in the LW-IMB-AAQ are likely to be applicable across diverse populations, the critical zones developed for the current measure was based on targeted elicitation work with the population involved in the LifeWindows project. Thus, it would be prudent for researchers to closely evaluate the extent to which the current measure's critical zones are appropriate for other specific study populations.

### CREATING SUBSCALES

Item sets can be used to quantify information, motivation, and behavioral skills strengths, or alternatively, weaknesses in regard the ART adherence. It is important to note that the resulting subscales are not intended to provide full representation of the IMB model of adherence, but do provide a brief measure of the level of informational, motivational, and behavioral skills deficits in the targeted population. The scoring strategies presented are based on our preliminary review of the LW-IMB-AAQ and primarily utilize a total score strategy (add responses across all items in subscale), although, as previously mentioned, an average score strategy could be instead (divide the summed responses by the number of valid items for each participant). Because the measure is under continued evaluation in the LifeWindows project, the measure and scoring suggestions and strategies may change over the course of the multi-site randomized clinical trial.

## INFORMATION

Scoring strategies suggested here create a scale that reflects strengths in ART adherence Information.

### TOTAL SCORE:

After reverse scoring I3 and I5, sum across all items to create a total score.

### ACCURACY SCORE:

Score only “Strongly Agree” to a value of 1 for all I items except I3 and I5. Set other for response values for those items to 0.

Score only “Strongly Disagree” to a value of 1 for items I3 and I5. Set other response values for those items are scored 0.

Sum across all items for a ‘total correct’ score. Our current research demonstrates an internal consistency for this scale that is expectedly low (.59), as information about diverse aspects of one’s ART regimen is not anticipated to be inter-related. According to our preliminary analyses, this accuracy score is best represented as a summed total score. Alternative strategies may include expanding the range of response options that would reflect a “correct” response (e.g., expand from Strongly Agree only to include both Agree and Strongly Agree). These alternative strategies are also under evaluation in our on-going LifeWindows project.

## MOTIVATION

### SCORING SUBSCALES:

Items designated with an M are used to quantify the motivation construct and to activate a potential motivationally based intervention in the LifeWindows program. Following the IMB Model of Adherence (Fisher et al., 2006), adherence-related motivation is comprised of personal and social motivation to adhere to one’s regimen. **Personal motivation** is represented as attitudes and beliefs about ART medications and one’s adherence to their specific ART regimen across situations and over time. Attitudes/beliefs about ART medications themselves are represented by items M9, M10, and M8, which represent the perceived consequences of these medications. Attitudes/beliefs about adherence are represented by items M1, M2, M3, and M7, each of which speak to the burden of adherence and its impact on daily life. **Social Motivation** is represented primarily by item M5. Additionally, items reflecting patient-provider relationship and collaboration (e.g., M4 and reverse score of M6) may represent another component of social motivation.

Preliminary data gathered from the LifeWindows project demonstrated an internal item-consistency of .70 for attitudes/beliefs regarding the burden of adherence (M9, M10, and M8) and .75 for attitudes/beliefs about the negative effects of ART medications (M1, M2, M3, and M7).

We are currently reviewing the most appropriate combination of the social motivation items. Preliminary results suggest a viable combination is summing M4 and M5 and representing social motivation as a single indicator item (sum of M4 and M5) or, alternatively, a strategy using M5 only as an indicator of social motivation has produced promising results.

Other M labeled items may be appropriately considered and combined depending on the target sample. Given the dual purpose of each M item (measuring constructs and flagging a need for intervention), it is likely that some items will perform better in one versus the other function and thus final analyses of the scale may not include all of the M items presented in the LW-IMB-AAQ.

**TOTAL MOTIVATION SCORE:**

If collapsing across all subscales and creating a total motivation score, where larger values reflect larger amounts of motivation towards adherence, items reflecting deficiencies (M1, M2, M3, M6, M7, M8, M9, M10) should be reverse scored prior to summing.

**BEHAVIORAL SKILLS**

**TOTAL SCORE:**

All B labeled items except B1 can be summed to represent a total behavioral skills score. Our preliminary work with LifeWindows project data suggests an internal consistency of .90 between these items. B1 appears to behave differently and does not share significant variability with the other behavioral skills items. B1 may be more valuable as an indicator of a barrier and need for intervention, but may also prove to be useful in explaining adherence for individuals who specifically use alcohol or drugs.

## REFERENCES

Fisher, J.D., Fisher, W.A., Amico, K.R., & Harman, J.J. (2006). An information-motivation-behavioral skills model of adherence to antiretroviral therapy. *Health Psychology, 25*, 462-473.

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### <sup>1</sup> **THE LIFEWINDOWS PROJECT: Changing ART Adherence Behavior**

**PI:** JD. Fisher

**CO-PIs:** KR. Amico, DH. Cornman, WA. Fisher

**Intervention and Measures Development Team Members:** KR. Amico, W. Barta, DH. Cornman, R. Ferrer, JD. Fisher, WA. Fisher, A. LeMieux, D. Portnoy, W. Norton, C. Redding, P. Shuper, Z. Strickler, C. Trayling

**Project Dates:** 9/19/03 – 6/30/07

**Region:** United States

**Research Area:** HIV Interventions – Medication Adherence

**Funding Agency:** NIMH

**Status:** Active

The questionnaire asks about the medications that you may have missed/ took with wrong time taking over the last three days

**Instruction: *please answer the three questions below.***

**Note: *IF YOU TOOK ONLY A PORTION OF A DOSE ON ONE OR MORE OF THESE DAYS, PLEASE REPORT THE DOSE(S) AS BEING MISSED.***

**Normally, how many doses do you take per day?**

.....

**How many doses did you miss in the last 72 hours?**

.....

**How many doses did you take with delay for > 2 hours in the last 72 hours?**

.....