ADHERENCE BEHAVIOR AND THE IMPACT OF HAART ON QUALITY OF LIFE

OF UGANDAN ADULTS

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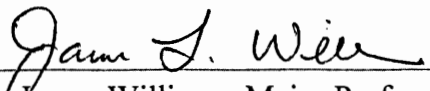DOROTHY JULLIET NANSIKOMBI KALANZI, B.A., MTS., M.S.

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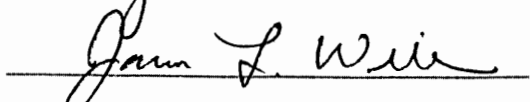
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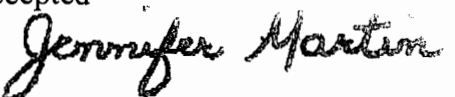
I am submitting herewith a dissertation written by Dorothy Julliet Nansikombi Kalanzi "Adherence Behavior and the Impact of HAART on Quality of Life of Ugandan Adults." I have examined this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for degree of Doctor of Philosophy with a major Sociology.

_____
Dr. James Williams, Major Professor

We have read this dissertation and recommend its acceptance:

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Dr. James Williams, Department Chair

Accepted

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Dean of Graduate School

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distress, thank you. This dissertation would not have been completed without your participation. Your input may contribute to improvements in the treatment of AIDS.

ABSTRACT

DOROTHY JULLIET NANSIKOMBI KALANZI

ADHERENCE BEHAVIOR AND THE IMPACT OF HAART ON QUALITY OF LIFE OF UGANDAN ADULTS

DECEMBER 2008

AIDS is no longer a death sentence due to the availability of highly active antiretroviral drugs (HAART) used to treat HIV. The international community is increasing access of HAART to low-resource regions. However, treatment failure and disease progression due to sub-optimal adherence are a public health concern. This study examines adherence behavior and the impact of HAART on perceived quality of life. Data utilized in this study were collected in 2007 and the sample is composed of 70 participants between ages 18 and 64 that were currently on HAART, who were selected using convenience sampling and were affiliated with three HAART providing centers in Uganda. Thirty seven percent of the participants were soldiers and 63% were civilians. The average years of schooling were 9. Fifty six percent of the participants were female. The median monthly income of respondents was $28. Eighty two percent of the participants began HAART after 2004. Some of the questions addressed include: How are individuals on HAART adhering to treatment? What factors influence highly active antiretroviral drug adherence behavior? What factors influence life style recommendations adherence behavior? What is the impact of HAART on perceived physical and psychological health among individuals undergoing treatment? Lack of

food was the major influential factor for skipping taking medication, and side effects had

the least impact on skipping taking medication. Gender power imbalances, economic

need and cultural beliefs increased adherence failure because they were a hindrance to the

regular use of condoms, having sex with only one partner, or having good nutrition.

The effects of HAART on perceived psychological health were reported to be somewhat

less as compared to physical health. In reference to physical health, respondents testified

of clinical gains. Although the majority of participants reported improvements in

psychological health, numerous respondents expressed continued feelings of anxiety,

fear, and loneliness. Theoretical and practical implications of the findings as well as

direction for future research are also discussed.

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CHAPTER I

INTRODUCTION

Robbins (2005) called HIV/AIDS the signature disease of the present age. For over twenty-six years, HIV/AIDS has affected tens of millions of people around the world (Morbidity and Mortality Weekly Report 2003). Two thirds of those affected by the virus live in sub-Saharan Africa (WHO 2006a). Currently, AIDS is no longer an automatic death sentence due to the introduction of highly active antiretroviral medications that enable those exposed to HIV to live longer and healthier lives (Wilson et al. 2002). Numerous studies pertaining to highly active antiretroviral therapy (HAART) adherence, the quality of life, and sexual behavior of those under treatment in the developed countries exist (e.g., Berg et al. 2007; Kalichman et al. 2001; Schonnesson et al. 2007; Weidle et al. 2006). However, although the greatest impact of the disease has been on developing nations, studies about the effects of HAART on individuals in low-income countries are few, which could be attributed at least partly to the fact that third world nations are only beginning to gain access to highly active antiretroviral drugs (Badri et al. 2002; Bunnell et al. 2006; Laurent et al. 2004; Weidle et al 2002; William et al. 2005).

Research Problem

The twenty-first century has seen an increasing effort on the part of the international community to scale up access to HAART in developing nations (UNAIDS

2006; WHO 2003). However, information on adherence, HAART effectiveness and its impact on the physical and psychological health of individuals under treatment is crucial, yet limited (Hardon et al. 2006; Moatti et al. 2003; Weidle 2002). The purpose of this study is to examine adherence behavior and the impact of HAART on perceived quality of life of Ugandan adults through the quantitative and qualitative analysis of data from 70 HAART clients at three treatment centers.

Significance of the Study

Increasing access to highly active antiretroviral drugs raises concerns of sub-optimal adherence in sub-Saharan Africa because many of the affected individuals are poverty stricken and they possess little or no formal education (Kalichman et al. 1999; WHO 2006). Failure to take highly active antiretroviral medications as directed by health care officials may lead to the development of resistant HIV strains (Berg et al. 2007; Kalichman et al. 2001; Rong et al. 2007). A review of the literature reveals only a few studies on HAART adherence in developing countries (Badri et al. 2002; Ferradini et al. 2006; Mills et al. 2006; Schwartlander et al. 2006). This study will help expand this very limited literature and it may provide additional data on adherence patterns of individuals under treatment in resource-limited countries.

Moreover, although the long-term effects are still unknown, it is well documented that since its introduction in the mid 1990s, HAART has enhanced the quality of life for those individuals that adhere to treatment regimens as seen in the West (Wilson et al. 2002). However, some studies reveal that poor medication adherence may enhance the severity of the impact of the disease (Berg et al. 2007). For example, Altice et al. (2007)

found that drug users in the United States have not had favorable outcomes from HAART partially due to poor adherence. Nevertheless, studies on the impact of HAART on the quality of life of affected individuals in resource-limited nations are still scarce (Bunnell et al. 2006). The findings from this study may increase knowledge in those areas.

Finally, the findings may also assist in the formulation of strategies and policies that may enhance HAART adherence and the quality of life for those under treatment in developing nations.

Setting

The data used in this study were collected in Uganda between July and August 2007. Uganda is about the size of the state of Oregon and it occupies an area of approximately 93,070 square miles with a 2007-estimated population of 31 million people (USDS 2008). In 2006, HIV morbidity in Uganda was estimated at 1.5 million people with over 135,000 new infections and the mortality toll was approximately one million people (AVERTing 2008; MOH-Uganda and ORC Macro 2006; Mugyenyi 2006). Researchers do not agree when HIV first occurred in Uganda, but they have speculated that although the first two cases of HIV were diagnosed in 1982, the first cases of HIV occurred soon after the 1978 –1979 civil war that deposed Idi Amin Dada's political regime (Buve et al. 2002; AVERTing 2008). HAART was first made available in Uganda at a cost in 1998 (Ministry of Health 2003; Mugyenyi et al. 2006). However few HAART providing centers existed by 2003 because the majority of those affected could not afford the high costs of highly active antiretroviral drugs at the time (Ministry of Health 2003; UNAIDS 2006c). It was after 2004 that a large number of marginalized

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Ugandans had access to free highly active antiretroviral drugs through public programs funded by organizations such as the World Bank, Global Fund, and the President's Emergency Plan for AIDS (PEPFAR) (AVERTing 2008; Mugyenyi et al. 2006). By 2006, Uganda had 175 centers that were providing free HAART to 75,000 of the estimated 190,000 individuals nationwide that were most in need of treatment at the time (AVERTing 2008; Hardon et al. 2006; WHO 2006d). The three centers that that participated in this study are located around the capital city of Uganda, Kampala and are: The AIDS Support Organization (TASO) at Entebbe, the Joint Clinical Research Center (JCRC) at Mengo, and JCRC at Bombo. HAART enrollment at TASO Entebbe center constitutes of about 1600 civilians. JCRC at Mengo has an enrollment of about 1600 civilians and that of Bombo is 1,000 soldiers and civilians. Although a few clients choose to travel from remote areas to access services at any of the respective centers under study, each center is obligated to serve individuals in a radius of about 75 km.

Differences Between US and Ugandan HAART Providing Centers

Although HAART providing centers in Uganda generally mimic those in the United States, several differences pertaining to the provision of services exist. To illustrate the differences, I will compare three HAART providing centers in Uganda with three centers in the US namely, the AIDS Services of North Texas (ASNT) in Denton Texas, 360: Positive Care Center in San Francisco California, and the HIV Center at Northwestern Memorial Hospital in Chicago Illinois (HIV CNMH).

The first difference is that HAART in Uganda only became accessible to the public in 2004 where as United States has been providing HAART for about 12 years

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(Hammer et al. 2006; TASO 2006). Also, HAART providing centers in the US and Uganda differ in terms of HAART recommended initiation time. Unlike in the US, HAART initiation in Uganda strictly follows the World Health Organization (WHO) guidelines and it is based on clinical and immunological assessments such as CD4 cell-count, and the manifestation of specific HIV/AIDS related illnesses (WHO 2003b; WHO 2008d). According to WHO (2004b), HAART in resource-limited nations may only be initiated under three conditions. First, WHO recommends that treatment be available only to individuals whose CD4 cell-count is 200 or below regardless of HIV disease progression stage (Daniels 2005; WHO 2008d). Second, individuals that have reached stage III of HIV that possess a CD4 cell-count of 350 or below and who have experienced any of the AIDS definitive illnesses like wasting syndrome, pulmonary tuberculosis, recurrent invasive bacterial infections, persistent mucosal candidiasis, chronic diarrhea or prolonged fever of unknown etiology can also access HAART (Daniels 2005; Laing and Hodgkin 2006; WHO 2004b). The third category of people that can access HAART in low income countries is those that have reached stage IV of the disease or who have been diagnosed with AIDS, irrespective of CD4 cell-count (WHO 2008d).

On the contrary, centers in the US follow Department of Health and Human Services (DHHS) guidelines for initiation of HAART. These guidelines recommend that all HIV positive expecting mothers and anyone with symptomatic HIV illnesses in the US should initiate HAART regardless of CD4 cell-count (Hammer et al. 2006; Sterling et al. 2003; Yen et al. 2004). In addition, DHHS recommends HAART initiation when one's CD4 cell-count is 350 or below, a count higher than that of individuals in

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developing nations (PAGAA 2008; Sterling et al. 2003; Wood et al. 2003). Asymptomatic HIV positive individuals in the US with a CD4 cell-count above 350 are discouraged from, but not prevented from starting HAART (Hammer et al. 2006).

Several reasons explain HAART access restriction guidelines both in Uganda and the US. In reference to resource-limited nations that strictly follow WHO's access guidelines, restrictions may pertain to forces of demand and supply for highly active antiretroviral drugs. For instance, WHO's goal is to treat everyone affected by 2010 (WHO 2004b). However, millions of individuals in developing nations have HIV and need access to free drugs. One of the problems is that these drugs do not cure HIV but they suppress its replication such that they must be administered for life once treatment is initiated (Hammer et al. 2006). WHO's dilemma is that highly active antiretroviral drugs are costly which limits their supply. Therefore, in order to reach WHO's 2000 access goal, it may be necessary to restrict access to these drugs, making them available only to those that need them the most in low-income nations- individuals in the last stages of HIV.

There are also several reasons that explain the DHHS recommended guidelines to initiate HAART. Prior to 1998, the DHHS recommended to treat anyone in the US infected with HIV regardless of clinical status, a policy referred to as the "hit early and hit hard" strategy established under the assumption that the virus could be eradicated with HAART (PAGAA 2008). However, these guidelines were revised after it was discovered that HIV cannot be cured and that treatment is a life long process (Hammer et al. 2006). This discovery was followed by public health concerns pertaining to drug side effects and

sub-optimal adherence. Sub-optimal highly active antiretroviral drug adherence is a concern due to the potential for the development of a drug resistant strain. Additionally, highly active antiretroviral drugs may have serious side effects. Equally important are concerns that studies regarding the long-term impact of these drugs on the quality of life for those under therapy do not exist (Laurence 2006b). In addition, starting treatment usually means significant adjustment in lifestyle such as changes in diet, complying with a complex treatment regimen, and so forth all of which may be challenging to the client that is obligated to take the medication for life, which may foster medication adherence failure (AIDSinfo 2008). In any case, it is important to realize that study results that associate the quality of life and HAART initiation time based on staging of the disease are inconsistent (Gao et al. 2000). Some scholars have demonstrated that disease progression is greater in persons that start HAART with a CD4 cell-count below 200 than in those starting therapy above this level (Garcia et al. 2004). However, Wood et al. (2003) compared benefits of HAART for individuals whose CD4 cell-count was between 200 and 350 with those of persons whose CD4 cell-count was below 200 and found that both groups equally benefited from treatment.

The Ugandan HAART providing centers and those of the US also take different treatment approaches. Although the Ugandan centers provide services such as the provision of highly active antiretroviral drugs, treatment of TB, and counseling services, they cannot provide all the needed services to clients that are available in the US due to financial constraints. For example, some of the opportunistic illnesses characteristic of individuals with advanced HIV like malignancies and skin rashes are manifested in

severe pain, but Ugandan centers can neither provide their treatment nor palliative care (USD 2007). All clients on HAART also need and are required by health care providers to access good nutrition (FAO 2002). However, although the majority of them cannot afford good nutrition, Ugandan centers cannot provide them with dietary supplements as seen in the US (WHO 2008b). Additionally, centers in Uganda also do not possess laboratory equipment for effective diagnostic tests such as those required for the CD4 cell-count and viral load. These functions are carried out by other organizations not affiliated with HAART providing centers.

US centers take a holistic approach to treatment as demonstrated by the 360: Positive Care Center (PCC) in San Francisco whereby 360 highlights the comprehensive services the center offers its clients (360:PCC 2008). Services provided by US HAART providing centers include diagnostic tests; provision of medical care and medication such as highly active antiretroviral drugs, laboratory and radiology services; medication services; outpatient surgical services; pain management; mental health counseling and treatment, physical therapy counseling; and comprehensive assessment and medical treatment for HIV and associated complications. Unlike Uganda, US HAART providing centers also offer social services that include referrals for assistance with community mental health, social support, housing assistance, disability services, nutrition, transportation, psychiatric care, and health insurance, and home health care coordination (360:PCC 2008; ASNT 2007; Northwestern Memorial Hospital 2008).

Because of the large numbers of low socioeconomic status individuals affected by HIV/AIDS in the US and in Uganda, many of the HAART providing programs are non-

government organizations that attempt to provide free or subsidized services to those in need within the local communities (US Global AIDS Coordinator 2008). Most of the HIV centers in both countries were founded in the late 1980s or early 1990s because of the delay on the part of the US government and world community in addressing the AIDS phenomenon after the first HIV case was diagnosed in the US in 1981 (Bongaarts 1996; Robins 2005; TASO 2006). Nevertheless, these programs expanded in size and efficiency over time. For example, JCRC and TASO Limited in Uganda are non-government organizations founded in 1991 that have grown in size over the years becoming the largest HIV service providers operating from numerous sites around the nation (TASO 2006; US Global AIDS Coordinator 2008). Currently, JCRC operates 35 centers nationwide that provide HAART to about 35,000 individuals (Mugyenyi et al. 2006). TASO Ltd. also operates 11 centers around the nation with a total enrollment of 63,431 HIV positive clients of which 14,089 were on HAART in 2005 (TASO 2006). The three centers under study are satellite clinics of the larger organizations.

Definition of Terms

The following terms and concepts will be used in the study.

1. Antiretroviral drugs (ARVs): Antiretroviral drugs refer to a class of therapeutic agents used to inhibit or slow the replication of retroviruses such as HIV. In so doing, ARVs slow the growth of the virus, and hence progression of the disease from HIV to AIDS (Last 2007). ARV drugs include reverse transcriptase inhibitors and the protease inhibitors (Concise Medical Dictionary 2007).

2. HAART: HAART is an abbreviation for highly active antiretroviral therapy and in this study it refers to aggressive treatment regimens used to suppress HIV viral replication and the progression of HIV disease, and the promotion of HIV healthy living behaviors such as good nutrition, abstinence, or protection during sexual intercourse. The usual HAART regimen combines three or more different drugs such as two nucleoside reverse transcriptase inhibitors (NRTIs) and a protease inhibitor (PI), two NRTIs and a non-nucleoside reverse transcriptase inhibitor (NNRTI) or other such combinations.

3. HAART Adherence: HAART adherence in this study is defined as how closely one follows a prescribed medication regimen as well as lifestyle recommendations. Adherence in this study is operationally defined by responses to questions that measure compliance to the providers' treatment regimens.

4. Life Style Recommendations: Life style recommendations in this study refer to abstinence from sex, or having sex with one partner, always using a condom, abstinence from alcohol, and having good nutrition.

5. Perceived Quality of Life: Quality of life is defined as the individual's perception of her or his physical and psychological well-being. Perceived quality of life in this study is operationally defined by responses to self-reported measures pertaining to an individual's perception of his or her physical and psychological health.

CHAPTER II

REVIEW OF THE LITERATURE

This chapter begins by addressing the origin, global distribution, impact, and treatment of HIV; followed by a discussion of adherence and its public health implications like treatment failure, disease progression, and increase in the infection rate. The chapter concludes with a discussion of factors that influence adherence, relevant theories and their limitations.

Global Distribution of HIV/AIDS

HIV/AIDS has been one of the most complex health challenges in the last three decades (Robbins 2005). AIDS is estimated to have claimed 25 million lives around the world, and it has been called the most destructive pandemic in history (Robbins 2005; UNAIDS 2006b). In 2005 alone, the virus claimed an estimate of 2.8 million people worldwide, of which 2 million lived in sub-Saharan Africa (Laing and Hodgin 2006). The estimated number of individuals infected with HIV worldwide is estimated to reach 100 million by 2010 and the cumulative loss of human life to the disease is expected to be 100 million by 2020 (USDS 2004). The disease was first diagnosed in the United States in 1981 (Bongaarts 1996; WebMD 2008). By the Millennium, HIV/AIDS had turned in to a pandemic that had spread across the corners of the world (UNAIDS 2006b). It is estimated that forty million individuals were living with HIV/AIDS in 2005 of which 95% percent lived in developing countries (USDS 2004). Although sub-Saharan Africa

represents 10% of the world population, about 70% of HIV cases are in this region (Mills et al. 2006; WHO 2006b). Recent statistics reveal that of the 14 thousand daily newly infected individuals worldwide, eight thousand live in sub-Saharan Africa (USDS 2004; WHO 2006b). HIV infects all ages, however, studies conducted in both developed and developing countries show that the most affected population group is that of ages 15 to 45 (Laing and Hodgkin 2006; UNAIDS 2006c; USDS 2006c). An increasing number of women of childbearing age worldwide are infected with the disease and in sub-Saharan Africa, close to 60% of adults living with HIV are women (Esu-Williams and Blancard 2002; Hammer et al. 2006; USDS 2004; WHO 2004). One of the public health implications pertaining to the increasing infection rate among females is the potential mother to child transmission of the virus during labor (Esu-Williams and Blancard 2002; Wainberg and Friedland 1998). Statistics indicate 1500 new infections daily in children under age 15 of which 90% occur in resource-limited countries like Uganda (WHO 2008).

Treatment of HIV/AIDS

Intensive research has led to important advances in HIV prevention and treatment (Crum-Cianflone 2006; Machtinger and Bangsberg 2008). The late 1980s saw the invention of antiretroviral drugs (ARV) that treat HIV (Hammer et al. 2006; Parella et al. 1998). Antiretroviral drugs control the virus by hindering its rapid replication and the destruction of CD4 cells, a process that fosters immune reconstitution (Deeks 2003; HIV Clinical Resource 2007; Laing and Hodgkin 2006). The US Food and Drug Administration has approved 20 antiretroviral drugs categorized into six classes:

Nucleoside/nucleotide reverse transcriptase inhibitors (NRTIs), Non-nucleoside reverse transcriptase inhibitors (NNRTIs), Protease inhibitors (PIs), entry inhibitors, fusion inhibitors, and integrase Inhibitors (AIDSinfo 2008; DHHS 2007; McNicholl 2007). The initial treatment of HIV referred to as antiretroviral therapy (ART) utilized one of the above drugs, but it was proved ineffective because of the high potential development of a drug resistant HIV strain (Yeni et al. 2004). A medical breakthrough in HIV treatment occurred in 1996 with the use of a combination of various drugs from the above different classes to effectively hinder the replication of the virus (WHO 2003). Treatment with two or more drugs per dose drawn from various classes is referred to as highly active anti-retroviral therapy (HAART) (AIDSinfo 2008; APHA 2004; Laing and Hodgkin 2006; Parella et al. 1998; Yeni et al. 2004). Most of the HAART combination drugs are drawn from three of the following classes: (NRTIs), (NNR-TIs) and protease inhibitors whereby each combination is referred to as a treatment regimen (GlaxoSmithKline 2008; Hammer et al. 2006).

Highly Active Antiretroviral Therapy and Quality of Life

Researchers agree that HAART has led to clinical gains like decreased morbidity from opportunistic infections, increased stamina, weight gain, and longevity for many that currently live with HIV as a complicated but manageable chronic illness (Gao et al. 2000; Gordillo et al. 1999; Laing and Hodgkin 2006; Palella et al. 1998). Statistical evidence reveals a decline of 38% in the AIDS incidence rate and 63% in the AIDS mortality rate worldwide between 1995 and 1998, a decline attributed to HAART (Berg et al. 2007; Garcia and Cote 2003; Harrigan et al. 2005; MMWR 2003; Ramirez and

Garcia 2003). For example, Lohse et al. (2007) refers to the "effectiveness of HAART against HIV as a medical success with evidence of a rise in the individuals' CD4 cell count and improvements in the physical and psychological well being of the patients." In a longitudinal study of HIV infected individuals enrolled in large multi-center antiretroviral clinical trials in U.S., Mannheimmer et al. (2005) also document significant improvements in the quality of life for those under therapy, especially in reference to the "biological health outcomes such as virological and immunological gains." Rowell and Shippy (2004) further show that participants' overall health, social function, mental health, and quality of life" significantly improved with HAART.

Studies pertaining to the impact of HAART on the quality of life for those infected by the virus in developing countries remain scarce, but the few extant studies reveal somewhat similar findings as those noted above (Bateganya et al. 2005; Bunnell et al. 2006; Moatti 2003). In a study conducted in South Africa, Jelsma et al. (2005) found improvement in health-related quality of life and increase in the survival rate for individuals that started receiving HAART after they were diagnosed with AIDS.

Access to Highly Active Antiretroviral Drugs

Although new medical innovations for controlling the virus exist, the majority of those that need HAART the most in resource-limited regions, including approximately 150,000 Ugandans, cannot access highly active antiretroviral drugs due to financial constraints (Laing and Hodgkin 2006; UNAIDS 2006c). The millennium began with the international community's mobilization efforts to provide and increase HAART access in these regions over a period of 10 years (UNAIDS 2006; WHO 2006b). For example, the

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President's Emergency Plan for AIDS (PEPFAR) was formulated in 2003 with a goal to provide treatment to about 2 million individuals affected by HIV/AIDS worldwide within 5 years (USDS 2004). Although it fell short of meeting its goal, WHO also introduced the 3 by 5 initiative in 2003 with an objective to "provide access to HAART to 3 million people in developing countries by 2005" (UNAIDS 2006; WHO 2006a). The United Nations member states scaled up these initiatives with a goal for every one affected by the virus to access highly active antiretroviral drugs by 2010 (WHO 2006b). In 2006, about 1.3 million individuals in resource-limited nations were taking highly active antiretroviral drugs (UNAIDS 2006b).

Public Health Implications of Adherence

Scaling up HAART access in resource-limited regions and the increased survival rate pose major public health implications that spring from sub-optimal HAART adherence like the emergence of a drug resistant HIV, disease progression, and increase in HIV infection rate, all of which undermine improvements in the international community's HIV control efforts (Munro et al. 2007; Redding et al. 2000).

Defining Medication and HAART Adherence

There is no standardized definition of medication adherence. However, researchers often refer to medication adherence as the extent to which patients take medications as prescribed by health care providers in terms of dosing, frequency, and timing; a definition adopted in this study (Machtinger and Bangsberg 2008; Park 1992; Park and Mayhorn 1996; Ramirez and Garcia 2003; Wainberg & Friedland, 1998). HAART adherence on the other hand refers not only to medication adherence, but also

following the health providers' lifestyle recommendations. Recommendations usually include the execution of lifestyle changes that include safe sex practices like regular condom use, being faithful to one sex partner and abstinence from sex, as well as good nutrition and refraining from alcohol use (APHA 2004; FAO 2002; Schmitt 2002; WHO 2003; WHO 2006b).

Degree of Medication Adherence Among Chronically Ill Patients

Researchers agree that effective treatment of HIV requires about 95% and above medication adherence, which is difficult to achieve especially when treatment is long-term as is the case for HIV (Garcia and Cote 2003; Hammer et al. 2006; Mannheimer 2002). Research is unclear about how to measure 95% adherence. However, Machtinger and Bangsberg (2008) indicate that 95% adherence is attainable by not missing 3 doses in a month. Although adherence studies are scarce, a few scholars reveal that sub-optimal adherence to HAART is common in all groups of treated individuals (APHA 2004; Machtinger and Bangsberg 2008; Munro et al. 2007; William et al. 2005). In Harrigan et al.'s (2005) study conducted in Canada, about 43% of individuals on HAART had an adherence level of less than 95%. In a study conducted in Spain, Carballo et al. (2004) found that 44% of the 235 participants on HAART had less than 95% adherence level. Various scholars indicate different adherence rates in the US, but the average is estimated at 70% (DiMatteo et al. 2002; Machtinger and Bangsberg 2008). Studies conducted in sub-Sahara Africa also reveal various HAART adherence levels (William et al. 2005). For example, Hardon et al. (2006) reviewed six quantitative studies in Africa and found that 65% to 99% individuals on HAART showed an adherence level of 95%. In another

study of 514 patients interviewed in Botswana, 23% of individuals indicated a dosage adherence level of less than 95% (WHO 2008b). The same study also found that 79% of the 207 patients interviewed in Tanzania were below the critical adherence level (WHO 2008b). Research further reveals that even when individuals do not miss a dose, they may fail to take medication at the exact appointed time (Williams and Friedland 1997). For example Melbourne et al. (1999) found that 50% of study participants with a 90% dosing adherence level took medication not at the exact time, but within two or more hours after the appointed time.

Adherence and Treatment Failure

One of the major public health concerns regarding sub-optimal medication adherence is treatment failure partially due to the development of a drug resistant HIV strain that cannot respond to treatment (Laing and Hodgkin 2006; Lohse et al. 2007; Lucas 2005; Patterson et al. 2000; Rong et al. 2007; Wainberg & Friedland, 1998; Wilson et al. 2002). The link between intermittent medication dosing or timing and treatment failure is supported by Bangsberg's et al. (2008) study conducted in San Francisco, which documents that the viral load doubles for each 10% decrease in adherence. Harrigan's et al. (2005) study conducted in Canada also reveals that individuals with a low concentration of antiretroviral drugs in the plasma due to sub-optimal adherence are more likely to develop drug resistant HIV strains as compared to those with high concentration levels.

In explaining the formation of a drug resistant HIV strain, it is important to understand that the purpose for treating HIV with highly active antiretroviral drugs is not

to cure, but to completely suppress the virus or halt its replication (Machtinger and Bangsberg 2008; Mills et al. 2006; UNAIDS 2006; WHO 2006a). Effective suppression of HIV requires a certain level of combination drugs concentration in the blood system to which the viral replication is exposed, a level which is maintained with 95% and above medication adherence (Descamps et al. 2000; Hogg et al. 2002; Laing and Hodgkin 2006; Lucas 2005; Machtinger and Bangsberg 2008; Paterson et. al. 2000). Less than 95% adherence causes treatment failure because drugs are continuously excreted from the body through the digestive system, kidneys and liver such that if not replaced in time the drug concentration level is diluted, giving the virus a chance to re-shape and replicate itself in resistance of drug detection (Descamps et al. 2000; Mills et al. 2006).

The process by which HIV changes shape is referred to as viral mutation and it is more likely to occur when the viral load is high as compared to when it is low (Laing and Hodgkin 2006). The re-shaped HIV is termed as the drug-resistant strain due to its potential to make drugs less effective at controlling it (Wainberg and Friedland 1998; Wensing and Boucher 2003). As the new drug resistant virus rapidly replicates itself, resistance to a particular drug also increases until the drug becomes completely ineffective in controlling the replication process (GlaxoSmithKline 2008; Wainberg and Friedland 1998). In that regard, specific drugs become ineffective creating the need for a new drug combination that can effectively suppress the re-shaped HIV (Laing and Hodgkin 2006). The problem is that resistance to one drug is frequently associated with cross-resistance to other members of the same class of drugs, which limits future treatment options (Deeks 2003; GlaxoSmithKline 2008; Hogg et al. 2002). This problem

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is compounded by the fact that multi-drug resistant viruses are transmissible (Hogg et al. 2002; Wainberg and Friedland 1998; Wensing and Boucher 2003; Wilson et al. 2002). For example, although it is unclear if transmitted drug resistant HIV was a result of adherence failure, at a public hospital in San Francisco very high rates of drug resistant HIV strains were found in recently infected individuals (Grant et al. 2002). This same study also looked at 225 untreated patients infected with HIV between 1996 and 2001 in San Francisco and found 25% to 27% resistance to one or more highly active antiretroviral drugs (Grant et al. 2002).

Sub-Optimal Adherence, Treatment Failure and Disease Progression

Another public health implication of sub-optimal adherence is disease progression and deterioration in the quality of life for those under therapy (Bangsberg et al. 2000; Munro et al. 2007). Treatment failure leads to a rapid replication of HIV and an increase in the level of the virus in the blood stream, which causes the rapid destruction of CD4 cells and disease progression from HIV to AIDS (Hogg et al. 2002; Machtinger and Bangsberg 2008; Vanhove et al. 1996). Machtinger and Bangsberg (2008) affirm that sub-optimal medication adherence is the second strongest predictor of progression from HIV to AIDS and death, after CD4 cell count. In Kitahata's et al. (2004) study, patients with low adherence had over five times the risk of disease progression as compared to patients with moderate to high adherence levels. Similarly, Hogg's et al. (2002) study correlated HAART adherence rates to viral suppression and disease progression.

Adherence to HAART Lifestyle Recommendations

Risk Free Sex Adherence Failure and Increase in the Infection Rate

Another public health implication of HAART adherence failure is increase in the

HIV infection rate that may result from an increase in the prevalence rate of sexual risk

behavior. Individuals under HAART are advised to engage in safe sex lifestyle behavior

such as regular condom use, having sex with one partner, or abstinence from sex (US

Global AIDS Coordinator 2008). Failure to adhere to safe sex practices is of public

health concern due to the potential of increasing the HIV infection rate especially in

developing countries like Uganda where the major HIV transmission mode is

heterosexual intercourse (APHA 2004; Essex and Mboup 2002; Tlou 2002; USDS 2007;

Wainberg and Friedland 1998; Wensing and Boucher 2003). As mentioned earlier,

highly active antiretroviral drugs do not cure HIV, but they suppress the retrovirus or

inhibit its replication to a point where HIV may be undetectable in the blood (Berg et. al

2007; Hammer et al. 2006; Laing and Hodgkin 2006; Mocroft et al. 2007). Even with an

undetectable viral load, memory T-lymphocytes with replication-competent HIV

continue to be present in a resting state and they may persist for many decades which

means that HIV positive individuals on HAART are still infectious (Deeks et al. 2003;

Hammer et al. 2006; Siliciano R. 2000). Information on the degree of transmissibility of

HIV from individuals with an undetectable viral load does not exist (Weinberg and

Friedland 1998). However, replication competent HIV from the secretions of patients on

HAART who have undetectable viral loads and transmission of HIV including the drug

resistant strain from HAART participants to uninfected patients have been documented,

and it is considered a growing problem in developed nations (APHA 2004; Wensing and Boucher 2003).

Failure to Adhere to Good Nutrition

Good nutrition cannot cure or suppress HIV. However, it is recommended because it contributes to a better overall quality of life since it helps boost the immune system's function, replace and repair cells and tissue, keep the body warm, carry out chemical processes such food digestion, and it helps to maximize the effectiveness of HAART (FAO 2002; San Franscisco AIDS Foundation 2007). Unfortunately, not everyone on HAART adheres to good nutrition. Some studies have revealed that individuals on HAART in low-income countries fail to adhere to good nutrition partially due to financial constraints (Hardon et al. 2007; WHO 2008b). Side effects like nausea, vomiting or diarrhea may also partially explain why individuals fail to adhere to good nutrition advice (Hardon et al. 2007). These conditions may make food intake difficult, modify the taste of food, lead to loss of appetite, and prevent the body from absorbing it (Moyer et al. 1999; San Franscisco AIDS Foundation 2007). On the other hand, good nutrition is essential because it may make conditions such as diarrhea and vomiting manageable and it may reinforce the effectiveness of the drugs (Brownell and Cohen 1995; FAO 2002). Diarrhea is sometimes a side effect of HAART and it leads to loss of water and minerals from the body, which loss is even greater if the person is vomiting (Brownell and Cohen 1995).

Factors Influencing HAART Adherence

Numerous studies attribute HAART adherence failure to illness and medication representation; complex treatment regimens in terms of frequency, dosing, timing and dietary expectations; psychosocial factors such as depression, alcohol use, social support; doctor-patient relationships; clinical setting; demographic characteristics; and other factors like stigma (GlaxoSmithKline 2008; Hardon et al. 2007; Munro et al. 2007).

Medication Representation and Adherence

Medication representation refers to beliefs pertaining to the effect of specific medications on a particular illness (Garcia and Cote 2003). Experiences with a particular medication may shape an individual's perception of that drug and its effects on a specific illness, and hence adherence behavior (Park and Mayhorn 1996). Numerous studies agree that if patients know the importance of the medication they are taking, they are more likely to remember taking it as opposed to those that have doubts about the same medication (Laventhal and Cameron 1987; Williams and Friedland 1997). As Park and Mayhorn (1996) put it, individuals who believe medications are effective in controlling an illness that interferes substantially with everyday life are more likely to adhere. Garcia and Cote (2003) also argue that how a patient perceives the seriousness of the disease and the degree to which she/he believes a given medication can control it affects adherence behavior.

Medication Representation, Side Effects, and Adherence

Scholars also agree that perception of medication as the source of undesirable side effects may influence adherence behavior (Berg et al. 2007; Giles and Brennan 2001;

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Hardon et al. 2007; Kalichman et al. 2001; Samet 1992). Park and Mayhorn's (1996) study reveals that individuals that believe usage of specific drugs results in side effects may reflect low levels of adherence, despite their trust in the effectiveness of the medication. A study conducted in Italy supports this argument by revealing strong correlations between medication side effects such as anxiety, fatigue, abnormal fat accumulation, nausea, anorexia, and insomnia and adherence to HAART (Ammassari et al. 2001). In another study conducted in India, Safren et al. (2005) also found that side effects were associated with irregular adherence behavior. A study of HAART adherence levels conducted in Uganda, Tanzania and Botswana, also revealed somewhat similar results (Hardon et al. 2007).

According to Ammassari et al. (2001), side effects are frequent in HIV positive individuals treated with HAART and they occur in 29% to 36% of the subjects, usually evidenced after 14 to 19 months of observation. All highly active antiretroviral drugs have side effects that vary by severity, drug, individual, and interaction with other drugs including alcohol (McNicholl 2007). Some of the side effects are severe or life threatening and may include liver problems, diabetes, high cholesterol, high levels of lactate in the blood, abnormal fat distribution, decreased bone density, and increased bleeding in patients with hemophilia (Laing and Hodgkin 2006).

Illness Representation and Adherence

Some scholars also argue that the more serious the disease, the higher is adherence because many serious illnesses result in pain, discomfort or unpleasant symptoms with a potential to become constant sources of anxiety and concern, acting as

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reminders to take corrective measures (Gao et al. 2000; Park and Mayhorn 1996; Williams and Friedland 1997). Illness representation and adherence association is important in resource-limited settings because based on WHO's access guidelines, individuals recommended to initiate HAART must have experienced serious opportunistic illnesses like tuberculosis, chronic diarrhea, prolonged fever, Pneumocystis and carinii pneumonia or their CD4 cell count must be 200 or less (Daniels 2005; Laing and Hodgkin 2006; Munro et al. 2007). Numerous studies associate prior history of opportunistic infections with HAART adherence failure (Gao et al. 2000; Gordillo et al. 1999; Singh et al., 1996).

Illness Representation and Failure to Adhere to Risk Free Sex Behavior Advice

Illness representation may also influence failure to comply with health providers' recommendations such as refraining from risky sexual behavior (Munro et al. 2007). Ramien et al. (2007) indicates that individuals on HAART tend to engage in risky sexual behavior with the belief that they are no longer infectious once on treatment. Similar studies conducted in high-income nations indicate that knowledge of an undetectable viral load or the "improved prognosis may cause people to become less afraid of infection and vigilant" leading them to engage in unsafe sexual practices (Lohse et al. 2007; Remien's et al. 2007). Schwartlander (2001) also found that risky sexual behaviors such as engagement in sexual intercourse with multiple sex partners and unprotected anal sex increased substantially in the United States for individuals on HAART. On the other hand, findings from a study by Crepaz et al. (2004) were mixed. Based on their study, heterosexual respondents receiving HAART were significantly less likely to engage in

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unprotected sex than untreated respondents even when their viral load was undetectable. However, this was not the case among men who have sex with men.

Few studies that link risky sexual behavior to HAART in developing countries exist (Krishnan et al. 2007). In Bateganya's et al. (2005) study, 35 percent of the 348 respondents on HAART in Uganda reported more than one sex partner. In another study conducted in India, a significant number of males on HAART did not utilize condoms (Krishnan et al. 2007). The same study also revealed that women on HAART expressed powerlessness to decide on safe sexual practices such as the use of condoms.

Complex Treatment Regimens - Number of Pills, Dosing Schedules, and Adherence

A complex treatment regimen in terms of the number of pills, dosing schedules, and dietary recommendations is another factor that influences medication adherence behavior (Machtinger and Bangsberg 2008; Mills et al. 2006; Moyer et al. 1999). HAART regimens may require intake of multiple pills several times a day whereby some pills must be taken on an empty stomach and others with food (Garcia and Cote 2003; Moyer et al., 1999; Weidle et al. 2002; Williams and Friedland 1997). Numerous scholars agree that taking antiretroviral drugs twice a day, usually taking multiple tablets per dose is a challenge and influences medication taking behavior (Bartlett et al. 2001; Laing and Hodgkin 2006; Laurence 2006a; Machtinger and Bangsberg 2008). Boyle et al. (2005) studied 219 patients in New York and found that, "treatment with a once-daily regimen led to higher rates of adherence than treatment with twice-daily regimens in an ambulatory urban cohort". According to Williams and Friedland (1997), disruption of one's lifestyle in reference to dosing scheduling and dietary recommendations also

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influences adherence behavior, whereby those with the greatest degree of lifestyle disruption are less likely to adhere.

Complex Treatment Regimens - Dietary Needs and Adherence

Dietary needs especially in resource-limited settings also influence adherence behavior. Some medication must be taken on a full stomach and HAART health care providers recommend good nutrition, however, most of those infected with HIV in Africa lack food security due to financial constraints which in turn influences adherence (Hardon et al. 2007; WHO 2008b). For example, a study conducted in Uganda revealed that people would stop taking medication because they could not afford to buy food to eat while taking the drugs (WHO 2008b). In a study conducted in South Africa, Abah et al. (2005) also found a link between access to food and adherence failure. Similarly, in Hardon's et al. (2000) study absence of food caused some participants on a twice a day dosing regimen to take their antiretroviral drugs only once a day.

Depression and Adherence

Clinical depression also influences adherence probably due to feelings of hopelessness, social isolation, fatigue, and impairments in cognitive focus (Ammassari et al. 2001; Cook et al. 2004; Dimatteo et al. 2002; Farinpour et al. 2003; Gordillo et al. 1999; Singh et al. 1996). DiMatteo et al.'s (2000) meta-analysis study showed that depressed people had three times the risk of low adherence behavior as compared to those who were not depressed. In a study conducted in Spain, Carballo et al. (2004) found similar results. In another study that was also conducted in Italy, Ammassari et al. (2001) found a link between non-adherence and depression. Studies conducted in the US reveal

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that clinical depression affects about 20% of individuals living with HIV/AIDS (Komiti et al. 2003).

Alcohol Use and Adherence

Alcohol may cause individuals to forget taking medication, reduce appetite, and it may deter the effectiveness of highly active antiretroviral treatment (FAO 2002; Hardon et al. 2006; Haubrich et al. 1999; Moatti et al. 2000; WHO 2008b). In Paterson's et al. (2000) study, patients' use of alcohol was significantly associated with less than 95% adherence. Halkitis's et al. (2008) study also associated mind altering drug use in the United States with low levels of adherence. Alcohol use may also foster engagement in risky sexual behavior such as failing to remember to use a condom, engagement in unplanned or casual sexual intercourse.

Social Support and Adherence

Furthermore, scholars highlight social support or the presence of other individuals in a household as an influential factor in adherence behavior (Machtinger and Bangsberg 2008; Munro et al. 2007; Park and Mayhorn 1996; Singh et al. 1999; WHO 2008b; Williams and Friedland 1997). Gordillo's et al. (1999) study reveals that individuals with social support are more likely to adhere to medication than those without support. Holzemer et al. (1999) also shows that sero-positive persons with a low sense of social support are less likely to adhere to medication regimens, health advice, and they are unable to keep health appointments than are people with a higher sense of social support. Failure to disclose one's serostatus for fear of being stigmatized may be a reason for lack of social support (Hardon et al. 2007). In a study conducted in South Africa, Abah et al.

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(2005) found that highly active antiretroviral drug users sometimes find it difficult to disclose to family members, which denies them access to adherence support.

Doctor-Patient Relationship and Adherence

Numerous studies also associate patient-provider relationship characteristics such as provider support, patient's opinion of the provider's competence as well as satisfaction and trust in the staff with adherence behavior (Machtinger and Bangsberg 2008; Williams and Friedland 1997). In Lucas' et al. (1999) study, higher medication and provider advice adherence was associated with health provider support. Gordillo's et al. (1999) study also found a strong association between HAART adherence and patients' health provider support. The same study also showed that patients that missed at least one appointment in the last month were significantly less engaged with their health providers. According to Park and Mayhorn (1996), provider support like caring is crucial in adherence given the challenging health experiences faced by individuals with HIV Carballa's et al. (2004). However, Hardon's et al. (2007) study found that provider support for individuals on HAART in Tanzania was poor due to the heavy workload of the health care professionals. The poor support may influence adherence failure.

Clinical Setting and Adherence

Features of the clinical setting like facility location, availability of transportation, childcare, waiting time, access to ongoing primary care and pleasantness of the clinical environment have also been associated with adherence behavior (Machtinger and Bangsberg 2008; Munro et al. 2007). In Uganda for example, some HAART clients indicated that the distance to health facilities was a hindrance to adherence due to

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transport problems to pick up medication from the clinic (WHO 2008b). Hardon's et al. (2007) study also found that although antiretroviral drugs are free of charge, transportation costs hindered individuals under therapy in Uganda, Tanzania and Botswana from traveling to clinics to refill prescriptions, a contributing factor to medication adherence failure.

<center>*Demographic Characteristics and Adherence Behavior*</center>

A few scholars link adherence behavior with some of the socio-demographic factors like age and education (Garcia and Corte 2003; Kalichman et al. 1999; Kerr et al. 2005; Machtinger and Bangsberg 2008; Wainberg and Friedland 1998). Much of the research indicates that some demographic factors are not good predictors of adherence behavior (Williams and Friedland 1997). For example, Uitenbroek's et al. (1996) comparative study of health behavior patterns by age and education conducted in Bulgaria and Scotland found the association between alcohol use and education inconclusive. On the other hand, other scholars reveal correlations between adherence and some demographic factors like age and education (Machtinger and Bangsberg 2008). For instance, Halkitis et al.'s (2008) 2004 study of 300 HIV positive men that have sex with men in New York revealed that individuals over 50 are more likely to adhere to highly active antiretroviral drugs as compared to their younger counterparts. The authors attribute these results to better medication taking experiences and less medication interruptions among the elderly as compared to those under age 50. In another study, Mannheimer et al. (2002) also found a correlation between old age and better adherence levels. In Patterson's et al. (2000) study, older patients were more likely to have 95% or

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greater adherence than the younger patients. Gordillo's et al. (1999) study conducted in Madrib between 1997 and 1998 also found that individuals above age 32 were more likely to adhere to medication as compared to their younger counterparts. Furthermore, Carballo's et al. (2004) study conducted in Spain found that individuals with higher education were more adherent to HAART as compared to those that had no primary education. Similarly, Gordillo et al. (1999) found that individuals with low education had the least adherence rates as compared to those that had college education. Studies that link low education to adherence failure lead to speculations that individuals in Africa on HAART many of whom live in poverty and lack formal education may fail to adhere to HAART, which could lead to the development and spread of drug resistance HIV (Mills et al. 2006).

Other Factors Influencing Adherence

Stigma, forgetting, failure to travel with medications, not getting time off from work to go to the clinic for a prescription refill, and sleeping through the dose have also been linked to adherence behavior (Kalichman et al. 2001). Due to stigma that follows AIDS, individuals may feel insecure disclosing their condition to their fellow workers such that concealing taking medication at work may become a challenge that leads to sub-optimal adherence (Hardon et al. 2007; Wurth and Perlow 2005). In Hardon's et al. (2007) study, participants indicated that disclosure had caused them to lose their jobs and to be abandoned by family and friends. Research reveals that individuals may skip taking their medication as prescribed because they fear being seen by colleagues, family, or friends that they have not disclosed to (Williams and Friedland 1997).

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Social Theories and HAART Adherence Behavior

This section begins by describing the sick role theory, followed by a discussion of other psychosocial and public health theories that attempt to explain why individuals may fail to comply with sick role behavior. A discussion of the limitations of these theories concludes this section.

Sick Role Theory

According to Talcott Parsons' sick role theory, illness is an anomaly to the human body that must be rectified partially by the ill person who must comply with sick role normative behavior (Parsons 1951). Parsons' argument is that the sick are blameless because illness is beyond their control. However, they are obligated to choose better health by seeking treatment whereby failure to do so qualifies them as deviants (Parsons 1951). In addition, illness should not be self-inflicted. In application of the sick role theory to HAART adherence, good health should be in the self-interest of those under therapy who are obligated by society to choose health promoting behaviors like medication adherence, risk free sexual behavior and adherence to good nutrition as advised by health professionals (Coreil et al. 2001; Thomas 2003). Individuals that fail to do so are accountable for their actions. Of concern to researchers is the question of why individuals fail to adhere to sick role behavior like taking medications as prescribed and complying with lifestyle recommendations like refraining from risky sexual behavior abstaining from alcohol, and having a good diet? Psychosocial and public health theories are often drawn on to answer this question.

Some of the theories used to explain adherence behavior like failure to take medication as prescribed often include the social support theory and those that take a cognitive approach like the health belief model (HBM), social cognitive theory (SCT) and the theory of reasoned action (TRA)/theory of planned behavior (TPB), (Redding et al. 2000). Rational choice theory (RCT), the theory of gender power, the communication-motivational theory and the communication theory are also applicable in the explanation of HAART adherence behavior, especially in resource-limited settings like Uganda (Munro 2007). However, it is important to note that none of the existing theories fully explains HAART adherence failure especially in developing nations, probably because these theories were initially formulated to explain health behaviors in the developed world. Hence, a better understanding of HAART adherence behavior in resource-limited settings requires the integration of various theoretical paradigms.

Social Support Model

Emile Durkheim was the first sociologist to explain health behavior using the theory of social integration and social support and his theory is mentioned in numerous studies that attempt to predict health behavior (Durkheim 1951). Durkheim theorized that suicide rates were higher among wealthy Protestants because this population group was more individualistic and less integrated in the community as compared to the less wealthy Catholics that experienced a higher degree of community integration (Durkheim 1951). Although Durkheim's study is limited due to its descriptive nature, later qualitative and quantitative studies have accumulated a substantial body of evidence that links social support to health outcomes that result from health risk behaviors like

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adherence failure. Researchers agree that loving affectionate relationships from kin and friends often have the potential to raise one's sense of self-efficacy or regulate one's thoughts, feelings, and behavior (Redding et al. 2000). For example, relationships may strengthen coping skills for those on HAART by helping them deal with adherence in the midst of side effects manifestations as well as building their self-efficacy. In a meta-analysis of studies, Cobbs (1976) found social support in the form of friends, family, and health care professionals to be a good predictor of medication adherence.

Health Belief Model

The health belief model (HBM) formulated by social psychologists in the 1950s is often used by behavioral scientists to examine health behavior (Holwerda 2000; MSUCARES 2001). According to the HBM, health behavioral change is based on a rational assessment of the barriers to and benefits of an action (Munro 2007). Scholars that utilize this theory reveal that perceived susceptibility, perceived seriousness, perceived benefits and perceived barriers that are sometimes influenced by demographic and socio-psychological variables are the driving forces behind adherence behavior (WHO 2003). In applying this theory to HAART, individuals are more likely to take medications as prescribed if they perceive their health status to be serious; perceive the progression of HIV/AIDS as a threat; perceive benefits such as better health; are not overwhelmed by costs like side effects; and if they are confident they can adhere successfully (Haisch and Hornung 2005; Holwerda 2000; MSUCARES 2001).

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Social Cognitive Theory (SCT)

Bandura's social cognitive theory (SCT) is also widely applied to health behaviors like those pertaining to adherence and other unhealthy lifestyles such as poor diet (Bandura 2002). Behavioral change from the SCT perspective depends on knowledge of health benefits, risks, self-efficacy, the negative or positive expected outcome, and perceived facilitators or barriers, where self-efficacy refers to one's belief in the ability to perform a specific action that is required to attain an expected outcome (Bandura 2002; Redding et al. 2000). For example, individuals are more likely to adhere to HAART if they are confident they can take their medications as prescribed, believe that they have the power to change their quality of life, believe that highly active antiretroviral drugs will do more good than harm, and have few barriers such as those relating to side effects (Luszczynska and Sutton 2005; Munro 2007). In a critical and systematic review of 27 studies conducted in the 1990s that applied the SCT in the examination of self-efficacy and physical activity behavior, Keller et al. (1999) found this model to be a good predictor of physical activity. One limitation of Keller's et al. (1999) review is that he only examined physical activity and not other health behaviors such as medication adherence or risk free sexual behaviors.

Theories of Reasoned Action (TRA)

The theory of reasoned action (TRA) is also used in numerous studies to explain health behaviors. Its limitations are addressed by the theory of planned behavior (TPB) (formulated as an extension of the TRA) to accommodate environmental control predictors of health behavior not addressed by the TRA (Munro 2007; Redding et al.

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2000). Based on the TRA, behavior is under volitional control and it is determined by one's level of intention, perception, outcome, and significant others' opinions in relation to a particular behavior (Luszczynska and Sutton 2005; MSUCARES 2001; Redding et al. 2000). Based on this theory, intention is influenced by attitudes or values, self-efficacy, and subjective norms (MSUCARES 2001). In that regard, individuals that conceptualize attitudes into values are more likely to adhere. For example, individuals that feel HAART adherence leads to a better quality of life are more likely to adhere than those that believe otherwise (Redding et al. 2000). In addition, HAART adherence may partially be determined by one's thoughts of how significant others feel about adherence. In other words, individuals who feel significant others expect them to adhere to HAART are more likely to do so because of the social pressure exerted on them (MSUCARES 2001).

Rational Choice Theory

Although missing from health behavior literature, the rational choice theory (RCT) may also partially explain HAART adherence. Based on this theory, behavior results from a rational decision-making process through a careful evaluation of the costs and benefits that follow a particular act whereby the goal is to maximize benefits while minimizing costs (Kerr et al. 2005). In the case of HAART adherence, costs may refer to physical pain due to disease progression. Benefits on the other hand may pertain to the temporary relief from side effects manifested through sub-optimal adherence, or peace of mind that may result from avoiding stigmatization from others if they learn one is taking HIV medications (Liska and Messner 1999). For example, a client on HAART that fails

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to adhere to medication due to side effects may choose the instant reward of avoiding the pain manifested in these side effects in exchange for future consequences of disease progression. The problem is that health risk behaviors such as intermittent medication usually provide instant benefits, whereas the costs are manifested later, which often prompts the affected individuals to choose immediate gratification that may cost them later (McDade-Montez et al. 2005).

The Theory of Gender Power

Robert Connell's emerging theory of gender power formulated in 1987 focuses on the influence of social and cultural gender inequalities on female health. This also partially explains HAART adherence behavior especially in low-income settings (Connel 1987; Crosby et al. 2002; Wingwood and DiClemente 2000). Several researchers have utilized this theory to explain the variance in risky sexual behaviors embedded in social contexts where cultural values render females powerless to control their sex behavior or their husband's extra marital affairs, which makes it a challenge for females to adhere to HIV positive living recommendations (Buve et al. 2002). For example, Pulerwitz et al. (2002) applied this theory to a study of Latino women in Massachusetts and reported that females that possessed higher levels of relationship power were five times as likely as those with lower levels to report consistent condom use. Sa and Larsen (2006) also found a strong association between gender inequalities and condom use among women in Tanzania.

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The Protection-Motivation Theory (PMT)

The protection motivation theory may also be used to explain adherence behavior. This theory asserts that changes in behavior are a product of one's perceived degree of severity of a threat, the degree of certainty that the threat will materialize, the efficacy of recommended preventive behavior, and the perceived self-efficacy or the level of self confidence in one's ability to undertake the recommended preventive behavior (Rogers 1975). According to this theory, from a hypothetical point of view individuals threatened by HIV progression due to non-adherence, certain about the development of drug resistant HIV, who believe in the effectiveness of highly active antiretroviral drugs, and who believe they are in control of adherence behavior, are more likely to adhere to medication regimens (Munro 2007; Prentice-Dunn & Rogers 1986). This theory may explain much of adherence behavior in low-income countries where enrollment in HAART is only possible for those diagnosed with AIDS.

Communication Perspective Approach

Although rarely utilized, the communication perspective theoretical approach (CPT) may also help understand adherence behavior (Munro 2007). Communication perspective theoretical analysts emphasize the importance of the patient-health provider relationship in influencing health behavior (WHO 2003c). Talcott Parsons was one of the first social theorists to stress the importance of a supportive doctor-patient relationship in effective treatment of the sick. In his sick role theory formulated in the 1950s, Parsons characterized the doctor's role in response to the sick as beneficent, which role is essential for positive treatment outcomes (Parsons 1951). Research reveals that

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individuals with health providers who possess skills that support and effectively communicate to clients in a comprehensible manner are more likely to adhere to HAART as compared to those that do not (WHO 2003c).

Limitations of Existing Theories

Significant theoretical contributions in the explanation of HAART adherence behavior are evident in literature. However, none of the existing theories fully explains HAART adherence behavior. The sick role theory, rational choice theory, PMT, and cognitive theories like the BHM, TRA, and SCT tend to blame the individual and they overlook behavior that is often constrained by external environmental controls such as religious and cultural beliefs like behavior which may be influenced by consequences of HIV/AIDS stigmatization or lack of economic (Becker 1985; Munro 2007). For example, some behaviors like engagement in sex with multiple partners may be rooted in cultural beliefs and could be beyond individual control. These theories also fail to address other environmental factors such as economic resource constraints like those that may hinder adherence to recommended dietary regimens, especially in resource-limited setting. For example, in the case of individuals on HAART in low-income nations, some studies attribute financial constraints to good diet adherence failure (Kerr et al. 2005).

To correct the flaws in the TRA, Icek Ajzen later attempted to extend the TRA that focuses on behavior under volitional control to include behavior influenced by social contexts after which he named this extended model the theory of planned behavior (TPB). However, even with Ajzen's extension of the TRA, the TPB remains limited because it fails to fully explain HAART adherence behavior. For example, Hardeman et

al. (2002) conducted a meta-analysis of 24 studies conducted in Australia, United States, Canada, and Netherlands that employed the TPB to predict intention and health behavior like exercise and cessation of smoking and found that the TPB could only explain variance in intention in only 50% of the studies, and it could only predict behavioral change in 33% of the studies.

Furthermore, although the HBM is one of the most widely utilized theories, some studies that use this theory to explain health behavior often leave a large percentage of unexplained variance in health behavior, and there are numerous studies that use this model whose results are inconclusive (Haisch and Hornung 2005; Munro 2007; Redding et al. 2000; Rosenstock 1974). For instance, Petosa and Jackson's (1991) study of safe sex predictors among adolescents in South Carolina found that the HBM could only explain 43% of the variance in safe sex among the seventh grade students, 27% among ninth grade and 17% of the variance among the eleventh grade students. Holwerda's (2000) study also found a positive correlation between perceived susceptibility and perceived barriers with self-breast examination, but the correlation was insignificant. The HBM is further criticized for overlooking the fact that belief formation does not always precede behavioral change and that this causation relationship has the potential to be reversed (Haisch and Hornung 2005; MSUCARES 2001; Redding et al. 2000).

Other theories like the social support theory and gender power theories may fill in the void by explaining health behaviors rooted in social contexts, but in turn these theories often overlook influential cognitive factors such as beliefs and perceptions. For example, Durkheim's study that links social support to health behavior is limited because

its descriptive nature makes it fall short of an in-depth qualitative driven understanding of the meaning of sanctions pertaining to suicide across the two population groups under study. For example, Catholic doctrine emphasizes eternal damnation for those that commit suicide, which is not the case for the Protestants (Weber 2002). The meaning of 'eternal damnation' as a penalty may have been influential in determining suicide rates among the Catholic communities as opposed to the Protestant (Downes and Rock 2003). Just as Durkheim's theory failed to exhaust all the possible predictors of suicide behavior in his study, the social support theory does not fully explain HAART adherence behavior.

In any case, as discussed above, none of the existing theories fully explains adherence behavior, especially in low-income contexts probably because existing theories were developed to explain health behavior in the developed world. The most commonly used is the HBM and it can be applied to HAART adherence in low-income nations. However, it does not address behavior rooted in cultural or religious institutions such as those related to gender power and poverty. The theory of gender power may explain condom use failure among females due to economic, social, and political structural institutional establishments whose outcome is to position women in the lower strata as compared to men. Given their position in society, females often find themselves economically dependent and subordinate to males such that they may fail to negotiate safe sex. Much of the work for females is often in the domestic setting, and it may not be economically compensated such that women may fail to comply with dietary regimen recommendations. Combining the theory of gender power with the HBM may attempt to explain adherence behavior in low-incomes nations like Uganda. However, it remains a

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challenge for researchers to formulate a theory that will integrate existing theories to

exhaustively explain adherence behavior in low-income nations.

CHAPTER III

DATA AND METHODS

This chapter begins with a discussion of the data collection methods, followed by research questions, indicator measures, definition of terms, data analysis and concludes with limitations.

Data and Data Collection

Data

Data consists of 70 client responses to a questionnaire collected over a four-week period from July 16, 2007 to August 15, 2007. The questionnaire instrument measured adherence behavior, the impact of HAART on sexual behavior, as well as perceived physical and psychological health of Ugandan adults over age 18 that were currently enrolled in HAART.

Participants

The sample is composed of 70 participants, 25 of whom were soldiers and 45 civilians. Participants were affiliated with The Joint Clinical Research Center (JCRC) at Bombo, JCRC at Mengo, and The AIDS Support Organization (TASO) at Entebbe. About 56% of the participants were female. The average age of participants was 38, but all participants were above age 18. I chose this age group because 18 is the age of legal adulthood in Uganda and because I expected the validity of responses from the self-reported quality of life measurements of the questionnaire to be higher for those over age

18 as opposed to their younger counterparts. In addition, I anticipated that many of those above age 18 would be enrolled in HAART because research reveals that HIV mostly affects individuals in this age group (Laing and Hodgkin 2006; MOH – Uganda and ORC Macro 2006; UNAIDS 2006c). Furthermore, I realized that an adult population sample would make it easier to obtain an IRB approval as compared to that of children under 18.

Recruitment

I used a convenience sampling technique because this technique appeared more feasible in terms of time and cost. Staff played a major role in soliciting client participation by first informing those that met the inclusion criteria about the study and its purpose. Interested clients were then directed to the private setting that had been assigned to me from where I conducted the study. I requested staff to make an effort at creating a representative sample in terms of gender, age, and how long a respondent had been under therapy.

Instruments

I used questionnaires to collect data from the clients. These instruments were adapted from those developed by the United States Department of Health and Human Services (DHHS). The questionnaire consisted of 119 closed ended questions that measured and explored experiences with HAART, knowledge of highly active antiretroviral medications, HIV serostatus disclosure, medical outcomes, sexual behavior, alcohol use, and demographic characteristics.

I first formulated the client questionnaire in English after which I developed the Luganda version. I used English because it is the official language in Uganda. However,

because I expected that some of the participants may not be able to understand English, I decided to translate the English questionnaire into Luganda. I chose Luganda because it is the most widely spoken native language in Uganda. In addition, Luganda is the native language in the area from where I was to collect the data (Gordon 2005).

Data Collection

Upon arrival in Uganda, I learned for the first time that all studies conducted in the country required approval by the Ugandan government prior to collecting data. Therefore, I dedicated the first two weeks in Uganda to seeking permission from the government and the respective centers' institutional review boards to conduct the study. Initially, I targeted five HAART providing centers around Kampala using a convenience sampling technique; two of which refused and three of which gave me access to conduct the study. The three centers that gave me access equipped me with authorization letters that I presented to the Ugandan government, which in turn gave me authority to conduct the study and provided me with a government identification card that identified me as a researcher. Immediately after being authorized by both the government and HAART providing centers, I began collecting data.

I collected data at JCRC, Bombo between July 16, 2007 and July 24, 2007 from 25 soldiers on HAART that verbally completed questionnaires. Next, I collected data from TASO Entebbe between July 25, 2007 and August 07, 2007 from 31 civilian clients on HAART that also verbally completed questionnaires. Between August 08, 2007 and August 15, 2007, I collected data from 14 civilians on HAART affiliated with JCRC Mengo.

On the first day at each center, I was given an official tour of the facility and introduced to staff. Each center also assigned me a private office or space from where to collect data. A private setting for data collection was necessary due to the sensitivity of the subject matter under study. In this setting, I informed each participant of the purpose, potential risks and benefits of the study. I also informed participants about the data collection procedure and that participation on their part was voluntary. Each informed consent was tape-recorded. To ensure maximum protection of confidentiality, no written consent were obtained from clients. The verbal responses to questionnaires were also tape recorded. The purpose of audio taping was to provide a transcription of the information discussed while completing questionnaires and to assure accuracy of reporting that information. The tapes, hard copies of the transcription, notepads, survey questionnaires, and the computer diskettes containing the transcription text files have remained secured in a locked filing cabinet. They will be destroyed in August 2012.

I used a triangular approach to collect data from clients on HAART. The reason for the triangular approach was to accommodate both quantitative and qualitative methods that would allow a deeper understanding of the social phenomena under study. The triangular approach was facilitated by a data collection strategy that combined both questionnaire and interview methods. First, I administered the questionnaire to each participant by reading each closed-ended question on the questionnaire to the respondent. Next, I recorded each response and then asked the respondent to explain or elaborate on the respective response to the closed-ended question. I probed each of the responses several times for detail and clarification purposes. Although I had assumed that most of

the data would be collected in English, 64 of the client questionnaires were completed in Luganda and only 6 were completed in English because many of the respondents could not understand, speak, or write English. In addition, all clients were given an option to choose a language of preference of which many chose Luganda. Completion of each questionnaire lasted approximately one hour. All data were collected on weekdays from 8 a.m. to 5 p.m. and the average number of respondents from whom data was collected in a day was 4.

<center>Research Questions</center>

The following research questions will be addressed in this study:

1. How are individuals on HAART adhering to treatment regimens?

2. What factors influence highly active antiretroviral drug adherence behavior?

3. What factors influence life style recommendations adherence behavior?

4. What is the impact of HAART on perceived physical and psychological health among individuals undergoing treatment?

<center>Measures</center>

There are four research questions. All measures included both open and closed ended responses. This approach was necessary to get a deeper understanding of phenomenon under study. Below are measures for each research question.

<center>*Research Question 1*</center>

Following are nine indicators that measure adherence behavior, which are used to answer the first research question, (a) skip dose, (b) on time, (c) condom use, (d) alcohol use, (e) sex partners, (f) good nutrition, (g) gender, (h) age, and (i) education. Coding

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discussion begins with original measures, followed by the recoded measures. Skip dose and take on time were initially measured at ordinal levels using a 4-point Likert scale with 1 for all the time, 2 for most of the time, 3 for sometimes, and 4 for never. Skip dose was dummy coded 1 for no, never skip a dose and 2 for yes, skips a dose. Similarly, on time was recoded 1 for no, does not always take medication on time and 2 for yes, always takes it on time. Condom use was also originally measured at an ordinal level with 1 for never use a condom, 2 for sometimes uses a condom, 3 for almost always uses a condom, and 4 for always uses a condom. Condom use was recoded at a nominal level with 1 for no, does not use a condom regularly and 2 for yes, always uses a condom. Alcohol was initially assessed by asking if respondent had an alcoholic beverage in the past 6 months and it was measured at a nominal level with 1 for no, never had an alcohol drink and 2 for yes, had an alcoholic drink. Alcohol was not recoded. Sex partners was initially measured at an interval ratio level by asking people to list the number of sex partners, but was later recoded to a nominal level with 1 for have more than one sex partner, and 2 for abstinence or one sex partner. Good nutrition was initially measured at an ordinal level with 1 for never has good nutrition, 2 for rarely has good nutrition, 3 for most of the time has good nutrition, and 4 for all the time has good nutrition. Good nutrition was then recoded 1 for no, does not always have good nutrition and 2 for yes, always has good nutrition. Gender was coded 1 for female and 2 for male. Age of the respondent was initially measured at an interval ratio level, but was later reduced to an ordinal level with 1 for 20 to 29, 2 for 30 to 39, and 3 for 40 to 65. Similarly, education was originally measured at an interval ratio level but was later recoded at an ordinal level

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with 1 for primary school or no education, 2 for senior or secondary school education, and 3 for higher school or college. One of the reasons for recoding measures from upper to lower levels of measurement was due to the fact that, the purpose of this question was to get a snap shot of two categories of people, those that completely comply with HAART regimens and those that do not. This knowledge would then be utilized as foundation for the discussion of adherence influential factors discussed in later research questions. In addition, it was necessary to get uniform measures that would allow fair comparisons across indicators. For example, skip dose was originally measured at an ordinal level using a 4-point Likert scale with 1 for all the time, 2 for most of the time, 3 for sometimes, and 4 for never. However, alcohol was initially measured at a nominal level with 1 for no, never had an alcohol drink in the past 6 months and 2 for yes, had an alcoholic drink. Reducing skip dose to a nominal level and recoding it 1 for no, never skips a dose and 2 for yes, skips a dose would allow comparison of skip dose and alcohol because both indicators are measured at the nominal level. Another reason measures were reduced from higher to lower levels of measurement was to accommodate the use of cross tabulations that require analysis of variables with less categories.

Research Question 2

There are nine indicators that measure the second research question: (a) Side effects, (b) alcohol, (c) embarrassment, (d) oversleeping, (e) forget to carry medication, (f) forget to take medication, (g) have no food, (h) social support, and (i) belief in effectiveness of highly active antiretroviral drugs. Asking if respondent skips taking medication because of side effects measured side effects. Alcohol was assessed by

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asking if respondent skips taking medication because of drinking alcohol. Asking if respondent skips taking medication because of embarrassment measured embarrassment. Oversleeping was assessed by asking if respondent skips taking medication because of sleeping through the dose. Forget to carry medication was measured by asking if respondent skips taking medication because of forgetting to carry it all times. Asking if respondent skips taking medication because of forgetting measured forget to take medication. Have no food was measured by asking if respondent skips taking medication because of lack of food. All of the above indicators were each initially measured at an ordinal level with 1 for skips all the time, 2 for skips most of the time, 3 for skips sometimes, and 4 for never skips. The same indicators were later recoded as 1 for never skips a dose, and for 2 yes, skips a dose. Asking if respondent has anyone to depend on taking medication assessed social support and was initially measured at a nominal level with 1 for has no social support, and 2 for yes, has social support. Social support was not recoded. Belief in effectiveness of highly active antiretroviral drugs in treating HIV was initially measured by responses to the statement that, 'I feel that if I keep taking my medication, my overall quality of life will definitely improve, probably improve, probably it may not improve, definitely it will not improve. This measure was recoded 1 for no, it will probably not improve or it will definitely not improve and 2 for yes, it will probably improve or it will definitely improve. The major reason for recoding these indicators was to create uniform measures that would allow fair comparisons across indicators.

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Research Question 3

Four indicators measure lifestyle influential adherence behavior and they are used to answer the third research question. These measures were: (a) condom use, (b) number of sex partner, (c) alcohol use, and (d) good nutrition. Asking if respondent always uses a condom assesses condom use and it was originally measured at a nominal level with 1 for always uses a condom, and 2 for do not always use a condom. Condom use was not recoded. Number of sex partners was initially measured at an interval ratio level by asking to state the number of sex partners a respondent has had since HAART initiation and it was recoded at a nominal level with 1 for abstinence or one sex partner, and 2 for more than one sex partner. Alcohol use was originally measured by asking if respondent had an alcoholic drink in the last six months and it is measured at a nominal level with 1 for never had an alcoholic drink and 2 for yes, had an alcoholic drink. Alcohol was not recoded. Asking if respondent finds it hard to follow doctor's dietary recommendations assessed good nutrition and it was initially measured at an ordinal level with 1 for never follows, 2 for follows rarely, 3 for follows most of the time, and 4 for follows all the time. Good nutrition was then recoded with 1 for no, does not always follow doctor's dietary recommendations and 2 for yes, always follows.

Research Question 4

There are three measures for perceived quality of life: (a) if respondent perceives physical health as much better, somewhat better, the same, or worse since HAART initiation; (b) if respondent perceives psychological health as much better, somewhat better, the same, or worse since HAART initiation; and (c) if respondent perceives

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overall quality of life as better, somewhat better, the same, or worse since HAART initiation. All measures for the fourth research question are recoded 1 for perceives health as somewhat better or much better, and 2 for perceives health as the same or worse than before HAART. It was necessary to recode these indicators to distinguish between two categories of people, those that perceived improvement in their quality of life since HAART initiation, and those that perceived their health to be no different or worse than before HAART initiation.

Validity

All measurements were tested for validity to make sure that they measured exactly what they were intended to measure. Firstly, the questionnaire used had validity because it was adapted from that used by the DHHS to measure HAART adherence related phenomenon in the US. Each item was inspected to ensure face validity. Additionally, construct validity was used to note the extent to which each measure performed according to the theoretical expectations of adherence behavior. For example, on the basis of prior literature, it is expected that females are less likely to use condoms as compared to males. In that regard, construct validity of gender as a measure of adherence was assessed to see if a positive relationship between gender and adherence behavior emerged.

Protection of Human Participants

Texas Woman's University Institutional Review Board (IRB) approved the study in June 2007 on condition that I acquire permission letters authorizing access from respective study centers in Uganda prior to collecting data. I did not possess permission

letters from potential study participating centers at the time of TWU (IRB) approval

because I perceived the chances of getting access to HAART providing centers in

Uganda for a study while in the US as tapered due to trust reasons.

<div align="center">Data Analysis</div>

The instrument used to collect data from clients was composed of both open and closed-

ended questions that facilitate quantitative and qualitative analysis. Data from all open-

ended questions to a questionnaire were transcribed, processed and entered into the

computer. Processing of client open-ended responses included language translation from

Luganda to English, response clarification and grammatical error cleaning while keeping

as much of the original information as possible. Similarly, questionnaire responses to the

closed ended questions were entered into a computer statistical software package after

which the quantitative data was cleaned, coded and stored for accurate analysis.

<div align="center">*Quantitative Data Analysis*</div>

Because the sample size was small (N = 70 clients), I employed elementary

quantitative data analysis. I used descriptive statistics to analyze the distribution patterns

and the general characteristics of the data. Cross tabulations were used because I wanted

to get some understanding of the structure of adherence behavior especially with

reference to gender, education, and age. I used phi and Cranmer's V to analyze the

significance, strength, and direction of associations between adherence measures and

gender, education, and age. The reason for choosing phi and Cranmer's V was because

most of the measures under analysis were measured at nominal levels. The analysis was

limited to adherence behavior and gender, education, and age because cross tabulation

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results revealed there were no differences between adherence behavior and other demographic characteristics like religion. Scholars agree that many of the demographic factors are not good predictors of adherence behavior (Williams & Friedland 1997).

Qualitative Data Analysis

I also utilized qualitative data analysis techniques to decode major themes pertaining to HAART adherence influential factors and the impact of HAART on health. I coded the concepts and themes in the data set while noting theoretical revelations as they unfolded, after which I used the code and theoretical notes to analyze the data. I employed an inductive approach in the qualitative analysis whereby I began with specific observations and continued into the discovery of patterns.

Limitations of the Study

One of the limitations of this study was the use of the convenience sampling technique. As a result, the findings cannot be generalized beyond the population group or geographical area that is being tested (Healey 2004). The participants in this study were also affiliated with the centers from where the data were collected. Participant and service provider relationship issues may have had an effect on the validity of the information. Because of time and financial constraints, the sample size in this study is small. A small sample size does not favor the utilization of more advanced statistical techniques. In addition, some of the measures pertain to sensitive personal issues such as sexual behavior. This may also raise reliability and validity concerns due to fear of the negative social stigma associated with certain sexual behaviors such as engagement in sex with multiple partners while HIV positive.

Another limitation is that the majority of the interviews were conducted in Luganda and they were translated in English for analysis. The translation process has a potential of losing some information. However, as a native born in Uganda, and having lived in the social, economic, cultural context of the participants, I tried as much as possible to maintain the original meaning of the responses. It is also important to note that, the data is limited to a cross sectional design such that changes in reference to the impact of highly active antiretroviral drugs, adherence, medical outcomes, and behavioral changes overtime cannot be investigated.

CHAPTER IV

FINDINGS

The purpose of this chapter is to present the central findings of the study. After a discussion of the characteristics of the participants, each of the research questions is discussed in detail.

Characteristics of the Participants

Table 1 presents a summary of the main characteristics of the respondents. Participants consist of 70 clients currently on HAART. Twenty five (37%) of the respondents are soldiers and 45 (63%) civilians. All participants are above age 18. This age group was chosen because it is the age of legal adulthood in Uganda. Based on this sample, the average age of participants is 37.6 with a standard deviation of 8.5. The youngest of the participants is 20 and the oldest 64 years of age, 92% of the respondents are below age 49. The average number of school years is 8.9 with a standard deviation of 3.9 and a range of 0 to 17 years of schooling. Forty one percent of the respondents report having primary or no education. About 56% of the participants are female. Fifty-four percent of the respondents are married or cohabiting, 24% widowed, and 22% never married or are separated. About 87% of the respondents are Christian, and 13% are Muslim. Eighty six percent of the participants indicate that they acquired HIV through heterosexual contact, 1% through blood transfusion, and 13% do not know how they contracted the virus. Sixty percent of the respondents report enrollment in HAART with

a CD4 cell count of below 100, 30% between 101 and 200, and 10% above 200. About 53% of the respondents began HAART between 2006 and 2007, 29% between 2004 and 2005, and 18% between 2000 and 2003. Thirty three percent of the participants were unemployed, 67% are employed. Income ranges from $0 to $600 (US) a month with a standard deviation of 7.6. The median income is $28 per month with 59% of the respondents reporting earning less that $1 (US) a day.

Table 1: Characteristics of Participants

Measure	N	%	Mean/Median	SD
Age	70		37.6[a]	8.5
Years of Schooling	70		8.9[a]	3.9
Gender				
Male	31	44%		
Female	39	56%		
Marital				
Married/Cohabiting	29	41%		
Widowed	17	25%		
Never Married	24	34%		
Religions				
Christian	61	87%		
Muslim	9	13%		
Civil Status				
Civilians	44	63%		
Soldiers	26	37%		
CD4 cell count				
0-100	37	60%		
101-200	19	30%		
Above 200	6	10%		
Year Enrolled in HAART				
2000-2003	13	18%		
2004-2005	20	29%		
2006-2007	37	53%		
Transmission Mode				
Heterosexual Intercourse	60	86%		
Blood Transmission	1	1%		
Don't Know	9	13%		
Employment Status				
Employed	47	67%		
Unemployed	23	33%		
Monthly Family Income			$28[b] (US)	
N	70			

[a] Mean
[b] Median
Source: Data collected in Uganda, 2007

HAART Adherence Behavior

The first research question is: How are individuals on highly active antiretroviral therapy (HAART) adhering to treatment regimens? The purpose of this question is to obtain a better understanding of HAART adherence behavior among individuals in Uganda. This is important since adherence failure may lead to the formation of a resistant virus that cannot be controlled by drugs (Berg et al. 2007; Kalichman et al 2001; Rong et al. 2007). Understanding adherence behavior may assist in the formulation of strategies necessary to enhance compliance with HAART in low-income nations. Several related questions are addressed below, including: Are individuals on HAART taking medication as prescribed in terms of dosing and timing? Are people on HAART adhering to lifestyle recommendations like safe sex, abstinence from alcohol, and having good nutrition? Who is more or less likely to adhere to medication regimens? Who is more or less likely to adhere to lifestyle recommendation? Some of the terms used in this question include skipping a dose of medication and not taking medication on time. Skipping taking medication means that the patient completely skips taking a given dose of medication. For instance, if medication is scheduled to be taken twice daily, the patient may just take one dose on a given day. On the other hand, failure to take medication on time means that the patient does not skip taking a dose of medication, but she/he takes it a few hours before or after the scheduled time.

Findings reveal that females are more likely to skip taking medication and less likely to use a condom as compared to males. Males on the other hand are less likely to take medication on time, have more than one sex partner, and to use alcohol as compared

to females. Younger individuals are more likely to skip taking medication and to drink alcohols as compared to their older counterparts. On the other hand, less educated individuals are more likely to skip taking medication and not using a condom as compared to the more educated. The more educated are more likely not to take medication on time, have sex with multiple partners and to drink alcohol as compared to the less educated.

Adherence behavior is examined across gender, age, and education level of the participants. However, although some of the findings are insignificant, I have included them in the discussion because the relationships portrayed are generally consistent with findings in the literature. Despite the fact that religion has the potential to reveal interesting adherence behavior patterns in the analysis of Muslims vs. Christians, it is not included because few participants (N=9) indicate they are Muslim as compared to those who indicate they belong to the Christian faith (N=60) faith.

As shown in Table 2, respondents were almost equally divided between those that always took medication on time (51%) and those that did not always take medication on time (49%). On the other hand, 41% of the participants indicated that they sometimes skipped taking medication, whereas 59% reported that they never skipped taking medication. Of all lifestyle recommendations, respondents were least likely to report having good nutrition, as most (83%) reported failure to follow doctor's orders of having good nutrition. Only 17% of the respondents reported that they always had good nutrition. Adherence behavior with regard to practicing safe sex and abstaining from alcohol was better as compared to that of medication regimens, in that a large majority

(84%) of respondents reported either having sex with only one partner or abstaining from sex, and over half (60%) reported using condoms regularly. A large number of participants (62%) also reported abstinence from alcohol.

Table 2: Measures of Adherence Behavior

Item	N	%
Medications Adherence Behavior		
Skips Taking Medication		
Sometimes or Always Skips	28	40.6
Never Skips	41	59.4
Total	69	100.0
Takes Medication on Time		
Sometimes or Never	34	48.6
Always	36	51.4
Total	70	100.0
Lifestyle Adherence Behavior		
Uses Condoms		
Does Not Always Use	19	40.4
Always Uses	28	59.6
Total	47	100.0
Abstains or Has 1 Sex Partner		
Does Not Abstain/has more than 1 partner	11	15.7
Abstains or has one partner	59	84.3
Total	70	100.0
Abstains from Alcohol		
Had at least one drink	26	37.7
Abstains	43	62.3
Total	69	100.0
Has Good Nutrition		
Not Always	58	82.9
Always	12	17.1
Total	70	100.0

Source: Data collected in Uganda, 2007

Adherence Behavior Across Sex

Results pertaining to adherence behavior by sex are shown in Table 3 and they reveal that overall, males were less likely to comply with the health provider's medication regimens than females. For example, about 58% of the males indicated that they did not take medication on time as compared to 41% of the females. Males were also less likely to comply with abstinence from alcohol and sex, or to have one sex partner as compared to females. For instance, males (52%) were twice as likely as females (26%) to report having used alcohol in the last six months. More males (19%) also reported having multiple sex partners than females (13%). More females (47%) on the other hand reported skipping taking medication as compared to males (32%). Females (42%) were also more likely to report failure to use a condom regularly as compared to males (39%). Gender differences in following the doctor's orders to have good nutrition were negligible. Except for alcohol and gender, despite the fact that scholars reveal somewhat similar results, the associations between measures discussed above are weak and insignificant at the 0.05 level.

Table 3: Adherence Behavior by Sex

| Item | Gender | | | | |
| | Male | | Female | | |
	N	%	N	%	Phi
Medication Adherence Behavior					
Skips Taking Medication					.153
Sometimes or Always	10	32.3	18	47.4	
Never Skips	21	67.7	20	52.6	
Total	31	100.0	38	100.0	
Takes Medication on Time					-.169
Sometimes or Never	18	58.1	16	41.0	
Always	13	41.9	23	59.0	
Total	31	100.0	39	100.0	
Lifestyle Adherence Behavior					
Uses Condoms					.028
Does Not Always Use	11	39.3	8	42.1	
Always Uses	17	60.7	11	57.9	
Total	28	100.0	19	100.0	
Abstains or Has 1 Sex Partner					-.089
Does Not Abstain/has more than 1 partner	6	19.4	5	12.8	
Abstains or has one partner	25	80.6	34	87.2	
Total	31	100.0	39	100.0	
Abstains from Alcohol					-.260*
Had at least one drink	16	51.6	10	26.3	
Abstains	15	48.4	28	73.7	
Total	31	100.0	38	100.0	
Has Good Nutrition					-.024
Not Always	26	83.9	32	82.1	
Always	5	16.1	7	17.9	
Total	31	100.0	39	100.0	

* = p < .05
Source: Data collected in Uganda, 2007

Adherence Behavior by Age

Findings indicate that HAART adherence failure is more common among younger individuals than their older counterparts. For example, Results in Table 4 show that, the largest percentage of those who reported skipping taking a dose of medication was that of individuals between ages 20 and 29 (50%), followed by that of respondents between ages 30 and 39 (47%). Table 4 also clearly indicates that the youngest age group (ages 20 to 29) was far more likely to fail to adhere by drinking alcohol (73%) than those over age 40 (only 33% reported failure to adhere by drinking alcohol). Younger people were also more likely to fail to comply with dietary regimens (92% report failure to comply) than older respondents. On the other hand, more individuals ages 30 to 39 (46%) and those over age 40 (40%) reported failure to use condoms on a regular basis as compared to those under 29 years of age (25%). Individuals over age 40 (52%) were also less likely to take medication on time as compared to those ages 20 to 29 (42%). The association between alcohol use and age group is significant and moderately strong (Phi 0.318, p<. 05). Other associations are not significant, but consistent with those found in literature.

Table 4: Adherence Behavior by Age

Item	Age						
	20-29		30-39		40-65		
	N	%	N	%	N	%	Phi
Medication Adherence Behavior							
Skips Taking Medication							.180
Sometimes or Always	6	50.0	14	46.7	8	29.6	
Never Skips	6	50.0	16	53.3	19	70.4	
Total	12	100.0	30	100.0	27	100.0	
Takes Medication on Time							.070
Sometimes or Never	5	41.7	15	48.4	14	51.9	
Always	7	58.3	16	51.6	13	48.1	
Total	12	100.0	31	100.0	27	100.0	
Lifestyle Adherence Behavior							
Uses Condoms							.152
Does Not Always	2	25.0	11	45.8	6	40.0	
Always Uses	6	75.0	13	54.2	9	60.0	
Total	8	100.9	24	100.0		100.0	
Abstains or Has 1 Sex Partner							.020
Does not Abstain/has more than 1 partner	2	16.7	5	16.1	4	14.8	
Abstains or has one partner	10	83.3	26	83.9	23	85.2	
Total	12	100.0	31	100.0	27	100.0	
Abstains from Alcohol							.318*
Had at least 1 drink in last 6 months	8	72.7	9	29.0	9	33.3	
Abstains	3	27.3	22	71.0	18	66.7	
Total	11	100.0	31	100.0	27	100.0	
Has Good Nutrition							-.142
Not Always	11	91.7	24	77.4	23	85.2	
Always	1	8.3	7	22.6	4	14.8	
Total	12	100.0	31	100.0	27	100.0	

* = p < .05

Source: Data collected in Uganda, 2007

Adherence Behavior by Education Level

Results in Table 5 show adherence behavior by education level. Based on the findings, less educated individuals were more likely to skip taking medication, and more likely to report failure to use condoms regularly as compared to those who are more educated. For example, nearly half (48%) of those with no education or only primary school education reported skipping a dose of medication, as compared to only 13% of those with higher schooling or college.

This trend is also true of condom use (Table 5) whereby individuals with no or primary school education were almost five times as much (68%) as those with college education (14%) to report failure to use a condom regularly. The relationship between education level and condom use is moderately strong and significant (phi = .474, p< .05). On the contrary, the percentages of more educated people that reported using alcohol (38%) and having sex with multiple partners are higher than those of individuals with primary or no education, probably due to economic reasons. Except for condom use and education level, other associations are weak and insignificant.

Table 5: Adherence Behavior by Education Level

| Item | Education Level | | | | | | Phi |
| | None/ Primary School | | Senior School | | College/ University | | |
	N	%	N	%	N	%	
Medications Adherence Behavior							
Skips Taking Medication							.220
Sometimes or Always	14	48.3	13	40.6	1	12.5	
Never Skips	15	51.7	19	59.4	7	87.5	
Total	29	100.0	32	100.0	8	100.0	
Takes Medication on Time							.138
Sometimes or Never	12	41.4	17	51.5	5	62.5	
Always	17	58.6	16	48.5	3	37.5	
Total	29	100.0	33	100.0	8	100.0	
Lifestyle Adherence Behavior							
Uses Condoms							.474*
Does Not Always Use	13	68.4	5	23.8	1	14.3	
Always Uses	6	31.6	16	76.2	6	85.7	
Total	19	100.0	21	100.0	7	100.0	
Abstains or Has 1 Sex Partner							.144
Does Not abstain/has more than 1 partner	3	10.3	7	21.2	1	12.5	
Abstains or has one partner	26	89.7	26	78.8	7	87.5	
Total	29	100.0	33	100.0	8	100.0	
Abstains from Alcohol							.187
Had at least 1 drink in last 6	8	27.6	15	46.9	3	37.5	
Abstains	21	72.4	17	53.1	5	62.5	
Total	29	100.0	32	100.0	8	100.0	
Has Good Nutrition							.171
Not Always	24	82.8	26	78.8	8	100.0	
Always	5	17.2	7	21.2	0	0.00	
Total	29	100.0	33	100.0	8	100.0	

* = p < .05

Source: Data collected in Uganda, 2007

In summary, the percentage of respondents that reported always taking

medication on time (51%), and those that reported failure to always take medication on

time (49%) is almost equal. About 60% of the respondents reported that sometimes they

skip taking a dose. A comparison of adherence behavior across gender, age and education reveals that males are less likely to comply with the health provider's treatment regimens as opposed to females. Males were more likely to have multiple sex partners, to drink alcohol due to cultural reasons, and not to take medication on time. Females on the other hand were less likely to use condoms regularly because they lack power to negotiate safe sex. Older people used condoms less than younger individuals probably because they were more likely to engage in monogamous relationships. However, overall younger people were less likely to adhere to medication regimes and lifestyle recommendations as compared to their older counterparts. Additionally, less educated individuals reported sometimes skipping taking medication and not using a condom regularly more than people with higher education, possibly because they do not fully understand public health implications of HAART adherence failure. On the other hand, more educated people report using alcohol and having sex with multiple partners more than those with primary or no education, probably due to economic reasons.

Factors That Influence Highly Active Antiretroviral Drug Adherence Behavior

The second research question is: What factors influence highly active antiretroviral drug adherence behavior? It remains a challenge for researchers why some individuals choose not to adhere to medication regimens. Medication adherence failure is problematic for those under HAART because failure to comply with prescription regimens may lead to the formation of HIV drug resistant strains that cannot be controlled by medication (Machtinger and Bangsberg 2008; Wensing and Boucher 2003). This research question attempts to shed light on the underlying reasons why some

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individuals on HAART fail to adhere to medication regimens, and what makes others comply. The data may contribute to the formulation of new, or improvements in existing strategies to promote HAART adherence behavior in low-income nations. In addition, findings may assist in the efficient distribution of resources geared towards enhancement of HAART effectiveness in developing countries.

Quantitative Analysis

Based on findings revealed in Table 6, lack of food was the major obstacle for skipping taking medication as reported by 59% of the respondents, followed by forgetting (33%) and failure to carry medication while traveling. Although studies conducted in developed countries reveal that side effects influence medication adherence failure, findings in this study show that side effects had the least influence on skipping taking medication with only 2% of the participants reported that they sometimes skipped taking medication because of side effects (Ammassari et al. 2001; Safren et al. 2005). An overwhelming majority (98%) indicated that they take medication regardless of side effects. Likewise, 94% of the participants reported that alcohol use does not make them skip taking medication. A large percentage of respondents also indicated that embarrassment (84%), sleeping through the dose (83%), and not carrying medication (81%) do not make them skip taking medication, which shows that these issues have minimal impact on medication adherence behavior. Medication representation may explain the high percentages of adherence indicated above because; almost all participants (99%) reported that, if they kept taking highly active antiretroviral drugs, they believed their overall quality of life would improve. Belief in the effectiveness of

medication or medication representation is highlighted in literature as influential in

medication adherence behavior (Garcia and Cote 2003).

Table 6: Factors Influencing Adherence Behavior

Item	N	%
Medication-Related Factors		
Side Effects		
Sometimes or always skip due to side effects	1	1.8
Never Skip Due to Side Effects	55	98.2
Total	56	100.0
Alcohol Use		
Sometimes or Always Skip due to alcohol use	4	6.3
Never Skip Due to Alcohol Use	60	93.8
Total	64	100.0
Embarrassment		
Sometimes or Always Skip Due to	10	15.6
Never Skip Due To Embarrassment	54	84.4
Total	64	100.0
Oversleeping		
Sometimes Skip Due to Oversleeping	11	17.2
Never Skip Due to Oversleeping	53	82.8
Total	64	100.0
Forget to Carry Medication		
Sometimes or Always Skip Because forget to	13	18.6
Never Skip Due to Forgetting to Carry	57	81.4
Total	70	100.0
Forget to Take Medication		
Sometimes or Always	22	33.3
Never Skip Due to Forgetting	44	66.7
Total	66	100.0
Have No Food		
Sometimes Or Always Skip Due to No Food	41	58.6
Never Skip Due to No Food	29	41.4
Total	70	100.0
Other Influential Factors		
Has Social Support		
No Social Support	13	18.6
Has Social Support	57	81.4
Total	70	100.0
Believes in Effectiveness of medication		
Probably or Definitely Will Help	69	98.6
Probably or Definitely Will Not Help	1	1.4
Total	70	100.0

Source: Data collected in Uganda, 2007

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The presence of social support may also partially explain the high percentages of those that claim to adhere to medication regimens. Research reveals that lack of social support may enhance adherence failure (Munro et al. 2007). The results in this study show that over three quarters of the respondents (81%) had someone they depended on to (help them) take medication.

<center>Qualitative Analysis</center>

Responses to Why Individuals Skip or Don't Skip Taking Medication

When asked specifically to give reasons for or against skipping, lack of food, fear of mixing alcohol with medication, and doctor communication emerged as the major reasons. Previous experiences with opportunistic diseases, illness or medication representation, and communication, confidence, and trust in the doctor surfaced as major reasons for adherence to medication regimens.

Why individuals skip taking medication. When asked to explain why respondents sometimes skip taking medication, lack of food was a dominant theme. Most of those that reported skipping taking medication due to lack of food often expressed the desire to take medication, but at the same time feelings of helplessness to take it regularly because they did not have the economic means to buy food. For instance, these feelings are detected in a 28-year-old female participant's statement when she claimed that,

> I do not want to miss taking medication. However, the doctor tells me to take it on a full stomach, yet at times I do not have money to buy food. When I have no food to eat that is when I skip taking medication. Otherwise merely swallowing the tablet is not an issue because I can easily and willingly do that.

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A 30-year-old female participant also relayed feelings of helplessness to adhere to the health providers' dietary recommendations as she indicated that, "I would rather the doctor does not put the food condition on taking medicine because if you have no food, then you may skip taking your medicine."

Males also reported skipping taking medication because of lack of food. For example, a 36-year-old male respondent claimed that, "I sometimes miss taking medicine because I have no food to eat before I take it. In Africa we have a general problem of following the doctors orders to take medication with food because of low income."

Fear of mixing alcohol with highly active antiretroviral drugs was another theme that surfaced as a reason for skipping medication. Some of the participants revealed that they skipped taking medication intentionally when they were under the influence of alcohol because of HAART education. For example, a 45-year-old respondent justified his medication taking behavior by saying that,

> When I take alcohol, I do not swallow medication because the health providers informed me it is dangerous to mix alcohol with medication as it may turn medicine into poison. They also told me that medicine does not work well if it finds alcohol in the system and I understood that. Therefore, when I drink alcohol, I find it justified skipping a dose as I reason within myself that, if I take the medication, I will be wasting it. Skipping that dose makes me feel I have done the right thing.

Another male respondent also conveyed this theme in a more explicit way when he said that,

When I drink, I intentionally skip taking mediation because the doctor told me that I can't mix spirits with medical drugs. In that case when I feel a craving for an alcoholic drink, I have to make a choice if it is the drink or medication. If I decide to cheat by taking alcohol, then I take the drink and not the medicine.

Other participants indicated that, skipping taking medication after drinking alcohol is not intentional, but they forget to take medication while under the influence of alcohol. For example, as a 31-year-old male soldier confessed, "When my friends join me, I'm forced to drink alcohol with them. The problem is that drinking often makes me forget taking medication."

Why individuals do not skip taking medication. Of the 59% who indicated they never skip taking a dose, previous experiences with opportunistic diseases, illness and medication representation as well as trust in the doctor emerged as major influences for not skipping taking medication. Illness representation in this discussion refers to individual beliefs about HIV, and medication representation to beliefs about the effect of medicine on HIV. The influence of illness and medication representation on not skipping taking medication may be detected in a 25-year-old female respondent's statement that,

I do not find any difficulty following the doctors orders to take medication in a given dose at the exact time because, based on my experiences with opportunistic illnesses, if someone tells me that this medication will soothe the pain, I swallow it immediately without question. This is because I cannot tell you the pain I

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experienced from some of the opportunistic illnesses. ... I do exactly as the doctor tells me to do.

The influence of medication representation on adherence is also detected in a 35-year-old female participant's affirmation that,

I have no problem following the doctor's orders because, in comparison to the situation I was in before I began HAART, I have hope that my health will continue improving. I know this because I feel energetic and I am no longer sickly as I used to be before I began HAART.

Males also portrayed experiences with opportunistic illness as well as illness and medication representation to be influential in not skipping taking medication. For example, a 45-year-old male respondent asserted that,

I do not skip taking medication because I see a change in my life. For seven years before I started HAART, I was often down with various illnesses, feeling extremely ill and completely under the control of AIDS. However, when I began HAART I decided to comply with the doctor's advice. I was told to eat, drink, and use medications as prescribed and I complied. My health improved month after month. Currently I feel that my health is good.

Confidence and trust in the doctor was another theme that surfaced in explaining why individuals do not skip taking medication. The influence of health providers on adherence is depicted in a 45-year-old male respondent's statement that,

I take medication as prescribed because my doctor convinced me to do so. For example, he asked me to tell him my age and I told him I am 43 years of age. He

then informed me that if I keep taking this medication as prescribed, I will be able to add 30 more years to my life's span and I was extremely happy. For that reason alone I try not to skip a dose.

A 32-year-old female also stressed that, "I follow the doctor's orders because I believe whatever he says is true. He told me to take the medication all the time and when I did, I got better. He told me not to drink alcohol and I stopped. He told me to use a condom and I do because I realize there is a change in my life."

Responses to Why Individuals Take or Fail to Take Medication on Time

Failing to take medication on time minimizes HAART's effectiveness in treating HIV because it lowers the required drug concentration level in the blood system, giving HIV the chance to mutate and multiply (Descamps et al. 2000). As shown in Table 2, about half (49%) of the respondents indicated they sometimes did not take medication on time, whereas another half (51%) revealed they always took it on time. In an attempt to further understand what influences individual medication taking behavior, respondents were asked to explain in depth why they did or did not take medication on time. This led to the emergency of various themes like stigma, being busy and traveling. On the other hand, choosing a convenient time, cues to action, and disclosure emerged as influential factors in taking medication on time.

Why individuals fail to take medication on time. Fear of stigma was reported as one of the main reasons why individuals did not take medication on time with respondents often expressing fear of ridicule. For example, a 28-year-old female participant revealed that,

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Sometimes I fail to take medication at the appointed time because I cannot find a way to get away from other people to take it, especially at work. In such cases, I just have to wait for that time when I can be alone to take it. ... I conceal taking my medication, and in so doing fail to take it at the appointed time.

Another theme highlighted by numerous respondents as an obstacle to taking medication on time was being busy. A 34-year-old female respondent who expounded on this theme stated that, "I sometimes fail to take medication on time. For example, I may be attending a business meeting and time may elapse unnoticed such that I may forget it is time to take medication."

As another female respondent put it, "I fail to take medication on time when I get so busy at work. However, I take it as soon as I remember."

Traveling away from home without taking medication along also surfaced as an influential factor in failure to take medication on time. For example, a female respondent stated that, "I sometimes fail to take medication on time if I travel. For example, I may go to the village to visit family or for a funeral and by the time I get back in town, the time to take my evening dose has elapsed."

Why individuals take medication on time. Of the 51% who indicated always taking medication on time, choosing a convenient time and cues to action as well as disclosure, emerged as influential factors for the timely intake of medication. For example, a 44-year-male respondent that was given a choice to decide a time to take medication confidently stated that,

I always take my medication on time because the doctor allowed me to choose a convenient time to take it and I chose 9 o'clock in morning and evening. At 9 O'clock in the morning, I have taken morning tea such that the next thing I do is to take medication. At 9 o'clock in the evening I am home and before I go to bed, I take the medication. Therefore, I see no reason for not taking my medication on time.

Likewise, a 24-year-old female participant that was given a choice to decide a time to take the medication and who chose a convenient time with a cue to action stated that,

I have no difficulty taking medication on time because the doctor told me to choose the most convenient time to take it and I chose 9 o'clock in the morning and evening. Nine o'clock is time for the national news broadcast such that, whenever I hear the news on Radio regardless of what I am doing, I know it is time to take my medication such that I just go and take it.

Physical pain as a cue to take medication on time was also mentioned as a factor influencing adherence to medication regimens. As a 26-year-old female indicated,

When I take long without taking medication, I feel as if my stomach is beginning to hurt. However, as soon as I try to take the medication like this, the pain in my stomach disappears immediately. That means that I have to take medication on time. If I go 5 minutes past that time my stomach begins to unravel and to hurt. However, as soon as I take the medication like this, the rumbling stops immediately.

Disclosure was another theme. Individuals that disclosed their serostatus to others, or who felt that other people knew they were HIV positive indicated that they had nothing to hide by concealing taking medication, which meant that they were able to always take medication on time and anywhere. The relation between disclosure and always taking medication on time was revealed in one of the female participant's statement that,

> I have no problem at all taking medication on time or before other people because most of my relatives and friends know that I have AIDS. I was forced to tell them because I developed "kisipi" (herpes zoster), which made it obvious to all who saw me that I have AIDS. For that reason, I have nothing to hide by concealing medication intake because people already know I have AIDS.

Responses to If Respondent Skips Taking Medication Because of Side Effects

Research also reveals that adherence failure is more likely for those that perceive medication to cause undesirable side effects (Berg et al. 2007; Hardon et al. 2007). Gao's el al. (2000) study reports that side effects from medications are the greatest perceived obstacle to taking medication regularly. However, as revealed in Table 6, despite the fact that some of the side effects caused by highly active antiretroviral drugs may be severe, when respondents in this study were asked specifically if side effects sometimes made them skip taking medication, almost all participants (98%) said side effects did not make them skip taking medication. Only 2% indicate side effects sometimes make them skip taking medication. Asked to support their responses, almost all participants who indicated side effects to be an obstacle in taking medication indicated that health provider

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communication and previous experiences with opportunistic infections were the factors that most influenced their medication-taking behavior. For instance, a 30-year-old female participant that had been on HAART for less than three months who was experiencing numerous side effects concurrently explained that,

Since I started taking this medication, I experience side effects often in the form of headaches, dizziness ... and nightmares. However, I do not skip taking my medication because I was warned by the doctor that these health conditions are expected, and that they usually disappear within three to six months.

Another female participant who portrayed the influence of doctor communication on medication adherence regardless of side effects manifestations also claimed that,

Taking highly active antiretroviral drugs makes me nauseated. However, nausea does not stop me from taking medication because the doctor told me that it is normal to experience side effects for those under HAART. Sometimes I may throw up after taking the medication. However, when that happens I don't re-take it because the doctor did not inform me how medicine reacts after it has been in the body for 30 minutes.

Male respondents were also adamant about taking medication regardless of side effects, which is also attributed to doctor communication. For instance, as a 30-year-old male respondent emphasized, "There is no time that I get sick and fail to take medication. Whatever illness hits, I swallow the medication because the doctor insisted that it is important I keep taking it regardless of side effects because they are temporary, and that they only last for a few months."

Responses to If Respondent Skips Taking Medication Because of Embarrassment

Research reveals embarrassment or shame may be an obstacle to medication adherence whereby individuals may fail to take or they may fail to take medication on time if the timing for taking it finds them in the company of other people (Wurth and Perlow 2005). When asked specifically if respondents sometimes skip taking medication because of embarrassment, the majority (84%) of the respondents reported they never skip. This shows that the influence of embarrassment on taking medication is minimal. All participants indicated that disclosure had a big influence on whether they sometimes skipped taking medication or not while others are watching. Participants that reported skipping taking medication due to embarrassment expressed concerns for stigma and social setting; whereas value for life, perception that HIV can infect anyone, and belief that spectators can't tell the type of medication one is taking surfaced as influential factors for those that complied with medication regimens in-spite of being watched by others.

Individuals that skip taking medication due to embarrassment. Stigma had a major impact on whether one skipped taking medication or not. For example, a 27-year-old female respondent that reported sometimes skipping medication because of embarrassment, and who expressed concerns for stigma explained that,

I find it difficult to take medication when others are watching and if possible I usually excuse myself and go into the back where no one can see me because AIDS is stigmatized. If I can't excuse myself, I may miss a dose or take it late.

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Another way that I hide my medication use, I may decide to swallow it on the way from work before I get home in order to avoid others from seeing me take it. However, this is usually before the appointed time for taking that particular dose.

Male respondents also expressed concern with stigma, shame, and disclosure. As a 36-year-old male respondent asserted that,

> I keep my medication in the bedroom such that only my wife and I know about it. You cannot put that medication in the office and take it when other people are watching because; you can't go reporting yourself by spreading the word to everyone that I am sick, I am sick, I have AIDS. It is like putting your business on the table for everyone to see.

Numerous participants also implicated social setting as having an influence on whether they sometimes skipped taking medication. Some individuals revealed that they were embarrassed or ashamed to take medication in certain environments. This is seen in a statement made by a 49-year-old male respondent that,

> I wouldn't take medication when other people are looking like at work because people do not understand, which sometimes makes me skip taking it. However, I can take it openly at this clinic (HAART providing clinic) without a problem because I know that people here share the same problem as I do.

Other participants reported that among those to whom they had not disclosed, they did not always take medication regularly. For instance, as reported by a 25-year-old female respondent,

When the people I am with know that I am HIV positive, I have difficulty taking

antiretroviral medication, and I may fail to take it. I can't show my medication to

everyone. For example, one person may notice you are swallowing medication.

The next thing you may hear is that, 'that person is at the end of the rope

(aweddeyo).' The funny thing is that, those that gossip may even fail to realize

the possibility that they could die from any other health condition before I do.

A 27-year-old female participant also identified concerns for disclosure and

stigma by stating that,

At times I may skip taking medication because I am embarrassed to take it before

other people. I don't care for those I have disclosed to, but there are other people

for example at work that I don't want to notice I am taking highly active

antiretroviral drugs... If people like that find out you have AIDS, they start

backbiting you. Because of that, I often use wisdom to make sure others do not

see me taking antiretroviral medication, but in so doing I may take it late.

Individuals that do not skip taking medication due to embarrassment. Disclosure

was also a dominant theme in explaining why individuals comply with medication

regimens. Other influential factors included prioritizing value for life before

embarrassment, perception of AIDS as for everyone, and belief that spectators can't tell

the type of medication one is taking. For example, the impact of disclosure of medication

taking behavior may be seen in a 36-year-old female respondent's statement when she

said that,

I always take medication on time because I can take it anywhere, since almost everyone knows my HIV serostatus. Even when I am in someone's office I may just mention that, oh! It is time to take my medication. I take out my bottled water and swallow it right there and then. What encourages me is the fact that this very medication is what made me whole again. Even when I am walking down the street no one can pin-point me out that she has AIDS based on physical appearance as used to be the case...

Another theme was value for life. Prioritizing the value for life before embarrassment was made clear by a 54-year-old male soldier who confidently stressed that, "Be it at a wedding ceremony I will openly pull out my medication and swallow it before everyone at the exact appointed time because I am not ashamed of trying to save my life."

A 28-year-old female respondent who regularly took medication on a timely basis regardless of who was around also claimed that, "I am not embarrassed to take my medication while other people are watching because I know that I am just trying to take care of my life. Regardless of where I am, when it is time to take my medication I just get it out and swallow it, regardless of who is watching."

Another female participant also asserted that,

I have no difficulty swallowing medication when others are watching because I take this medicine to save my life. Even if someone is sitting right in front of me, she/he will not stop me from swallowing my medication at the appointed time because this is my life and I am going to take care of it.

Perception of AIDS as a global pandemic that affects all humanity was another theme. As a 41-year-old male participant reported,

I have no difficulty taking antiretroviral medication on time or because other people are watching due to the fact that, whatever is happening to me is not just for one person. If I choose to hide my condition and refuse to take medication as prescribed, I will be killing myself. When I realize that the disease has spread around all corners of the earth, I take comfort that I am not alone, and it motivates me not to be ashamed ....

Numerous participants also revealed that they do not skip taking medication because they believe those around them often do not know the type of medication being taken. A common response was by a 38-year-old male respondent, who said that,

I have no problem taking highly active antiretroviral drugs when others are watching because no one will know the medication I am swallowing is for AIDS. I have never shown any of the visible HIV/AIDS symptoms such as a skin rush. People may speculate that I am taking medication to fight off a normal illness like malaria, just like anyone else that does not have HIV.

Responses to If Respondent Skips Taking Medication Because It Is Not on Her/Him

As shown in Table 6, when asked if respondents sometimes skip taking medication because it is not on them, the majority (81%) indicated they never and only 19% said they sometimes skip taking medication because it is not on them. This would indicate that the influence of traveling on medication adherence is minimal. Unexpected delays emerged as a major theme that influenced skipping taking medication for those

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that reported adherence failure due to traveling without carrying medication. Remembering to carry medication at all times on the other hand emerged as one of the major themes in explaining why traveling away from home did not influence skipping taking medication.

Individuals that skip taking medication because it is not on them. Many of the 18% who reported sometimes skipping taking medication because of failure to carry it at all times indicated this was due to unexpected delays. For instance, as a 42-year-old male respondent explained,

> I have difficulty taking medication on time because, sometimes I may find that I have gone to look for maize floor (wage labor that will buy food) at a certain location and then find I have to go to a different location unexpectedly, which location may be much further than home. In the process, time takes me by surprise. As you may imagine the world in which we live here in Uganda, the one who owes you hides from you. Yet he may be your transportation ticket back home. So you find that time elapses when you are waiting for your pay and you may not get home on time to take medication.

Individuals that don't skip taking medication while traveling. The major theme that emerged for those that did not skip taking medication while traveling was always remembering to take medication along. For example, a 33-year-old male participant stated that, "I always put my medicine in the bag first whenever I have to go somewhere. I may forget my shirt, but not my drugs."

Female participants responded in a somewhat similar manner. For example, a 40-year-old female reported that, "Whenever I have plans to travel anywhere away from home, my medication goes in my purse first. I always remember to carry my medication with me because I never know if I will delay getting back home."

The Influence of Social Support on Adherence Behavior

According to Gordillo et al. (1999), individuals with social support are more likely to adhere to medication taking regiments. Other studies associate the presence of other individuals in the home with medication adherence behavior (Machtinger and Bangsberg 2008). Social support was included in this study to see if it would give some understanding as to why some individuals fail to adhere to medication regimens as opposed to others. Based on statistics shown in Table 6, social support appears to have some influence on medication adherence behavior because, when asked if respondents have anyone that supports them to take medication, the majority (81%) indicated having someone or people that reminded them to take medication. Only 19% said they did not have social support.

Individuals with lack of access to social support. One of the interesting findings not reported in literature was that individuals that reported not having social support referred to reminder cues and self-efficacy as substitutes for social support, and hence influential in helping them take medication regularly, even in the absence of social support. For example, a 32-year-old female participant reported that, "I don't have anyone to support me (in taking) because I live by myself. However, I dedicated myself

to follow the Dr.'s orders from the time I started HAART. I am a strong independent woman. I use my mobile phone alarm clock to remind me of the time to take it."

A 55-year-old male soldier that reports lack of social support, but who relies on self-efficacy to take medication also expressed that,

It is my will and in my power to take medication at all times. I do not believe it is anyone else's responsibility to remind me to take medication. I have to be self-supportive because I was also alone on the deathbed, not anyone else. I care about my life too much to depend on anyone for it. I don't need someone else telling me that I need to take medicine when it is I that is interested in life.

Or as a 24-year-old male participant put it that, "I do not have anyone to remind me to take medicine at work, but I still take it because I know it is my responsibility."

Respondents that reported having access to social support. Of the 81% that reported access to social support, family or friends were implicated as being supportive in enforcing medication-taking behavior. For example, a 50-year-old male participant illustrated that,

I do not miss taking medication and I always take it on time because there are three people in my household that are on HAART, my wife, one child and myself. We all chose to take it at the same time. It is not easy for all of us 3 to forget taking the medication. If one forgets, another one reminds them.

Another male participant also asserted that, "I take my medication as prescribed because my wife and children support me to take it. When it is time to take the medication, one of my children or my wife may bring the medication to me with a glass

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of water. However, even if my family is not around I still remind myself to take the medication."

Respondent's Attitudes Towards Highly Active Antiretroviral Drugs

Research indicates that medication representation, or beliefs about the effect of medication on a given illness, is influential in determining medication-taking behavior. According to Laventhal and Cameron (1987), patients are more likely to remember taking medication if they know its importance as opposed to those that have doubts about it. According to Table 6, when asked how respondents feel about the outcome of taking highly active antiretroviral drugs, almost all participants (99%) indicated they felt their quality of life would improve if they kept taking medication as prescribed. Only 1% said it would not improve. Here, almost all respondents were optimistic about a better quality of life outcome if they kept taking highly active antiretroviral drugs, which may explain the high percentages of those that claimed not to skip taking medication (Table 6). Clinical immunological gains such as the disappearance of opportunistic illnesses, CD4 cell count, weight gain, and physical energy emerged as the major themes that explain why respondents believed highly active antiretroviral drugs are effective in HIV treatment. For example, as a 28-year-old female participant reported,

> Based on how I feel now, I believe if I continue taking this medication as prescribed my health will continue to improve because this is not how I was. Soon after testing I was diagnosed with AIDS and came to this facility for treatment. I was started on HAART immediately because I had a severe fever of which I almost died from. I had reached the end of life. However, when I came

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to this facility the health professionals pampered me and started me on HAART after which my condition improved. This is how I appear today and that is why I believe my quality of life will continue to improve.

Or as 33-year-old female respondent put it that, "As I swallow each pill I feel my life is improving because since I started HAART, my health has been getting better. I have put on weight and the health problems that were bothering me such as a chest pain and other opportunistic illnesses cleared."

Males also reported belief in the effectiveness of highly active antiretroviral drugs in treating HIV, given improvements in their health. For example, a 33 year-old male reported that,

If I follow the treatment regimen as prescribed, I believe I will stay healthy because, I cannot tell you otherwise but that, even if I died at this hour I cannot underrate what this medication has done for me. I gained consciousness, my health improved. I feel healed because I am not ill anymore. All health issues stopped as soon as I began HAART and I feel my health will remain good.

Similarly, a 46-year-old male participant who attributed an increase in the CD4 cell count and weight gain to the effect of highly active antiretroviral drugs on HIV also stressed that,

I do not want to skip taking my medication. HAART brought my health to its originality. I had been sick for over 7 years. Most of the severe illnesses that used to bother me are gone, except for minor fevers and a cough sometimes.

Before I started taking this medication, I could not sit down for 4 hours without sleeping. Currently I can stay awake for 24 hours.

Another theme was the respondents' hope for HIV cure. For example, a 28-year-old female participant asserted that, "I believe that if I keep taking this medication I will be completely healed because compared to what I was before I started HAART, to where I am currently, it is a very big difference. I used to have illnesses like a fever, a cold, and a cough that could not heal. I no longer have those conditions."

A 47-year-old male participant also indicated that, "I really feel that the more I continue taking antiretroviral medication, I will indeed be cured of HIV because the soldiers (CD4 cell count) in my body were only 27 when I started this medication. Six months later they have accumulated to about 190."

In summary, lack of food (59%) and forgetfulness (33%) had the biggest influence on skipping taking medication. Side effects (2%), alcohol use (6%), embarrassment (16%), sleeping through the dose (17%) and not carrying medication (19%) had the least influence on adherence failure. The high percentages of individuals that reported belief in highly active antiretroviral drugs as effective in treating HIV (99%), and to have access to social support (81%), may partially explain the moderate to high percentages of those that claim to comply with medication regimens. Respondents also reported fear of mixing alcohol with medication, being busy, embarrassment, social setting, and unexpected delays when traveling to be influential in skipping taking medication. On the other hand, experiences with opportunistic infections, illness and medication representation, doctor communication, trust in the doctor, choosing a

convenient time, cues to action, disclosure, value for life, and remembering to carry medication at all times emerged as influential factors in medication adherence (not skipping medication).

Factors That Influence Lifestyle Recommendations Adherence Behavior

The third research question is: What factors influence HAART lifestyle adherence behavior among Ugandans on therapy? This question attempts to identify the underlying reasons why some individuals on HAART comply with lifestyle recommendations like safe sex, regular use of condoms, abstinence from alcohol and good nutrition as opposed to those that do not. This knowledge is essential for maximizing benefits from HAART, and it may assist in the development of strategies geared towards effective treatment and control of HIV in developing societies.

As noted in Table 2, despite HAART efforts to promote healthy lifestyles among those under treatment, 40% of the participants reported they did not use condoms regularly and 38% revealed failure to abstain from alcohol. Respondents complied least with dietary recommendations with 83% of the individuals reporting failure to access good nutrition. Participants complied most with abstinence from sex or having one sex partner (84% of the respondents). When asked to explain why some respondents chose not to engage in sex with multiple sex partners as opposed to those that did, resentment for people of opposite sex emerged as an influential factor. Analysis of open-ended responses reveals additional influential factors, which include the regular use of condoms, abstinence from alcohol, and having good nutrition. On the other hand, poverty, gender power imbalances, and mental health emerged as factors associated with

risky sexual behavior, the use of alcohol, and poor nutrition. The discussion below

begins with a brief description of lifestyle recommendations, presented in the context of

Talcott Parsons' sick role theory (1951), followed by a discussion of the quantitative

findings. The final section analyzes qualitative responses to provide a more in-depth

portrayal of factors that influence adherence to HAART lifestyle recommendations.

HAART Life Style Recommendations

Before proceeding, it is important to understand HAART lifestyle

recommendations from Talcott Parsons' perspective. The basic lifestyle

recommendations are (a) abstinence or engagement in sex with one sex partner, (b)

always using a condom, (c) abstinence from alcohol, and (d) and having good nutrition.

According to Parsons' sick role theory (1951), illness ought not to be self-inflicted for

instance by engaging in health risk behaviors. In addition, those affected by illness must

have a desire to get well, seek help from health professionals, and once under treatment

must comply with the health providers' treatment recommendations. Individuals enrolled

in HAART are obligated to comply with the sick role expectations, one of which pertains

to safe sex practices. This is because the goal for HAART is not only to prevent HIV

from replicating and destroying the CD4 cells after infection, but also controlling the

infection rate. Other lifestyle recommendations include abstinence from alcohol because

alcohol is a drug and its chemistry may interfere with HAART results. In addition, the

literature reveals that alcohol consumption may contribute to medication adherence

failure whereby its consumption may cause individuals to forget taking medication, and it

may lead others to engage in unsafe sexual intercourse. Participants are also

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recommended to have good nutrition. Adequate nutrition is necessary for the functional

maintenance of the immune system and to carry out chemical processes within the body

(FAO 2002; Williams and Friedland 1997). Failure to adhere to the above lifestyle

recommendations may minimize the effect of HAART for those under treatment.

Quantitative Analysis

Results are presented in Table 2. Findings show that only 17% of the respondents

report having good nutrition as opposed to the 83% who don't. Participants comply most

with abstinence from sex or having sex with one partner (84% comply) as well as alcohol

(62%). However, 40% use fail to use condoms regularly and 38% fail to abstain from

alcohol, and (Table 2).

Qualitative Analysis

Respondents were asked to explain in detail why they complied with or failed to

adhere to HAART lifestyle recommendations. A number of themes emerged in this

analysis. These included resentment of the opposite sex, illness representation, perceived

threat of AIDS, birth control, and alcohol representation. On the other hand, poverty,

gender power imbalances, cultural beliefs, anxiety, addiction, and peer pressure emerged

as themes explaining why individuals failed to adhere to HAART lifestyle

recommendations.

Responses to Why Individuals Engage or Don't Engage in Sex with Multiple Partners

One of the goals for HAART is to promote abstinence, or having sex with one

partner. Table 2 indicates that the vast majority (84%) of the respondents reported

abstinence from sex or having one sex partner with only 16% that indicated having

multiple (more than one) sex partners. When asked to give reasons for or against engagement in sex with multiple partners, economic need and alcohol use surfaced as major explanatory themes. On the other hand, the major theme that emerged for those that abstained or had sex with one partner was resentment for individuals of the opposite sex.

Reasons for engaging in sex with multiple partners. Although scholars in developed countries report that one of the effects of HAART is to increase the prevalence of risk sex behavior because those under therapy perceive themselves as non-infectious due to decreased viral load and CD4 cell count, these data indicate that it is not HAART, but economic need and alcohol use which induce risk sex behavior (Remien et al. 2007). The theme of economic need was more common among females than males, whereas that of alcohol use was more common among males. For example, a 29-year-old female respondent expressed that,

> Since I started highly active antiretroviral drugs, I have had sex with 3 men. I don't usually want men to bother me. If they keep on disturbing me I give in, sometimes because nature kicks in. After one relationship I may get into another relationship with someone else. I am usually expecting some money from the male partner. When I realize he is not giving me anything I leave him and find another one.

Another female participant driven by economic need to have sex with multiple partners also reported that,

In the last 12 months, I had sex with 2 men. One of them was a casual partner; the other is my boyfriend whom I think is also having a sexual relationship with another woman. I am still with him regardless of all that because he supports me financially in a significant way, and I think he loves me. I can't get rid of him because he also will not leave me alone. There is no way I can jam (okwekyanga) on him when he shows me love by giving me money.

Males mostly implicated alcohol use as having an effect on the number of sex partners. For example, as a 33-year-old male participant put it, "Alcohol sometimes makes me sleep with women unexpectedly. I become like a hyena, I may even stop and buy someone to sleep with me. However, even if I am drunk, I still use a condom."

Why individuals on HAART abstain from sex or have one sex partner. Both females and males expressed feelings of resentment for the opposite sex as reason to abstain from sex, or to have sex with one sex partner. For example, a 35-year-old female participant who attributed abstinence to disliking males, stated that, "I have not slept with any man since I started HAART because I no longer like men. I don't even have a thought of men in my mind to tell you the truth. After knowing my condition, I turned to God and right now it is my God and I."

Another woman that chose abstinence and who attributed not having sex to a resentment for men also asserted that,

I do not want to sleep with men. I already had a lover I lived with at the time I started HAART. However, currently I tell him that, if you feel like having sex, you need to go find another woman because I will not have sex with you.

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Regardless of if I were to use a condom, from deep down my heart I no longer desire men. I gave up on them.

A male participant who claimed to have had numerous female lovers before, but who has maintained only one girl friend since HAART initiation also explained that, "I used to have many girlfriends. Since I started HAART, I have only been with one girlfriend because I feel women lovers give me a heart-burn (bankeeta). I do not like women any more."

Responses to Why Individuals Use or Fail to Use Condoms

The use of condoms is relatively new in the Ugandan setting and it was stressed more after the advent of AIDS. HAART promotes the regular use of condoms for individuals on treatment as a means to control the spread of HIV. To understand why some individuals chose to use condoms regularly as opposed to those that did not, participants were requested to give reasons behind condom use behavior. Gender inequalities, birth control, and cultural beliefs emerged as major themes among those that said they did not use condoms regularly. On the other hand, doctor communication, illness representation, perceived threat, and birth control emerged as major themes explaining why individuals used condoms regularly.

Why individuals on HAART do not always use condoms. One of the themes that emerged when respondents were asked to explain failure to use condoms regularly was gender power imbalances that situate females in settings where they lack power to decide whether or not to use condoms. This finding is in line with other global studies that

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portray females in powerless positions to negotiate safe sex (Pulerwitz's et al. 2002). For examples, as a 37-year-old female participant stated,

> I personally believe it is important to use a condom during sexual intercourse, but my husband refuses to use it. I don't know if my husband has other women but he makes the final decision in regards to condom use, and that means that we do not use condoms in our house. He says condoms are too much for him and he does not like them, which I do not understand.

Cultural beliefs pertaining to gender stratification and procreation were also given as reasons for not using condoms. Some respondents reported they did not believe in using condoms with spouses probably because the institution of marriage values procreation, and condoms may hinder pregnancy. It could also be true that males assumed their wives are not seeing other men given the cultural social contexts that expect females to have one sex partner if not to totally abstain from sexual intercourse, a norm that does not usually apply to males. Females in numerous African settings are also perceived as possessions without a voice. These characteristics are detected in a statement of one male respondent, who authoritatively and confidently asserted that,

> I do not use a condom with my wife at home because I believe it is only important to use it with outsiders. I will never use a condom at home with my wife. Why would I bring a condom when it is my wife, except if the purpose for using it is to control pregnancy but not safe sex? We do not discuss the condom because it does not concern us, period. However, since I started HAART I have had sexual

relationships with 2 wives. I use a condom with the wife that does not live with me.

Women also portrayed concerns of using condoms with spouses. For example, a 25-year-old female participant stated that, "I do not agree that just because I am enrolled in HAART I must use a condom with my husband."

Another female respondent also indicated that, "I have no problem following the doctor's orders to take medication. However, I do not agree with some of his advice like when he says I must use a condom even though I am married."

Females that had issues pertaining to using condoms with spouses may have responded in such a manner because they may have felt the need to have children, given the fact that procreation is a cultural value. Belief in procreation is reflected in one of the male respondent's statement that,

I think it is very important to use a condom but I already had 2 wives before I started HAART. My wives and I had never heard of the word "condom" until very recently. After being introduced to the condom, we tried to use it but it did not go well for us. When I discussed the need to use a condom to both my wives after enrollment in the HAART program, one of them did not agree to use it because she wanted children, which stirred a lot of conflict between us. She accused me of the possibility of having other women saying that I want to use a condom because I do not love her any more. The other wife also did not agree to use a condom. To somewhat balance these differences, we decided to have sex only once in two weeks or a month because having sex is a call of nature.

Why individuals on HAART use condoms regularly. Among the 60% who reported using condoms regularly, doctor communication was one of the themes that surfaced in explaining regular use of condoms. For example, a male participant that used condoms regularly stated that, "I always use a condom because the service providers counseled my wife and I and told us it is very important to use it. Ever since, I use a condom during sexual intercourse.

Perceived threat of re-infection with a different HIV strain was another emergent theme associated with doctor communication in explaining why some individuals always used condoms. Like a 49-year-old male respondent illustrated,

I was informed by the doctor that there are various types of HIV strains and that not everyone is infected with the same type such that, it is dangerous to mix the different strains through failure to protect oneself. This danger scared me. For that reason alone, even when I pick up someone that is not already HIV positive, I would like to use the plastic (condom) so that we do not mix different strains of HIV. So, whenever I sleep with a woman I make sure that I use the condom, 100 percent.

Further indication of how effective HAART education can be in promoting condom use can be seen in a female respondent's statement that,

I don't know if it is necessary for us who have been living with HIV as a married couple to use the plastic (condom) as we have never discussed this issue with a health provider. We have not been using a condom because we neither know what a condom is, nor the difference in using it or not. If the health provider says it is necessary, then we shall use it

In addition to HAART, numerous respondents reported other factors like birth control to be influential in if to use a condom. For instance, as a 53-year-old male participant argued,

> I always use a condom because my girlfriend is young and anytime she may become pregnant. Otherwise, if she becomes pregnant, where will I put that child? For that reason I discuss safe sex with my girlfriend and I believe that the man has the power to decide if to use a condom or not. If a woman refuses it, the man should take control because the woman may become pregnant.

Illness representation also explains why some individuals used condoms regularly. This is clear from a 34-year-old-male participant's statement that,

> I believe that it is important to use a condom because slim (HIV/AIDS) is extremely painful such that it is not good to pass it on to any other person. If the other person does not have slim (AIDS), even if they want to have a child through sexual intercourse, let them first think about the consequences of slim. AIDS really hurts. Because I know how AIDS hurts, I always have condom use on my mind.

Responses to Why Individuals Abstain or Use Alcohol

HAART care providers advise participants to refrain from the use of alcohol because alcohol may foster health risk behaviors such as engagement in unprotected sexual intercourse or forgetting to take medication (Hardon et al. 2006; Haubrich et al. 1999; Moatti et al. 2000). The results in Table 2 indicate that 38% of the respondents reported having used alcohol in the past six months. To gain an in-depth understanding

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of why some individuals on HAART abstain from alcohol use while others continue to drink, participants were asked to state reasons for and against alcohol use. Anxiety, addiction, and peer pressure emerged as influential factors for individuals that reported to have used alcohol in the last six months, whereas provider communication emerged as a major theme in explaining why others abstained from alcohol use.

Why individuals on HAART drink alcohol. Many of those who reported having used alcohol in the past six months indicated that they were well informed by health providers that HAART does not work well with alcohol. When asked to explain why they choose to drink alcohol despite the health providers' recommendations, anxiety surfaced as an influential factor. Many of those that referred to anxiety as an impetus to drinking alcohol revealed concerns of poverty as well as fear of dying and leaving their children orphaned. For example, a 28-year-old female respondent stated that,

The doctor told me not to drink. However, anxiety induces my drinking of alcohol. I sometimes say to myself, alcohol will help soothe my emotional pain. If I drink alcohol, I will just fall down and sleep soundly without worries that are usually triggered by questions as to how I am to provide for my children or pay for rent." When I drink I feel relaxed.

Another female respondent also reported that, "I sometimes drink, but not because I like alcohol. I drink to get a temporary escape from worries. However, afterwards I regret as I ask myself why I took it when the doctor advised me not to drink alcohol"

Or as 26-year-old female participant put it, "I drink to make worries disappear so that I can go to sleep."

One of the female respondents also tried to justify alcohol use by arguing that,

Additionally, alcohol does not make me have unprotected sex.

> I cannot lie to you. A craving for alcohol comes every now and then and I may take some traditional beer. However, alcohol does not make me miss a dose because I begin drinking it in the afternoon and I stop earlier than the time I am supposed to take medication. If time is close to that when I am supposed to take medication, I do not drink alcohol, even if it is offered free of charge. Additionally, alcohol does not make me have unprotected sex.

Addiction was another highlighted theme that appears in the explanations of some individuals drink alcohol. For example, a 44-year-old male with issues of addiction explained that,

> Initially I was addicted to alcohol. Currently I may refrain from alcohol use for about three to four months. However, when I start drinking I take it daily. I do not want to crave for alcohol and many times I regret 100 percent asking myself why I have taken it when the doctors advised me otherwise. During such times it feels like someone who is going to fall into hell.

Another influential factor was peer pressure. Participants reported they knew they should not drink alcohol while under therapy and that they did not want to take it. However, they used alcohol for social reasons. For example, a 40-year-old male participant reported that,

> I sometimes take alcohol, often with peers when I am looking for work. I am in the construction business and many times I have to meet with fellow workers waiting for a customer to give me a plan of work. While waiting my peers may

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give me an offer of alcohol such that I end up drinking despite the fact that the purpose for meeting with my friends was not to drink. However, based on my alcohol use experience, I know how much alcohol to consume.

Another male participant also reported that, "I drink alcohol daily because after work, I am at home where many of my friends come for a social gathering during which alcohol is served. I don't want to drink but my friends usually influence me to drink. The problem is that drinking makes me forget to take my medication."

Females were as likely as males to report the influence of peer pressure on drinking alcohol, despite the efforts of HAART providers to curb its use. Like a 34-year-old female stated, "Health providers advised us not to drink. However, I drink because people offer me drinks at work, usually at a time when I am really thirsty. For example, someone may come and say, give her a very cold beer. If I take the offer I feel guilty afterwards because I know alcohol use is not good for me. "

Another female participant also reported, "The doctor told us to refrain from alcohol use because it interferes with the effects of medication. The problem is that I am often influenced by my peers while on the job."

Why individuals on HAART abstain from alcohol. Some respondents stated that HAART had an effect on decisions not to drink. Numerous respondents referred to information relayed by health providers against alcohol use. For example, a 37-year-old female respondent stated that, "I used to drink alcohol, but not any more because the health providers advised us not to drink. In addition, I understood the dangers or

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consequences of taking alcohol like making me to forget taking my medicine. I also realized that alcohol adds nothing to my life apart from the temporary happiness."

A 22-year-old female respondent also alleged that, "I do not drink alcohol because the doctor told me that if I take alcohol while on treatment I am wasting medicine. Because of that, I excused myself of alcohol"

Another theme that emerged in explaining why some individuals refrain from drinking alcohol was alcohol representation. For example, a 52-year-old male respondent who perceived alcohol to cause disease progression explained that,

> I used to drink daily, but I completely suspended alcohol use after I realized alcohol had an effect on my health. I felt that the more I used alcohol, the more my health deteriorated. For that reason, I suspected alcohol use because I realized that it was a hindrance to the treatment progress. That made me terminate its use.

Responses to Why Individuals Have or Fail to Have Good Nutrition

HAART health providers also recommend good nutrition for individuals on treatment. Good nutrition is essential for the human body because it boosts the immune system and it assists in processes such as digestion. To study the effect of HAART on promoting good nutrition, respondents were asked if they follow the doctor's orders to have a good diet. Findings revealed in Table 2 show that 83% of the participants did not follow the health providers' dietary recommendations, as compared to the 17% who did. When prompted to explain failure to do so, poverty emerged as the major theme. Many of the respondents expressed feelings of inability to acquire the recommended diet due to

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economic need. For example, a 29-year-old female respondent reported that, "The doctor says that if you enroll in the HAART program you need to have a good diet. The health providers also inform us that a poor diet makes one feel bad physically. But if you have no money to buy food, what can you do?"

Powerlessness to acquire good nutrition was also expressed by a number of male participants. For instance, as indicated by a 43-year-old male respondent,

I cannot have a good diet because I have no money to buy food. Currently, I am not working because I cannot find a job due to my health condition. My wife is the breadwinner in my household and her job does not pay her well. If I were working, maybe I would be able to access good nutrition as the doctor recommends.

A 36-year-old male respondent also asked,

Is there any way we can get some assistance with nutrition? This illness needs to affect the rich because without money, even treatment with highly active antiretroviral drugs may not be effective. Regardless of the doctor's orders that I must eat well, as a client I also understand that I need good nutrition including diary products, fruits, meat, and vegetables. However, without money I can't afford a good diet.

As a 33-year-old male respondent reported,

When I had first started HAART, they used to give us food supplements from international donors and that was very helpful because, most of the people with AIDS begin HAART when we are extremely ill such that we are extremely weak

and cannot work. We usually do not have jobs that can support us to buy food. It is sad that as soon as I became somewhat better, food support ended. The problem is that, people with AIDS cannot get jobs that offer a descent pay due to discrimination. It is difficult to have a good diet when you have no money.

In conclusion, participants revealed that failure to adhere to HAART lifestyle recommendations is most influenced by poverty, gender inequality, anxiety, addition, and peer pressure. On the other hand, findings indicate that resentment for people of opposite sex, birth control, and illness representation were the main factors that influenced individuals not to have sex with multiple partners, use condoms regularly, and abstain from alcohol.

The Impact of HAART on Perceived Quality of Life

The fourth research question is: What is the impact of HAART on perceived physical and psychological quality of life? Studies, especially those conducted in resource-rich nations reveal that HAART has been effective in improving the overall quality of life for those under therapy (Lohse et al. 2007; Rowell and Shippy 2004). However, few studies on the effect of HAART on physical and psychological health for those under therapy in resource-limited nations exist (Bunnell et al. 2006; Jelsma et al. 2005). As Table 7 indicates, more individuals (91%) reported better physical health since HAART initiation as opposed to those that reported better psychological health (83%). Almost all respondents (94%) indicated improvement in the overall quality of life since HAART initiation. Major themes that explain better physical health include a decrease in opportunistic infections, rise in the CD4 cell count, weight gain, as well as recovery from

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immune reconstitution syndrome and side effects. On the other hand, anxiety, hopelessness, and loneliness rooted in poverty and discrimination emerged as major themes in explaining poor psychological health. The discussion begins an analysis of quantitative responses and is followed by an analysis of the qualitative responses.

Quantitative Findings

Findings discussed below are shown in Table 7 and they reveal that HAART has had a major impact on improving the overall quality of life for those under treatment (94% of the participants). The biggest impact of HAART has been on physical health as opposed to psychological health. Statistics in Table 7 show that almost all respondents (91%) reported physical health as somewhat better or much better than before HAART initiation. On the other hand, a somewhat smaller percentage (83%) of the participants reported that their psychological health was somewhat better or much better since HAART initiation. An analysis of the responses reveals the states of physical health, previous experiences with opportunistic illnesses, immune reconstitution syndrome, and side effects are the major explanatory themes. On the other hand, anxiety rooted in poverty and perceived threat of disease progression surfaced as themes that explain poor psychological health. A discussion of the impact of HAART on physical health is followed by a discussion of its perceived impact on psychological health.

Table 7: Perceived Quality of Life Outcomes

Item	N	%
Physical Health		
Somewhat better or Much Better	64	91.4
The Same or Worse	6	8.6
Total	70	100.0
Psychological Health		
Somewhat better or Much Better	58	82.9
The Same or Worse	12	17.1
Total	70	100.0
Overall Quality of Life		
Somewhat better or Much Better	66	94.3
The Same or Worse	4	5.7
Total	70	100.0

Source: Data collected in Uganda, 2007

Qualitative Findings

The Impact of HAART on Perceived Physical Health

Participants gave detailed accounts of how HAART transformed their physical health through testimonies that reveal clinical, virological, and immunological gains such as increase in CD4 cell count, decreased opportunistic infections, and weight gain, which findings agree with those conducted in developed societies. Almost all participants reported experiences with opportunistic infections characteristic of AIDS diagnosis. The reader should keep in mind that it is normal for individuals with AIDS to experience multiple different opportunistic illnesses concurrently. In that regard, previous experiences with opportunistic infections were one of the dominant themes in rating

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physical health as participants compared the current states of their health to those before HAART.

How HAART Has Improved Physical Health

In order to fully grasp the meaning of HAART to participants in the discussion of quality of life below, it is important to realize that palliative care is almost non-existent in Uganda. In that regard, respondents who indicated that HAART has improved their physical health described experiences with opportunistic infections before HAART as characterized by excruciating, agonizing pain. Their distress was relayed through their body language, gestures, voice tones, and verbal expressions in a depth that no English words could express. In addition to Herpes zoster, participants revealed experiences with skin rashes, sores from the mouth down to the esophagus into the stomach, weight loss, vivid dreams, weakness, and lack of appetite as manifested in the most severe way. With the advent of highly active antiretroviral drugs and medication adherence, these illnesses improved or healed. Below is a glimpse of how respondents described manifestations of opportunistic illnesses in the absence of palliative care as well as testimonies in reference to the impact of HAART on health. The first testimony is that of a 45-year-old male participant who stated that,

Before I started HAART, I lived in so much physical pain that if poison was in my reach, I would have taken my life, and there were times when I pleaded to my relatives to bring me poison so that I could end it all. For example, when kisipi (Herpes Zoster) hit me I was in severe pain, it hurt me to the extreme. I used to

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move around in a towel, for 2 weeks. It is now five years since kisipi hit me, and although with HAART I feel healed from it, I am still experiencing its impact.

The impact of HAART in improving physical health is also detected in a 45-year-old female respondent's testimony.

My health is somehow good because I was in a severe condition. I used to have sores in my mouth down to the esophagus and stomach. At the same time I constantly experienced nausea, fever and a headache for which I continuously took panadol and whatever pill I thought would be of help, but nothing improved these health conditions. However, it is two months since I started HAART and I have not scratched since. I was healed of the fever and the headache.

Likewise, a 37-year-old male participant that had been on therapy for over six months testified that,

My overall health is good because six months can go by without becoming sick, except for a cough or cold. Before I started this medication, I used to have piercing pain in the chest and a constant fever. If I tried to do manual work, I would get a piercing pain in the chest after which I would start panting for air and coughing. However, since I started taking highly active antiretroviral drugs, I feel good physically.

Some of the respondents reported experiences with chronic sexually transmitted infections, which disappeared when they began taking highly active antiretroviral drugs. For instance, as a 29-year-old female participant remarked, "Before I started taking highly active antiretroviral drugs, I was frequently affected by sexually transmitted

diseases and they had taken away all my peace. In addition, I always had fever and I was so weak. Since I began taking this medication, I don't have most of these conditions and I have energy."

Another theme that emerged as evidence for the impact of HAART on physical health was the immune reconstitution syndrome. Although HAART leads to improvements in the quality of health in the long run, the initial impact may be deterioration of health as revealed by some respondents that reported experiences with the immune reconstitution syndrome. Immune reconstitution syndrome refers to a cluster of opportunistic illnesses that emerge during treatment when the CD4 cells begin to increase and to fight against latent opportunistic illness causing agents that may exist within the body system before taking highly active antiretroviral drugs. That is, one of the purposes for highly active antiretroviral therapy is to enable reconstitution or repair of the immune system, which leads to an increase in the CD4 cells whose function is to fight off infections. However, in some people the reconstitution of the immune system may trigger the onset of opportunistic illness manifestations, whose agents may have been latent before HAART initiation. Although the immune reconstitution syndrome often lasts for a few weeks or months with continued use of highly active antiretroviral drugs, some of the illnesses may become severe before one's physical health begins to improve (Cheonis 2005). Some of the participants in this study reported a deterioration of health soon after HAART initiation, attributable to the immune reconstitution syndrome. A few participants who had been on therapy for less than six months and were still experiencing this syndrome reported poor health. Many of the respondents that had been on treatment

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for more than six months and who reported physical health as somewhat better or much better, than before HAART recalled experiences with immune reconstitution syndrome. Like a 23-year-old female respondent exclaimed,

As soon as I started taking highly active antiretroviral drugs, it appeared like the drugs unraveled every illness in my body, exposing every hidden health condition that had ever existed in my system. For example, I developed a terrible skin rash manifested in the most extreme pain. However, the doctor had informed me about getting side effects and he had encouraged me to be strong .... In my case, it took 3 months to recover from these illnesses before I began feeling good.

Another respondent also stated that,

Soon after beginning to take highly active antiretroviral drugs, I developed a severe pounding headache. It would pound, and pound, and pound. At the same time, water would flow from my head such that I would tie a headscarf around it, but within 6 minutes, it was dripping wet. As I continued taking highly active antiretroviral drugs, everything was healed. I feel good today.

Side effects were another theme that emerged as participants explained the impact of HAART on physical health. Side effects normally affect those that have been on treatment for less than six months. Some of the side effects mentioned included numbness in the limbs, fever, skin rush, chest pain and vivid dreams. Participants that had been on HAART for over six months testified that their physical health was better or much better than before because they had been healed of side effects. As a 56-year-old-male respondent recalled,

When I first took the highly active antiretroviral drugs, I frequently had vivid dreams, I think it was the medicine. This would go on everyday, all night or as long I lay down sleeping. However, as I continued to take highly active antiretroviral drugs, the vivid dreams decreased in number, until when they totally stopped. I have no trouble sleeping at the moment as used to be the case when I had vivid dreams.

However, a number of participants that had been on therapy for less than six months reported better physical health, though they had not yet reached a point where they could say their physical health was very good because of side effects. As explained by a 50-year-old male soldier that had been on therapy for four months,

> Compared to how I was before HAART, I feel I am beginning to get some energy. However, after beginning therapy I developed numbness in my foot. I cannot use my right foot to walk if I am not wearing boots. My right arm is also paralyzed and it shakes occasionally, but I would say that although my health is not excellent, it is much better than before I started HAART.

A 27-year-old female participant also indicated that,

> Before I started taking this medication, I was in such a bad state. I used to be extremely skinny. I had sores running from my mouth, down the esophagus to the stomach. It is about four months now and I no longer experience those illnesses. However, I can't say that I feel very good because, even if I don't have the fever, my legs began to swell when I began taking this medication, they feel numb and hurt at the bottom.

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Another female participant that had been on HAART for five months also indicated, "Since I started taking highly active antiretroviral drugs, there is a difference in my physical health because am no longer constantly sick as before. However, I usually get a fever and a cold. Those are my illnesses. I also can't carry firewood or fetch water. Sometimes I feel weak."

Males that had been on treatment for less than six months also revealed that although their health was better, they still experienced a few health conditions. As detected in one of the statements made by a 34-year-old male participant, "I have been on treatment for about one month, but I am still sickly. I experience severe pain mainly in the lower limbs where I constantly feel a burning sensation. My health sometimes limits my bending and lifting light objects. Sometimes my health limits my dressing and bathing."

Among the few respondents that indicated physical health to have remained the same or worse than before HAART initiation was a 36-year-old female who reported that, "At times I feel very discouraged because, since I started treatment, I am not sure if my physical health is improving. Probably I feel it is about the same because I still feel bad."

In summary, the vast majority of respondents (91%) reported HAART had been largely effective in improving physical health. However, although numerous participants especially those that had been on treatment for less than six months revealed that their physical health was somewhat better than before, they reported they were not completely well due to experiences with immune reconstitution syndrome, side effects or, as some

reported, they had not been totally healed of opportunistic infections. Very few respondents reported physical health as being the same or worse than before HAART initiation.

The Impact of HAART on Perceived Psychological Health

A vast majority (83%) also reported improvements in psychological health, though the percentage is somewhat smaller than that of those who reported improvements in physical health (91%). The major themes that resounded in explaining psychological states of health include anxiety, fear, and loneliness, which participants revealed as rooted in poverty, discrimination and feelings of helplessness to care for family. The reduced impact of HAART on psychological health may be due to the fact that these programs do not provide medical mental health services, and in addition they do not address the underlying causes of psychological distress embedded in the socioeconomic contexts like poverty and discrimination. For instance, a 50-year-old female participant expressed anxiety because of her poverty by stating that,

> I don't worry about my physical health, but I worry because of poverty because after my husband died I became the man in the household (breadwinner), and at the same time I remained the mother who provides care for my children, yet I do not have a job. Sometimes I ask myself how I will be able to put my children through school. I may also ask myself that, if I get extremely sick, who will take care of me or who will raise them?

A significant number of male participants also referred to anxiety due to poverty and expressed concerns for not being able to care for their family. For example, a 39-

year-old male respondent indicated that, "Poverty is the source of my worries not AIDS because we do have antiretroviral medication such that, I feel I can even live another 50 years. However, I worry about my job and the money I don't have. Now I am gambling for money to take care of my children."

A 42-year-old male also expressed concerns about lack of food by stating that,

Health providers recommend that we remain worry free. However, I sometimes feel anxious because of the economy. What worries me most is lack of food. If I have food to eat such that I am able to take medication as prescribed, I am at peace. The only time I am scared is when I fail to adhere to the doctor's orders because I don't have food to eat.

Others referred to concerns for unemployment as a source of anxiety. For example, a 40-year-old male explained that,

My physical health is better, but most of the time I am sad because I am not working. As a man if you have no money in your pocket, it is worrisome and it makes you feel hopeless. I usually ask myself that in reality if I die today, what will happen to my daughter? I have nothing to think of at the moment that I can leave for her for financial support.

Some participants associated poverty with loneliness or lack of social-economic support. As indicated by a male respondent,

Poverty and loneliness is what worries me. I may begin thinking; my old man (father) just left us yesterday (died), which makes me feel lonely. Perceiving my health, I realize it has also narrowed my territory. Then I become restless because

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of those conditions. Most of the time I may take time to be silent, reflect on my life and try to imagine where the world is taking me. There are times when I feel hopeless... The only time I am at peace and happy is when I have some money to provide for my family, and I can see my children playing and laughing because they have had something to eat. However, if I am in a crashing situation as is usually the case, I feel sad in my heart and sometimes so afraid because of my health and what would become of my children without me.

Discrimination was another theme that surfaced as participants discussed their psychological health. For example, a 35-year-old male respondent explained that,

I don't worry about health anymore because I have highly active antiretroviral drugs that have made me well. However, I worry about employment. The problem is that, when people find out that one has AIDS; they discriminate against that person from work such that it would be difficult for anyone to give him/her a job. The employer may say, I cannot hire someone that has the insect (HIV). It is difficult for us who have HIV to understand why employers feel that way because if the employer gives me a job, I will do it well for them. If I can get a job that will provide something to eat and drink, I would be happy and at peace.

Other job related concerns were also mentioned as reasons for anxiety. For instance, a 43-year-old male soldier explained that,

Anxiety usually arises from duty related issues. I am a soldier. I may go to work one day and my superiors may inform me that I have been stationed somewhere

on the front line when my health status is not good for conditions there. That is when I become extremely anxious and I begin to worry, but not because of having AIDS.

Some of the respondents referred to perceived threat of AIDS as a source of anxiety, sadness, and loneliness. This is detected in a statement made by a 43-year-old male respondent who reported that,

Sometimes I am so afraid that I tremble, especially after I look at a fellow HIV patient because I start wondering if I am about to reach that stage. There was a time when I came here for treatment and saw a patient with a condition that I had never seen in my life. By just looking at him, I felt sicker. After a few minutes of looking at my fellow patient, I told the nurse that I was going home without treatment because I could not bear the fear any more.

The same respondent also related another scenario stating that,

One time I had just boarded a taxi (seats about 15 passengers), but at the next stop someone with AIDS also boarded the same taxi. The patient appeared to be in such a bad shape and he was so skinny. Looking at his condition, I told the taxi driver that I forgot something and that I needed to get off the taxi at the next stop. I did that to avoid being on the same taxi with my fellow patient because it was difficult to travel with him.

Numerous respondents also expressed fears of socializing with others, and they often pointed to stigma as an impediment to mix with others. As one of the female respondents indicated, "This illness hinders me from socializing with family and friends.

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I have specific places that I do not want to go because I feel I will run into people who will discover I have AIDS."

Another female participant also stated that,

My health stops me from socializing because I feel I don't fit in with people I perceive to be healthy. For example, my lips are red because of an HIV related health condition, which is a sign that others may see and immediately realize that I have AIDS. The reddening of my lips has taken my peace away. Sometimes I want to socialize or travel but I say to myself that, eh! there will be a lot of people and they may notice my health condition. That alone hinders me from socializing with others making me feel extremely lonely.

Some of the respondents that reported better psychological health indicated that health providers advised them not to worry, which advice functioned as an antidote for anxiety. For example, a female respondent that related to health provider communication and religion as antidotes for anxiety explained that, "I don't worry anymore. For one thing I have been counseled. Another thing is that, I believe in God who gives me peace of mind. I used to feel sad and lonely, but not after I started HAART. The Bible is also my comfort. It tells me how to overcome anxiety. I am not afraid of my health outcome anymore."

On the other hand, despite health providers' recommendations to refrain from anxiety, some participants reported that anxiety was difficult to overcome. This is revealed in a statement given by a 46-year-old male who revealed that,

My counselors say not to worry as it cannot change any situation. In that case, I often dismiss worries. However, soon after I do that, I snap back into thinking for example, that I am an adult obligated to take care of my children and myself. In addition, I realize that my clan or relatives know that I sick and cannot work. Although they could help me with financial support, they don't care because they have the assumption that I will die tomorrow. Then I may think, if I ceased to exist today, with whom will I leave my children? That thought brings tears to eyes. Additionally, sometimes I have no money, yet my children need school fees and at the same time I have to pay for my rent. I become even more hopeless when I realize I do not own a home, and I don't have a job that would enable me to build a home for my family such that at least if I die, they will have a place to stay. Such thoughts generate anxiety. However, I have confidence in God as my hope because I believe that He knows my situation and He cares.

In conclusion, an overwhelming majority (94%) agreed that HAART has had a big impact on improving the overall quality of life. The biggest impact of HAART had been on physical health as opposed to psychological health with 91% of the respondents who reported better physical health since HAART initiation. Many of the participants reported a decrease in opportunistic infections, increase in CD4 count, as well as recovery from immune reconstitution syndrome. The percentage (83%) of those that reported psychological health as somewhat as or much better than before HAART was somewhat smaller than that (91%) of those who reported physical health as somewhat or much better. Anxiety, hopelessness, and loneliness rooted in poverty and discrimination

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emerged as major themes in explaining poor psychological health. HAART programs do not address these issues, which may explain why the impact of HAART on psychological health has been less than that on physical health.

CHAPTER V

CONCLUSIONS

Chapter five begins with a summary of key findings, followed by a discussion of theoretical, practical, and future research implications.

Summary of the Findings

Demographic Characteristics of HAART Adherence Behavior

The first research question described the distribution patterns of HAART adherence behavior by gender, age, and education level. The percentage (49%) of participants that did not always take medication on time is about the same as that (51%) for those that always took medication on time. Likewise, almost half (41%) of the respondents reported that they sometimes skipped taking medication. On the other hand, 82% of the respondents indicated they did not always follow health providers' advice to have good nutrition, 40% did not always use a condom, and about 38% failed to abstain from alcohol. These findings should be taken seriously, especially given the dangers of sub-optimal adherence that leads to the formation of a transmissible drug resistant HIV strain and the potential increase in HIV infection rate, all of which undermine the effects of HAART.

Findings reveal that females and the less educated were more likely to skip taking medication as compared to other population groups. This could be attributed to economic need that may hinder access to food necessary to take medication. That is, highly active

antiretroviral drugs are free, but health providers require that some medication be taken on a full stomach whereby individuals are accountable for their food supply. Gender-constructed roles that deny women a good education and employment opportunities usually position females low in the social stratification system whereby they often earn less than males, which may make them more susceptible to a lack of food as compared to males (Kerbo 3003). Likewise, education acts as key to positioning in the social stratification system because, lack of education limits employment opportunities. Less educated individuals if employed often acquire low paying jobs as compared to those with more education (Morowsky et al. 2000). Because females and less educated individuals are less likely to access food necessary to take medication as required, these population groups are also more likely to skip taking medication as compared to males and the more educated groups that are often positioned at the top of the social stratification system.

On the other hand, males and more educated individuals were more likely to take medication late as compared to females and the less educated individuals. This could be attributed to the fact that, males and more educated individuals are more likely to work outside of the home as compared to females and the less educated, which makes them more likely to forget it is time to take medication if they are busy at work, or to forget to carry it to the work place. In many parts of the developing world such as Uganda, females often work in homes raising children and performing other domestic tasks. Working from home may have made it more feasible for females than males to take medication on time.

Findings also revealed that less educated individuals and females were less likely to use condoms than males and the more educated. Individuals on HAART in Uganda have free access to condoms. In that regard, one would question why these population groups failed to use condoms. One of the reasons could be partially attributed to social positioning. As Weiss and Lonquist (2003) reveal, population groups at the bottom of the social stratification system such as females and the less educated are more likely to reject healthy lifestyles. Some scholars argue that less educated individuals are less likely to engage in proven healthy behaviors because lack of education diminishes their sense of personal or social control over their lives, and that these population groups have less social support as compared to the more educated (Morowsky et al. 2000). Cultural beliefs may also partially explain why females utilized condoms less than males. For example, in many African patriarchal societies like Uganda, people generally believe females are inferior to males, which creates a lack of control for females to negotiate safe sex (Pulerwitz et al. 2002). This theory is supported in this study as numerous females expressed feelings of powerlessness in taking control over the issue of using condoms during sexual intercourse.

On the other hand, males and more educated individuals were more likely to engage in sex with multiple partners and to drink alcohol as compared to females and those with no or primary education. This could also be explained by social positioning in that, males and more educated individuals possess more economic power than females and those with less education such that they are more likely to afford to engage in such behavior.

Furthermore, findings in this study reveal that individuals over age 30 used condoms less than those of ages 20 to 29. This could have been due to the fact that individuals over age 30 are more likely to engage in monogamous relationships that carry a higher degree of trust for one another as compared to those between ages 20 to 29 who may still be searching for life partners. Another finding was that, respondents between ages 20 to 29 were about twice as much as those over age 30 to report using alcohol.

Although some of the findings were statistically insignificant, these results are consistent with the literature (e.g., Morowsky et al. 2000: Pulerwitz et al. 2002). One of the reasons why some of the results were insignificant may pertain to the fact that the sample in this study was small (N=70). Additionally, convenience sampling was utilized to select participants such that the sample was not representative of the entire population on HAART in Uganda from which it was drawn.

Highly Active Antiretroviral Drug Adherence Behavior Influential Factors

The first research question revealed that some of the population groups under study did not adhere to treatment regimens. The second research question was concerned with why some individuals did not take medication as prescribed as opposed to those that did. Results revealed that lack of food was a major influential factor in skipping taking medication. One of the reasons why lack of food was reported to be a key obstacle to medication adherence may be attributed to the impact of HIV/AIDS on the social and economic well being of the family. Often individuals affected by AIDS are the breadwinners, yet they may find themselves without employment due to illness, or discrimination due to the stigma attached to HIV. Unemployment may lead to economic

insecurity, poverty, and hence lack of resources to buy food necessary to take medication regularly (FAO 2002). The median income for the participants in this study was $28 (US) per month, which means that many of the respondents earned less than one dollar a day. It is important to note that participants were between ages 18 and 64 and a large percentage of them may have had children that shared the meager economic resources. Lack of sufficient income is an obstacle to food access, which may have influenced skipping taking medication.

Another finding was that, unlike studies conducted in developed nations, side effects had the least influence on skipping taking medication. This could be attributed to medication representation, trust and confidence in health providers, as well as the presence of social support. Numerous respondents did show courage to take medication in the midst of side effects because they strongly believed highly active antiretroviral drugs were effective in treating HIV. Almost all participants (99%) believed that the quality of life improves if one takes medication regularly. In addition, participants expressed confidence in the health providers as they often mentioned that they trusted their counsel that side effects would be temporary, which motivated their continual intake of medications regardless of side effects.

This study also found that embarrassment, sleeping through the dose, and not carrying medication had somewhat minimal impact on skipping taking medication. The minimal impact may be explained by access to social support and previous experiences with opportunistic illnesses. Over three quarters (81%) of the participants reported that they had someone that reminded them to take medication. On the other hand,

respondents that reported not having social support revealed that memories of physical suffering from opportunistic illnesses motivated them to take medication as prescribed.

HAART Lifestyle Adherence Behavior Influential Factors

The third research question was concerned with what influences compliance or non-compliance with lifestyle recommendations. Respondents revealed that they were well informed by health professionals about the dangers that may arise from failure to adhere to HAART lifestyle recommendations like safe sex, abstinence from alcohol and good nutrition. However, some individuals chose non-compliance. The main reasons for non-compliance were gender power imbalances, cultural beliefs, and economic need. For instance, participants indicated that they had free access to condoms; however, females expressed feelings of helplessness to negotiate safe sex because they believed males possessed the power to decide whether to use condoms or not. Females were also more likely than males to report engagement in sex with multiple partners because of economic need. These findings are in line with other studies which have revealed that females often engage in sex with multiple partners for material gains like money, housing, food, or education (Rieker and Bird 2000). This behavior may also be attributed to gender-constructed roles that position females in the lower social strata, often making them more economically insecure as compared to males.

Another finding was that, although cultural beliefs are often deeply embedded in the mosaic of social contexts, psychological forces had potential to break through cultural barriers to change sexual behavior. For instance, polygamy is generally tolerated in many African settings that encourage procreation like Uganda. However, individuals that

abstained from sex or had sex with one partner reported that resentment toward the opposite sex influenced their decisions to refrain from having sex with multiple partners.

The Impact of HAART on Perceived Quality of Life

The fourth research question explored individuals' perceptions on health outcomes. The vast majority (94%) of the participants reported improvements in the overall quality of life since HAART initiation. HAART was perceived as more effective in improving physical health with respondents testifying of clinical gains like control of opportunistic illnesses, increased CD4 cell count, weight gain, and acquisition of physical energy. Even many of those that had been on therapy for less than six months who were still experiencing manifestations of side effects and immune reconstitution syndrome perceived their health as better than before HAART initiation. Very few individuals (6%) perceived health as the same or worse than before HAART. Respondents attributed improvements in physical health to highly active antiretroviral drugs.

On the other hand, the effects of HAART on perceived psychological health were reported to be somewhat less than those reported on perceived physical health. Numerous respondents expressed feelings of anxiety, fear, and loneliness often resulting from concerns for poverty, discrimination, feelings of helplessness to care for family, and fear of leaving children orphaned without financial security in case of death. The reason HAART had less impact on psychological health may be due to the fact that these programs neither provide medical treatment for mental health, nor do they address underlying causes of psychological distress like poverty and discrimination, which are often embedded in the social or economic contexts of developing societies like Uganda.

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Theoretical Implications

In chapter two I discussed relevant existing psychosocial and public health theories of adherence behavior. At that point, I also noted that none of these theories fully explains HAART adherence behavior in low-income nations, which creates a need for a theory that attempts to exhaustively explain such behavior in these settings.

The HBM is most applicable to this study, but it is limited in that it only addresses the cognitive aspects of adherence behavior, while understating the sociological. For example, according to the HBM, individuals are more likely to take medication as prescribed if they perceive illness to be serious, an assertion that is supported in this study. In addition, the HBM also states that individuals are more likely to take medication as prescribed if they perceive that they will benefit from taking highly active antiretroviral drugs. This is also supported in this study because the majority (99%) of the respondents believed that the quality of life improves with the regular intake of highly active antiretroviral drugs. The HBM further states that, individuals are more likely to take medication as prescribed if perceived barriers (such as lack of food and side effects) do not overwhelm them. The above statement is also partially supported in this study. For example, respondents that sometimes skipped taking medication reported lack of food to be an overwhelming obstacle in taking medication regularly. However, although side effects may also be perceived as an obstacle to medication intake, findings in this study reveal that they had almost no impact on skipping taking medication, an indication that the HBM does not fully explain HAART adherence behavior.

A more comprehensive explanation of medication adherence behavior may require the integration of the HBM with other psychosocial theories like the social support model, which may partially explain why side effects in this study did not influence failure to take medication as prescribed. For instance, the majority (81%) of respondents indicated that they had family or friends that supported them in taking medications. Scholars have noted that loving affectionate relationships with kin and friends often have the potential to regulate one's thoughts, feelings, and behavior; or to raise one's self-efficacy by strengthening coping skills and building self-efficacy (Redding et al. 2000). In that regard, family and friends may have played a role in enhancing adherence to medication taking regimens for those that were experiencing side effects manifestations.

Another flaw in the HBM is that it assumes HAART adherence behavior to be volitional, whereas participants in this study revealed the existence of obstacles that made it difficult to comply with the health providers' treatment regimens of which they had no control. For instance, respondents expressed feelings of helplessness to take drugs regularly because they lacked economic power to buy food necessary to take medication. This was also true where females reported a desire to use condoms, but felt powerless to negotiate safe sex because they believed males had the power to decide if to use condoms or not. This flaw in the HBM may be rectified by drawing from Robert Connell's (1987) theory of gender power that may explain the role of gender power inequalities in shaping HAART adherence behavior. The gender power theory explains variance in risk sexual

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behaviors rooted in social contexts where cultural beliefs and values may render females powerless to control their sex behaviors, such as the regular use of condoms.

Overall, a challenge remains for scholars to formulate an integrated theory that fully explains HAART adherence behavior in low-income nations. While the HBM helps to explain much of this behavior, it is limited because it assumes health behavior to be volitional, which undermines influential factors embedded in the social, economic, and cultural contexts, especially as seen in low income nations like Uganda. A more effective, integrated theory for explaining HAART adherence behavior in these settings may combine the HBM, social support model and the theory of gender power.

Implications for Practice

Widespread access to HAART in low-income regions is increasing but still in its infancy. Nevertheless, future efficient provision of HAART related services might require that we learn from the operation of existing centers. Based on the results in this study, individuals currently enrolled in HAART providing programs in Uganda need more comprehensive care. For instance, in chapter four I discussed the dilemma of an obligation to adhere to HAART regimens in the midst of poverty. Many of the respondents indicated that they sometimes skip taking medication due to lack of food, do not always have good nutrition, or they sometimes engage in sex with multiple partners due to economic need. Given the dangers pertaining to sub-optimal adherence and the potential increase in HIV infection rate, HAART providing centers need to incorporate nutritional and economic support services. It is important however to realize that an endeavor to provide nutritional support may be costly given the millions of people

receiving free HAART in low-income nations. In that regard, access to nutritional support may be profitably targeted to individuals that may need these services the most, like those that have been in treatment for six months or less.

That is, HAART initiation in Uganda strictly follows the World Health Organization (WHO) guidelines whereby those enrolled must be in the last stages of the disease, often characterized by severe outbreaks of opportunistic illnesses. After HAART initiation, the restoration of the function of the immune system may take about six months before it can effectively fight off opportunistic infections. Nutritional support is needed during the first six months because individuals under therapy may be sickly due to opportunistic illnesses or the immune reconstitution syndrome such that they may sometimes be unable to work and thus to access basic needs like food due to financial constraints. As the quality of life improves, follow up services like helping individuals acquire employment may be provided with a goal to wean them off nutritional support. At the same time, long-term strategies such as those that address issues of stigma and discrimination should also be devised. For example, numerous respondents in this study portrayed a desire to work, but could not find employment due to discrimination. In that regard, it may be necessary for government at the national level to enact equal opportunity employment laws that would constrain employers and fellow employees from discriminating against those with HIV.

Furthermore, in order to increase the effects of HAART on psychological health, it is necessary to provide access to mental health medical treatment for conditions like anxiety and addiction to alcohol. Findings in this study revealed that the impact of

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HAART on improving psychological health has been less as compared to that on physical health. Numerous respondents expressed feelings of anxiety, most of which were rooted in poverty. Although treated with medication in developed nations, anxiety in many of the developing countries like Uganda is not medically treated due to financial constraints. Some of the participants reported using alcohol as an antidote for anxiety. Others indicated addiction as the reason why they used alcohol. Alcohol consumption poses the danger of interfering with HAART treatment outcomes. Individuals that take alcohol may forget to take medication or engage in risk sexual behaviors like failure to use a condom or engaging in sex with multiple partners, all of which undermine the effects of HAART on those affected. Many of the respondents expressed feelings of guilt after drinking alcohol, which shows that medicine, as an alternative to using alcohol in the treatment of anxiety may be preferred.

There is also a need for long-term goals like attempting to normalize HIV/AIDS through nationwide education programs that may utilize media in an endeavor to reduce stigma. Employers should also be educated on how to support individuals with HIV. Sensitizing employees about the issues of AIDS, the rights of those with HIV in the work place, and holding employees who violate these rights accountable could do this. The long term effects of such education could help those infected with the virus to feel more at ease in public settings such that, they may be less embarrassed to take medication as required. In the short run, individuals on therapy may be counseled and encouraged to disclose their HIV serostatus to those around them like friends, family members, and fellow employees that may be present when they are taking medication. As revealed in

chapter four, individuals that reported taking medication regularly indicated that they did so because they were not ashamed to take it among individuals to whom they had disclosed.

Future Research

There is a need for longitudinal studies that examine adherence behavior and the impact of HAART on the quality of life for those under therapy. Unlike this cross sectional study that examined such phenomenon at one point in time, longitudinal studies may reveal changes in adherence behavior and quality of life overtime. Such studies are crucial especially due to the fact that long-term effects of HAART on those affected in Uganda are largely unknown. It is important to note that, unlike in the US where HAART has been available to the wider community since 1996, access to HAART for the public in Uganda is a recent phenomenon that began in 2004. As Table 1 reveals, over half (53%) of the respondents in this study had been on HAART for one year or less and only 18% reported enrollment in HAART before 2003.

More studies with larger and more representative samples are also necessary to effectively isolate differences in adherence behavior and the impact of HAART on the quality of life by demographic characteristics. As mentioned above, although some of the findings in this study were consistent with the literature, they were insignificant. This could have been partially due to the fact that, the sample was small (70), selected using convenience sampling and therefore unrepresentative. For example, the median income of the respondents was $28 (US), which means that a large number of participants were earning less than $1 (US) a day. In addition, only 13% of the respondents were Muslim

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as compared to the 87% Christians. Hence, results in this study excluded the more affluent individuals, and they did not explain the effects of religion on adherence behavior. Studies that take a quantitative approach may enrich qualitative studies of this nature. Some of the advantages of quantitative studies are that, they make the study of large samples feasible, allow the use of advanced social statistical techniques and findings may be generalized if the sample is selected at random.

Correspondingly, future research may also benefit from quantitative studies generated from medical records instead of using self-reported data that is often used in studies of this nature. Quantitative studies from medical records may also take a longitudinal approach which may reveal changes pertaining to the impact of HAART on physical health over time, say in reference to levels of increase in CD4 cell counts and viral loads; as well as frequency and duration of specific opportunistic illnesses, side effects, or immune reconstitution syndrome after HAART initiation. Other quantitative studies from medical records that may increase knowledge may be those that measure the effects of nutritional support on improvements in physical and psychological health of those under HAART.

Moreover, this study was conducted in areas around the capital city of Uganda. There is a need for qualitative and quantitative studies conducted not only in the urban, but also in rural areas across Uganda and other developing countries, some of which studies may facilitate a comparative meta-analysis of the findings in search for a deeper understanding of adherence behavior and the quality of life for those on HAART in low income nations.

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There is also a need for developing and testing a comprehensive theory that would explain HAART adherence behavior across demographic characteristics in low-income nations like Uganda. As indicated above, existing theories do not fully explain such behavior.

In conclusion, this dissertation reveals new information pertaining to HAART adherence behavior in Uganda, which knowledge may enrich the body of literature. In addition, public health, policy makers, and scholars may also benefit from these findings. For instance, it has been revealed that about half of the individuals on HAART do not adhere to medication taking regimens. Sub-optimal medication adherence pauses dangers like the development of drug resistant HIV strain. Population groups facing a high risk of skipping taking medication like females and the less educated have been identified. This is also true of males and the more educated in reference to being at the highest risk for failing to have sex with one partner or abstaining from alcohol use. Adherence influential factors like economic need, stigma, and gender power imbalances have also been highlighted. On the other hand, although it has been revealed that the majority of respondents perceived quality of life as somewhat or much better than before HAART initiation, findings show that there is a need to increase HAART effectiveness through the provision of more comprehensive care that may include services like nutritional support and mental treatment. This study also reveals that there is a need for a more integrated theory that explains HAART adherence behavior, especially in low-income nations like Uganda.

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APPENDIX A

Human Subjects Consent

<u>Consent</u>

My name is Dorothy Kalanzi. I am doctoral student at Texas Woman's University in Denton, Texas. I would like to seek your consent to participate in a study entitled *Adherence Behavior and the Impact of HAART on Quality of Life of Ugandan Adults*. The purpose of this study is to examine adherence behavior and the effects of HAART on quality of life for those under treatment in Uganda.

<u>Research Procedures</u>

If you agree to participate, I will ask you to respond to questions I will read to you from this questionnaire. The questions I will ask pertain to if you always follow the doctor's treatment recommendations. I will use an audiotape to record our conversation. The purpose of audio taping is to provide a transcription of the information discussed in the interview and to secure the accuracy of reporting that information. The maximum total time commitment that will be required of you in this study is estimated to be approximately one hour and a half.

<u>Potential Risks</u>

The potential risks related to your participation in the study may include fatigue and physical or emotional discomfort during the interview. To avoid fatigue, you may take a break/s during the interview as needed. If you experience physical or emotional discomfort regarding the interview process, you may stop answering any of the questions at any time.

Other possible risks to you include the release of confidential information or being viewed by the public during the interview process. To eliminate this risk, confidentiality will be protected to the extent that is allowed by the law. Only my advisor/s and I will have access to this information. The tapes, hard copies of the transcription, notepads, survey questionnaires, and the computer diskettes containing the transcription text files will be stored in a locked filing cabinet at my office. The tapes and transcription diskettes will be erased; and the hard copies of the transcriptions, notepads, and questionnaires will be shredded on August 30, 2012. It is anticipated that the results of this study will be published in research publications. However, no names or other identifying information will be included in any publication.

I will try to prevent any problem that could happen because of this research. You should let me know if there is a problem and I will help you. However, TWU does not provide medical or financial assistance for injuries that might happen because of your participation in the study.

<u>Participation Benefits</u>

Your involvement in this research is completely voluntary, and you may discontinue your participation in the study at any time without penalty. One of the

benefits from this study is that, it may increase the international community's awareness of the effects of HAART on individuals that take the drugs in Uganda. This may also help improve treatment of HIV among individuals affected around the world.

Do you have any questions?
Would you like to participate in this study?
Thank you.

APPENDIX B

Client Questionnaire

THE HIV HIGHLY ACTIVE ANTIRETROVIRAL THERAPY AND ADHERENCE, QUALITY OF LIFE, AND SEXUAL BEHAVIOR QUESTIONNAIRE

Demographic Information

1. What is your gender?   ___ Female   ___ Male   __ Other

2. What is your age?   ____ (Years old)

3. What is your marital status?
    ____ Never Married
    ____ Married
    ____ Separated
    ____ Divorced
    ____ Cohabiting
    ____ Widowed

4. How many years of education have you completed?   _____ (Years)

5. Are you currently employed? ___ Yes   ___ No

6. What is your occupation? (Specify) _____

7. What is your monthly salary? _____ (Ugandan Shillings)

8. What is your religion?
    ___ None
    ___ Traditional Religion
    ___ Islam
    ___ Catholic/Protestant
    ___ Other (Explain) _____

9. What is the highest educational level you have completed?
    ___ No education
    ___ Primary School
    ___ Secondary School/Higher Senior Secondary School (HSC)
    ___ College/University

10. How many children under age 18 do you have?   _____ (Number)

11. How many children under age 18 are living with you?   _____
    (Number)

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12. How old is your spouse or sexual partner?_____ (Years Old) ___ Other (Specify)

13. Do you currently live with your spouse/sex partner? __ Yes   __ No

14. What is the highest educational level that your spouse/sexual partner has completed?

> ___No education
> ___Primary School
> ___Secondary School/Higher Senior Secondary School (HSC)
> ___College/University

15. What is your spouse/partner's religion?

> ____ None
> ____ Traditional Religion
> ____ Islam
> ____ Catholic/Protestant
> ____ Other (Explain)

_____

16. Have you disclosed your HIV status to your spouse/sexual partner? _Yes _No

17. Has your spouse/sex partner been tested for HIV? __Yes   __No   __DK

18. If so, has your spouse/sex partner disclosed her/his HIV/AIDS status? _Yes _No

19. Does your spouse/partner have HIV/AIDS?   __Yes   __No   __DK

20. What was your CD4 cell count before you started the HIV/AIDS antiretroviral therapy? _____(CD4 Count) ___ Don't Know

21. What is your CD4 count now? _____ (CD4 Count)   ___ Don't Know

22. What was your viral load when you first started the HIV/AIDS antiretroviral therapy? _____ (Viral Load)   ___ Don't Know

23. What is your viral load now? _____ (Viral Load)   ___ Don't Know

24. How often are you supposed to undergo laboratory tests to test your CD4 count and viral load? (Specify) _____

Treatment and Medication

25. Please indicate the number of days, months or years since you were first diagnosed with HIV. _____Days _____Months _____Years

26. When did you start taking the HIV/AIDS antiretroviral medications?
    __Within the last 3 month
    __Within the last 6 months
    __Within the last 12 months
    __Over 12 months (Specify) _____

27. Which year did you start HAART? _____

28. What kind of treatment are you on?
    __ART __HAART __Other (Specify) _____

29. How many types of medication do you take a day? _____(Number)

30. Please list the type of medications that you are taking
    1 _____ 2 _____
    3 _____ 4 _____
    5 _____ 6 _____
    7. Other (Specify _____

31. Please indicate the medications you have to take on an empty stomach, and those that you must take with food. For example, if you take medication number 1 as named above on an empty stomach, next to 1 below write "*empty*", if medication number 2 must be taken with food, next to 2 write "*food*".
    1 _____ 2 _____
    3 _____ 4 _____
    5 _____ 6 _____
    7 Other (Specify) _____

32. How many pills do you take per dose? _____

33. How many pills do you take a day? _____

34. What is your treatment regimen/schedule? (Specify, for example, if you take medication number 1, 3, 5, 4, at 8:00 a.m., you should enter medicine as follows, 8 a.m. 1, 2, 3, 4.
    7 a.m. _____ 1 p.m. _____ 7 p.m. _____ 1 a.m. _____
    8 a.m. _____ 2 p.m. _____ 8 p.m. _____ 2 a.m. _____
    9 a.m. _____ 3 p.m. _____ 9 p.m. _____ 3 a.m. _____

10 a.m. _____	4 p.m. _____	10 p.m. _____	4 a.m. _____
11 a.m. _____	5 p.m. _____	11 p.m. _____	5 a.m. _____
12 p.m. _____	6 p.m. _____	12 p.m. _____	6 a.m. _____

Access To Highly Active Antiretroviral Drugs

35. Do any other member/s in your nuclear family have HIV? __Yes __No __DK

36. If so, in your home, who is currently taking the HIV/AIDS antiretroviral drug
    1. Husband
    2. Wife
    3. Children
    4. Other (Specify) _____

37. Is there a reason why this person/people are on medication as opposed to others?

38. Who prescribes your medications? __Medical professional __Other (Specify)
    ____

39. If finances are tight, who is given priority in your immediate family to remain on therapy? __Child/children ___Mother/female sex partner __Father/male sex partner

40. How much does your medical supplies cost? (Specify) _____

41. How much does the CD4 laboratory test cost? _____
    (Shillings)

42. How much does the viral load laboratory test cost? _____ (Shillings)

43. Where do you get your medication?
    _____

44. I am able to get the medications that I need. Please choose one of the following:
    __All the time __Most of the time ___Sometimes __Never

Adherence Behavior

Which answer comes closest to how often you do the following things?

1	2	3	4	5
Never	Sometimes	Most of the time	All the time	Not Applicable

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45. I have a hard time doing what the doctor suggests I do   1   2   3   4   5

46. I follow my doctor's suggestions exactly as advised   1   2   3   4   5

47. I am unable to do what is necessary to follow treatment orders   1   2   3   4 5

48. I find it easy to do the things my doctor suggests for me to do 1 2   3   4 5

Please use the scale below to tell me which answer comes closest to how often you do the following listed things?

1	2	3	4	5
All the time	Most of the time	Sometimes	Never	Not Applicable

49. I miss the CD4 count and viral load laboratory tests   1   2   3   4   5

50. Strictly follow the treatment regimen   1   2   3   4   5

51. Take all my medication on time as scheduled   1   2   3   4   5

52. Skip taking a dose of medication   1   2   3   4   5

53. Always take medication as instructed, say with or without food 1   2   3   4   5

54. Exercise regularly   1   2   3   4   5

55. Socialize more than usual with others   1   2   3   4   5

56. Drink alcohol   1   2   3   4   5

57. Smoke cigarettes   1   2   3   4   5

58. Carry my medication with me   1   2   3   4   5

59. Stress out   1   2   3   4   5

60. I skip taking medication because I have no food.   1   2   3   4   5

61. I skip taking medication because of embarrassment   1   2   3   4   5

62. I skip taking medication because I forget   1   2   3   4   5

63. I skip taking medication because I am sleeping   1   2   3   4   5

64. I skip taking medication because it is not on me   1 2 3 4 5

65. I skip taking medication when I am traveling   1 2 3 4 5

66. I skip taking medication because of side effects   1 2 3 4 5

67. I skip taking medication when I drink alcohol   1 2 3 4 5

68. How often do you follow doctors' instructions to have good nutrition?
     1 Never
     2 Rarely
     3 Most of the time
     4 All of the time
     9 Not applicable/Don't know/Refused

Effects Of HIV Medication Taking

Since you started this regimen, have any of the following symptoms made you miss, stop, or change your HIV medicines?

69. Problems with sleep, feeling dizzy or headaches   __No __Yes __DK

70. Nausea or stomach problems (swelling, pain, bloating)   __No __Yes __DK

71. Bowel problems (diarrhea, loose stool)   __No __Yes __DK

72. Skin problems (rashes, discoloration)   __No __Yes __DK

73. Hair loss or changes in the way your hair looks   __No __Yes __DK

74. Problems with muscles or joints   __No __Yes __DK

75. Pain, numbness or tingling in the hands/feet   __No __Yes __DK

76. Changes in your body shape due to fat deposits, weight gain __No __Yes__ DK

77. Weight loss   __No __Yes __DK

78. Loss of energy or fatigue   __No __Yes __DK

79. Hepatitis or problems with your liver   __No __Yes __DK

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80. Loss of appetite or a change in the taste of food   __No __ Yes __ DK

81. Fevers or sweating   __No __ Yes __ DK

82. Feeling sad, down or depressed   __No __ Yes __ DK

83. Vivid dreams   __No __ Yes __ DK

84. Other problems (please specify) _____

85. How much difficulty do you have taking HIV medications because of side effects?
        1 No difficulty
        2 Little difficulty
        3 A lot of difficulty
        9 Don't know/Refused

Social Support

86. Is there someone who you regularly depend on to help you take medications?
    __ No   __ Yes   __ NA/Refused/DK

87. Who is this person/persons? _____

88. Does this person/people live with you?   __ No __ Yes __
NA/Refused/DK

89. Thinking about the adults who are important in your life, how many would you say know that you have HIV?
        3 All
        2 Most
        1 Some
        0 None
        9 Don't know/Refused

90. Who are these people? _____

91. Why did you choose to tell these people?

92. How comfortable are you taking your HIV medications in front of other people? Would you say...

      __Very comfortable
      __Somewhat comfortable
      __Mixed feelings--neither comfortable nor uncomfortable
      __Somewhat uncomfortable
      __Very uncomfortable
      __Don't know/Refused

Medical Outcome Study (MOS)

Please circle the most appropriate response based on the scale below

1	2	3	4	5
Excellent	Very Good	Good	Fair	Poor

93. In general, would you say your health is: 1   2   3   4   5

Please use the scale below to rate your feelings

1	2	3	4	5
Much Better	Somewhat Better	About the Same	Worse than Before	Don't Know

94. How would you rate your physical health since you started HAART?
   1 2 3 4 5
95. How would you rate your psychological health since you started HAART?
   1 2 3 4 5
96. In general, how would you rate your quality of life since you started HAART?
     1 2 3 4 5

Please circle the most appropriate response based on the scale below
I feel that if I keep take the highly active antiretroviral drugs my overall quality of life will...

      __Definitely improve
      __Probably improve
      __Probably it may not improve
      __Definitely it will not improve
      __Don't know

Alcohol Use

97. In the past 6 months, have you had any alcoholic beverage? __No __Yes __Refused

98. Have you ever felt bad or guilty about your drinking since you started taking your HIV medicine? __ No __Yes __Refused

Please answer the following questions using these responses. Since you started taking the HIV medicine, how often has your drinking caused you...

·1	2	3	4	5
Never	Rarely	Often	All the time	DK/refused

99. To have a hangover?   1 2 3 4 5

100. To make you skip taking your HIV medication? 1 2 3 4 5

101. To feel regretful?   1 2 3 4 5

102. To have an argument?   1 2 3 4 5

103. To have unexplained sex?   1 2 3 4 5

104. To have unsafe sex?   1 2 3 4 5

For each statement, please let me know how much you agree or disagree.

1	2	3	4	5
Strongly agree	Disagree	Agree	Strongly Disagree	DK/refused

105. Side effects of HIV drugs are too severe for most people 1 2 3 4 5

106. HIV drugs decrease the number of HIV/related illnesses 1 2 3 4 5

107. HIV combination extends people's lives   1 2 3 4 5

108. HIV drugs can keep people from becoming very ill   1 2 3 4 5

109. Side effects from HIV drugs are worse than people think they are   1 2 3 4   5

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Sexual Behavior

Please choose one of the following:

110. In the past 12 months, have you engaged in sexual intercourse?   __Yes __No
      __refused

111. If so, what was the relationship with the last person you had sex with
      __ Spouse
      __ Boyfriend/girlfriend
      __ Sex worker
      __ Other (Specify_____)

112. How many sex partners have you had in the last 12 months? _____ (number)

113. How many sex partners have you had since you began HAART? _____ (specify)

114. Do you discuss safe sex like using a condom before sex? __ No __ Yes __ (Other)

115. Who makes the final decision if to use a condom or not?
      __Mainly respondent __mainly partner __Joint decision __Other (Specify____)

116. How often do you use a condom during sexual intercourse?
      __Never   __Sometimes __Almost Always __Always   __
      Other

117. If you use condoms, where do you usually get them?
      __ Government hospital/Govt. health center
      __ Family planning clinic
      __ Pharmacy
      __ NGO based community Distributor
      __ Shop
      __ Other (Specify_____)

118. Have you had any STD's since you began the highly active antiretroviral drugs
      therapy?
         If so, specify

_____

119. Do you have an idea on the number of sex partners your spouse/partner has had
      since you began therapy?   __Yes   __No

Thank you so much for participating in this study. I am sure I have learnt a lot from you.
I appreciate your time.

Treatment and Medication

25. Please indicate the number of days, months or years since you were first diagnosed with HIV. _____Days _____Months _____Years

26. When did you start taking the HIV/AIDS antiretroviral medications?
    __Within the last 3 month
        __Within the last 6 months
        __Within the last 12 months
        __Over 12 months (Specify) _____

27. Which year did you start HAART? _____

28. What kind of treatment are you on?
        __ART __HAART __Other (Specify) _____

29. How many types of medication do you take a day? _____(Number)

30. Please list the type of medications that you are taking
        1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___

31. Please indicate the medications you have to take on an empty stomach, and those that you must take with food. For example, if you take medication number 1 as named above on an empty stomach, next to 1 below write "*empty*", if medication number 2 must be taken with food, next to 2 write "*food*".
        1 ___ 2 ___ 3 ___ 4 ___ 5 ___ 6 ___ 7 Other (Specify) _____

32. How many pills do you take per dose? _____

33. How many pills do you take a day? _____

34. What is your treatment regimen/schedule? (Specify, for example, if you take medication number 1, 3, 5, 4, at 8:00 a.m., you should enter medicine as follows, 8 a.m. <u>1, 2, 3, 4</u>.
        7 a.m. ___ 1 p.m. ___ 7 p.m. ___ 1 a.m. ___ 8 a.m. _ 2 p.m. ___ 8 p.m. ___
        2 a.m. ___ 9 a.m. _ 3 p.m. _ 9 p.m. _ 3 a.m. _ 10 a.m. _ 4 p.m. _
        10 p.m. ___ 4 a.m. _ 11 a.m. _ 5 p.m. _ 11 p.m. _ 5 a.m. _ 12 p.m. _
        6 p.m. ___ 12 p.m. _ 6 a.m. _

Access to Highly Active Antiretroviral Drugs

35. Do any other member/s in your nuclear family have HIV? __Yes __No __DK

36. If so, in your home, who is currently taking the HIV/AIDS antiretroviral drug
    1. Husband
    2. Wife
    3. Children
    4. Other (Specify) _____

37. Is there a reason why this person/people are on medication as opposed to others?

38. Who prescribes your medications? __Medical professional __Other (Specify) __

39. If finances are tight, who is given priority in your immediate family to remain on therapy? __Child/children ___Mother/female sex partner __Father/male sex partner

40. How much does your medical supplies cost? (Specify) _____

41. How much does the CD4 laboratory test cost?   _____
    (Shillings)

42. How much does the viral load laboratory test cost?   _____ (Shillings)

43. Where do you get your medication? _____

44. I am able to get the medications that I need. Please choose one of the following:
    __All the time   __Most of the time   ___Sometimes   __Never

Adherence Behavior

Which answer comes closest to how often you do the following things?

1 Never	2 Sometimes	3 Most of the time	4 All the time	5 Not Applicable

45. I have a hard time doing what the doctor suggests I do   1   2   3   4   5

46. I follow my doctor's suggestions exactly as advised   1   2   3   4   5

47. I am unable to do what is necessary to follow treatment orders   1   2   3   4 5

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48. I find it easy to do the things my doctor suggests for me to do 1 2   3   4 5

Please use the scale below to tell me which answer comes closest to how often you do the following listed things?

1 All the time	2 Most of the time	3 Sometimes	4 Never	5 Not Applicable

49. I miss the CD4 count and viral load laboratory tests   1   2   3   4   5

50. Strictly follow the treatment regimen   1   2   3   4   5

51. Take all my medication on time as scheduled   1   2   3   4   5

52. Skip taking a dose of medication   1   2   3   4   5

53. Always take medication as instructed, say with or without food 1   2   3   4   5

54. Exercise regularly   1   2   3   4   5

55. Socialize more than usual with others   1   2   3   4   5

56. Drink alcohol   1   2   3   4   5

57. Smoke cigarettes   1   2   3   4   5

58. Carry my medication with me   1   2   3   4   5

59. Stress out   1   2   3   4   5

60. I skip taking medication because I have no food.   1   2   3   4   5

61. I skip taking medication because of embarrassment   1   2   3   4   5

62. I skip taking medication because I forget   1   2   3   4   5

63. I skip taking medication because I am sleeping   1   2   3   4   5

64. I skip taking medication because it is not on me   1   2   3   4   5

65. I skip taking medication when I am traveling   1   2   3   4   5

66. I skip taking medication because of side effects   1 2 3 4 5

67. I skip taking medication when I drink alcohol   1 2 3 4 5

68. How often do you follow doctors' instructions to have good nutrition?
      1 Never
      2 Rarely
      3 Most of the time
      4 All of the time
      9Not applicable/Don't know/Refused

Effects of HIV Medication Taking

Since you started this regimen, have any of the following symptoms made you miss, stop, or change your HIV medicines?

69. Problems with sleep, feeling dizzy or headaches   __No __ Yes __ DK

70. Nausea or stomach problems (swelling, pain, bloating)   __No __ Yes __ DK

71. Bowel problems (diarrhea, loose stool)   __No __ Yes __ DK

72. Skin problems (rashes, discoloration)   __No __ Yes __ DK

73. Hair loss or changes in the way your hair looks   __No __ Yes __ DK

74. Problems with muscles or joints   __No __ Yes __ DK

75. Pain, numbness or tingling in the hands/feet   __No __ Yes __ DK

76. Changes in your body shape due to fat deposits, weight gain __No__Yes__ DK

77. Weight loss   __No __ Yes __ DK

78. Loss of energy or fatigue   __No __ Yes __ DK

79. Hepatitis or problems with your liver   __No __ Yes __ DK

80. Loss of appetite or a change in the taste of food   __No __ Yes __ DK

81. Fevers or sweating   __No __ Yes __ DK

82. Feeling sad, down or depressed   __No __ Yes __ DK

83. Vivid dreams   __No   __ Yes   __ DK

84. Other problems (please specify) _____

85. How much difficulty do you have taking HIV medications because of side effects?

> 1 No difficulty
> 2 Little difficulty
> 3 A lot of difficulty
> 9 Don't know/Refused

Social Support

86. Is there someone who you regularly depend on to help you take medications?
> __ No   __ Yes   __ NA/Refused/DK

87. Who is this person/persons? _____

88. Does this person/people live with you?   __ No   __ Yes __
NA/Refused/DK

89. Thinking about the adults who are important in your life, how many would you say know that you have HIV?

> 3 All
> 2 Most
> 1 Some
> 0 None
> 9 Don't know/Refused

90. Who are these people? _____

91. Why did you choose to tell these people?

92. How comfortable are you taking your HIV medications in front of other people? Would you say…

        __Very comfortable
        __Somewhat comfortable
        __Mixed feelings--neither comfortable nor uncomfortable
        __Somewhat uncomfortable
        __Very uncomfortable
        __Don't know/Refused

Medical Outcome Study (MOS)

Please circle the most appropriate response based on the scale below

1	2	3	4	5
Excellent	Very Good	Good	Fair	Poor

93. In general, would you say your health is: 1   2   3   4   5

Please use the scale below to rate your feelings

1	2	3	4	5
Much Better	Somewhat Better	About the Same	Worse than Before	Don't Know

94. How would you rate your physical health since you started HAART?
     1   2   3   4   5
95. How would you rate your psychological health since you started HAART?
     1   2   3   4   5
96. In general, how would you rate your quality of life since you started HAART?
     1   2   3   4   5

Please circle the most appropriate response based on the scale below
I feel that if I keep take the highly active antiretroviral drugs my overall quality of life will…

        __Definitely improve
        __Probably improve
        __Probably it may not improve
        __Definitely it will not improve
        __Don't know

Alcohol Use

97. In the past 6 months, have you had any alcoholic beverage? __No __Yes __Refused

98. Have you ever felt bad or guilty about your drinking since you started taking your HIV medicine?   __ No   __Yes   __Refused

Please answer the following questions using these responses. Since you started taking the HIV medicine, how often has your drinking caused you...

1	2	3	4	5
Never	Rarely	Often	All the time	DK/refused

99. To have a hangover?   1 2 3 4 5

100. To make you skip taking your HIV medication? 1 2 3 4 5

101. To feel regretful?   1 2 3 4 5

102. To have an argument?   1 2 3 4 5

103. To have unexplained sex?   1 2 3 4 5

104. To have unsafe sex?   1 2 3 4 5

For each statement, please let me know how much you agree or disagree.

1	2	3	4	5
Strongly agree	Disagree	Agree	Strongly Disagree	DK/refused

105. Side effects of HIV drugs are too severe for most people 1 2 3 4 5

106. HIV drugs decrease the number of HIV/related illnesses 1 2 3 4 5

107. HIV combination extends people's lives   1 2 3 4 5

108. HIV drugs can keep people from becoming very ill   1 2 3 4 5

109. Side effects from HIV drugs are worse than people think 1 2 3 4 5

Sexual Behavior

Please choose one of the following:

110. In the past 12 months, have you engaged in sexual intercourse? __Yes __No __refused

111. If so, what was the relationship with the last person you had sex with
      __ Spouse
      __ Boyfriend/girlfriend
      __ Sex worker
      __ Other (Specify_____)

112. How many sex partners have you had in the last 12 months? ____ (number)

113. How many sex partners have you had since you began HAART? ____ (specify)

114. Do you discuss safe sex like using a condom before sex? __ No __ Yes __ (Other)

115. Who makes the final decision if to use a condom or not?
      __Mainly respondent __mainly partner __Joint decision __Other (Specify____)

116. How often do you use a condom during sexual intercourse?
      __Never __Sometimes __Almost Always __Always __ Other

117. If you use condoms, where do you usually get them?
      __ Government hospital/Govt. health center
      __ Family planning clinic
      __ Pharmacy
      __ NGO based community Distributor
      __ Shop
      __ Other (Specify_____)

118. Have you had any STD's since you began the highly active antiretroviral drugs therapy?
      If so, specify _____

119. Do you have an idea on the number of sex partners your spouse/partner has had since you began therapy?   __Yes   __No

Thank you so much for participating in this study. I am sure I have learnt a lot from you. I appreciate your time.