

ART adherence in resource poor settings in sub-Saharan Africa: a multi-disciplinary review

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1.1 Introduction

Patient adherence¹ to Antiretroviral Treatment (ART) is an issue that is growing in prominence and generating a burgeoning interest with ART roll-out. In the absence of a cure, ART is the only available option that offers the possibility of dramatically reducing HIV/AIDS-related morbidity and mortality, while improving the status of people living with AIDS (hereafter referred to as “PLWHAS”). However, successful administration of this treatment depends on sustained and strict adherence to the prescribed regimens (Lewis *et al* 2006; MacNabb *et al* 2001; Mannheimer *et al* 2006; Mills *et al* 2006a; Nilsson *et al* 2006; Paterson *et al* 2000; Remien *et al* 2006). To achieve the beneficial outcome of suppression of viral replication, decrease in viral load, increases in CD-4 cell count, and improvement of the quality of life, ART requires near perfect adherence rates (as high as 95%) (Paterson *et al* 2000; Amico *et al* 2007; Nilsson *et al* 2006; Sarna *et al* 2005). Failure to observe this adherence threshold leads to treatment failure, disease progression and emergence of drug resistant HIV/AIDS strains (Poppa *et al* 2006; Nilsson *et al* 2006).

With the realisation of the central role played by adherence in the success of ART, there has been a proliferation of studies aiming to identify factors that influence such adherence. These studies have established that non-adherence rates range from 50%-80% in different contexts (Amico *et al* 2007; Remien *et al* 2006; Weiser *et al* 2003). A majority of these studies have been conducted in the more developed countries in the North, while studies in resource-poor settings such as sub-Saharan Africa (SSA) are limited. In addition, there is a disciplinary emphasis on medical and psychological approaches. Other social science perspectives are poorly represented in studies of ART adherence. In common with adherence to medical regimes for other diseases, studies on ART by medical and psychological scientists centre on the individual as an autonomous decision- making agent. While this work has provided invaluable information on the association between individual-level variables with adherence, it does not present a complete picture of the factors that are associated with ART adherence. The central argument for this study is that such an emphasis on individual-level factors is inadequate for ART adherence, because it ignores household-, community- and structural-level factors.

This study is a multi-disciplinary and multi-method literature mapping of factors associated with (non-) adherence to ART in resource poor settings in SSA. Although ART is a relatively new phenomenon in SSA, efforts to scale-up access has made tremendous strides. While attempts to have 3 million people on treatment by 2005 failed to reach its target, substantial achievements have thus far been registered such as an eight-fold increase in the number of PLWHAS on ART in SSA from 100,000 to 810,000 between 2003-2005, representing more than half of the number of people receiving HIV/AIDS treatment in low- and middle- income countries (WHO 2006).

The overall objective of this paper is to map out factors that affect ART adherence for PLWAS in sub-Saharan Africa (SSA). To achieve this aim, the study frames one methodological and three theoretical research questions:

- 1) What are the strengths and weaknesses of current methodologies for measuring adherence to ART, and how could they be improved?
- 2) What individual-level factors are associated with ART (non-)adherence?
- 3) Which are the household-, community-, and structural-level factors that affect (non-) adherence to ART?
- 4) What medical- or treatment-related factors contribute to (non-)adherence to ART?

¹ Adherence is defined as the extent to which a person's behaviour in terms of taking medications, following a diet and executing lifestyle changes-follows agreed recommendation from health care provider (WHO 2003)

The paper is structured as follows: Following an introduction and a brief description of methodology, section 2 is a review of the existing literature. The section outlines and discusses, development of research of ART adherence, methods for measuring adherence, theoretical models of health seeking behaviour and factors that influence adherence at the global level. Section 3 presents a case study of ART adherence in SSA, where qualitative and quantitative evidence on adherence factors is presented and a framework of adherence comprising of individual-, community- and structural-level factors is proposed. Section 4 discusses these findings, linking them with the literature review. Finally, section 5 concludes the study by summarising the main argument, case study findings and outlining the significance of the study and implications for future research.

1.1.1 Methodology

This study employs a systematic, multi-disciplinary and multi-method mapping of factors, at a range of levels (individual-, household-, and community-), associated with (non-) adherence. The process moves from a global review before narrowing down to SSA. The study also reviews methods for measuring ART adherence, and reviews and critiques various health seeking behaviour models that have been applied to adherence. The process involved a search of electronic resources such as Pubmed, Popline, Web of knowledge, International Bibliography of the Social Sciences (IBSS), using the keywords-adherence, compliance, ART, HAART, HIV/AIDS treatment, health and behaviour and (model or theory). Traditional academic journals such as AIDS, AIDS Care, JAIDS and African Journal of AIDS were utilized in the collection of secondary data, as was available government and NGO data sources. Finally, a hand-search of the reference lists of the articles selected was done to identify potential articles for inclusion. Relevant qualitative and quantitative articles were selected for this study.

2 Literature Review

2.1 Perspectives on Adherence

Adherence to medications has generated substantial amount of academic interest for both medical and social science researchers over the past few decades. The growth of interest in this topic has seen over 4, 000 articles on the topic listed on Medline alone by 1990 (Donovan and Blake 1992). This enormous interest can be attributed to the fact that a large number of treatment methods are self-administered by patients outside the clinical setting. For these people, therefore, following the recommendations of health professionals is essential to their recovery. However, studies estimate that about half of the patients on chronic diseases do not adhere to the treatment regimes prescribed (Ogden 2004; Stimson 1974).

The attention on this topic has also seen the associated terminology change from compliance to adherence. The idea of compliance is patients doing what they have been told by the doctor. In essence it is an act conforming, implying lack of patient participation (Trostle 1988). Conversely, adherence involves a mutual decision making process between the patient and the health care provider. In adherence, therefore, the patient plays an active role in the decision and commitment to follow the prescribed regimen (Population Council *et al* 2004). This change in terminology thus represented an effort to boost adherence by moving away from the authoritative directions to a more collaborative process between the patient and the health care provider.

There are two perspectives in the literature on compliance/adherence, namely medical-centred and patient-centred. The concept of compliance is an embodiment of the medical-centred orientation. The concept of compliance suggests a dominant powerful professional and a powerless lay patient.

The powerful health provider is seen as an authoritative figure who instructs and directs the lay patient, and the patient obediently carries out the orders (Ogden 2004; Trostle 1988). From this perspective, non-compliance is, therefore, regarded as deviant and irrational behaviour occasioned by ignorance and forgetfulness on the part of the patient. The bulk of studies on compliance have been done by medical scientists who invariably employ the medical-centred perspective. This perspective received support from Armstrong and Savage (19990, cited by Ogden 2004) study of the patients attending NHS facilities. The study found out that patients were more satisfied with the consulting style that was more authoritative than a sharing type of consultation. These findings suggest that, contrary to recent thinking, many a patient may prefer a doctor who gives a formal and directive diagnosis than the one who asks for their views. That said, recent research has shown that involvement of the patients leads to significant improvement in interaction and adherence outcomes (Marelich *et al* 2002).

The patient-centred perspective is the hallmark of adherence. This perspective views patients as active participants in their treatment (Donovan and Blake 1992). Patients get information about medication and other health related issues from a myriad of sources. To be sure, some of this information does, indeed, come from doctors and other practitioners. However, most of it comes from the general public, media, family members and, increasingly, through the Internet. It is therefore likely that doctor's or clinician's actions and prescriptions will be discussed and appraised in this broader network of support, with subsequent adherence decisions stemming from these consultations.

2.2 Antiretroviral Therapy adherence

A growing body of literature mainly from western countries has underscored the importance of adherence for the successful administration of ART. Already the WHO (2003) has identified adherence to ART as the most important issue. Adherence is defined as the extent to which a person's behaviour in terms of taking medications, following a diet, and executing lifestyle changes follows agreed recommendations from a health care provider (WHO 2003). In the case of ART this implies taking the drugs in the right quantities, at the right time, and following dietary and other lifestyle changes for a lifetime. To obtain a successful treatment outcome the current treatment for HIV/AIDS requires adherence levels of greater than 95% (Garcia *et al* 2003; Nilsson *et al* 2006; Paterson *et al* 2000; Sarna 2005). This required adherence rate is significantly higher than that required by other chronic diseases such as hypertension and diabetes, where adherence rates of 70%-80% are sufficient to attain treatment goals (Population Council *et al* 2004). But despite this elevated adherence requirement, studies have shown that non-adherence to ART is widespread. For example, Rao *et al* (2007) report that adherence rates for youth ranges from 27% to 41%. Similarly, Chesney *et al* (2000) point out that as many as 10% of patients miss a dose or more in a day, and that about 33% report missing a couple of doses in the past two to four weeks. On aggregate, non-adherence to ART is estimated at between 50-80% in different social and cultural settings (Amico *et al* 2003; Chesney *et al* 2000; Remien *et al* 2007).

Near-perfect adherence to ART is needed to keep the correct amount of the drugs in the bodies to fight the virus. With optimal adherence rates, studies have demonstrated that ART can suppress the viral load to undetectable levels, boost the immune system by increasing the number of CD-4 cells, and improve the quality of life of PLWHAS (Lewis *et al* 2006; Rao *et al* 2007). However, the virus is never completely eliminated from the body, and hence an inability to sustain a minimum 95% adherence rate has been associated with increases in the viral load (Garcia *et al* 2003). Non-adherence can lead to inadequate halting of the multiplication of the virus, continued damage to the immune system, progression of HIV/AIDS, and the development of drug resistance to ART medications (Population Council *et al* 2004; Family Health International 2007). To reiterate the significance of adherence, Lewis *et al* (2006) observe that a non-adherent patient is 3.8 times more likely to die than an adherent one who follows the same treatment.

Since its introduction about 10 years ago, ART has progressed from a single therapy, to double-therapy, and finally to the current combination therapy commonly known as Highly Active Antiretroviral Therapy (HAART). This development was necessitated by the desire to reduce the number of pills taken by the patient in order to foster adherence. This was borne out of the realization that adherence rates were inversely proportional to the number of pills, capsules or tablets necessary for treatment (Garcia *et al* 2003). Today, the standard ART treatment is a combination therapy consisting of two or three regimens, or a fixed drug where one pill contains multiple drugs. HAART can be grouped into three broad categories, namely, Nucleoside Reverse Transcriptase [NRTIS- e.g Zidovudine(AZT)], Nonnucleoside Reverse Transcriptase(NNRTIS-eg Nevirapine) and protease inhibitors-e.g Nelfinavir (Family Health International 2007).

One of the most significant developments in recent research on ART is the embracement of the patient-centred perspective. This perspective is discernible from the titles of the research papers where the term adherence has replaced compliance, thus denoting patient involvement in the treatment programme. However, a major problem with the current ART research is the use of medical and psychological models that focus on the individual aspects of the patient. Mackian (2003) has drawn our attention to the fact that the health behaviour models treat individuals as autonomous decision making agents. There is increasing concern that such models ignore the socio-cultural and structural context in which decision making process is made. This recent development has heightened the need for a multidisciplinary approach in order to gain a full picture of all adherence correlates.

2.3 Methods for measuring adherence to ART

It is imperative to note that, to date, there is no standard tool that has been developed to measure adherence to ART. That said, there are a number of tools that have been employed to assess levels of adherence. As a means of simplifying the process, Garcia *et al* (2003) grouped the tools into two categories: those that use information derived from the patient, and those that independently monitor drug intake. The rest of this section discusses the strength and weaknesses of these methods.

2.3.1 Self reports

Patient self-reporting is the most commonly used method for assessing adherence in PLWHAS. In this method, patients are asked to report on their own adherence through a series of questions. The recall period used could be four days, one week, one month or the most recent recall of missing a dosage (Population Council *et al* 2004). The most widely used tool for such self-reporting, especially in clinical trial research, is the Patient Medication Adherence Questionnaire (PMAQ) (Doung *et al* 2000; Garcia *et al* 2003). Most PMAQs have questions on social-demographic variables, family history, psychological variables, whether or not the patient missed a dosage for a reference point, and reasons for missing a dose (Garcia *et al* 2003; McNabb *et al* 2003). Therefore, in addition to establishing the level of adherence, PMAQs endeavour to provide the reasons for non-adherence. However, most of these reasons are sought from individual level socio-demographic or psychological variables, while far too little attention is paid to the social and structural level variables.

Self-reporting is clearly a simple and quick tool to use in a clinical or field research setting (Population Council *et al* 2004), especially in resource-poor settings. Nevertheless, there has been mounting concern about its accuracy in measuring adherence. Many studies have observed that self-reporting over-estimates adherence, as patients may report to be perfectly adhering when, in actual sense, they are not (Garcia *et al* 2003; Wagner *et al* 2001). It is on this basis that Wagner *et al* (2001) calls for health care provider verification of the adherence reported by the patient. They further posit that a patient's report of non-adherence is more accurate than the report of adherence. Conversely, Doung *et al* (2001) provides evidence that contradicts the widely held notion that self-reporting over-estimates levels of

adherence. Their findings indicate that for a short recall period of four days, the self-reported adherence rates correlated with adherence rates obtained from other measures such as the viral load monitoring. Consequently, the best way to improve the utility of self-reporting is to use a short recall period, and to ask about the entire medication intake rather than for each type of medication.

2.3.2 Pill counts.

Pill counts by the health care provider are another means of measuring adherence. In this method the patients are asked to bring their medications to scheduled visits, at which time the medications are counted by the health care provider (Poppa *et al* 2004). This method has the advantage of being simple, cheap, and objective in assessing adherence. However, it is fraught with several problems. First, the method relies on the patients to bring all their medications during visits. But studies have noted some phenomena of pill dumping or pill sharing on the part of the patients prior to their scheduled clinical visits (Population Council *et al* 2004; Wagner *et al* 2001). As a result, relying on this method may lead to an over-estimation of adherence. Unannounced pill count visits could help with boosting the accuracy, but could undermine patients' confidentiality, and is a more costly exercise to implement. A less controversial approach would be to analyse dispensing records for drug distribution which would allow a more formal means of flagging non-adherence.

2.3.3 Medication Event Monitoring System (MEMS)

MEMS is a method that uses an electronic device that is fitted on the lid of the medication bottle. This device records the time and date of opening and closing of the lid, which is assumed to coincide with intake of the medications (Poppa *et al* 2004; Population Council *et al* 2004). This information is downloaded by the computer software, which then provides a written report (McNabb *et al* 2001). MEMS has an obvious advantage of objectively allowing for the monitoring of drug intake and the intervals between doses. However, there are various problems associated with MEMS. First, MEMS is thought to under-estimate adherence because studies have shown that in the real world patients take out multiple doses at once to be taken at later times (Garcia *et al* 2003). Secondly, the method can be rendered useless if patients lose the lid or leave it off for any period of time. Most importantly, it is very expensive and its use is not feasible in resource constrained settings. To improve the effectiveness of this, patients need to be educated not only on how to use it, but also advised only to open the lid whenever they take out the number of medication needed for administration at that point.

2.3.4 Pharmacy refill tracking.

This method uses pharmacy refill data to gauge adherence. In this method, it is assumed that patients who collect their medications regularly are adhering to the treatment (Population Council *et al* 2004). For this method to work effectively, an effective record keeping system needs to be set up in the pharmacy. This method has the advantage of being a simple and an objective measure of adherence. Nevertheless, this method is not without pitfalls. For one, the assumption that collecting medications when due is equal to perfect adherence is erroneous as patients may not actually be taking them, could be sharing them with kith and kin, or pill dumping. In addition, the timing of the dosage can never possibly be known in this method. This method relies on good records, which is hardly the case in most poor parts of the region in question, where computers let alone power are largely non-existent in healthcare facilities. Finally, the method requires that patients use the same pharmacy for all refills (Ibid).

2.3.5 Biological makers

This method assesses adherence by monitoring the level of the viral load in the blood stream. Since the goal of HAART is to suppress the multiplication of the HIV/AIDS virus, low levels of viral load is an indication of adherence to the regimen. Despite this method being objective, and perhaps a state of the art way of measuring adherence, it has problems which renders it inapplicable in some settings. First, there is mounting evidence that shows that viral loads could still remain high even when the patient is adhering perfectly. This could be due to a number of reasons; among them treatment failure, ART drug resistance, and poor absorption of the drug (Wagner *et al* 2001; Population Council *et al* 2004). Of major concern is that viral load monitoring is a very expensive method, which may not be available in resource poor settings.

2.4 Models for Health seeking behaviour and ART

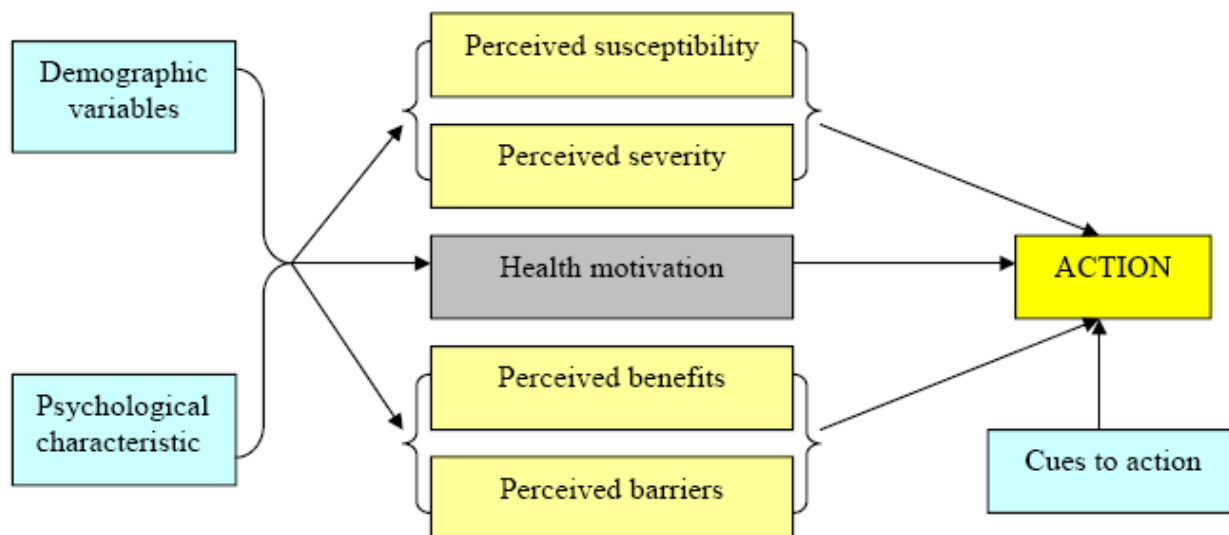
In the course of their studies, scholars have come up with different approaches and models to explain health seeking behaviour. Such models draw on social psychology, medical sociology and medical anthropology to explain factors that enable or prevent people from making health choices. Their basic assumption is that human behaviour is shaped by individual perception of the social environment (Mackian 2003). The Health Belief Model and the Theory of Planned Behaviour and information, both with their roots in social psychology, are the most widely used models in public health. The Health Care Utilization and the Four “As” Models are largely associated with medical anthropology and medical sociology. These models, as applied in public health, serve to identify variables that need to be considered in the research design rather than as behavioural models themselves (Hausmann-Muela *et al* 2003).

2.4.1 The Health Belief Model (HBM)

The HBM (figure 1) is one of the most widely used models in public health. Developed in the 1950s by Hochbaum and associates from the U.S. Public Health Service, it served to explain people’s participation in health screenings. Its aim is to predict whether or not people choose a healthy action in order to prevent or reduce the chance of disease or premature death. The HBM is used in health behaviour that can be grouped into 3 main categories: Preventative health behaviours, sick role behaviours, and clinical use (Mackian 2003). Some of the studies that have employed HBM include predicting behaviours such as risky sexual behaviour, exercise, eating sweet and fried foods, smoking and driving while intoxicated (Nejad *et al* 2005).

The HBM initially focused on 3 elements, namely: threat perception, behavioural evaluation, and socio-demographic and psychological variables. In its later evolution, health motivation and cues for action were added (Sheeran and Abraham 1995 in Hausmann-muela *et al* (2003). Threat perception is about beliefs on the impact and

Figure1: The Health belief Model



Source: Hausmann-muela *et al* (2003)

consequences of illness (perceived severity and susceptibility to illness or health problem); behaviour evaluation consists of perceived benefits of a health practise and barriers to it; health motivations refers to the readiness of the individual to be concerned about health matters; cues to action refers to internal and external factors, which influence action (mass media, family, illness symptoms) and finally, beliefs and health motivation are conditioned by individual socio-demographic and psychological characteristics (Munro *et al* (2007). Various studies can be identified as having utilized the HBM. For example, studies have found that in areas of endemic malaria the disease was not considered as a severe condition by those affected, and that mosquito nets were not seen as effective in the control of malaria because mosquitoes bite day as well as night (Hausmann-Muela *et al* 2003; Mackian 2003). This study used the threat perception and behaviour evaluation components of the HBM to help explain its findings. In terms of adherence, HBM would predict that an individual who believes that HIV/AIDS is severe, sees more benefits of ART than barriers, and has confidence in taking the pills even in difficult situations such as when drinking or using drugs, will adhere to the regimen.

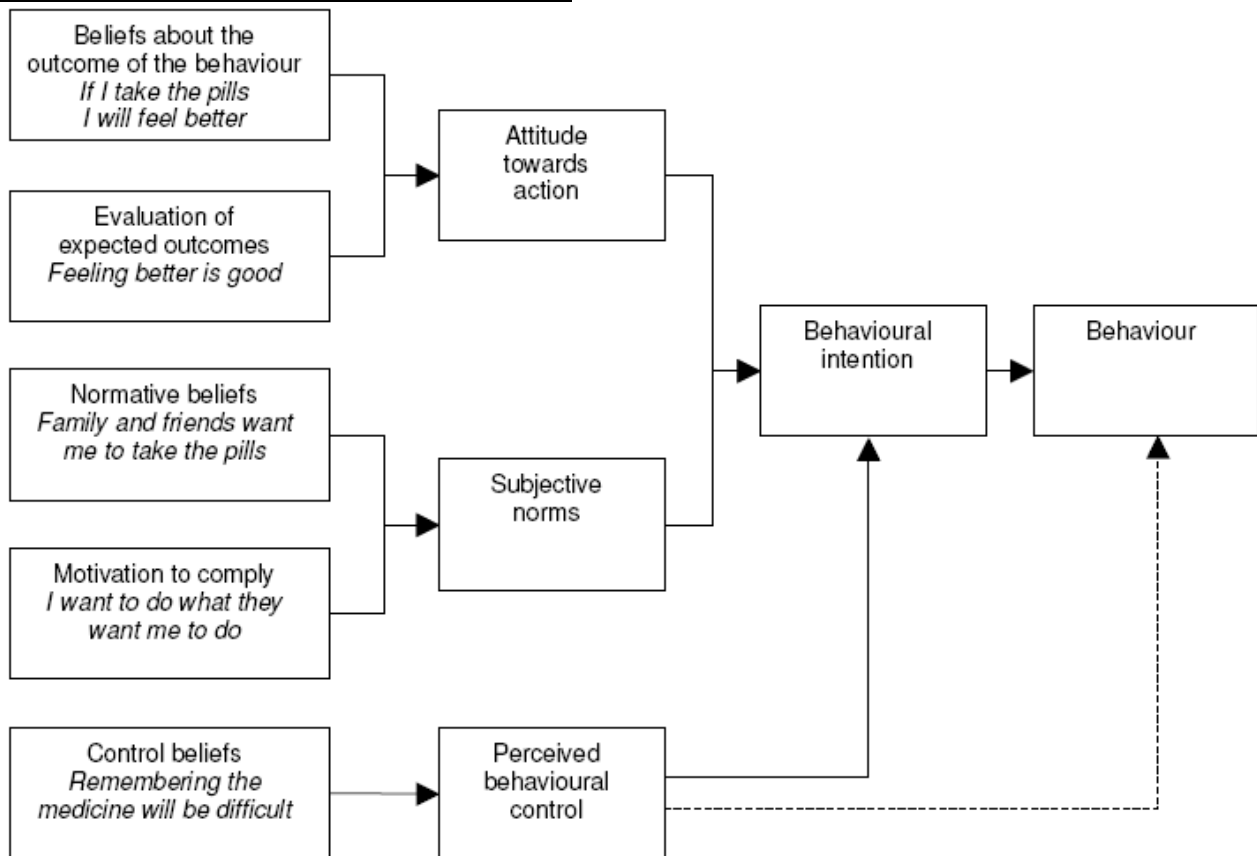
The HBM has, however, been subjected to considerable criticism. For instance, Munro *et al* (2007) observe that the relationships amongst variables in the model is not clearly spelt out. The assumption is that these variables do not moderate each other. For instance, if perceived seriousness is high and susceptibility is low, the model assumes that the likelihood of action would still be high when the reverse could be true. In addition, despite the fact that perceived severity, susceptibility, benefits and barriers are important, the theory neglects other factors such as social influence, previous experience, behaviour intentions and perceived control (Munro *et al* 2007; Noar 2007).

2.4.2 Theory of Planned Behaviour.

The Theory of Planned Behaviour (TPB) is an extension of the Theory of Reasoned Action (TRA). TRA was proposed by Fishbein and Azjen (1975 cited in Noar 2007). This theory postulates that an individual's behaviour is determined by one's intention, which in turn is determined by 3 main predictors: attitudes; subjective norms; and, perceived behaviour control. Attitudes in TRA refer to an individual's beliefs about the outcomes of his/her behaviour and an evaluation of the importance of such an outcome. Subjective norms refers to social pressure, that is, expectation of approval or disapproval of such an action by significant others (Nejad *et al* 2005; Armitage and Conner 1999). Behavioural control is an individual's belief in the availability of the requisite resources to accomplish an action such as information, abilities, dependence or independence from others etc. As an extension, TPB has four principal areas: attitudes towards behaviour; subjective norms; perceived behavioural

control; and socio-demographic variables. In this respect, we can see TPB (figure 2) as an extension of TRA with the addition of socio-demographic variables from the HBM. Perhaps the most important aspect of the TPB is the centrality placed on the role of social network support such as family, friends, partners, etc, and feelings of self-control and self-efficacy. Because of this, the theory has been used extensively in HIV/AIDS research and programmes (Hausmann-Muela *et al* 2003; Mackian 2003). TPB has been hailed by Armitage and Conner (1999) and Hausmann-Muela *et al* (2003) for taking into account the motivational aspects of personal (disease) control, and the role of social networks and peer pressure in health behaviour. However, it has been criticised by some scholars such as Munro *et al* (2007) for placing greater emphasis on psychological factors at the expense of structural and social factors such as limited access or availability of resources and stigma.

Figure 2: The theory of planned behaviour



Source: Munro et al 2007.

2.4.3 The Health Care Utilization Model (HCUM)

The HCUM (figure 3) was originally developed by Andersen and Newman (1973 cited in Hausmann-Muela *et al* 2003) to explore the use of biomedical health services, although it has been applied by Weller *et al* (1997) to utilization of traditional and home treatment. It groups the factors that influence health care utilization into three sequential factors: Predisposing factors, Enabling factors and Need factors(*ibid*). It defines these three areas as follows:

Predisposing factors: socio-demographic variables (age, sex, education etc); prior experience with illness; knowledge about illness; attitudes towards health service

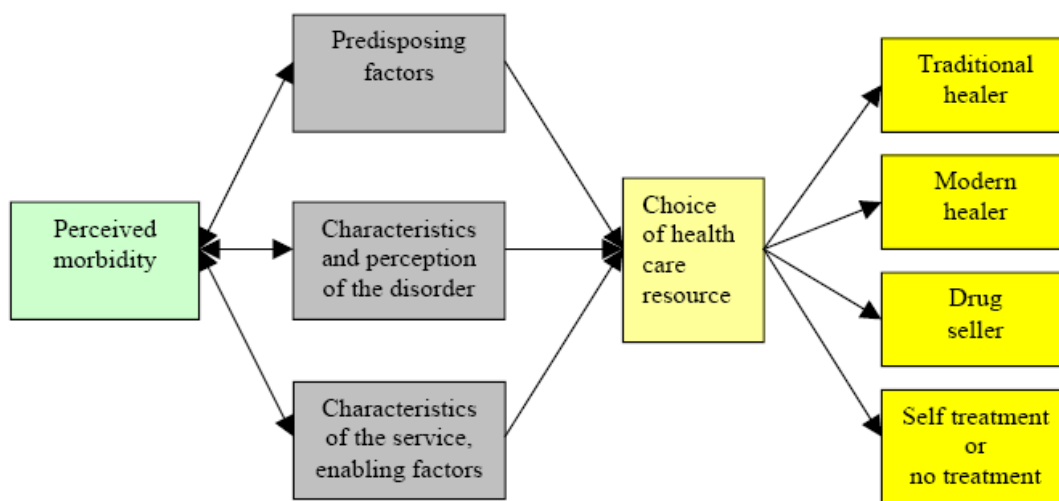
Enabling factors: availability of services, financial resources, health insurance, social networks

Need factors: perception of severity, duration of illness, number of days missed from work.

A later modification of this model by Kroger *et al* (1983) is the inclusion of health services system factors such as the structure of the health care system and its link to the social and political system, and characteristics of the health condition (severe or trivial, acute or chronic, etiological model etc). A

further addition by Weller *et al* (1997) is treatment actions, which include home treatment, over the counter drugs, traditional healers, and modern health services.

Figure 3: Health Care Utilization Model



Source: Hausmann-Muela *et al* 2003

The merit of the HCUM is that it provides a variety of factors that are organised in categories making therapeutic interventions feasible. However, it does not specify how and why different factors affect selection of treatment (ibid).

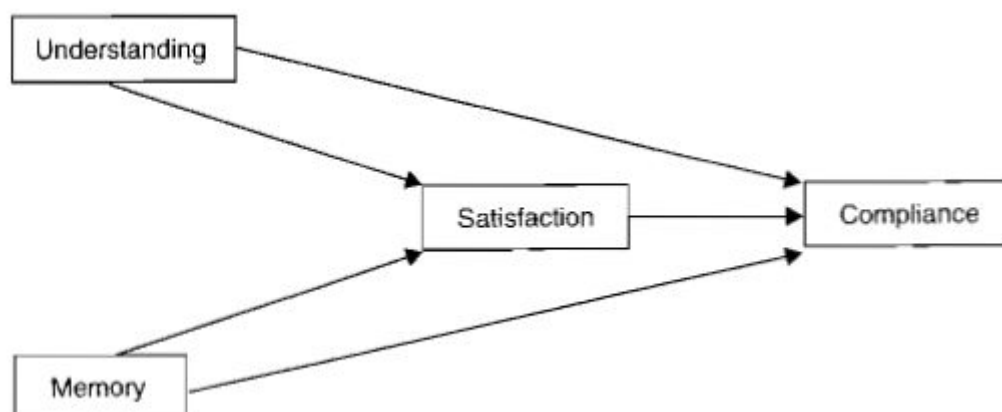
2.4.4 The Four A's

This model proposed by Good (1987 in Hausmann-Muela *et al* 2003) groups key factors of health seeking into four groups: Availability (geographic distribution etc); Accessibility (Transport etc); Affordability (of treatment costs .i.e direct and opportunity costs); and Acceptability(cultural and social distance etc). The emphasis of this model is on social, economic and geographical factors. However, it has been criticised by Mackian (2003) for placing too much emphasis on barriers to treatment at the expense of other health-seeking behavioural factors.

2.4.5 Cognitive Model of Compliance (CMC)

This cognitive model proposed by Ley (1989 cited in Ogden 2004) postulates that compliance is influenced and can be predicted by three factors: patients satisfaction with the whole process of consulting with the health care provider, the extent to which the patient understands the information provided by the healthcare provider, and the ability of the patient to remember the information provided (ibid). Figure 4 represents the relationship of these elements in the CMC model. It can be observed that this model considers a successful provider-patient relationship as the core element in the ability of the patient to follow the medical advice recommended. Indeed, research in the recent past has documented the importance of provider-patient interaction in facilitating positive health outcomes. For example, Duggan (2006) points out that a consultation that is characterised by the health provider's display of empathy, concern, respect and sharing, is associated with patient satisfaction and adherence. Berry *et al* (2003 cited in Ogden 2004) found that patients who received more personalised information showed greater satisfaction.

Figure 4: Cognitive model of compliance



Source: Ogden 2004

It is worthwhile to note that despite there being some debate in the literature about the implication of patient satisfaction, most studies suggest that patient satisfaction is associated with adherence (ibid). However, this model is too narrow. While it draws attention to the importance of the relationship between patient and healthcare provider, it leaves out a host of other factors such as social support, the disruptive nature of adherence on daily lifestyle, and the patients beliefs and attitudes in the efficacy of the medications (Coaley 1999 in Ogden 2004).

2.4.6 Information Motivation Behaviour Skills (IMB) model.

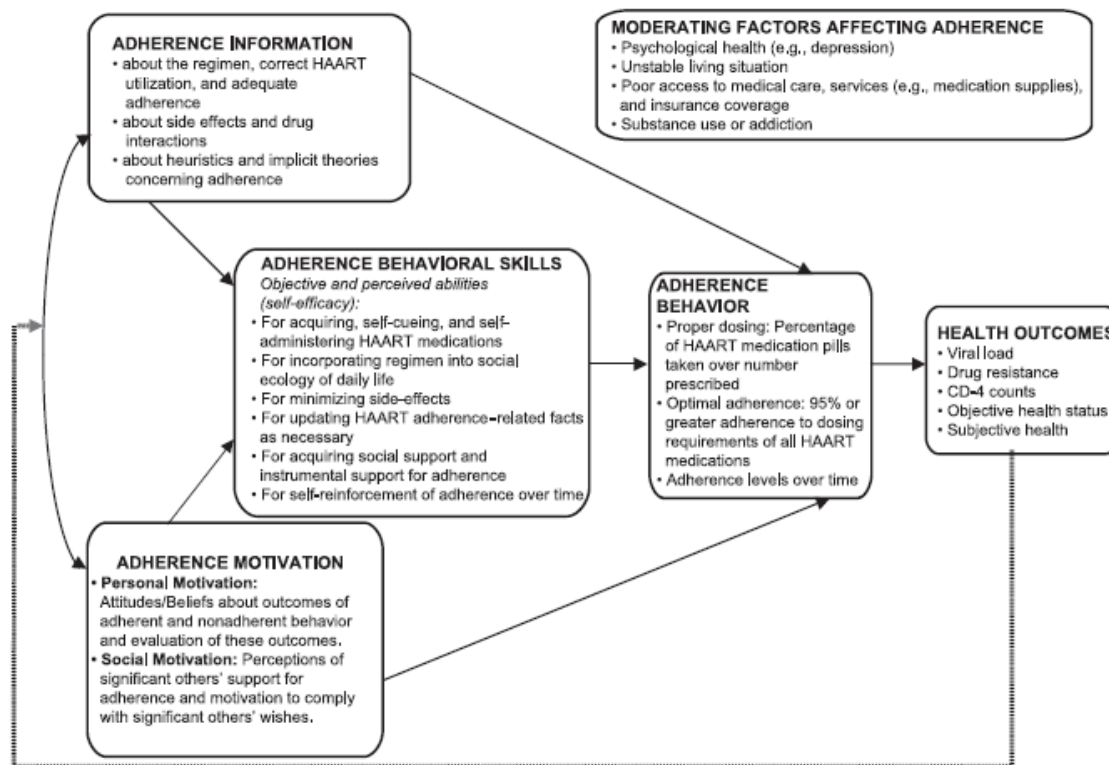
In an effort to move from a uni-variate focus of factors that affects adherence at the individual level to a multivariate analysis, Fisher *et al* (2006) have proposed an IMB model (figure5). The IMB model, which borrows heavily from other health seeking models such as HBM, TRA and TPB, has been used in a wide range of health related studies such as contraceptive use and HIV/AIDS prevention (Munro *et al* 2007). The IBM model posits that information, motivation and behavioural skills are principle determinants of health related behaviour (Amico *et al* 2005; Starace *et al* 2006). In terms of ART, this model holds that PLWHAS who are well informed, motivated to act and possess the behavioural skills that enable them to act effectively, will adhere to the ART treatment programme (Fisher *et al* 2006) . Conversely, a well informed, highly motivated person who lacks the requisite skills to acquire/take medications as prescribed, or lacks confidence in his/her ability to perform recommended medication intake would have problems with adherence(Starace *et al* 2006).

For PLWAS, therefore, adherence related information includes accurate information on particular regimens, correct ART intake and optimal adherence, and side effects associated with the regimen (Starace *et al* 2006). In addition, it could be inaccurate information such as the belief that skipping medication here and there would help the body to fight the virus on its own (Amico *et al* 2006; Fischer *et al* 2006). On its part, adherence-related motivation includes attitudes towards outcomes of adherence, perceived social support for adherence behaviour and the ability of the person to comply with the wishes of their significant others (Munro *et al* 2007). Behavioural skills, however, include such factors as the skills, tools and capabilities to adherence as well as the belief that they can effectively accomplish the adherence behaviour (Starace *et al* 2006; Munro *et al* 2007). Finally, this model states that the three components can be moderated by contextual factors such as living conditions or access to health services (Munro *et al* 2007; Fischer *et al* 2006).

One can observe that the IMB model has an advantage of being simple, and is promising as it isolated adherence related factors from other health seeking behaviour models. Given its recent emergence, not much has been done to evaluate its applicability and effectiveness in predicting adherence (Munro 2007). Nevertheless, this model can be critiqued up-front for not adequately dealing with social-cultural and structural adherence-related factors. For example, issues such as stigma associated with HIV/AIDS in many contexts in the developing world does have an impact on patient adherence to ART.

It can be observed that the health seeking behaviour model shares common and overlapping variables. Conversely, there are elements in these theories that are peculiar to certain models only. Table 1 gives a summary of these overlapping and peculiar factors in the health seeking behaviour models following this review.

Figure 5: IBM Model of ART adherence



Source: Fischer et al 2006

Table 1: Similar and unique features of health behaviour theories

Concept	HBM	TRA	TPB	4AS	HCUM	IBM	CMC
Attitudes	✓	✓	✓	✓	✓	✓	✓
Knowledge		✓	✓			✓	✓
Social norms		✓	✓	✓		✓	
Perceived threat	✓		✓		✓	✓	
Self efficacy	✓	✓	✓	✓	✓	✓	✓
Intentions		✓	✓			✓	✓
Satisfaction						✓	✓
Affordability	✓			✓	✓		
Accessibility	✓		✓	✓	✓		
Availability	✓		✓	✓	✓		
Demographics	✓						
Motivation	✓					✓	

2.5 Factors that influence adherence

There is little evidence of the causes of non-adherence to ART in resource poor-settings. Studies in resource rich countries have identified key factors to include: 1) patient-related factors such as psychological disorders(depression), alcohol and substance use (Bartlett 2002; Paterson *et al* 2002; Rao *et al* 2007), patient beliefs (Fergusson *et al* 2002; Lewis *et al* 2007; Remien *et al* 2003); 2) treatment related factors such as side effects (Bartlett 2002; Rao *et al* 2007), pill burden and complexity of regimen (Bartlett 2002; Chesney *et al* 2000; WHO 2004) and 3) doctor-patient relationship (Garcia *et al* 2003; Remien *et al* 2007; Nilsson *et al* 2006). A few studies done in resource-poor settings seem to suggest that financial constraints, such as the cost of medication, predominate the reasons for poor adherence (Hardon *et al* 2007). Studies done in resource-abundant settings shows that there is no association between individual socio-demographic such as age, sex and education, and ART adherence. As a result not many attempts have been made to investigate the effect of such factors in resource-limited setting. However, given the general low literacy levels in this part of the world, it is very probable that the inability to read the prescriptions will greatly undermine ones ability to adhere. This certainly calls for further research in order to disentangle the relationship between education status and ART adherence.

3 ADHERENCE IN SUB-SAHARAN AFRICA

3.1 Background

It is without doubt that sub-Saharan Africa (SSA) is the most affected region by the HIV/AIDS pandemic. Available statistics indicate that this region, which constitutes only about 10% of the world population, is home to about 65% of HIV/AIDS infected patients (UNAIDS 2006). The current figures indicate that over 24.5 million were infected by 2005, with 2.7 million being new infections. It is estimated that 2.5 million people died of the disease in 2005 (UNAIDS 2006). There are regional variations in the prevalence rates of the sub-Saharan epidemic. Southern Africa is the epicentre of this epidemic with prevalence rates ranging from above 25% in Zimbabwe, South Africa, and Botswana to as high as 35% in Swaziland. Western and Central African rates have consistently remained below 4%, with the lowest rate registered in Senegal (1%). As well, hope is provided by the steady decline that seems to be underway in two East African countries, Kenya and Uganda, as well as in Zimbabwe (UNAIDS, 2006).

Several factors have been suggested to account for these high rates of prevalence, which include among others: Poverty that may lead to high risk sexual behaviour (Buve *et al* 2002; Zulu *et al* 2000); presence of cofactors such as ulcerative STIs (Banertt and Whitesand 2002) and lack of male circumcision in some parts of the region (Ayuvert 2005; Caldwell 1995); and the nature of sexual mixing that is characterised by concurrent and intergenerational sexual mixing (Halperin and Epstein 2004). The region is also characterised by rural-urban differentials where urban rates are higher than rural rates to the order of about 3 (Dyson 2002), and gender differentials where women bear a disproportionate share of the burden (UNAIDS 2006).

In the absence of a cure for HIV/AIDS, anti-retroviral treatment represents the only available option to reduce HIV-related morbidity and mortality in SSA. Though access to ART has been low in this region, efforts are underway to scale- up availability. For instance, the 3 by 5 initiative by the WHO, in conjunction with UNAIDS, despite failing to meet its stated objective, ensured that about 1.3 million people in need gained access to the treatment in low- and middle- income countries (Hardon *et al* 2007). However, progress related to the expansion of ART has not been even throughout the region. According to the UNAIDS (2006), at least a third of the people in need in countries such as Botswana and Uganda are on ART, compared to 10% to 20% of those in need in Kenya, Malawi and Zambia. Despite there being an obvious unmet need in the region, access to ART has rapidly expanded in the

last 3 years. The 2006 UNAIDS report indicates that over 1 million PLWHAS were on the treatment by mid 2006, this represents a 10-fold increase since 2003. Furthermore, there is a new initiative towards universal access by 2010 mooted the G8 countries (WHO 2006).

3.2 ART Adherence Status in sub-Saharan Africa

There is paucity of studies on ART adherence in resource poor settings such as SSA (Byakika 2005). Thus the expected patient adherence rates commonly used are derived from studies performed in resource-rich countries. This could be due, in part, to the fact that much of the effort in the South has been devoted to providing access to those in need, rather than concerted efforts to study adherence rates. However, given recent roll-out initiatives, the challenge is changing from gaining access to maintaining adherence in order to realise the full benefits of reduced HIV- related mortality and morbidity, as well as improved quality of life (Sarna *et al* 2005). With this realisation, studies focused on the topic of adherence in SSA have begun, notably in South Africa, Botswana and Uganda.

These studies show varying rates of adherence depending on the time and place studied. One of the pioneer studies conducted by Weiser *et al* (2003) in three private clinics in Botswana found self-reported and provider assessment adherence rates of 54% and 56%, respectively. In another study done in Dakar, Senegal by Laurent *et al* (2002), the authors found that 78% of the patients were adherent while the optimal level of adherence was set at 80%. A similar adherence level was reported by a study conducted by Mukhtar-Yola *et al* (2006) in Amino Kano Teaching Hospital, Nigeria. This study found that 80% of studied patients achieved the optimal adherence level. A relatively lower adherence level of 66% was reported in a study conducted in Uganda by Byakika *et al* (2005). A meta-analysis of adherence studies done in sub-Saharan Africa and North America established an estimated 77% in Africa compared to 55% found in North America (Mills *et al* 2006a). This suggests that, contrary to expectations, adherence rates in Africa are favourable. However, with growing pill fatigue given increases in time of exposure, and with a move towards universal access that will bring people with adherence difficulties on board, it is unlikely that these favourable rates will persist.

3.3 FACTORS THAT AFFECT ADHERNCE IN SUB-SAHARAN AFRICA

This review of studies in SSA has identified factors that can generally be grouped into: Structural-level, treatment-related, community- and individual-level factors.

3.3.1 Socio-economic and community level factors

3.3.1.1 Cost of medication.

There is evidence in the pioneering studies on adherence in resource-poor settings to suggest that medication-related costs are one of the main barriers to ART adherence. For instance, a meta-analysis of 10 studies conducted in poor countries by Ivers *et al* (2005) found that the cost of treatment was a major obstacle to treatment. Studies conducted so far in sub-Saharan African show similar results. A study done by in Botswana by Weiser *et al* (2003), found that financial constraints presented a major obstacle. In this study 70% of the respondents identified the cost of ART to be a major problem and 44% thought that the cost of the treatment would affect their ability to adhere. As shown in table 2 those who said that cost was a barrier were 85% less likely to adhere than who did not identify cost as a barrier, and this was statistically significant at any conventional level ($P < .001$) in the uni-variate analysis. In the multivariate analysis when controlling for age, sex, education, disclosure, the related likelihood was 89% (adjusted odds ratio was 0.11) and $p < .001$ (Weiser *et al* 2003), meaning that the results were similar.

Table 2 . Predictors of adherence

Predictor	OR*		
	Adherence	95% CI	P Value
Cost a barrier to treatment	0.15	0.06–0.35	<0.001
Cost a problem	0.43	0.18–1.03	0.06
Incomplete secondary education†	3.87	1.21–12.40	0.02
Side effects a barrier to treatment	0.18	0.04–0.88	0.03
Disclosed HIV status to others	3.55	0.91–13.92	0.07

*Univariate unadjusted OR.

†Patients who did not complete secondary school compared with patients with higher education.

Source: Weiser et al 2003

Treatment costs include the actual cost of the drug, and this was observed to be a barrier in studies done in Uganda and South Africa respectively:

“Inability to pay for ART was the most important barrier to adherence to therapy. Patients who earned less than 100, 000 Ush(50 US\$) were 2.8 more likely to achieve less than 95% adherence”(Byakika-Tusiime et al 2005:40).

“My family an I ran out of money so I took medicines every other day to make them last longer” (ARV user south Africa, in Friedland 2006:S3).

Even when the drugs are given for free as is the case in some parts of the SSA, more general financial constraints may force people to sell their drugs as reported in the Kenyan newspaper. *“I know I should not do it because it interferes with my treatment. But when you have no food and your neighbour is willing to buy the medicine from you, what choice do you have but to sell the medication to them because they fear being seen going to Blue House?”* (Daily Nation, Saturday, March 17, 2007).

The cost also goes beyond the actual cost of the drug to include transport cost, registration cost and user fees. On transportation cost, a participant in a qualitative study observed:

“I have many people in the village. They are dying because they don’t have money to transport themselves to the hospital. You need to have this money monthly. Like me, from the village where I come from, getting up to this place costs Ushs 15 000 (US\$8.50). To and fro is Ushs 30 000 (US\$17), which is a lot of money...Right now only Lira Referral Hospital gives ARVs, and that is 130 km from our place (Kyoga). Very far!” (ART user, Uganda in Hardon et al 2006: 283).

Transportation problems are more than just bus fare in this part of the world. Lack of the means of transport to far away facilities is another problem that people have to contend with:

“I once missed my appointment for refill because there were no vehicles coming here. I was at the stop from early morning and by noon I went back home. Fortunately I still had some medications.” (Male ARV user, Botswana in Hardon et al 2007:660).

“Some people have failed to report to the clinic on time because they failed to get transport to reach the clinic. Some people come from the Islands, and they will tell you that they did not get money to cross the waters and they will tell you that is why they did not come on time. And when you are told that, you cannot do much but to hope that when the next visit comes, he can afford to come on time” (Health worker, Uganda in Hardon et al 2006:283)

3.3.1.2 Stigma and Disclosure

HIV/AIDS elicits stigma from society more than any other disease. Stigmatising attitudes and actions include discrimination, avoidance, ridicule, harassment and even forceful removal from homes (Rao *et al* 2007; UNAIDS 2005). In a study by Rao *et al* (2007) about half of the questionnaire respondents admitted to have faced stigma in one form or another. These excerpts in Hardon *et al* (2006:199) illustrate different forms of stigma meted towards PLWAS:

“I lost my job after my boss noticed that I was HIV - positive.” (Female FGD, Tanzania)

“I work in a drug store. I am told not to touch medicine because my hands have black spots and have been told that if customers notice, they will stop buying medicine from our store.” (Female FGD, Dar es Salaam, Tanzania).

The fear of stigmatisation may force PLWAS to hide their HIV status. For instance, Weiser *et al* (2003) found that as a result of stigma, 69% kept their HIV status secret from their families, and a further 94% kept it secret from their society.

“If I disclose I will be stigmatized. They look at us as if we are prostitutes. We are treated like leprosy patients.” (Male FGD, Dar es Salaam, Tanzania in Hardon *et al* 2006:199)

“Disclosure brings problems. You can lose business. Sometimes I am not invited to attend ceremonies because I have disclosed.” (Female FGD, Tanzania (*ibid*)).

Stigma and fear of disclosure may affect adherence in various ways:

‘I cannot take my drugs when people are seeing. I always go and hide when I take them. Otherwise, people start whispering about you all the time.’ (ARV user, Uganda in Hardon *et al* 2007:662).

“I usually miss my medications when I visit friends because I have not told them about my HIV and so I do not want them to see my medications.’ (Male ARV user, Botswana in Hardon *et al* 2006:112).

To cope with stigma and non-disclosure, some PLWAS take the medication under the pretext of treating their old conditions or different ailments altogether:

“She took her medication openly and explained that it was a contraceptive. Other participants who already had other medical problems that were known to members of the household explained that the medication was meant for this” (Skhosana *et al* 2006:20).

3.3.1.3 Social support

There is some emerging evidence to show that social support is vital in fostering adherence for PLWHAS on treatment. Social support is obtained from different sources such as partners, children, kiths and kin. These could help adherence behaviour by taking a leading role in reminding the PLWHAS to take the pills. For instance:

“My husband is HIV negative but he always reminds me to take my ARVs. My children also remind me.” (ARV user, Botswana in Hardon *et al* 2006:119).

“I once went to my mother and told her that I am taking life-long treatment and she accepted me. My husband also accepted me. He is the one who wakes me up to come for treatment.” (ARV user, Botswana) (*Ibid*).

Kiths and kin could also provide support by purchasing the necessary dietary requirements recommended for ART intake programme, thus:

“My children after seeing the state I was in and after getting ARVs, I called them and told them about my state. They got encouraged and as a result they buy me passion fruits and sugar because they know the drugs I am taking are so strong. I even wrote my file number in TASO on the wall and told them that just in case I am badly off they can go to TASO and get me help. My children know very well that my drug needs to drink enough and to eat on time....” (Female ARV user, Uganda in Hardon *et al* 2006:286).

“..They have been very supportive in my adherence ever since. Because I told my children that I take the drug on time they endeavour to rush to anyone who has a watch or radio and ask the time for me to take my drug. Telling them has helped me so much because of the comfortable relationship that exists between me and my children and neighbours.” (ARV user, FGD Uganda in Hardon *et al* 2006:287).

There is an indication that PLWHAS gain social support when they disclose their HIV status:

“I have told my family and if the time of taking medication comes they remind me.” (Male FGD, Tanzania in Hardon *et al* 2006:199).

3.3.1.4 Food and hunger

Studies show that there is an increased demand for food, especially at the initial stages of the treatment as the body regains strength Population Council *et al*(2004). The elevated demand for food may not be met by a section of PLWHAS in resource –poor settings as shown by the excerpts below:

‘The problem I have with ARV is related to food. I have no money and ARVs increase appetite. I am not capable of buying food.’ (Male ARV user, Tanzania in Hardon *et al* 2007:661).

Lack of food has been reported as one of these reasons that PLWHAS have cited for their poor adherence:

“I missed on Sunday because I could not find what to eat and yet I had to eat first before taking the tablets.” (Female ARV user, Uganda, (ibid).

“Some patients have expressed lack of food as a reason for not wanting to swallow the life-saving drugs. In fact we have one woman who has declined her life-saving drugs because she does not have enough food to feed herself” (Doctor, Uganda in Hardon *et al* 2007:661).

3.3.2 Medical or treatment related

3.3.2.1 Pill burden and drug complexity.

The current ART treatment consists of a treatment combination of three or more ARVs. This regimen could include up to 20 pills a day (Population Council *et al* 2004). Studies have shown that the higher the pill burden the lower is the adherence (WHO 2003). A study in Botswana by Weiser *et al* (2003) found that 30% of the respondents believed that they had to swallow too many pills per day. Another study in Senegal by Orell *et al* (2003) found that three times a day therapy was the strongest predictor of poor adherence in both univariate (odds ratio=5.58) and multivariate (odds ratio=2.57) analysis as shown in table 3:

Table 3 : Predictors of poor adherence

Variables	Univariate analysis		Multivariate analysis	
	RR	95% CI	RR	95% CI
Age	0.98	0.97–0.99	0.96	0.92–0.99
Baseline viral load (log ₁₀)	2.71	1.74–4.25	2.57	1.57–4.22
Dosing (three times a day)	5.58	2.96–10.52	2.64	1.23–5.66
Adherence (< 95%)	2.13	1.22–3.57	1.92	1.10–3.57
Antiretroviral therapy (two NRTI)	3.94	1.96–7.89	2.69	1.17–6.15
Tablets (> 10 a day)	1.85	1.08–3.16	1.11	0.57–2.17
Food restrictions	3.57	1.97–6.49	1.95	0.95–4.03

RR, Risk ratio; CI, confidence interval. NRTI, Nucleoside reverse transcriptase inhibitor.

Source: Orrell et al 2003.

The statement by one medic in one of the qualitative studies seems to corroborate the magnitude of the pill burden faced by the ART users:

“Sincerely, adherence is not a joke. Sometimes when people fail we feel it. But you have to keep pumping them about the importance of adherence. It can be worse when you have to combine ART with treatment for opportunistic infections.” (Doctor, Uganda in Hardon et al 2006:288).

In addition to the number of pills, ART users are required to take their drugs at the same times at regular intervals for life and follow dietary requirements. Some PLWHAS on the treatment have a problem with strictly following the treatment schedule as illustrated by the following excerpts:

“It is a problem to take the medicines at the right time every day” (female ARV user, Tanzania, in Hardon et al 2006:201).

“It is true you can forget taking drugs according to schedule but it is not good to exceed the recommended time interval by more than five hours.” (a male FGD participant Tanzania) (Ibid).

3.3.2.2 Side effects

ART treatment is known to cause some side effects to some patients. Some of the documented side effects include vomiting, nausea, anaemia, hepatitis, skin rashes, dizziness and hallucination (Laurent et al 2003; Rao et al 2007). A Botswana study by Weiser et al (2003) established that about half (51%) of the survey respondents reported experiencing one sort of side effects or another. As it can be observed from table 2, the relationship between side effects and non-adherence in the population was statistically significant at 5% level (P=0.003). The people who reported side effects were 82% less likely to adhere than those who had no side effects. Some of these side effects affected adherence in different ways as illustrated by the excerpts below:

“Sometimes when you drink them as you were told, they would burn you-have this burning sensation that could last up to two days. What is needed is to take a break for a while from taking. Sometimes during weekends I used to stop taking them. May be on Saturday stop for a while”(Female ARV user, Soweto, South Africa in Skhosana et al 2006:22).

“I had side - effects and decided to take medication only once per day.” (Male FGD, Tanzania in Hardon et al 2006:202).

“You fear to take the drug because of the weird dreams. You can see dead bodies and you are walking with them. You are in races struggling and many other struggles. It frustrates and soon you get fed up.” (ARV user, Uganda in Hardon et al 2006:289).

3.3.2.3 Provider-patient relationship

There is a growing recognition that a great deal of adherence hinges on the positive interaction between patients and their health care providers (Marelich *et al* 2003). The complexities of ART treatment require that patients are involved in their treatment decisions. This entails a frank and open discussion between the two parties. Patients need to be adequately informed about their treatment schedule and the importance of adhering to the treatment regimen. In turn patients need to communicate any side effects and other lifestyle inconveniences to the health provider (*ibid*). The specific needs and peculiar circumstances of PLWAS need to be given due consideration (WHO 2003). There are, nonetheless, cases where patient-provider interaction is less than perfect. There are instances where PLWAS are not provided with adequate information concerning use of ARVs as illustrated by the excerpts below:

“I was not informed of side effects and what will happen to me if I stop taking medication.” (Male ARV user, Tanzania in Hardon *et al* 2006:202).

“I don’t know, I have not been told of impending side - effects.” (Female ARV user, Tanzania, *ibid*).

In other cases the information is given albeit not in adequate measure:

“Even though initially we are given a lot of information, counselling is not adequate because it is only done once. Follow up at home should be done to find out if one is really taking the medicines” (female ARV user Botswana in Hardon *et al* 2006:119)

That said, there is also a substantial amount of good provider-patient interactions where PLWHAS are given adequate adherence information, thus:

“...my health providers have explained it to me. They told me to take them at the same time. Also told me some of the side effects I might get like dizzy, nausea, sometimes headache or diarrhoea” (ARV user, Uganda, in Ware *et al* 2006:S19).

“If side effects are very severe patients may stop medication, but due to continuous counselling and education we give them we advise to continue and most follow” (health worker, Tanzania in Hardon *et al* 2006:202).

3.3.3 Structural level factors

Qualitative studies have highlighted a number of structural problems relating to access and service provision that have potential to negatively impact on adherence. These factors include:

3.3.3.1 Provider-patient ratio

The scaling up of ART treatment in sub-Saharan Africa has occurred without a commensurate increase in the number of medical personnel, thereby exacerbating the already poor provider-patient ratio. This has translated into a number of problems. Firstly, the medical personnel are overworked:

“You overwork like this without even a break because there are too many people all coming one day and yet you are very few.” (Health worker FGD, Uganda in Hardon *et al* 2006:291).

“There is a lot work in this clinic we are overworked” (Nurse, Tanzania in Hardon *et al* 2006:204).

The workload on the hands of the health providers may lead to poor adherence because there would not be enough time for patient counselling. This issue is illustrated by the following excerpts:

“If the situation remains like this, doctors will be tired and the last patient will not be Attended to properly.” (Female FGD, Tanzania in Hardon *et al* 2006:205).

“You find 25 patients and only one person attending all these patients and he just tells you to go and collect your medication.” (Male FGD participant, Tanzania in Hardon *et al* 2006:198).

3.3.3.2 Health facilities

There are issues with health facilities in SSA that are potential obstacles to adherence. To begin with there is lack of adequate health facilities or services as illustrated by the excerpts below:

“I was registered to start ART clinic in Kilimanjaro Christian Medical Centre (KCMC) in Moshi a year ago. At that time there was no ART clinic near my village...

KCMC is very far from here, about 170 km away. Sometimes I do not have the fare to travel to KCMC, hence missing my doses.” (FGD , Tanzania in Hardon *et al* 2006:203).

“ART clinics should be increased and more private hospitals should also be included in the programme.”(key informant, Tanzania) (ibid).

Secondly, there is not enough room in health facilities that would allow for confidentiality. These ethnographic observations in Uganda and Tanzania respectively illustrate this:

“The public facility had no adherence counsellors and did not have adequate designated rooms/offices for counselling or for patients to discuss personal issues with the health workers. At times, the health workers have to try and locate a suitable room before they can start a counselling session or private discussion with a patient.”(Hardon *et al* 2006:292).

“Some of the health care facilities studied did not ensure adequate confidentiality for patients. The worst example of this was a situation in which three doctors were sharing one consultation room and consulting with three different patients at the same time. This can inhibit some patients from attending consultations or from communicating openly, and so impair adherence”.(Hardon *et al* 2006:121).

3.3.3.3 Medical supplies

Inadequate supply of ARV is a problem that health facilities contend with forcing PLWHAS to miss taking ARVs as required as shown in the ethnographic observation below:

*“However, it was learned retrospectively during the course of this study that ARV drugs were out of stock for a whole month in Arumeru Hospital, causing an interruption in treatment for ARV users. During the survey period, there was also a shortage of supplies of Triomune 40 at the Mt. Meru Hospital. When needed for dispensing during the clinic day, the hospital had to borrow supplies from Arumeru (Hospital)”.*Hardon *et al* 2006:206).

3.3.4 Individual level factors.

Studies in resource-rich countries have identified a host of individual level factors that affect adherence to ART. All these factors have been organised into an information, motivation and behavioural skills (IBM) model already discussed in the literature review section. Few studies done in resource-poor settings have similarly identified some of these factors as follows:

3.3.4.1 Patients beliefs

Evidence shows that patient beliefs about illness and the efficacy of the treatment affect adherence behaviour. A belief in the efficacy of HAART cultivates faith in the treatment regime (Mills *et al.* (2006b). A number of PLWHAS have developed faith in ART treatment as illustrated in the excerpts below:

“If you had seen me a few months ago I could hardly get out of bed. I was like this (showing the smallest finger). Now here I am. You cannot even believe it.”(ARV user, Botswana in Hardon *et al.*2006:118).

“My CD4 cell counts were down but after using ARVs now they have gone up. I’m not getting opportunistic infections.” (Male ARV user, Tanzania in Hardon *et al* 2006:197) .

The faith in the ART treatment motivates people to take the treatment:

“ARVs have improved my quality of life. If I stop using them I will die.”(ARV user, Tanzania) (*ibid*).

“I will continue taking them until I die. This is because I love my life but also my health”(ARV user, Uganda in Ware *et al* 2006:S20).

There are beliefs about the meaning of medications in people’s daily lives, which could undermine adherence. A number of people believe that medications are supposed to be taken only when one is ill, and/or to cure an illness for a short duration, not for life:

“One of the patients stopped the medicines because he was told that his viral load was undetectable, so he stopped taking his pills because he thought he was cured.” (Health provider, Botswana in Hardon *et al.* 2006:116).

“I don’t think it is realistic to take drugs or treat a disease until you die. Treatment should be for a limited time and the disease is treated and you don’t have it any more. So, now we have nothing to do. It is like a failure.” (Female FGD, Uganda in Hardon *et al* 2006:290).

3.3.4.2 Patient knowledge and information

Available evidence suggests that a good level of understanding about HIV/AIDS and awareness of the consequences of non-adherence are associated with good adherence (Fisher *et al* 2006). For example, understanding of the issues around HIV/AIDS such as what the CD-4 cells mean can enhance adherence as shown by this statement:

“My ARVs read 30mg and for Njeri, they are 40mg. Now we understand that there is a difference between our CD4 counts and we cannot take chances sharing medication with each other,” (Female ARV user in Daily Nation, Saturday, March 17, 2007).

It is, therefore, expected that misinformation and misconceptions about the treatment would compromise an individual’s ability to adhere. Indeed cases of lacking correct information are abundant, leading to some PLWAS sharing medications or not taking them correctly as shown by excerpts below:

“It only happened occasionally when some of us were too sick, then we would take some of her medicine. Some of us feared the backlash caused by the medication. We did not want to be full-time on medication because that meant we would be helpless. We did not know that we were making our situations worse,” (Female ARV user in Daily Nation Saturday, March 17, 2007).

“I was just told that I should take my medication every day...I had not been told to take my medication at the right time. For me I thought it was like any other medication” (Female ARV user, Soweto, South Africa in Skhosana *et al* 2006:22).

3.3.4.3 Patient forgetfulness.

The role of patient forgetfulness in contributing to non-adherence is an issue of considerable debate. As already mentioned, the patient-centred perspective on adherence points an accusing finger at the habit of forgetting on the part of the patients, while the patient-centred perspective discounts this. Similarly, evidence on this issue is mixed. On one hand, cases of PLWAS failing to take medication as required on account of being forgetful has been documented as illustrated below:

“Sometimes one forgets, just like now I was supposed to take them at nine. I will take them when I arrive at work; I make sure that I take them for the day” (female on treatment, Soweto, South Africa in Skhosana *et al* 2006:23).

On the other hand, PLWAS on treatment observed that forgetting to take medication is out of question, thus:

“My tablets, I never forget them. They are like my underwear (ARV user, South Africa in Friedland 2006:S3).

“The tablets and me are married. I drink them like nothing; they are not something I can forget. They are something that is in me. When you do something everyday it ends up a habit’ (male ARV user, Soweto, South Africa, Skhosana *et al.* 2006:21).

3.3.4.4 Alcohol and substance use

Alcohol use has been linked to non-adherence, especially in resource-rich settings. There is evidence of their use affecting adherence in SSA as well as illustrated below:

“Some of the patients who take alcohol end up forgetting to take their tablet or omitting treatment” FGD participants, Botswana in Hardon *et al* 2006:116).

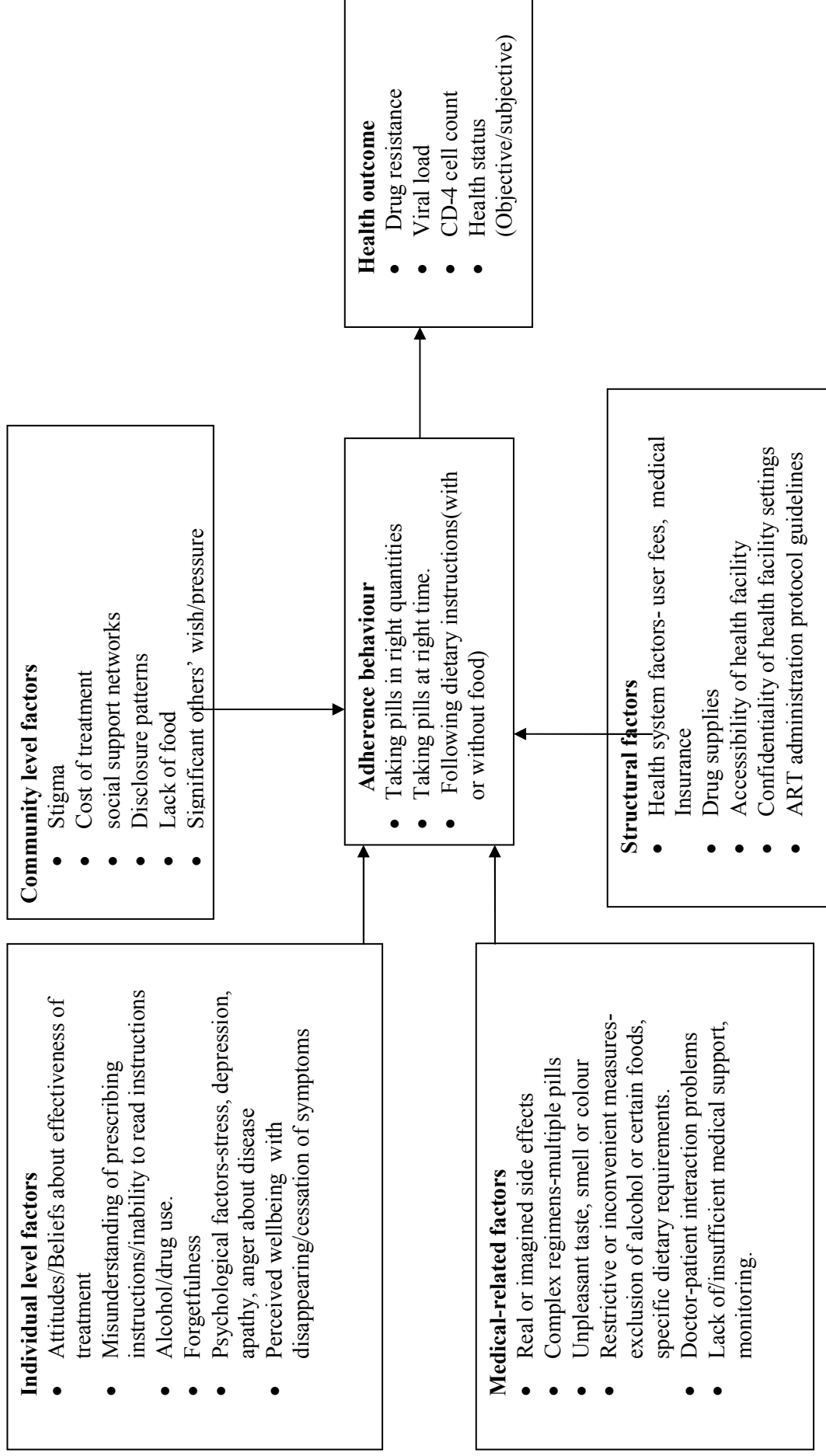
As a result of the problems associated with alcohol and smoking in as far as taking medication is concerned, some PLWAS report to have either quit or cut down on their consumption, hence:

“I no longer take alcohol because when one drinks one forgets to do what one is supposed to do” (male ARV user, Soweto, South Africa (Skhosana *et al.* 2006:21).

“My wife and I agreed that since this is our status we would have to mend our ways. I used to drink a lot but after I discovered my status I cut down my drinking. I stopped smoking. I am on treatment, but the only thing that really helps is quitting. If I was still drinking I doubt if I would still be alright. Alcohol makes one to forget to take meals, to take tablets...”(male ARV user, Soweto, South Africa)(*ibid*).

This study proposes the ART adherence model for SSA (figure 7) that takes into account the aforementioned factors.

Figure 7: Proposed conceptual model of ART adherence for sub-Saharan Africa



4 Discussion

This review has established that there is a general dearth of studies on ART adherence in sub-Saharan Africa. The bulk of studies on this topic have been done in the resource-rich countries in the North. This raises the issue as to whether the estimated rates are applicable to resource-limited settings. There has been growing concern that the PLWHAS who reside in this part of the world cannot achieve optimal adherence levels needed for the treatment. An USAID spokesman succinctly captured this when he said “*Ask Africans to take their drugs at a certain time of day, and they do not know what you are talking about,*” (Washington Post 2001 in Orell *et al* 2003:1370). Contrary to this expectation, emerging evidence from the few studies done this far suggests that adherence rates in sub-Saharan Africa are comparable to the North, if not better. For instance, Mills *et al* (2006) meta analysis of studies done so far found an average adherence rates of 77% in SSA compared to the 55% found in North America.

These findings might seem to suggest that fear of poor adherence in SSA could be unfounded. However, to make such a conclusion may not be entirely correct. It can be stated with some degree of certainty that until quite recently, access to the treatment in SSA has been the privilege of the relatively well- to-do segments of society. This is because a vast majority of the PLWHAS in this region has been acquiring the treatment by direct purchasing (Byakika *et al* 2005). But with the move towards universal access by 2010, which will ensure that the relatively poor patients with adherent difficulties gain access (WHO 2006), it remains to be seen if the high rates will be observed. Indeed, there is some emerging anecdotal evidence of poverty presenting some barriers to adherence in some parts of the region. It was, for instance, reported by one of the Kenyan newspaper, The Daily Nation of March 17, 2007 that poor patients in the Mathare Slums in Nairobi were selling HIV drugs given to them for free to buy food for their families.

It also has been established in this study that theorizing and conceptualisation of ART adherence is still at its infancy stage. This can be discerned by the fact that, to date, only one autonomous model of ART adherence-IBM model has been proposed and tested by Fischer *et al* (2006). To reiterate the dearth of a theory-based approach, Munro *et al* (2007) point out that out of the 7 randomized controlled studies on ART adherence, only 1 used an explicit theoretical framework. Few studies that have attempted to be theory –based, have adopted theories that have been developed to explain health seeking behaviour. Questions remain about the applicability of these theories to ART adherence. For one, most of these theories have been developed to explain specific short term behaviour changes such as quitting smoking or uptake of exercises (Munro *et al* 2007). Adherence to long term therapies such as HAART is, certainly, different from such behaviours. Indeed, ART adherence is a complex phenomena involving, not just taking the correct number of pills at regular sequences for life, but also involves executing some adjustment to some aspects of lifestyle (WHO 2003). There is, therefore, need for an autonomous theoretical framework that takes such matters into account.

To this end, the IBM model is, hence, an important step in the direction. Despite its merit in focussing exclusively on ART adherence, the IBM model, nonetheless, is similar to other health seeking models in that it places the individual at the heart of the attention. Consequently, much as this individual “rational perspective” approach may explain health behaviour in Western societies, it is inappropriate in non-western cultures. The African behavioural system is based on collectivism rather than individualism. In these settings, the

“...family and community are more central to the construction of health and well-being than the individual, even though the individual is always recognised as an important part of the cultural context. In these cultures, individuals are less likely to express themselves and less likely to articulate their level of well- being from the stand point of “ego” (the “I”). It is the state of well

being of the family and community that regulates how individuals measure their state of health”.(Airhihenbua and Obregon 2000:9).

It is in this light that this study has proposed a conceptual model that tries to underscore this complex context in which an individual is just one component. The conceptual model proposed in this study underscores the prominence of the community and structural level factors in influencing adherence to ART in SSA. The evidence in this study indicates that in SSA, in contrast to the West, where patient and treatment factors are central (Chesney *et al*, 2000), the social, community and structural factors such as the cost of treatment, stigma, and service provision infrastructure are central. These findings parallel those found in other resource-constrained settings. For instance, Safren *et al* (2005) found out that the cost of treatment was a major obstacle to ART adherence in Chennai, India. Similarly, Mukherjee *et al* (2006) study in Haiti found out that medication-related costs and lack of integration of HIV testing to other services such as Tuberculosis, sexually transmitted infections or women health services are responsible for non-adherence. The prominence of this factor could be attributed, for most part, to the fact that, in this part of the world, approximately half live below the poverty line (Sachs 2002). In addition, medical insurance schemes are not accessible by the majority of the populace in these locales. Therefore, the elimination of user fees on ART would greatly enhance access and adherence to the life-saving treatment. That said, it seems certain that financial obstacles will persist for sometime even when treatment is free of charge. It is likely that in these environments, PLWHAS will still have to contend with transport-related costs and/ or lack of means to far away health facilities. Perhaps, it would be imperative to give consideration to home-based care alongside initiatives for universal access. In addition, provision of food as part of the ART package for some segments of the society such as the rural and urban poor may be necessary to dissuade them from selling pills in order to buy food.

Stigma as a barrier to adherence has been shown in this study to manifests itself in either subtle behaviour or overt acts of discrimination, ridicule, harassment and violence. PLWHAS often face stigma and discrimination from their community, including their own family members. Fear of stigma may force PLWHAS to conceal their HIV status even to close members of the family. The failure to disclose leads to non-adherence as the PLWHAS have to hide when taking the pills. Stigma and discrimination associated with HIV/AIDS largely has its roots in the mode of its transmission and in the history of the epidemic. HIV is mainly a sexually transmitted infection, which first appeared among certain groups of people such as prostitutes and homosexuals. Consequently, HIV/AIDS has been associated with promiscuity and other improper sexual behaviour. The PLWHAS are, thus blamed for having contracted the disease or the infection is seen as a form of punishment for the person's immoral behaviour (Parker *et al* 2002). Not having a cure for this infection has exacerbated the situation. Therefore, anti-stigma sensitisation campaigns should be enhanced and sustained so that PLWHAS could get adherence support from the family and community.

Structural barriers to adherence that have been highlighted in this study include lack of capacity for the health system, inadequate laboratory and patient care infrastructure and lack of continued drug supply. Evidence was provided where the few numbers of the available medical staff could not cope with increasing demand from ARV users. ART treatment requires close monitoring from the health care providers in order to achieve optimum adherence. For instance, Sarna *et al* (2005) established that PLWHAS in Mombasa, Kenya, who were on directly administered antiretroviral therapy (DAART), a health facility-based monitoring mechanism, achieved better adherence levels. Lack of sufficient medical supplies means that patient follow-up and counselling is poor there by undermining adherence. There is, therefore, a need to train more health personnel and motivate them by providing better working conditions and terms of service.

Pilot studies have shown that routine ART follow-ups and counselling can be performed by trained community workers (Economic Commission for Africa, 2004), and hence, training more

community workers will ease the burden of medical personnel. The international initiatives such as the Global Fund for AIDS, Malaria and Tuberculosis, and Bill and Melinda Gates foundation should be sustained in order to guarantee continued supply of ARV drugs in this region.

This study has also highlighted treatment-related factors that influence adherence in SSA. Treatment-related factors include side effects, the number of pills and dosing frequency and provider-patient relationship. ART is known to have some side-effects, especially at the beginning of the treatment starting, but go away, for most people, after a short period (Population Council *et al* 2004). PLWHAS should be informed before hand about the possible side effects and how to deal with them before being put on the treatment. The findings show that some PLWHAS were well advised on this, while others were not. Yet there is good evidence that shows that an informative, sharing, and open patient- provider interaction is associated with good adherence outcomes (Duggan 2006; Marelich *et al* 2003). On dosing frequency, it was found that the more the pills, the less the probability of adhering. Combinations taken three or more times a day are more difficult to adhere to than combinations taken less frequently. Dosing requirements may also affect PLWHAS ability to adhere, particularly if there is need to take medication with or without food. Taking three doses a day may be more difficult to fit into day-to- day realities of living. It means that people have to carry along their pills to their work places, as they would be required to take a midday dose. Therefore, efforts to have once daily dosing available would greatly improve adherence.

Finally, this study has documented individual-level factors that affect adherence. One of the most prominent individual-level factor was the patient belief in the effectiveness of the treatment in achieving a good health outcome. The drug's efficacy is evaluated against its past performance. It was observed that PLWHAS "faith" in the ART to improve their well-being motivated them to continue with medication intake. It is highly likely that some PLWHAS will stop the medication if they were not to respond to treatment. Treatment failure may also lead them into revising the aetiology of the illness and seek alternative medication. Evidence is abound to show that people's etiological concepts affect their definition of appropriate treatment (Helman, 1994). The meaning of medication in people's life will affect adherence. The belief that treatment is taken only when sick, may make one to stop ART medication with the cessation of symptoms thinking that they are cured. Evidence of this happening was reported in this study where one ARV user stopped taking the pills when told that her viral load was undetectable. There is clearly the need for patient follow-up and monitoring, and support to counteract such from happening.

5 Conclusion

This study set out to systematically map the factors, at a range of levels (individual-, household-, and community-) associated with ART non-adherence in resource-poor settings, with a focus on sub-Saharan Africa, and develop a theoretical model thereof. To achieve this objective, the study framed four research questions: (1) What are the strengths and weaknesses of the methodologies used to measure adherence and could they be improved? (2) What individual-level factors are associated with ART (non-)adherence? (3) Which are the household-, community-, and structural-level factors that affect (non-) adherence to ART? (4) What medical- or treatment-related factors contribute to (non-)adherence to ART? This review has revealed that there is a disciplinary emphasis on medical and psychological approaches, rather than social science ones. It has been argued that the mainstream health-seeking behaviour models, with an emphasis on individual-level factors are inadequate for ART adherence, because they ignore household-, community- and structural-level factors. Therefore, the expertise of biomedical, behavioural and social scientists is required in order have a comprehensive conceptualisation of ART adherence factors.

The findings suggest that adherence in SSA is influenced by a whole range of level-community, socio-cultural, structural, treatment and individual factors. The study has revealed that unlike, in Europe and North America where individual- and treatment- related factors are important, community- and structural-level factors are central in sub-Saharan settings. In these locales adherence barriers go beyond the individual's ability because of social and structural forces. Such social and structural barriers that were identified in this study include cost of treatment, stigma, lack of food, access to health care, inadequate capacity of the health care system and lack of continued drug supply. Hence, the ART scale-up efforts should go beyond provision of free drugs to include issues of access, quality health care, stigma and food security. Such a comprehensive approach would ensure that ART drugs are taken properly and not shared with family members or sold. In addition to socio-structural factors, this study found that patient- and treatment-related factors- patient beliefs and knowledge, side-effects, frequency of dosing and pill burden, also play a role in influencing adherence. To this end, an informative, sharing doctor-patient consultation and adequate patient support, and availability of once-a day doss in this locale would go a long way in fostering adherence. Furthermore, the role of education needs to be investigated given the low rate of literacy levels in SSA.

This study has raised a number of important issues around ART adherence in sub-Saharan Africa. First, it has been observed that contrary to the wide expectations, ART optimal adherence in sub-Saharan Africa is accomplishable. Already, emerging evidence from the few studies completed so far indicate a favourable ART adherence rates that are comparable to other settings. But are these rates sustainable? Certainly, it is a massive challenge to sustain these adherence rates in the long-run because evidence from other settings shows that adherence rates tend to go down with the duration of exposure as treatment fatigue sets in. This challenge would be compounded further as more poor people with potential adherence difficulties access treatment with the scale-up efforts that are underway. Second, ART adherence theory-based approach is lacking. An autonomous context specific ART adherence theoretical conceptualisation is needed to guide effective interventions to improve adherence. Third, there is a dearth of studies on ART adherence in resource poor-settings. There is, therefore, need for a multi-disciplinary research on this topic in these contexts to, not only identify factors, but also relevant questions to be included on adherence measurement questionnaires. Finally, given the evidence that with optimal adherence, PLWHAS can live a healthy and quality life, there is need for research on their fertility intentions and (risky) sexual behaviour henceforth.

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