Seton Hall University eRepository @ Seton Hall

Seton Hall University Dissertations and Theses (ETDs)

Seton Hall University Dissertations and Theses

2010

Psychosocial Correlates of Adherence to Antiretroviral Therapy (ART) in People Living with HIV in Kenya

Thomas M. Kamau Seton Hall University

Follow this and additional works at: https://scholarship.shu.edu/dissertations Part of the <u>Public Health Commons</u>, and the <u>Social Psychology Commons</u>

Recommended Citation

Kamau, Thomas M., "Psychosocial Correlates of Adherence to Antiretroviral Therapy (ART) in People Living with HIV in Kenya" (2010). *Seton Hall University Dissertations and Theses (ETDs)*. 1386. https://scholarship.shu.edu/dissertations/1386

PSYCHOSOCIAL CORRELATES OF ADHERENCE TO ANTIRETROVIRAL THERAPY (ART) IN PEOPLE LIVING WITH HIV IN KENYA

ΒY

Thomas M Kamau

Dissertation Committee:

Dr. Valerie P. Olson, Chair

Dr. Genevieve Pinto-Zipp

Dr. Mary Ann Clark

Approved by the Dissertation Committee: Date 🖪 10 Date_3 イス Date

Submitted in partial fulfillment of the requirements for the degree of

Doctor of Philosophy in Health Sciences

Seton Hall University

.

Acknowledgments

I would like to express my profound gratitude to several people who have assisted me in many ways to develop, refine, and complete this dissertation and, most importantly, in shaping my academic life.

I am thankful to my academic advisor and chair of the dissertation committee, Dr. Valerie Olson, for her guidance and commitment to enriching my academic experience. She has had important roles and responsibilities throughout the doctoral process. Dr. Olson was always there for me to discuss the many facets of this dissertation. She provided me with remarkable guidance in generating, expressing, and organizing complex ideas with clarity. She has been an excellent listener and encourager and always diligent in providing direction.

I would also like to express my appreciation to members of my Dissertation Committee, Dr. Genevieve Zipp and Dr. MaryAnn Clark. Both Drs Zipp and Clark, who are remarkably talented, generously shared with me their extensive teaching and mentoring experience. Both were extremely resourceful in providing timely feedback, fostering development of preparation skills in the research forum, and developing my self-confidence in undertaking difficult and challenging tasks. It was great fortune to work with each of them and as a team. I would also like to express my thanks to the secretary of the Department of Graduate Programs in Health Sciences, Ms. JoAnn DeBerto. Joann was instrumental in linking me with my Dissertation Committee and provided a lot of

technical assistance in the preparation of the Institutional Review Board Application.

There are many other faculty members who were also very helpful in various ways. I want to thank Dr. Lee Cabell for always being available to explain and question my use of statistic. He challenged and inspired me to learn statistics. I would like to thank Dr. Pamela Foley, my multivariate statistics professor in the Department of Psychology. Dr. Foley continued to assist me by responding to my emails. Dr. Foley fostered my confidence in multivariate statistics, which I have used to test the study hypotheses as well as conduct factor analysis. I must also thank Dr. Sheldon Cohen, the author of the Interpersonal Support Evaluation List (ISEL), and Dr. Margaret Chesney, the author of both the Adult Clinical Trial Group Adherence Questionnaire and the Coping Self-Efficacy Questionnaire, for permitting me to use these instruments and have them translated from English to Kiswahili.

This study would not have been possible were it not for men and women living with HIV in Kenya who volunteered to respond to the questionnaires with great courage, understanding, and sacrifice. I thank the management of Nazareth Hospital; the Franciscan Sisters of Immaculate Heart of Mary; the Medical Officer in charge of Nazareth Hospital; and the coordinators, physicians, and staff of the comprehensive care and treatment centers for their tremendous support. I thank the hospital management for providing me with free room and board throughout the period of the field study.

I also thank the Institutional Research and Ethics Committee of Moi University, Eldoret, Kenya, and Seton Hall University's IRB for reviewing, finetuning, and granting timely approval of my research protocol. Professor Ngare, Dr. Stephen Njure, and Dr. Joseph Abuya played pivotal roles in the process. 1 also thank my research assistants for their well done jobs: Helen, Christopher, Susan, and Samuel.

I am also particularly very grateful to my mother, brothers, sisters, nephews, and nieces and friends for their support and encouragement. Special thanks to Sister Margaret Manganga for providing me with financial support, prayers, and encouragement. I owe each of my family members and friends a debt I cannot repay: their unconditional love.

I also thank Father John Fraser, my pastor, and all the parishioners of Holy Rosary Church, in Hawthorne, New York, for their prayers and generous financial contribution to support my Kenya trip and to reimburse bus fare to the respondents in my study.

It is not possible for me to list all who have helped as they are too many. To all, I am thankful to you and promise to repay your goodness by being good to all those who will need my help in future.

Table of Contents

ACKNOWLEDGEMENT2
List of Tables
CHAPTER I INTRODUCTION 10 Antiretroviral therapy (ART) 13 Adherence and Nonadherence to ART 15 Factors Associated with Adherence or Nonadherence to ART 16 Social Support as a Buffer to Psychological Distress 18 Summary 20 Significance of the Study 21 Research Questions and Hypotheses 22 Study Hypotheses 23
CHAPTER II REVIEW OF THE LITERATURE 26 Stress, Appraisal, and Coping Theory 27 Cognitive Appraisal 29 Coping 31 Coping Self-Efficacy 32 Social Support Theory 33 Perceived and Received Support 35 Dimensions of Support 36 Social Support and Adherence to ART 38 Support and States of Mind 41 Need for Research 44
CHAPTER III METHODOLOGY 46 Survey Tools 46 Demographic Characteristics of Respondents. 47 Translation of Validated Instruments. 47 Interpersonal Support Evaluation List (ISEL). 55 Coping Self-Efficacy (CSE) Questionnaire. 56 Adult Clinical Trial Group Adherence Questionnaire. 57 Study Approvals 58 Setting. 59 Sample Size and Procedures for Sample Recruitment and Selection 59 Inclusion and Exclusion Criteria. 61 Anonymity and Confidentiality 61 Procedures of Respondents Identification 62 Procedures of Administration of the Survey Tools 63 Training of Research Assistants 64 Data Analyses 64

Descriptive Statistics	65
Factor Analysis	
Scale Reliability	
Testing of Study Hypotheses	
CHAPTER IV RESULTS	73
Characteristics of the Sample	73
Factor Analysis for Coping Self-Efficacy Scale (CSE)	
Exploratory Factor Analysis (EFA) and Confirmatory Factor Analysis	
(CFA)	74
Scale Reliability	
Descriptive Statistics	
Correlational Analyses	
Results of the Tests of Hypotheses	
Summary of Findings	
CHAPTER V DISCUSSION	96
Findings from Study Hypotheses	. 103
Social Support and Adherence to ART	. 103
Social Support and Coping Self-Efficacy	
Coping Self-Efficacy as a Predictor of Adherence to ART	. 108
Coping Self-Efficacy as a Mediator of Support and Adherence	. 108
Limitations	
Study Implications	. 111
<i>,</i> .	
CHAPTER VI SUMMARY AND CONCLUSIONS	112
Future Studies	. 116
References	.119
APPENDICES	
Appendix A: List of Abbreviations	
Appendix B: Survey Tools	
Appendix C: Nazareth Hospital Acceptance letter	
Appendix D: Moi University's Institutional Research and Ethics Commit	
	. 169
Appendix E: Seton Hall University Institutional Review Board Approval.	
Appendix F: Flyer and Recruitment Form	
Appendix G: Informed Consent Form	
Appendix H: Training Protocol for Research Assistants	.180

List of Tables

Table 1: Total Variance Explained by Exploratory Factor Analysis for the CSE ($N = 354$)	. 66
Table 2: Rotated Factor Matrix for the CSE (Using Exploratory PrincipalComponents Factors Analysis) (N = 354)	. 67
Table 3: Interpersonal Support Evaluation List (ISEL) Scale Reliability (Cronbach's Alpha) ($N = 354$)	. 68
Table 4: Coping Self-Efficacy Reliability (CSE) Scale Reliability (Cronbach's Alpha) (<i>N</i> = 354)	68
Table 5: During the past 4 days, on how many days have you missed taking all your doses? ($N = 354$)	69
Table 6: When was the last time you missed any of your medications? $(N = 354)$	70
Table 7: Pearson Correlational Analysis for Social Support and Coping Self- Efficacy ($N = 354$)	71
Table 8: Pearson Correlational Analysis of Coping Self-Efficacy (CSE) and Subscales of Social Support ($N = 354$)	72
Table 9: Social Support as a Predictor for Adherence to Antiretroviral Therapy (ART) ($N = 354$)	, 74
Table 10: Dimensions of Social Support as Predictors of Adherence toAntiretroviral Therapy (ART) ($N = 354$)	76
Table 11: Subscales of Coping Self-Efficacy (CSE) and Adherence to ART $(N = 354)$	78
Table 12: Relation Between Social Support and Coping Self-Efficacy (CSE)	. 80

ABSTRACT

PSYCHOSOCIAL CORRELATES OF ADHERENCE TO ART IN PEOPLE LIVING WITH HIV IN KENYA

Thomas M Kamau

Seton Hall University

2010

Antiretroviral therapy (ART) dramatically slows the progression of HIV/AIDS, reduces incidences of opportunistic infections, and significantly extends the survival time of people living with HIV. The proportion of men and women living with HIV who are being prescribed ART has exponentially grown from less than 10% in 2003 to over 75% in 2009. However, nonadherence to the ART may result in virologic failure to suppress HIV adequately, which may cause development of drug resistant strains. Consequently, the benefits of ART may be lost. Furthermore, HIV strains may be sexually transmitted from those who are nonadherent to other persons.

This study sought to determine whether individuals' perceptions of availability of social support and coping self-efficacy influence adherence to ART in people living with HIV in Kenya. A cross-sectional study design using questionnaires was conducted at nine comprehensive care and treatment centers managed by a major healthcare provider serving populations in the central metropolitan city of Nairobi, Kenya.

Data were collected from a convenience sample (N = 354) of men and women who were prescribed ART. The Interpersonal Support Evaluation List (ISEL), Coping Self-Efficacy (CSE) Scale, and Adult Clinical Trial Group (ACTG) Adherence Questionnaires were used to collect data.

Social support and coping self-efficacy were predictive of adherence to ART. The composite measure of social support accounted for 24.2%. Tangible and emotional dimensions of social support were the strongest predictor variables for adherence to ART among the four dimensions of social support. Although coping self-efficacy (CSE) was a significant predictor of adherence to ART, it ceased being a significant predictor when the effect of social support on adherence to ART was controlled.

Social support was predictive of CSE, accounting for 13.2% of variance in CSE. Emotional, informational, and belonging support were statistically significant predictors of CSE, but tangible support was not. A model with the three significant dimensions of support accounted for about 14% of variation in CSE. Thus, significant relations exist between social support, CSE, and adherence to ART, as measured by self-report for the previous 4 days. Implications, limitations, and future directions are discussed.

CHAPTER I

INTRODUCTION

The Joint United Nations Programs on Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (UNAIDS) estimated that the human immunodeficiency virus (HIV; (see Appendix A: List I of abbreviations) has caused over 25 million deaths worldwide since 1981 (United Nations Programs on Human Immunodeficiency Virus/Acquired Deficiency Syndrome [UNAIDS], 2009). The number of people living with HIV worldwide is significantly higher than the number of those with other diseases. Most people afflicted with the HIV virus live in sub-Sahara Africa. Sub-Sahara Africa has less than 12% of the world's population, but it is home to more than 25.8 million (more than 60%) of the 39.5 million people living with HIV worldwide (UNAIDS, 2009). Further, Africa as a whole has a higher rate of HIV occurrence than any other continent in the world. The United Nations estimates that of the 2.7 million people who were newly infected with HIV in 2008, 2.8 million (67%) lived in sub-Sahara Africa (UNAIDS, 2009).

Kenya is among the countries in sub-Sahara Africa with the largest HIV population and the highest HIV prevalence rate. According to the Kenya AIDS Indicators Survey of 2007, more than 1.4 million of the 36 million Kenyans are living with HIV or acquired immune deficiency syndrome (AIDS; National AIDS Control Council, 2008). Furthermore, more women are infected with HIV (8.7%) than men (5.6%); thus, 3 out of 5 HIV infected Kenyans are women. The report

indicated that, among the younger women, ages 15-24, women are 4 times more likely to be infected than men. Additionally, 1 out of 10 pregnant women in Kenya are infected with HIV (9.6%). These figures indicate that women are disproportionately affected by the HIV pandemic in Kenya.

According to the World Health Organization (WHO) *Country Fact Sheet* of 2006, HIV was the number one cause of all deaths in Kenya in 2002. HIV alone accounted for 38% of all deaths. The findings were not surprising given that less than 10% of all eligible patients were on ART in 2003 (National AIDS and STI Control Program [NASCOP], 2007). However, the situation is likely to change with more men and women who are living with HIV accessing HIV medication.

ART is increasingly becoming accessible in Kenya. The dramatic rise in recent years in the number of HIV patients who are able to access ART is attributed to the declining cost of HIV medication, coupled with increasing global funds. The number of people on ART increased from 44,700 in 2005 to 156,000 in 2007. By end of end of July 2008, nearly 54% (212,000) of all patients eligible for treatment were receiving ART (World Health Organization [WHO], 2008). This growth is astronomical when compared to the less than 10% of all eligible patients who were on ART in 2003 (NASCOP, 2008). Until 2004, ART drugs were largely inaccessible to HIV patients living in developing countries, particularly those in sub-Sahara Africa, which accounts for more than two-thirds of all people living with HIV worldwide (UNAIDS 2009). The number of those accessing ART is projected to grow even more as those infected become eligible

for the treatment. ART and the importance of adherence will be discussed further following a brief description of HIV and AIDS.

HIV is a virus that attacks the body's immune system. It is considered by many to be one of the most destructive epidemics recorded in history. HIV can be transmitted in several ways. It is possible to transmit HIV from one person to another through sexual contact, through blood products, or by sharing HIV-contaminated needles, or it can be transmitted from mother to child during pregnancy and delivery (UNAIDS, 2005). Although HIV progresses through many stages, the last stage is the most devastating. The final stage of the HIV infection is referred to as *acquired immunodeficiency syndrome* (AIDS). In this stage, an individual's immune system is weakened to the point that the body becomes vulnerable to a host of life-threatening illnesses known as *opportunistic infections* (Center for Disease Control and Prevention [CDC], 2007; UNAIDS, 2005).

HIV attacks the body by destroying white blood cells (i.e., T cells or CD4 cells which are an essential part of the immune system), by attaching itself to these cells thereby gaining entry into the host cell. The virus then replicates itself, increasing viral load (i.e., the number of viral particles) in the plasma. As the viral load increases, HIV progressively destroys more CD4 cells. Thus, the CD4 count is the best indicator of the severity of HIV and determines when physicians can initiate treatment with antiretroviral drugs in HIV-infected patients (CDC, 2007).

Antiretroviral therapy (ART)

ART is a pharmacological treatment for HIV that works by inhibiting the ability of HIV to destroy white blood cells. ART consists of a combination of at least three antiretroviral drugs that suppress the virus and stop or slow the progression of the disease (CDC, 2007). The treatment reduces the HIV viral load and increases CD4 cell counts, thereby dramatically lessening HIV-related morbidity and mortality (Collier et al., 1996).

The ART drugs are classified as nucleoside reverse transcriptase inhibitors (NRTI), non-nucleoside reverse transcriptase inhibitors (NNRTI), and protease inhibitors (PI; Yerly et al., 1999). The goal of ART is to impede the life cycle of the virus, thereby disrupting the replication of HIV and resulting in damaged HIV copies. These damaged copies cannot reverse DNA. Without the DNA, HIV is unable to make functional copies. Thus, HIV's proliferation in the body is inhibited. Further, NNRTI physically prevent the reverse transcriptase enzyme from working. Similarly, a protease inhibitor (PI) drug disables the functioning of the enzyme protease so that HIV cannot use the enzyme in the final stages of its reproduction process (Yerly et al., 1999).

HIV therapeutic choices have continued to expand from monotherapy to double drug therapy to triple drug therapy. Although the three drugs have been combined in a single drug therapy, the efficacy of this therapy has not been tested widely and is not one of the recommended treatments of HIV in sub-Sahara Africa. ART has shown notable success in suppressing viral load and in increasing the production of CD4 cells (Collier et al., 1996; Hogg et al., 1999;

Paterson et al., 2000; Yerly et al., 1999). Thus, it has transformed HIV/AIDS from a terminal illness to a manageable chronic illness (Montaner et al., 1998; Palella et al., 1998; Paterson et al., 1999). A combination of ART drugs has been shown to slow disease progression, reduce incidences of opportunistic infections, and significantly extend the survival time of people living with HIV (Collier et al., 1996; Palella et al., 1998). Thus, patients on these medications have improved clinical health, improved immune functioning, and decreased short-term mortality (Kelly, Otto-Salaj, Sikkema, Pinkerton, & Bloom, 1998; Montaner et al., 1998). ART not only slows the progression from HIV to AIDS but also reduces the cost of health care associated with HIV and AIDS (Simoni, Frick, Lochart, & Liebotiz, 2002). However, ART is not a cure.

Based on the available research, the World Health Organization (WHO) and the Joint Programs of United Nations on AIDS (UNAIDS) have recommended that a triple-drug combination of ART be started for asymptomatic adolescents and adults with CD4 cell counts of less than 200 cells per mm³. These organizations also have recommended that clinicians initiate treatment for symptomatic patients regardless of CD4 cell counts (UNAIDS, 2005). Consistent with WHO recommendations, Kenya has implemented ART guidelines incorporating these standards (The National AIDS and STD Control Program [NASCOP], 2008).

Adherence and Nonadherence to ART

Despite the widespread success of ART as a treatment for HIV/AIDS, adherence remains a problem. For patients to achieve maximum durable suppression of the HIV viral load and gain reconstitution of CD4 cells, they must uphold high levels of adherence to the prescribed treatment. According to Paterson et al. (2000), patients must adhere to more than 95% of the prescribed doses to suppress viral load effectively and to restore the needed CD4 cells. This level of adherence to ART regimens is higher than the 80% breakpoint adherence level needed for other chronic illnesses, such as cancer (Paterson et al., 2000). A patient's failure to take even a single dose in a 28-day period during a 365-day clinical treatment course has shown a strong association with treatment failure (Montaner et al., 1998).

Suboptimal or nonadherence to ART may significantly reduce the health benefits of ART treatment in HIV-patients (Collier et al., 1996; Palella et al., 1998). Knobel et al. (2001) found that failure to adhere to the ART regimen was the main reason for virologic failure to suppress HIV adequately. Nonadherence allows the virus to replicate rapidly, increasing the viral load and, consequently, allowing it to develop strains that counter the antiretroviral drugs (Catz, Kelly, Bogart, Benotsch, & McAulife, 2000; Collier et al., 1996). These drug-resistant strains decrease treatment efficacy and, as a result, require treatment using another line of antiretroviral drugs (Weinberg & Friendland, 1998). Such alternative treatments are difficult to obtain and often are more costly. Moreover, these resistant strains are still transmissible, further magnifying the problem. Given the necessity of strict adherence to treatment regimens, it is important to consider the factors that predict adherence versus nonadherence in HIV patients. Researchers using cross-sectional studies have found factors related to medication regimen, social contexts, and personal characteristics that can predict patients' adherence to treatment (Catz et al., 2000; Reynolds et al., 2004; Tix & Frazier, 1998).

Factors Associated with Adherence or Nonadherence to ART

People living with HIV have chaotic and stressful lives. HIV/AIDS induces many stressors that may lead to anxiety and symptoms of depression in people living with the disease. HIV-positive results potentially can lead to fear of discrimination and isolation, stress over complex treatment regimens, fear of side effects from medication, fear of disease progression from HIV to full blown AIDS, and anxiety about dying (Catz et al., 2000). These stressors related to ART medication can be categorized into medication-related stressors, environmental factors, and psychological factors.

Medication-related stressors. Researchers have shown that, as the complexity of a dosage increases, adherence to its regimen decreases (Samet et al., 1992). ART regimens consist of multiple doses with different sequencing, timing, and dietary controls (Catz et al., 2000). Physicians may prescribe additional medications to treat opportunistic infections, to control side effects, and to improve antiretroviral absorption (Kelly et al., 1998). For example, although normal dosing of amprenavir, a drug used to treat HIV, is 1200 mg twice per day for adults, this drug typically is available only in 50-mg and 150-mg dosages.

Therefore, a patient must take at least 16 tablets per day. In addition, whereas patients taking didanosine, an NRTI drug used to treat HIV, would be advised to take it on an empty stomach, doctors advise taking atanazavir on a full stomach. Further, to avert the effects of drug interactions, patients are told to take tenofovir, a drug used to treat HIV, 2 hours before or one hour after taking didanosine. For these reasons, following an ART regimen is a challenge to most people (Collier et al., 1996; Kelly et al., 1998). The complexities of sequencing, timing, dosage amounts, and dietary needs for antiretroviral medications are potential barriers to adherence and can thwart the effectiveness of the treatment. In summary, the success of ART depends on patients' ability to adhere to the treatment regimen (Hammer et al., 2006; UNAIDS, 2005).

Environmental (social) factors. One's social environment and context can induce stressors, which can influence psychological and behavioral outcomes. In 2001, at the launch of the UNAIDS Compendium on Discrimination, Stigmatization and Denial, in Durban, South Africa, Dr Peter Piot, Executive Director of the Joint United Nations Program on HIV/AIDS (UNAIDS), underscored the need to create environments that mitigate HIV-related stressors. He noted that fear of discrimination may prevent people from seeking treatment for AIDS or disclosing their HIV status. People with or suspected of having HIV/AIDS may be denied employment, shunned by their friends and colleagues (UNAIDS, 2001), and so on. Patients who find themselves in such an environment may fail to adhere to ART as they struggle to prevent others who might judge and discriminate them from knowing that they are HIV positive.

Psychological factors. Physical stressors may lead to psychological distress, depression, and other mental problems, all of which can interfere with behavior of adherence to ART. Research presented at a recent World Federation for Mental Health Expert Forum in South Africa (January 29-31, 2008) demonstrated the need for mental health services for people living with HIV in Africa. Eighty-five percent of pregnant women living with HIV in Zambia had episodes of major depression and suicidal thoughts. In addition, 58% of HIV-positive individuals had diagnosable mental health problems (35% major depression, 6% bipolar disorders, 37% panic disorders, 15% social phobia, and 21% generalized anxiety disorder). In summary, psychological distress may impede people living with HIV/AIDS from organizing and executing important actions influencing adherence to ART.

Social Support as a Buffer to Psychological Distress

Not all social environments discourage patients' adherence to ART. Some social contexts are supportive to improve the psychological states in people living with HIV. To create an understanding of how social support reinforces adherence to ART, Gonzalez et al. (2004) investigated the influence of social support on HIV medication compliance in 90 homosexual men living with HIV. The study demonstrated that social support influenced patients' adherence to ART through positive states of mind, which are necessary to understand the efficacy of ART and boost patients' confidence in adhering to the treatment. Chesney et al. (2000) studied a convenience sample of 75 patients living with HIV/AIDS enrolled in clinical trials on adherence to ART. The study showed a

strong relation between efficacy of treatment, self-confidence, and adherence to ART. Higher scores on perception of self-confidence related to higher scores on adherence to ART. Similarly, nonadherence to ART correlated with individuals' perceptions that they were less confident in their ability to take their medications as directed.

Researchers have postulated that social support has preventive and therapeutic effects in a variety of diseases and conditions (Bottari, Robert, Ciesla, & Hewitt, 2005; Gonzalez et al., 2004; Igreja et al., 2000). Mounting evidence suggests that social support may influence adherence to HIV treatment (Gonzalez et al., 2004). In addition, social support may enhance mental resources and strategies, which in turn may influence healthful behavior, such as an individual's ability to adhere to the complex prescription regimen required in HIV treatment. Prior to exploring the nature of HIV treatment, it is important to explain HIV and how it affects an individual living with this virus socially and psychologically.

People living in supportive social contexts can have more healthful behavior (Gonzalez et al., 2004) than those who are not. Social resources may influence a patient's level of adherence to ART. Individuals who receive or perceive social support from a social network typically believe that they can manage difficult tasks better than those who do not have similar resources. Catz et al. (2000) found that patients who perceived less emotional support were less confident in their ability to adhere to ART. Thus, in theory, social support may be associated to better adherence to ART. To understand HIV-related stressors and their relation with psychological and behavioral outcomes in people living with HIV, it is necessary to establish the nature of the relations between HIV-related stressors with psychological distress, social support and beliefs in one's ability to plan and execute difficult tasks and compare these states of mind with adherence to ART. Understanding why people affected by similar stressors react to them in different ways is critical in determining what factor might be associated with or predict adherence to ART in people living with HIV.

Summary

Clearly, ART has dramatic health outcomes in suppressing viral load, improving immune function, and delaying the progression of HIV disease. However, this treatment is indefinite and inconvenient and has difficult regimens because of the high pill burden, frequent dosing, and dietary restrictions. Thus, achieving adherence is difficult. However, nonadherence to ART can reverse or impede the potential gains of ART (e.g., the improved health and lives of people living with HIV and their dependents) and can have disastrous public health ramifications because HIV-drug resistant strains can be passed sexually to others. Studies conducted in developed nations have identified some psychosocial correlates and predictors of adherence to ART, but few studies have been conducted among people living in Africa, the home of over 65% of all people living with HIV worldwide. Perhaps, this lack of research is because, it was only recently, in 2004, that ART became accessible to the majority of Kenyans living with HIV and most people living with HIV in Africa. Prior to 2004,

issues of adherence were irrelevant because ART was inaccessible and unaffordable. Although ART has dramatic impact on mortality and morbidity of people living with HIV, patients' nonadherence can reverse these benefits.

The objective of this study was to explore the psychosocial correlates of adherence to ART in people living with HIV in Kenya. This research examined the relationship between perceived social support, coping self-efficacy, and adherence to ART. In this research, I argue that an individual living with HIV may adhere to ART because of confidence he or she has in his or her ability to cope with HIV-related and or unrelated stressors (Lazarus & Folkman, 1984). Confidence in an individual's ability to cope with the stressors may depend on his or her perceptions that support would be available if needed.

Specifically, the researcher investigated whether perceived availability of social support correlates with adherence to ART among people living with HIV, whether perceived availability of social support correlates with coping self-efficacy, and whether coping self-efficacy correlates with adherence to ART and determined whether coping self-efficacy mediates the relation between perceived social support and adherence to ART.

Significance of the Study

The findings of this study might have significant clinical benefits for people living with HIV in Kenya and in greater Africa. Identification of psychosocial correlates of adherence will aid in designing interventions aimed at enhancing adherence to ART. The findings also might play an important role in advancing appraisal of coping self-efficacy and social support theories.

The purposes of this research is to (a) delineate the relation of functional support (perceived availability of support) with adherence to ART in people living with HIV and (b) investigate whether coping self-efficacy mediates the relation between social support and adherence to ART in people living with HIV in Kenya.

Research Questions and Hypotheses

Question 1: Is there a relation between perceived social support (composite) and adherence to ART in people living with HIV in Kenya?

Question 2: Is there a relation between the dimensions of social support and adherence to ART in people living with HIV in Kenya?

Question 3: Is there a relation between coping self-efficacy and adherence to ART in people living with HIV in Kenya?

Question 4: Is there a relation between perceived social support and coping self-efficacy in people living with HIV in Kenya?

Question 5: Is there a relation between the dimensions of social support and coping self-efficacy in people living with HIV in Kenya?

Question 6: Does coping self-efficacy mediate the relation between perceived support and adherence to ART in people living with in Kenya?

Hypothesis 1: There is a significant relation between composite social support and adherence to ART.

Hypothesis 2: There is a significant relation between the subscales of social support and adherence to ART.

- a) There is a significant relation between tangible support and adherence to ART.
- b) There is a significant relation between emotional support and adherence to ART.
- c) There is a significant relation between informational support and adherence to ART.
- d) There is a significant relation between belonging support and adherence to ART.

Hypothesis 3: There is a relation between coping self-efficacy and adherence to ART.

Hypothesis 4: There is a significant relation between composite social support and coping self-efficacy.

Hypothesis 5: There is a significant relation between the subscales of social support and coping self-efficacy.

- a) There is a significant relation between tangible support and coping self-efficacy
- b) There is a significant relation between emotional support and coping self-efficacy.

- c) There is a significant relation between informational support and coping self-efficacy.
- d) There is a significant relation between belonging support and adherence to ART.

Hypothesis 6: Coping self-efficacy is a mediator in the relation between social support and adherence to ART.

. .

. .

.

CHAPTER II

REVIEW OF THE LITERATURE

Humans are social creatures, sustained and affected by their interactions with other people within their environments (Glanz, Rimmer, & Lewis, 2002). An individual's health behavior is not only determined by that individual's lifestyle but also partly by his or her social context. The following is a review of theories that analyze how social relationships are linked to health or healthful behavioral outcomes.

Coping, in this context, will refer to cognitive and behavioral efforts directed toward regulating distress and efforts focusing on solving the problem. A belief in one's ability to organize, execute, and sustain efforts to regulate or solve the problem causing distress is contingent upon an individual's perception of availability of social support from existing social networks if needed (Cohen & Hoberman, 1983). A social cognitive theoretical framework is identified, which will be the basis for testing the possible role of social support in buffering a person from potential effects of stressors or challenging life circumstances and investigating how support may enhance one's confidence in performing difficult tasks under challenging life circumstances such as those that surround people living with HIV. This interplay of individual and situational factors cuts across three theories: (1) stress, appraisal, coping theory; (Lazarus & Folkman, 1984), (2) the self-efficacy part of the social cognitive theory (Bandura, 1997), and (3) social support theory (Cohen & Hoberman, 1983; Cohen & Wills, 1985).

Stress, Appraisal, and Coping Theory

The stress and appraisal theory describes cognitive appraisal as a factor that determines how people feel about and react to stressful life situations. Lazarus and Folkman (1984) illustrated the interplay between stressors (defined as being external to the focal person) and cognitive appraisals in the evaluation of the significance of a stressor. An individual in a stressful environment can judge his or her environment as stressful when harm has already occurred, when he or she feels threatened, and/or when he or she is challenged by the environment (Lazarus & Folkman, 1984).

Psychological stress is defined as "a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (Lazarus & Folkman, 1984, p. 19). The effects of a stressor are assumed to occur only when the situation is judged as both taxing and exceeding a person's resources available to cope with it (Cohen, Kamarck, & Mermelstein, 1983). People living with HIV confront multiple stressors daily in managing their routine medical care especially in third world countries such as Africa.

Despite the fact that treatment for HIV/AIDS is more widely available today to people living with HIV in sub-Saharan Africa than it was 6 years ago, it is probable that many of them still have chaotic and stressful lives. Availability of HIV medication to men and women living with HIV solves only one of the many problems they face; the clinical aspect of HIV. Siegel and Schrimshaw (2004) studied a sample of 79 women living with HIV to determine whether there were

significant differences in stress appraisal between women on ART and women living with HIV prior to the ART era. The results showed that HIV treatment alone may not assure an improved state of mind. Health problems (e.g., declining CD4 cell count, physical impairment, and adverse side effects), interpersonal conflicts, stigma and disclosure fears, and problems with healthcare or social service were some of the stressors that posed threats to women living with HIV, whether on ART or not.

In Kenya, major HIV-related stressors are stigma, discrimination, and the fear of rejection that results from disclosure of HIV-positive results. The Kenya Demographic Health Survey indicated that over 40% of women and 26% of men in Kenya said they would not buy fresh vegetables from a vendor who is HIV-positive (Central Bureau of Statistics [CBS], 2004). In addition, 43% and 40% of Kenyan men and women, respectively, believe that a female teacher who is HIV-positive should not be allowed to continue to teach in school. The Leserman, Ironson, O'Cleirig, Fordiani, and Balbin (2008) study of a sample of HIV-infected men and women in Florida shows that individuals who perceived stressful events in the previous 6 months were 2.5 to 3 times as likely to be nonadherent, compared to those without such events.

Theorists have attempted to understand and explain psychological stress and human behavior. Abramson, Metalsky, and Alloy (1989) explained that negative life events and a lack of social support could cause what they called *hopelessness depression*. They posited that stressful life experiences can affect cognitive processes, which can interfere with behavior. The interference can be

manifested through the deceleration of thinking processes, sadness, psychomotor retardation, sleep disturbances, difficulty in concentration, dependency, lowered self-efficacy, and lowered self-esteem. Thus, it is important to understand the underlying cognitive processes that can influence behavioral outcomes.

Cognitive Appraisal

Cognitive appraisal is central to understanding the transaction between a potential stressful encounter and the reaction as exhibited by human behavior (Lazarus & Folkman, 1984). Lazarus and Folkman defined *cognitive appraisal* as the "processes that intervene between the encounter and the reaction" (p. 52). They identified three types of cognitive appraisal: (a) primary appraisal, (b) secondary appraisals, and (c) reappraisal. Lazarus and Folkman theorized that, although these three forms of cognitive appraisal should be considered separately, they often occur simultaneously because they are related.

In the primary appraisal, an individual judges the significance of an event to his or her well-being. Individuals might judge events as causing harm, as being threatening, or as being challenging. Lazarus and Folkman(1984) explained that people under comparable conditions can react differently to the same event. One person might judge a situation as minimally stressful, whereas another person might judge it as extremely stressful. The appraisal of stress is a function of both the external condition and the manner in which a person construes the stressor. Accounting for differences in responses to similar external events among people living in the same environment is probably the key

to understanding differences in coping and adherence among people living with HIV.

In secondary appraisal, an individual evaluates his or her ability to do something about the already-suffered harm, threat, and challenge. An understanding of secondary cognitive appraisal might help in the attempt to account for stressor response variability among people under comparable conditions. The question he or she strives to answer is "What can I do?" given the cognitive appraisal of a situation as harmful, threatening, or challenging. At this level, an individual evaluates the coping options to determine whether a given coping option will accomplish what it is supposed to accomplish (Lazarus & Folkman, 1984). Some of the questions that people ask themselves in secondary appraisal include "Can I apply a given strategy effectively?" or "What would be the consequences of using a particular strategy in the context of other internal and external demands and constraints?" Whether people can perform specific tasks depends upon (a) their confidence in themselves and (b) their perception of the available support from their social network. Details about types of support and how they may or may not be useful in understanding coping are discussed under the section addressing social support.

Third, *reappraisal* refers to a changed appraisal based on new information from an environment. For example, a person living with HIV may change his or her appraisal of HIV as threatening following an improvement in health and a significant drop in viral load.

Coping

Coping is defined as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984, p. 141). This definition suggests that coping is process-oriented and requires resources to meet the person's insufficient resources. Coping also is an effort, which indicates this process includes all things that an individual thinks or does regardless of the outcome. Lazarus and Folkman used the word manage in this definition to ensure that coping is not equated with mastery. Instead, they conceptualized coping to include minimizing, avoiding, tolerating, and accepting the stressful condition as well as exerting some effort to master the environment. The authors' explanations suggest that coping in this context ought to be understood as a function rather than as an outcome. In this respect, coping functions that are directed toward regulating the emotional response to the problem are referred to as *emotion-focused coping*, and coping functions that are directed toward managing the problem causing the distress are referred to as problem-focused coping (Lazarus & Folkman, 1984).

Emotion-focused coping. Some of the strategies in emotion-focused coping lead to changes in the way an encounter are construed. For example, a person living with HIV could say, "I decided to focus on the brighter part of my life" or may use positive comparisons such as telling himself or herself, "I realized I am alive and others like me died or are worse off." These strategies may mitigate the effect of stressors and may allow individuals to adapt to living with

HIV. Furthermore, they may create the positive states conducive to problemfocused coping. Conversely, a lack of emotion-focused coping may lead to psychological distress, which can affect an individual's ability to manage controlled events.

Problem-focused coping. Problem-focused coping is directed at defining the problem, enlisting various alternatives, weighing these alternatives in terms of their advantages and disadvantages, choosing among the available alternatives, and acting upon the choice (Lazarus & Folkman, 1984). Lazarus and Folkman also pointed out that problem-focused coping can be directed inward. Thus, problem-focused forms of coping can be either a strategy directed toward altering the external pressures, barriers, resources, procedures, or strategies directed toward motivational or cognitive changes in the person's ability to manage stressors.

Coping Self-Efficacy

Coping self-efficacy refers to beliefs in one's capabilities to organize, to execute the courses of action required to manage prospective situations, and to deal with barriers that arise in order to ensure sustained action (Bandura, 1997; Chesney et al., 2006; Schwarzer & Renner, 2000). Individuals who are prescribed ART face several barriers, such as the stress of living with HIV, fear of disclosure of HIV and resulting stigma, fear of discrimination, symptoms of AIDS, and side effects, all of which can interfere with their ability to adhere to medication for HIV (Catz et al., 2000). Nevertheless, a person who perceives himself or herself as efficacious (having perceived self-efficacy) has confidence in the self and may respond to stressors with better strategies, more effort, and prolonged persistence to overcome those barriers (Bandura, 1997; Schwarzer & Renner, 2000; Chesney et al., 2006). Self-efficacious people refuse to give in to discouragements.

Bandura (1997) postulated that beliefs determine whether one will exert some effort while executing certain actions or not. If an individual believes that he or she is incapable of producing the desired result or of avoiding undesirable outcomes, he or she will not attempt to do anything. One source of influence on self-efficacy is vicarious experiences. Vicarious experiences provided by social models influence beliefs of self-efficacy (Bandura, 1997). This theory may be applicable to people living with HIV and embedded in community-based organizations that provide support. Adherent patients living with HIV may model skills and patients new to the treatment can learn or obtain information from them. In contrast, if the social model performs poorly, (for example, being nonadherent) the expectations of the observer decline. It becomes important to understand whether people living with HIV are surrounded by people who fail to adhere or by people who are adherent.

Social Support Theory

Social support refers to the resources that are provided by others in one's interpersonal ties (Cohen & Hoberman, 1983; Schwarzer, Dunkel-Schetter, & Kemeny, 1994). Social support is thought to affect mental and physical health through its influence on emotions, cognitions, and behaviors (Cohen, 1988). In the stress, appraisal, and coping theory, Lazarus and Folkman (1984) postulated

that social support can probably contribute to health either by preventing extreme responses associated with dysfunction or by providing resources to meet the demand of taxing situations. If a person knows that support can be availed from one or more interpersonal networks, such knowledge can prompt him or her to appraise a stressful situation as controllable. Cohen, Underwood, and Gottlieb (2000) theorized that social relationships can influence human behavior with positive implications for health, such as adherence to medical regimens.

Social support is a multifaceted concept. It has been conceptualized and explained as networks of people, quality of connections among people, or social resources provided by these networks (Hutchinson, 1999; Cohen & Wills, 1985; Cohen & Hoberman, 1983). Thus, one of the questions sociologists have addressed is whether measures of social support should focus on social networks, the quality of networks, or on the roles that these networks serve. However, to clearly capture the concept of and understand the dynamism of social support, all play a pivotal role. As Langford et al. 1997 argues, without a structure of people (network), with quality of connectedness, (Embeddedness), needed to generate an atmosphere of helpfulness and protection , social supportive behaviors cannot occur.

Despite the relatedness of these three constructs, each represents a different process through which social support may affect one's well-being (Cohen & Wills, 1985). Having broad or dense networks may not necessarily mean that support has been received or would be available if needed. A lack of

needed resources may impede a network's ability to provide what an individual may need. Furthermore, a social network can be a source of conflict and, therefore, provide stress (Cohen & Wills, 1985).

Cohen, Mermestein, Kamarck, and Hoberman (1985) have argued that these types of support are interrelated in the sense that interpersonal networks function as conduits through which needed support can be provided. It would be impossible to conceptualize the quality of a relationship without a network of at least two people. In sum, in order to receive support, we need networks of people with quality connections.

Functional measures of social support can detect how social support buffers one from the effects of negative life events (Cohen & Hoberman, 1983; Cohen & Wills, 1985; Cohen et al., 2000). Cohen and Wills (1985) showed that, when the chronically or terminally ill receive or perceive the availability of support to be relevant to the needs elicited by their conditions, that support has a buffering effect. The buffering effects of support can lead to a positive appraisal of negative events because received or perceived coping resources reduce the negative psychological effects of stress, allowing individuals to adapt and to manage difficult conditions. Thus, measures of functional social support are suitable for studies that examine the extent to which support protects individuals from the deleterious effects of negative events.

Perceived and Received Support

Whereas social networks show the existence of an individual's ties, functional social support shows the functions that these networks might serve

(Cohen & Wills1985). Thus, measures of functional social support are more relevant in detecting individuals' perceptions of support from others. Received support refers to past actual received support, and *perceived support* refers to the support an individual believes exists for him or her in the social network (Cohen & Wills, 1985). One's belief that support exists in social structures can lead to positive cognitive appraisals of stressful events. In this sense, the demands created by a stressful event are appraised as controllable or manageable because of the perceived available coping resources. The perceptions of controllability and management of stress may reduce psychological and physiological reactions to negative events and may help individuals return to normal or to better functioning. Thus, measures of perceived social support are more applicable in understanding how individuals cope with negative events or how support buffers one against challenging situations than measures of received support. Past support resources are not an assurance that such resources or other specific support would be available if needed.

Dimensions of Support

To determine how social support buffers one from stress or provides resources, functional social support is appropriate. Functional support has different dimensions, sources, and forms.

Functional social support is effective only if it is specific, that is, to the extent that it is well matched to the needs of the intended recipients. Cohen and Wills (1985) have suggested using multidimensional measures of functional social support to understand how it buffers people against stress or negative life

situations. *Stress* is defined as the relationship between the person and the environment (Lazarus & Folkman, 1984). This definition of stress allows for the detection of response variations among people under comparable external conditions. Support is said to buffer stress when it enhances one's coping response to a demanding situation. Theoretical discussions of the buffering effects of support emphasize the importance of a multidimensional measurement of the functions of social support (Cohen & McKay, 1984; Cohen & Wills, 1985). Cohen and colleagues have identified four such dimensions of support: emotional, informational, tangible, and belonging.

Emotional support refers to information that a person is esteemed and accepted (Cohen & Wills, 1985). Emotional support is what makes a person feel loved, cared for, and understood. This support communicates to persons that they are "valued for their own worth and experiences and are accepted despite any difficulties or personal faults" (Cohen & Wills, 1985, p. 313). It has to do with an individual's perception of others' confidence in him or her, and it measures one's perceptions of his or her ability to do things as well as others.

Informational support, also termed *advice* or *appraisal support* helps people to define, to understand, and to cope with problematic events. An individual perceives others' supportiveness in coping with problematic events if he or she perceives at least one person whose advice can be trusted, knows someone who can provide objective feedback about the himself or herself, or feels that there is one person with whom he or she can share his or her most private worries and fears (Cohen et al., 1985). HIV patients, for example, may

have a wide range of need for information about HIV/AIDS, adherence to ART, opportunistic infections, and other related information.

Tangible support refers to material assistance needed by recipients (Cohen & Wills, 1985). People perceive tangible support to be available if they are optimistic that they would obtain this type of support with ease. For example, an individual would perceive this support to be available if he or she would not have trouble finding someone to take him or her to the hospital or if he or she had someone who could lend money in case of an urgent and important matter.

Finally, *belonging support* is a sense of being connected with others or belonging to the human family. This support refers to the perception that there are people with whom one can do things, for example, going to a movie; being invited to celebrate a birthday, graduation party, or wedding ceremony; or even simply enjoying the same things as others do (Cohen & Wills, 1985).

Social Support and Adherence to ART

Despite reports of high adherence to ART in Sub-Saharan Africa among people living with HIV is high, it is not clear what factors influence it. Mills et al. (2006) evaluated and compared estimates of adherence to ART in sub-Saharan Africans and North Americans. The authors examined 31 studies from North America and 28 full-text articles and three abstracts from sub-Saharan African countries relating to adherence to ART. The investigation of 17,573 patients' self-reported adherence in North America and 12,116 patients in sub-Saharan Africa demonstrated that, of all patients in North America, 55% of the patients were adherent to ART and, in sub-Saharan Africa, 77% were adherent to ART.

However, the study did not explain why adherence was higher in sub-Saharan Africa. However, the study did not find out factors that could be contributing to adherence among people living with HIV in the Sub-Saharan Africa.

Ware et al. (2009) attempted to explain the reason for higher adherence in sub-Saharan Africa. In an ethnographic study, these researchers investigated why adherence to ART is high in sub-Saharan Africa. They used a comprehensive qualitative approach to describe and explain human behavior and culture as they relate to adherence to ART. The high level of adherence in people living with HIV in sub-Saharan Africa may indicate a person's effort to fulfill social responsibilities, which go beyond a person's need to improve health. They also include the need to protect and preserve one's ties or social capital. In brief, the efforts to adhere to ART in people living with HIV in sub-Saharan Africa are driven by the need to preserve the social structures that provide resources and to improve health. Although this argument is suitable to explain how social structures or ties are preserved, it does not create an understanding how social support helps people to cope with taxing events.

Consistent evidence has shown an association of support with adherence to ART. Williams et al. (2006), in a randomized controlled trial, investigated whether visits to patients who were prescribed ART home improved adherence. The intervention group had greater than 90% improved adherence compared with the control group. The author suggested that home visits from a nurse and a community worker were associated with better medication adherence among people living with HIV in North America.

Other researchers have gone further to investigate whether some specific dimensions of support influence adherence to ART more than others. DiMateo (2004) found evidence suggesting that material and emotional social support had significant correlation with adherence to medication, but not informational or belonging support. The study also demonstrated that the odds of adhering to treatment in patients who were nested within cohesive families were 3.03 times higher than in patients who were in less cohesive families. These findings reinforce one of the perspectives of social theorists, explaining social support as quality social ties rather the mere existence of ties.

Other researchers have examined the relationship of individual's perception of lack of social support with failure to adhere to ART. Catz et al. (2000) investigated whether poor social support was related to nonadherence to ART. They examined a sample of 72 individuals who were prescribed antiretroviral medication regimens and who were attending an outpatient infectious disease clinic. They found that a person's perception of lack of support significantly correlated with poor adherence to medication for HIV.

Studies investigating the relation between social support and adherence to ART have shown some inconsistencies. Ncama et al. (2004), in a crosssectional design study, examined correlates of social support in a sample of 149 persons on medication for HIV from four outpatient settings in Durban, South Africa. Participants had 7 close friends and family to rely on. However, the study did not find significant relations between measures of social support and measures of adherence. Nonsignificance in the correlation between support and adherence to medication may be a methodological issue rather than a sample characteristic. As described earlier in theory of social support, having close friends and family may not guarantee that support would be available to an individual if he or she needed it. Friends and family may be close to an individual in need, but they may the lack resources (skills, information, or material) needed by the individual to cope with a situation that demands or exceeds his or her own resources. Thus, measures of a person's perception that needed support would be available are appropriate in gauging the relevance of support to deal with a specific need of an individual. In order to understand how perceived availability of support may be related to adherence to HIV medication, it is important to explore its influences on an individual's psychological state.

Support and States of Mind

To understand why relevant social support may influence a person's behavior, it is critical to understand how this support reinforces a state of mind, which in turn influences the behavior. According to the buffering hypothesis of Cohen and Wills (1985), support may intervene between a stressful event and a stress reaction by attenuating the stress appraisal response, thereby "buffering" the response. In brief, a person who perceives that relevant and sufficient support will be available from existing social structures within which he or she is nested may evaluate a stressful event as less threatening and dangerous to his or her well-being.

Researchers have examined several transactional models of stress, coping, lack of social support, and nonadherence to HIV medication. Simoni,

Frick, et al. (2002) interviewed 50 patients at an inner-city outpatient HIV clinic to determine mediators of social support and adherence to ART among the indigent population in New York City. Specifically, they sought to determine whether self-efficacy, negative affective states, and knowledge of medication regimen mediated social support and medication adherence. They found that the need for social support was positively correlated with nonadherence. Also, depression was a potential mediator between the need for support and acknowledged nonadherence to treatment.

Other researchers have investigated the relation between positive states of mind and adherence to ART. Gonzalez et al. (2004) studied whether positive states of mind (e.g., focused attention, productivity, responsible caretaking, restful repose, sensuous nonsexual pleasure, sharing, and sensuous sexual pleasure) and fewer depressive symptoms mediated social support and medication adherence in HIV-positive patients. Regression analysis revealed that 38% of the relation between social support and medication adherence was mediated by positive states of mind. This study also found that depressive symptoms were inversely related to medication adherence. The researchers suggested that social support first bolsters states of mind, which in turn foster better adherence to treatment.

Inability to regulate emotions has been correlated not only with psychological distress but also with poor behavioral outcomes. Specifically, negative emotional and psychological states have been associated with poor adherence to ART regimens (Bottonari et al., 2005). Bottanari et al. aimed to

advance knowledge of the psychosocial processes that may affect HIV patients' ability to adhere to treatment. They investigated the impact of life stress on treatment adherence and viral load in a sample of 24 treatment-seeking HIVpositive individuals. They examined three different aspects of life stress: perceived stress, acute life events unrelated to the HIV illness, and HIV-related acute life events. The study indicated that perceived stress prospectively predicted adherence. Individuals with excellent adherence had significantly lower scores on perceived stress than those with suboptimal adherence. Conversely, the relations between general and acute HIV-related life events and adherence were not statistically significant. Thus, individuals' perceptions of an event as stressful, rather than the event itself, control the psychological or behavioral outcome of the stressed individual. An individual who believes that a stressful event is uncontrollable is likely to give up effort to control it. Their study showed that psychologically stressed patients are more likely to find no sense in using antiretroviral medication, a feeling that would cause them to be nonadherent to ART (Bottanari et al., 2005).

Murphy, Marelich, Hoffman, and Steers (2004) examined adherence to ART and the factors associated with it in a sample of 115 people living with HIV. They found that patients with less emotional control were less likely to adhere to ART. Their results support the notion that strong mental health and emotional control can improve adherence to medication treatment.

Need for Research

Few studies have examined the relation of social support and adherence to ART in sub-Saharan Africa. Findings from studies investigating the relation between social support and adherence to ART have not been consistent. However, results from most of the reviewed studies show that there is a significant correlation between support and adherence to medication for HIV (Catz et al., 2000; Chesney et al., 2000; Gonzalez et al., 2004). In addition, Simoni, Frick, Huang (2006) found a negative correlation between a need for support (lack of support) with nonadherence. However, Ncama et al. (2004) found no significant correlation between social support and adherence to a medication regimen for HIV. Social support has been measured differently in these studies, which might explain the inconsistent findings. As Cohen et al. (2000) posited, the type of research questions being answered should determine the appropriate measure of social support. Furthermore, measures of social integration and social networks are designed to answer different questions from measures of functional support (received or perceived support). Finally, no known studies have been documented in Kenya seeking to understand how social support is related to adherence to ART.

Knowledge of what promoted adherence among people living with HIV will benefit individual patients living with HIV because evidence-based interventions can be designed. Adherence promotion interventions can benefit the society as it can be educated concerning what to do to improve clinical outcomes for people living with HIV. Promotion of adherence has a public health benefit will minimize

significantly the possibility of transmission of drug-resistant HIV strains. Furthermore, the findings may demonstrate and reinforce a multidisciplinary approach to promoting health and healthful behavior. The present study shows the interplay of sociology, psychology, and medicine in enhancing physical and mental health as well as promoting needed healthful behavior, such as adherence to ART in men and women living with HIV in Kenya.

CHAPTER III

METHODOLOGY

This project used a cross-sectional study design which assessed subjects at a single time. Although no inference of cause and effect can be made, this design is useful when the objective is to find out the nature of associations or relations among variables. The methodology and design of this study fit the hypotheses because the questions concern the relations between demographic, social, and psychological variables to the outcome variables, that is, adherence to ART. It is possible with this design to determine the direction of a relation (positive, negative, or no relation) and the strength of these relationships (Munro, 2005; Thorkildsen, 2005). In addition, correlational design was used to explore the nature of the association between the demographic variables and the outcome. Subsequently, demographic variables found to have statistical significance with the outcome were controlled for in the analyses of the study hypotheses.

Survey Tools

The survey tools were administered in three languages: English, Kiswahili, and Kikuyu. These tools were: Demographic characteristics of Respondents, Interpersonal Support Evaluation List (ISEL), Coping Self-Efficacy (CSE), and Adult Clinical Trial Group (ACTG) Adherence Questionnaire (See Appendix B. Survey Tools)

Demographic Characteristics of Respondents

Data were collected on age, gender, marital status, education, employment status, and religious affiliation. Respondents indicated the age ranges provided within which their age fell: (a) 18-29, (b) 30-40, (c) 41-50, (d) 51-64. Gender was categorized as either male or female. Marital status had five classifications: (a) single, (b) married, (c) separated, (d) divorced, or (e) widowed. Respondents indicated their educational level with one of the following classifications: (a) no formal education, (b) some primary (elementary) education, (c) some high school education, or (d) some college or vocational training. Employment was defined as one of the following: (a) formal employment, (b) selfemployment, (c) farming, or (d) unemployed. Finally, respondents classified themselves in one of the following groups: (a) Roman Catholic, (b) Protestant, (c) Muslim, or (d) African traditional religion.

Translation of Validated Instruments

The Interpersonal Support Evaluation List (ISEL), Coping Self-Efficacy, (CSE) and Adult Clinical Trial Group (ACTG) Adherence questionnaires were translated from English into Kiswahili and Kikuyu. Chapman and Carter (1979) aptly noted that many developing countries have few developed measurement instruments for use in their local settings. Kenya is not an exception. Development of a new measure is a time-consuming process (Guillemin, Bombardier, & Beaton, 1993). Because development and validation of a new instrument requires resources, the alternative for researchers in developing countries is to translate previously validated instruments into a language of the target population. Thus, the researcher chose to translate the ISEL, CSE, and ACTG Adherence questionnaires from English into Kiswahili because of the lack of validated measures of social support, coping self-efficacy, and adherence to ART.

Because translation was the preferred option, the researcher ensured that translated instruments would not result in flawed new versions of the ISEL, CSE, and ACTG Adherence to ART questionnaires. Incorrectly translated survey tools may lead to misleading data and, thus, flawed conclusions concerning outcome variables (Flaherty et al., 1988).

The translators of the tools were instructed to produce a semantic translation rather than a literal or word translation. Because the original versions had been tested for and demonstrated evidence of validity and reliability (Cohen & Hoberman, 1983; Chesney et al., 2000; Chesney et al., 2006), the task was to re-examine each item's relevance to the culture and lifestyles of Kenyans Flaherty et al., 1988) because a common phenomenon in one culture may be unfamiliar in another culture.

As an illustration of the limitation of a forward-only translation, Flaherty et al. (1988) cited the Peruvian-Cangallo project (PCP), which studied individuals who migrated from an Andean village of Lima, Peru. In the course of the study, the researchers assessed instruments established in the U.S. to determine their appropriateness for use in targeted South American cultures. A team of experts with experience in these cultures eliminated antisocial items because these items were irrelevant to the lifestyle and culture of South Americans. Some questions in their scale were irrelevant. Examples of such questions included whether a person had at least four traffic tickets for speeding or running a red light. Such questions were irrelevant because the populations under study did not drive but used public transportation.

To examine effectively the relevance of items, the translators needed to have experience with the culture being studied. Flaherty et al. (1988) suggested that translators need to identify any item that depicts an improbable occurrence of an event and either drop that item or modify it to reflect probable phenomena among the target population (Flaherty et al., 1988; Guillemin et al., 1993). They also suggested that translators identify equivalent idioms or expressions to replace similar idioms or expressions in a source language version because idioms are untranslatable.

Semantic equivalence is defined as equivalence in the meaning of words and statements (Guillemin et al., 1993). While content equivalence requires modifications of reality and experiences that occur in the target language, semantic equivalence attempts to retain meanings contained in the source instrument. Thus, another critical task of a translator of an instrument is to ensure that those translations do not alter the construct that an item is meant to capture (Flaherty et al., 1988). To ensure semantic equivalence between the original version and a translation, researchers need to verify the meaning of the translated items against the original version of the instrument. Ideally, the meaning of items in the source language should be maintained and ambiguity avoided.

The way to verify semantic equivalence is by back-translation (Flaherty et al. 1993)). The translated instrument is back translated from the target language to the source language. A back-translation provides a way for bilingual experts to compare the new version of an instrument to the original source version. Sources of inconsistencies, if any, can be traced either in the back-translation version or in the items of the new version in the target language. Inconsistencies caused by the new versions should be addressed by the expert and relevant action taken to reword or rephrase items to bring their meanings as close as possible to the source language based on culture and experience of the target language (Flaherty et al., 1988). Thus, back-translation may not result in an identical version of the original version because a back-translation may reflect cultural adaptation of the new version to the target population (content equivalence). As much as it is impossible to translate idioms or some expressions from a source language to a target language, the reverse is also true.

The ISEL, CSE, and ACTG Adherence Questionnaire are reliable and valid instruments and have been extensively tested and found to be psychometrically sound (Chesney et al., 2000; Chesney et al., 2006; Cohen & Hoberman, 1983). Because these instruments are written in the English language and have not been translated and validated in Kiswahili and Kikuyu for implementation in Kenya, it was necessary to have them translated.

However, translation is not enough. The cultural practices, experiences, and development of each culture demands translation are adapted to the context

in which it is to be applied. The social, cultural, and economic contexts of Kenyans are different from those of Americans. For example, flying in airplanes, use of automobiles, and keeping pets are common phenomena in the U.S.; the same is not true in Kenya. Such items that aim to measure certain constructs must be adapted to familiar experiences among people living in Kenya in order to measure the same constructs. The right approach is to address these differences in the process of translation instruments if results based on data collected using the translation can be justifiable (Maneesriwongul & Dixon, 2004).

Further, it is necessary to establish face-validity of each of these tools. Face validity indicates whether an instrument appears to be a good measure or not, based on the judgment made on the "face" of the research tool (Portney & Watkins, 2000).

The researcher requested and obtained permission from Dr. Sheldon Cohen to translate and use the Interpersonal Support Evaluation List (ISEL). Permission was also requested from Margaret Chesney to translate and use the Coping Self-Efficacy (CSE) and ACTG Adherence questionnaires. Both Cohen and Chesney granted permission and requested copies of the translations, once translation and testing of the Kiswahili and Kikuyu versions were completed so that they could post them on their websites. This research was submitted to the Seton Hall University Institutional Review Board (IRB) however, the IRB decided that the application did not fall under its purview.

Four multilingual translators and 10 multi-lingual individuals assisted with translating and pre-testing the final Kiswahili and Kikuyu versions of the ISEL,

CSE, and ACTG Adherence survey tools. To qualify to participate as translators and raters of the translations, the following inclusion criteria were used: Translators were proficient in English, proficient in Kiswahili and Kikuyu, and had experience in semantic translation or experience with English-to-Kiswahili or English-to-Kikuyu translation. A review committee then reviewed and produced final versions of the instruments. Then, trilingual raters rated the new versions to the extent that the new versions reflect the contents of the original versions. All participants were over 18 years of age or older, and their participation in this study was voluntary.

The Kiswahili forward-translator has over 25 years experience teaching Kiswahili literature (fasihi) in high school. The Kikuyu translator is an expert in English, Greek, and Hebrew and has 9 years of experience translating the Old Testament and New Testament of the Bible from Hebrew and Greek into contemporary Kikuyu, a version launched in 2008 by the International Bible Society and Kenya's Bible Society.

After being accepted to participate in the study and subsequent selection as either translators or raters of translation, each person was contacted by the researcher via his or her preferred method of phone or email. The study was introduced to raters and translators in telephone conversation or email.

The complete translation of the ISEL, CSE, and ACTG Adherence questionnaires was a four-step process: (a) forward translation, (b) back to English translation, (c) review of translations and modification if necessary, and (d) pretesting of final translation among multilingual men and women.

Two volunteers proficient in English, Kiswahili, and Kikuyu as per the inclusion criteria participated in the translation of the original versions of ISEL, CSE, and ACTG Adherence survey tools. The translators were instructed to translate the survey tools from original English into either Kiswahili or Kikuyu. The objective was to produce new Kiswahili and Kikuyu versions of ISEL, CSE, ACTG Adherence survey tools equivalent in semantics and contents to the original versions. Upon completion of the translations, the translators sent new versions to the researcher.

Two other volunteer translators proficient in English, Kiswahili, and Kikuyu different were given the new Kiswahili and Kikuyu ISEL, CSE, and ACTG Adherence survey tools. They were instructed to translate these new Kiswahili and Kikuyu versions into English without consulting the original English versions. The goal was to establish a basis for comparison between the new Kiswahili and Kikuyu versions with the original versions of these scales. This process resulted in English ISEL, CSE, ACTG versions of the Kiswahili and Kikuyu versions.

Next, the investigator convened a review committee consisting of translators who assessed the equivalence of the three versions: (a) the new Kiswahili and Kikuyu versions, (b) the English translations of the new versions, and (c) the original versions in English. The committee compared item by item of the original English versions against the English versions translated from Kiswahili. The same process was used for the Kikuyu versions. When an item was deemed not similar in the two English versions, the source of the retranslated English version (Kiswahili or Kikuyu) was revisited. The committee

deliberated and generated a translation closer in meaning to the original version. Some of the problems identified and modified included use of inappropriate examples. For example, item 2 of the ISEL was modified for both Kiswahili and Kikuyu versions to read "fixing something at home, or in the farm" without giving specific examples. The example "fixing appliances, or repairing my car" may not be comprehensible to most Kenyans because they do not own cars.

Similarly, item 9, which originally read "if I needed a ride to the airport . . ." was modified to read "if I had an emergency to attend to a personal need" because air travel is largely inaccessible to the Kenyan population. In addition, English idiomatic expressions such as "getting down in the dumps" (item 1 in the CSE) have no Kikuyu and Kiswahili translation. Such phrases were replaced with other descriptive expressions ensuring comprehensibility of the item in either Kiswahili or English while keeping the original meaning. A further example, in item 12 of the ISEL, "spending time" was replaced with a better Kikuyu phrase "Kunyihia muthenya, kana utuku," which literally means "shortening the day or night," which makes no sense in English. Translation of such a phrase does not make sense in either Kiswahili or Kikuyu.

After reviewing, correcting, and modifying the Kiswahili and Kikuyu versions of the ISEL, CSE, and ACTG, the committee produced the final versions. These final versions are, to the best of committee's knowledge, equivalent to the original English instruments. These versions have been adapted to the Kenyan culture, are comprehensible to the population in Kenya, and thus may be able to measure the same theoretical constructs as the ones

measured by the original instruments. A consensus of the review committee was necessary before any changes were made to the new Kiswahili and Kikuyu versions. Thus, final versions of the Kiswahili and Kikuyu ISEL, CSE, and ACTG Adherence survey tools were created.

To determine face validity, 10 men and women who speak Kiswahili, Kikuyu, and English participated in the pretesting of the equivalence of the new versions to the original versions of the survey tools. Each rater read item by item in the original versions of each tool, compared it to its corresponding Kiswahili or Kikuyu version, and made judgment as to the accuracy and completeness of the translations. The results of the 10 trilingual translators indicated that the new Kiswahili and Kikuyu version of the ISEL, CSE, and ACTG were accurate and complete reflections of the original English versions. Thus, they were deemed valid to be used in this study.

Interpersonal Support Evaluation List (ISEL)

The ISEL was designed to provide a measure of perception of social support. Correlation between the ISEL and other social support measures has demonstrated that, even though it is somewhat different from others ISEL measures of similar constructs (social support), the ISEL correlated .30 with the total scores of the Moos Family Environment (Cohen & Wills, 1985). Adequate internal and test-retest reliabilities have been found in the general scale and the subscales. Internal reliability (alpha coefficient) ranges from .88 to .90. Cohen and Wills (1985) reported an internal consistency (Cronbach's alpha) of .90 for

the full scale and .70 or higher for the subscales. These correlation coefficients are acceptable in social sciences (Cohen, 1988).

The ISEL is a measure of respondents' perception of availability of social support if needed. It consists of 40 items classified under four dimensions that measure emotional, informational, material support and belongingness. Each of these four dimensions of perceived social support consists of a list of 10 statements. The items are rated on Likert-type scales. Participants are asked to indicate their level of agreement with each statement using the following possible responses: 1 - *definitely false*, 2 - *probably false*, 3 - *probably true*, or 4 - *definitely true* (Cohen & Wills, 1985; Cohen & Hoberman, 1983). The ISEL has been tested and found to be valid and reliable for assessing perceived social support and is a potentially powerful tool because various functions (dimensions) of support can be tested for their usefulness in mitigating the specific elicited stressor.

Coping Self-Efficacy (CSE) Questionnaire

The CSE is a 26-item questionnaire that measures belief in one's ability to cope with stressors (negative life events). Chesney et al. (2006) indicated that Cronbach's internal consistency coefficient alpha for "Use problem-focused coping" is alpha = .91, "stop unpleasant emotions and thoughts" is alpha = .91, and "get support from friends and family" is alpha = .80. Chesney et al. (2006) assessed concurrent validity.

Partial correlations assessing the independent relations between measures of psychological distress and well-being ranged from .20 to .28, all at p

value < .001. The problem-focused coping, use of emotion-focused coping, and seeking support from friends and family scales derived from CSE and the ways of coping subscales provided evidence of convergent validity. Greater use of problem-focused coping (part of CSE) was associated with greater use of planned problem-solving as a coping style (partial r = .27, p < .001; Chesney et al., 2006). Similarly, ability to stop unpleasant emotions and thoughts (CSE) was shown to have a negative correlation with cognitive escape-avoidance (partial r = .20, p < .001) and less use of distancing (partial r = .22, p < .001) of the measure of ways of coping.

The CSE is a 26-item measure that measures an individual's belief that he or she can perform behaviors important to adaptive coping by sorting out what is controllable and what is uncontrollable. On a scale of 0-10, participants are asked to indicate how confident they are that they can do certain things when things are not going on well. For example, "when things are not going on well with you, how confident are you that you can talk positively to yourself" or "sort out what can be changed and what cannot be changed" or "get emotional support from Triends and family" (Chesney et al., 2003). The scale ranges from 0 (*cannot do at all*), through 5 (*moderately certain I can do*), to 10 (*certain can do*). An overall CSE score is created by summing the item ratings ($\alpha = .95$; scale mean = 137.4, *SD* = 45.6).

Adult Clinical Trial Group Adherence Questionnaire

The ACTG Adherence questionnaire is a 5-item tool that measures a patient's adherence to doses, pills, timings, and dietary instructions. This

instrument also measures patients' reasons for any missed medication or dietary requirement. It has been widely used in adherence studies and found to be a reliable measure of self-reported adherence to ART (Chesney et al., 2000; Gonzalez et al., 2004; Simoni, Frick et al., 2002; Simoni et al., 2004). *Medication adherence* is defined as the percentage of prescribed medications taken in any form for the last 4 days; *pill adherence* is defined as the percentage of medications taken for which the correct number of pills were taken at each dose; *instructions adherence* is defined as the percentage of medications for which the correct special instructions were followed at each prescribed dose, and *dose adherence* is defined as the percentage of doses taken of the doses prescribed. Adherence to ART in this study was defined as patients compliant to HIV medication in previous four days.

Study Approvals

The management of Nazareth Hospital granted the principal investigator permission to conduct the study, to display flyers, to recruit patients, and to use its facilities for the administration of the survey tools at a small fee (see Appendix C: Nazareth Hospital Acceptance Letter). Before commencement of the study, the investigator held meetings with the management of the healthcare provider, the medical officer in charge of the hospital, and a team of physicians who oversee and manage the nine centers of treatment and care for people living with HIV/AIDS.

In accordance with the international guidelines for research conducted outside the U.S., this research proposal was submitted for ethical review to Moi University's Institutional Research and Ethics Committee (IREC), Eldoret, Kenya. The Institutional Research and Ethics Committee (IREC) reviewed the proposal and approved it on August 25th, 2009 (see Appendix D). Subsequently, another application was submitted to the IRB of Seton Hall University and approval was obtained in October 2009 (see Appendix E: Institutional Review Board, Seton Hall University).

Setting

This study was conducted at nine comprehensive care treatment centers managed by a major healthcare provider serving populations in parts of Central Province and the metropolitan city of Nairobi, Kenya. These centers are specifically designed to provide counseling, treatment, and care to people living with HIV/AIDS. This research was conducted in designated counseling rooms in each of the centers. These rooms provided a private environment in which respondents could feel free to respond to the questionnaires.

Sample Size and Procedures for Sample Recruitment and Selection

A convenience sampling (nonprobabilistic) was used to recruit 403 men and women volunteers living with HIV, aged 18-64 years, and having Art prescribed, who were being cared and treated for HIV in any of the nine comprehensive care and treatment centers under the umbrella of a healthcare provider serving parts of Central Province and the metropolitan city of Nairobi, Kenya. Of the 403 who consented to participate and take the self-administered survey tools, 354 completed the questionnaires; thus, they were included in the study. A power analysis for behavioral sciences was used to determine the sample size needed to detect statistically significant results. To achieve a power of .80 and a medium effect size ($f^2 = .15$), a sample size of 127 was required to detect a significant model (F(12, 114) = 1.83). This model contained 16 interaction variables; with the demographic factors, it resulted in a total of 20 variables. To achieve a power of .80 and a medium effect size ($f^2 = .15$), a sample size of 157 was required to detect a significant model (F(20, 136) = 1.64).

The alpha for the tests of all hypotheses was set at .05 for results to be statistically significant. An alpha level of .05 is the probability of a type I error, that is, the probability of rejecting the null hypothesis given that that the null hypothesis is true.

Several models were examined using multivariate statistics. The first model tested whether certain variables (gender, age, employment, levels of education) predicted adherence to ART over the previous 4 days. Then, a composite measure of social support, including the four social support subscales (emotional, material, informational, and belonging), a composite measure of CSE and three CSE subscales (Meaning-Based Coping [MBC], Problem Management Coping [PMC], and Seek Social Support [SSS]), were taken to predict adherence to ART.

Based on the results of the initial model, a second model consisted of interaction terms. More specifically, the model examined whether social support variables interacted with the coping self-efficacy variables to predict adherence.

Thus, the final sample size consisting of 354 respondents was adequate for the desired power level to predict a significant result if an effect exists.

Inclusion and Exclusion Criteria

Participants included an equitable number of men and women living with HIV who were (a) at least 18 years old (18 being the legal age at which a person can give informed consent), (b) able to communicate in either Kiswahili, Kikuyu, or English, (c) prescribed ART, and (d) attending any of the HIV treatment clinics within the metropolitan area of Nairobi and Kiambu district in the Central Province of Kenya. Individuals who (a) were under 18 years of age, (b) were prisoners, (c) were pregnant women, and/or (d) could not make competent or rational decisions were excluded from the study.

Anonymity and Confidentiality

To ensure the anonymity of the subjects, administration of the survey was carried out in private rooms in each of the nine centers. Research data were kept separate from identifiable information, such as the informed consent forms of respondents. Each respondent was assigned a code, which was entered on the first page of the booklet that contained all the study survey tools. Thus, there were no personal identifiers associated with the survey responses, and it was not possible to identify who said what except by general demographic characteristics. The demographic characteristics did not include specific details of the respondents such as names, birth dates, national identification numbers, addresses, telephone numbers, email addresses, or any other identifying information. As soon as data were collected, the principal investigator assigned

codes to questionnaires and was the only one who could interpret the codes. Identifiable numerical identifiers necessary for editing were shredded as soon as the editing was complete. All information collected remains confidential and kept anonymous.

Procedures of Respondents Identification

Through self-identification respondents self-identified themselves through the staff at their centers. To ensure that subjects felt free to decline to participate in the study, the following procedures were observed. The flyers and recruitment forms in each of the nine HIV comprehensive care and treatment centers were displayed in waiting rooms and pharmacies. The flyer stated why the study was being conducted, why participants were being recruited, the procedures involved, and the eligibility (inclusion) criteria and exclusion criteria (see Appendix F: Flyer and Recruitment Form). The flyer indicated that participation in the study was voluntary, that informed consent was needed before administration of the survey tools, and that qualified participants had the right to decline to participate during the study without penalties.

Interested participants were requested to complete recruitment forms placed in an eye-catching site in the center. These recruitment forms were used to obtain contact information such as names addresses and telephone contacts. All completed forms were dropped in a drop-box at a designated location in each of the centers. The staff at the clinic gave the contact information to the principal investigator. Respondents were given an opportunity to ask questions regarding their participation in the study. Patients expressing their willingness to take part in the study were scheduled for an interview at a date and time convenient to them.

Procedures of Administration of the Survey Tools

Respondents were informed that all data would be in aggregate form. As such, it will not be possible to identify any respondent when the data are reported or discussed. Because the administration of the survey tools took place in the care and treatment sites, counseling services were readily available to participants. However, there was no incident requiring such services throughout the administration of the survey. Administration of the survey tools was implemented in rooms or locations that provided privacy.

The principal investigator or the research assistants introduced themselves and the study to the respondents. Completion of the four survey tools took respondents about 45 minutes. Before administration of the survey tools, informed consent was sought from every respondent (Appendix G: Informed Consent Form). Participants' right to decline to participate in the study was explained. Participants also were informed of their right not to answer any question, to withdraw from the study, or to seek clarification at any time during the administration of the survey. The informed consent was issued to each respondent. It gave a brief explanation of the survey tools and the voluntary nature of the study; assurances of anonymity and confidentiality; and described risks, benefits, and the right to decline to answer any question at any time for any reason or to withdraw from the study without penalty.

Respondent were asked to answer all questions honestly because no one would be judged based on his or her responses and there was no right or wrong answer.

Training of Research Assistants

Four research assistants were selected and trained to assist in the recruitment, selection, and administration of both the informed consent form (Appendix G) and survey tools (Appendix B). See Appendix H: Research Assistants Training protocol.

Research Assistants successfully completed web-based National Institute of Health training on protecting human participants in research. They were also were trained how to issue to each participant the informed consent form. Roleplay was used to ensure standard procedures of obtaining informed consent, in interviewing, and in handling questions before or in the process of administration of the questionnaires. The research assistants were informed of the need to resolve a difficult issue with the principal investigator before or during the administration of the questionnaires.

Data Analyses

SPSS Version 18.0 was used for data analysis. Prior to analysis of variables, each variable was examined separately through various SPSS functions for accuracy of data entry, missing values, and fit between their distributions and the assumptions of multivariate analysis (Tabachnick & Fidell, 2001). Accuracy of data entry was confirmed by checking univariate descriptive statistics for anything that appeared strange, such as values out of range, means and standard deviations, and univariate outliers. Because the sample size was large (N = 403), cases with missing values were removed from the analysis. Forty-nine cases had at lead one missing value.

Normality was checked by examining skewness, kurtosis, and probability plots, and nonlinearity and heteroscedasticity. An analysis was conducted to detect any multivariate outliers. A multivariate outlier is one with a significant Mahalonobis Distance at *p*-value < .001, as evaluated using a chi square with *df* = number of variables.

Descriptive statistics were used to summarize and present data through tables and figures. Descriptive statistics are used to describe and summarize sample characteristics (Portney & Watkins, 2000). Descriptive statistics used in this study included means, standard deviations, percentages based on the six demographic characteristics of the sample and adherence to ART, perceptions of social support, and coping self-efficacy scores.

Inferential statistics were used to test the six relations between variables (the hypotheses), and conclusions about the sample and population from which it was drawn were made based on the sample data.

Descriptive Statistics

Then, descriptive statistics procedures were used to calculate frequency distribution, central tendency such as means and percentages of the study variables, demographic characteristics, social support, coping self-efficacy, and adherence to ART. Measures of variability were applied to characterize the differences that existed among the scores and the central tendency of the data

(Portney & Watkins, 2000). Measure of variability included range, percentiles, quartiles, standard deviations, and coefficients of variations.

Factor Analysis

Factor analysis was performed on the measure of CSE for two purposes: (a) to determine the underlying structure of the 26 variables of CSE and (b) to reduce the number of items by determining an adequate number that could measure the construct of CSE. According to Green and Salkind (2004), Tabachnick and Fidell (2001), and Portney and Watkins (2000), exploratory factor analysis is used to uncover underlying structure of items in a scale as well as to reduce number of items of a measure in a measure.

Although the construct of CSE has a reliable theoretical foundation, Lazarus and Folkman (1984) deemed it necessary to find what factors and items would load onto them among population in Kenya. Exploratory factor analysis (EFA) was performed to determine whether dimensions underlying CSE were the same for the population under this study as the dimensions found in populations of developed countries. Chesney et al. (2006) established the validity and reliability of the measure of CSE in the United States. Their study identified 13 variables loading onto three factors: using problem-focused coping, using emotion-focused coping, and seeking support from family and friends.

Thus, exploratory factor analysis (EFA) using factor extraction and rotation was performed to uncover the underlying structure of the 26-variables of the CSE Scale (Green & Salkind, 2004). Based on stress, appraisal, and coping theory (Lazarus & Folkman, 1984) and factor analytic studies (Chesney et al., 2003;

Chesney et al., 2006), a confirmatory factor analysis (CFA) was performed. While EFA searches for the best structure to fit the data, CFA begins with a preestablished structure and determines how well the data fit the factor structure (Munro, 2005; Tabachnick & Fidell, 2001). CFA was used to test a three-factor structure of the measure of CSE.

Scale Reliability

General reliability of the measures of the ISEL and the CSE were calculated. Additionally, because these scales were administered in three languages—English, Kiswahili, and Kikuyu—, Cronbach's alphas for each of the new Kiswahili and Kikuyu versions were calculated as well. *Reliability* is defined as an "estimate of extent to which a test score is free from error" (Portney & Watkins, 2000, p. 64).

Cronbach's coefficient alphas were calculated for the composite measure of ISEL and its subscales—tangible, emotional, informational, and belonging using the sample of the study. Additionally, Cronbach's coefficient alphas were calculated for the composite measure of CSE and its subscales—Meaning Based Coping, Problem Management coping, and Seek Social Support—using the sample of the study. Finally, Cronbach's alpha correlation coefficients were calculated for the English, Kiswahili, and Kikuyu versions of ISEL and CSE. An acceptable level of reliability in this study was .50, which would suggest moderate reliability with values above .75 indicating good reliability (Portney & Watkins, 2000).

Testing of Study Hypotheses

Alpha level testing for all the hypotheses was set at .05 to be statistically significant. An alpha .05 is the probability of rejecting a true null hypothesis. Several regression analyses were used to test the significance of the six study hypotheses.

The potential influence of demographic characteristics on the outcome of adherence to ART was examined. Variables that were statistically significant in predicting adherence to ART were used as control variables in the subsequent test of significance of each of the hypotheses.

Logistic regression was used to test four hypotheses in this study. This method is appropriate for predicting a discrete outcome, such as group membership based on a set of predictors. Whereas the outcome variables have to be dichotomous (binomial or multinomial), predictor variables may be continuous, discrete, or categorical. Logistic regression analysis was appropriate to test the hypotheses because the outcome variable of adherence was dichotomous (adherent or nonadherent) over the previous 4 days. Direct logistic regression analysis was used to test three of the six hypotheses, and sequential or hierarchical logistic regression analysis was used to test one step of the sixth hypothesis, as explained later.

Tabachnick and Fidell (2001) indicated that logistic regression has fewer and less stringent data assumptions. Logistic regression has no requirement for normal distribution of residuals and no requirement for homogeneity of variance. The disadvantage of logistic regression, though, is that it generally requires larger sample sizes: with one rule of thumb of subjects-to-variable ratio of 30:1. However, the large sample size in this study (N = 354) met this requirement as the subjects-to-variable ratio with all predictors in any of the models was more than double the requirement.

Direct logistic regression analysis was used to test Hypotheses 1-3. In direct logistic regression, predictors enter the equation simultaneously if a researcher has not specified order or importance of some predictors (Tabachinick & Fidell, 2001). These hypotheses tested the significance of composite social support, emotional, tangible, informational, and belonging support, and coping self-efficacy as predictors of adherence to ART.

In addition, logistic regression was used to provide more information. Specifically, logistic regression was used to determine the probability of adherence to ART by fitting data to a logistic curve based on the predictor variables. In this analysis, the researcher attempted to determine whether knowing a person's scores on his or her perceptions of availability of social support, its subscales (emotional, tangible, informational, and belonging), and coping self-efficacy predict a person's score on adherence to ART. Finally, odds ratio was computed. In this analysis, odds ratio is the probability of adherence to ART or belief in self to perform certain action (coping self-efficacy) over the probability of nonadherence and perceptions of low coping self-efficacy.

Interpretation of the SPSS output of direct logistic regression analysis included understanding the output of the overall model, the Nagerkerke R-square estimate of the variance accounted for in the analysis, the chi-square test of

Hosmer and Lemeshow, the classification table, and most importantly, the results of each of the variables in the equation (Tabachnick & Fidell, 2001; Munro, 2005). The overall model tested the significance of all predictor variables in predicting the outcome, which is adherence to ART. A significant model indicated that it was possible that some of the predictors in the equation were statistically significant when controlling for all other variables in the model.

Nagerkerke R-square estimates the percentage of the variance or change of adherence to ART that was accounted for by all predictors in the model (Tabachnick & Fidell, 2001). Hosmer and Lemeshow chi-square tested whether the data fit the model. The Hosmer-Lemeshow tests the null hypothesis that there is a linear relation between the predictor variables and the log odds of the criterion variable. Cases are arranged in order by their predicted probability on the criterion variable. A nonsignificant goodness-of-fit test of Hosmer and Lemeshow in SPSS indicates that the data fit the model, which is what a researcher wants.

The Wald chi-square statistic was used to test the unique contribution of each predictor. Wald chi-square assesses the significance of every variable in the model in the context of the other predictors, that is, holding constant the other predictors in the equation (Tabachinick & Fidell, 2001).

Standard multiple regression analysis was used to test Hypotheses 4-5. This method was used because the outcome variable, CSE, is a continuous variable and falls under a normal distribution (Tabachinck & Fidell, 2001; Munro, 2005). Multiple regression analyses allow a researcher to assess the relation between one outcome variable and several predictor variables. Like direct logistic regression, the first step of a multiple regression analysis is to test how strong the relationship is between the outcome variables and predictor variables and then assess the significance of each predictor in the model (Munro, 2005; Tabachninck & Fidell, 2001). The SPSS output for multiple regression was interpreted. R-square was interpreted as the percentage of the variance accounted for by a linear combination of all predictors in the model.

Sequential (hierarchical) regression was performed to assess the significance of particular predictors to adherence to ART controlling for other predictors. Several regression analyses were performed to test whether CSE is a mediator of social support and adherence to ART.

A mediator variable helps to account for the relation between the independent variables and the criterion (Baron & Kenny, 1986; Frazier, Tix, & Barron, 2004). In this study, CSE, believed to be a mediator between social support and adherence to ART, may partially account for changes in adherence to ART. Specifically, CSE was hypothesized to mediate the relation between perceived social support and adherence to ART. According to Baron and Kenny's (1986) proposed model of mediating hypothesis, for self-efficacy to function as a mediator, it must meet the following conditions: (a) variations in the levels of perceived social support should account for significant variations in CSE; (c) variations in CSE should account for significant variations in the levels of perceived social support should account for significant variations in the levels of perceived social support should account for significant variations in the levels of perceived social support should account for significant variations in the levels of perceived social support should account for significant variations in the levels of perceived social support should account for significant variations in the levels of perceived social support should account for significant variations in the levels of perceived social support should account for significant variations in the levels of perceived social support should account for significant variations in the levels of perceived social support should account for significant variations in the levels of perceived social support should account for significant variations in the levels of perceived social support should account for significant variations in the levels of perceived social support should account for significant variations in the levels of perceived social support should account for significant variations in the levels of perceived social support should account for significant variations in the levels of perceived social support should account for significant variations in the levels of perceived social

relation between perceived social support and CSE are controlled, the previously significant relation between social support and adherence to ART should be not be significant. The strongest demonstration of a mediating hypothesis would occur when the path between social support and adherence to ART is zero. Nevertheless, a decrease in this path is sufficient evidence to support the mediating hypothesis (Baron & Kenny, 1986; Frazier et al., 2004).

CHAPTER IV

RESULTS

Characteristics of the Sample

Of the 403 men and women living with HIV who consented to the survey tools, 354 (87%) completed all the survey tools. The survey tools were administered in English, Kiswahili, or Kikuyu. The majority of participants self-administered the questionnaires in Kiswahili (60.17%) and in English (33.9%).

Descriptive analysis of the participant background characteristics was conducted and included frequencies and percentages. The majority of participants were females 253 (71.47%). Participants' ages were categorized into four classes: 18-30, 31-40, 41-50, and 51-64. The majority were between 31-40 years of age (43.5%) and were females (45.5%). The participants were classified into four religious groups: Catholic, Protestant, Muslim, and African religious traditional. The sample consisted of diverse religious affiliations, the majority being Protestants (49.2%) and Catholics (39%) while the Muslims (0.6%) and Africans were the minority (11.3%).

Marital status category was classified under five groups: never married, married, separated, divorced, and widowed. The bulk of the participants were married (56.5%), and 16.9% were widowed. More men were married (74%) than women (49%). A greater percentage of women were widowed (19%) than men (11%). A greater proportion of women were separated (13.6%) than men (5.7%). Only 4.7% of all participants were divorced.

The educational level of most participants was primary education (42.1%) or secondary education (38.4%). A greater percentage of males (50.4%) had a high school education when compared to females (33.6%). Most men and women were engaged in some economic activities (formal, informal, or farming sectors) (71.2%). Twenty eight percent were unemployed. A greater percentage of men were employed in the formal sector (40.6%) than women (32.2%). A greater percentage of women were in the farming sector (27.7%) or not unemployed (30.4%) than men (18.6% and 24%, respectively).

Factor Analysis for Coping Self-Efficacy Scale (CSE) Exploratory Factor Analysis (EFA) and Confirmatory Factor Analysis (CFA)

Exploratory Factor Analysis (EFA) was calculated to determine the underlying dimensions of variables loading onto each of the dimensions of CSE and to reduce the 26 variables of the original CSE for the population in this study. Exploratory and confirmatory analyses for CSE for the populations in the U.S. revealed a reduced measure of CSE consisting of 13 variables loading onto 3 factors: use of problem-focused coping, stopping unpleasant emotions and thoughts, and getting support from friends and family (Chesney et al., 2006).

The analysis was performed in two stages of factor extraction and factor rotation (Green & Salkind, 2004). The initial factor extraction revealed four uninterpretable factors with an eigenvalue greater than one. These four factors accounted for 38.9% of the total variance. Variables loading onto factor four appeared not to be theoretically meaningful, so a decision was made to conduct a CFA with three fixed factors based on the theory of stress, appraisal, and coping (Lazarus & Folkman, 1984) and a previous validity and reliability study of the measure of CSE (Chesney et al., 2006).

The three factors were rotated using a Varimax rotation procedure. The rotated solution yielded three interpretable factors: Meaning-Based Coping (MBC; seven variables), Problem Management Coping (PMC; two variables), and Seeking Social Support (SSS; three observed variables). MBC observed variables accounted for 16.95% of the variance, PMC accounted for roughly 10% of the variance, and SSS coping also roughly accounted for 10% of the variance. The 3-factor model reduced the 26 items to 12 items (variables) and accounted for 36.66% of the total variance explained (Table 1).

Table 1

Factor	Total	% of Variance	Cumulative %					
		Initial Eigenvalues						
1	8.630	33.190						
2	1.435	5.51	38.710					
3	1.288	4.95	43.664					
Extraction Sums of Squared Loadings								
1	8.030	30.78	30.78					
2	0.839	3.22	34.00					
3	0.687	2.64	36.65					
	Rotation	Sums of Squared Loadi	ngs					
1	4.41	16.90	16.95					
2	2.60	9.99	26.94					
3	2.52	9.70	36.65					

These factors (MBC, PMC, and SSS) are consistent with the stress, appraisal, and coping theory (Lazarus & Folkman, 1984) and past findings from a validity and reliability study of the measure of CSE (Chesney et al., 2006).

Scale Reliability

Responses for each subscale were summed to obtain a total score. The Cronbach's alpha for the subscales and total had acceptable alpha coefficient values and were deemed reliable for further analysis. The result indicated, on one hand, that the Cronbach's alpha was .905 for the composite score for the ISEL. On the other hand, the Cronbach's alpha was .864 for the composite measure of CSE. All of the scales had acceptable alpha coefficient values of .5 and above (Portney & Watkins, 2000) so were deemed reliable for further analysis (Table 2).

	Fact	or load	ling
Item	1	2	3
Factor 1: Meaning-Based Coping (MBC)			
Pray or meditate	.613		
Take your mind off unpleasant thoughts	.597		
Keep yourself from feeling lonely	.588		
Keep from feeling sad	.577		
Stand your ground and fight for what you want	.544		
Resist the impulse to act hastily	.539		
Stop yourself from being upset by unpleasant thoughts	.510		
Factor 2: Problem Management Coping (PMC)			
Find solutions to your most difficult problems		.599	
Break an upsetting problem down into smaller parts		.572	
Factor 3: Seek Social Support (SSS)			
Get friends to help you with things you need			.692
Get emotional support from community organizations			.606
Get emotional support from friends/family			.582

Rotated Factor Matrix for the CSE (Using Exploratory Principal Components Factors Analysis) (N = 354)

The Cronbach's alphas for the English, Kiswahili and Kikuyu versions were calculated. Cronbach's Alpha for the ISEL subscales ranged from .811-.581. CSE Cronbach's alphas ranged from .806 - .703 for the composite score and .806 - .587. Thus, all of the scales had acceptable alpha coefficient values.

The results also indicated that the Kiswahili and Kikuyu versions of ISEL and

CSE are conceptually equivalent and reliable.

Table 3

Interpersonal Support Evaluation List (ISEL) Scale Reliability (Cronbach's Alpha) (N = 354)

Subscale	Number of Items	Alpha
Tangible support	10	.729
Emotional support	10	.674
Informational support	10	.763
Belonging support	10	.667
ISEL total	4	.905

Table 4

Coping Self-Efficacy Reliability (CSE) Scale Reliability (Cronbach's Alpha) (N = 354)

Subscale	Number of Items	Alpha
Meaning-Based Coping	7	.864
Problem Management Coping	2	.616
Seek Social Support	3	.772
Coping Self-Efficacy total	12	.860

Descriptive Statistics

The ISEL mean score was 91.76 (SD = 19.80). The ISEL subscale with the highest average score was informational support (M = 23.24, SD = 5.70) and tangible support had the lowest mean (M = 22.50, SD = 5.9). The CSE mean score was 80.91 (SD = 17.77).

The majority of respondents were medication adherent. More specifically, 94.5% of the participants indicated that they had not missed any of their medication in the previous 4 days (Table 5). Ninety-one percent (91%) indicated they had not missed taking medication during the previous weekend. Again, a majority (88.8%) had not missed medication in the previous 28 days. Asked when the last time was they had missed any of the medications, 78.5% of all participants indicated never having skipped any medication (Table 6).

Table 5

Valid responses	Frequency	Percent	Valid percent	Cumulative percent
None	335	94.6	94.6	94.6
1 day	13	3.7	3.7	98.3
2 days	4	1.1	1.1	99.4
4 days	2	.6	.6	100.0
Total	354	100.0	100.0	

During the past 4 days, on how many days have you missed taking all your doses? (N = 354)

Participants' own reasons for missing medications were as follows: "busy with other things" (11.3%), "simply forgot" (7.5%), "did not want others to notice you taking medications" (5.7%), "felt sick" (4.7%),"felt good" (4.8%), "had problem taking medication at specific times" (5.7%), and "slept through the dose" (3.8%). Only 1% indicated missing the dose because they ran out of pills (Table 6)

Valid responses	Frequency	Percent	Valid percent	Cumulative percent
Never skip medications	278	78.5	78.5	78.5
More than 3 months ago	28	7.9	7.9	86.4
1-3 months ago	7	2.0	2.0	88.4
2-4 weeks ago	11	3.1	3.1	91.5
1-2 weeks ago	11	3.1	3.1	94.6
Within the past week	19	5.4	5.4	100.0
Total	354	100.0	100.0	

When was the last time you missed any of your medications? (N = 354)

Correlational Analyses

The continuous variables of the composite ISEL, total CSE, and subscales of the CSE were evaluated for significant relations using bivariate statistics. The relationship between ISEL and CSE were significantly correlated (r = .335). MBC was significantly correlated with CSE (r = .802) and also SSS (r = .767; see Table 7).

	ISEL Total	MBC	PMC	SSS
MBC				
Pearson Correlation	.288**			
Sig. (2-tailed)	.000			
PMC				
Pearson Correlation	.160**	.383**		
Sig. (2-tailed)	.003	.000.		
SSS				
Pearson Correlation	.313	.487**	.382**	
Sig. (2-tailed)	.000	000.	000.	
CSE total		<u>-</u>		
Pearson Correlation	.335**	.902**	.620**	.767**
Sig. (2-tailed)	.000	.000.	.000	.000

Pearson Correlational Analysis for Social Support and Coping Self-Efficacy (N = 354)

Note. ISEL = Interpersonal Support Evaluation List; MBC = Problem Management Coping; SSS = Seek Social Support; CSE = Coping Self-Efficacy.

** Indicates correlation is significant at the 0.01 level (2-tailed).

The CSE, ISEL total, and its subscales were tested for significant relationships using Pearson correlation analysis. CSE significantly correlated with all the subscales of social support. The subscales of social support were significantly correlated with one another and the ISEL total score (e.g., tangible and informational support, r = .776, and ISEL total and tangible support, r = .912 (Table 8).

	Tangible Support	Emotional Support	Informational Support	Belonging Support
Emotional Support				
Pearson Correlation	.721			
Sig.	.000			
Informational Support				
Pearson Correlation	.776**	.685**		
Sig.	.000	.000		
Belonging Support				
Pearson Correlation	.754**	.721**	.762**	
Sig.	.000	.000	.000	
CSE total				
Pearson Correlation	.299**	.330**	.335**	.237**
Sig.	.000	.000	.000	.000

Pearson Correlational Analysis of Coping Self-Efficacy (CSE) and Subscales of Social Support (N = 354)

** Correlation is significant at the 0.01 level (2-tailed).

All demographic variables were further examined to determine whether, as a group and also individually, they predicted adherence to ART for the past 4 days. A direct logistic regression analysis was performed on adherence to ART as outcome with all the six demographic predictors—gender, age, educational, marital status, employment status, and religion—as predictor variables. A test of the full model with all six predictors against a constant only model was not statistically reliable, χ^2 (19, N = 354) = 29.90, p < .053. A further evaluation of the significance of the relation between each of these predictors with outcome indicated that gender was statistically significant χ^2 (1, N = 354) p < .019) as a predictor of adherence to ART, such that females were more adherent (less nonadherent) to ART. The odds of adherence among females were 3.70 times greater than the odds for males.

Results of the Tests of Hypotheses

Several regression analysis models were fitted to determine the effect of measures of support and CSE on adherence to ART. Also, the effect of measures of support on CSE was assessed. Direct logistic regression analysis was performed, whereby independent variables were entered into the model simultaneously. This method was used to examine each predictor variable, whether it was significantly positively or negatively associated with the dependent variable or adherence while holding constant the effect of all other variables in the model. Furthermore, the associations of predicted probabilities and observed responses were obtained to provide additional information about the relation between variables in the models. Linear regression analysis was used to assess the relation between measures of support and CSE. This method was used because the dependent variable of CSE is a continuous variable and was normally distributed.

Hypothesis 1: There is a significant relation between composite social support) and adherence to ART in people living with HIV.

A model was fitted with social support (composite score) as a predictor variable for adherence (medication missed in the previous 4 days). A test of the

full model with gender and social support against a constant-only model was statistically reliable χ^2 (2, N = 354) = 30.531, p < .001 indicating that the predictors, as a set, reliably distinguished between individuals who were adherent and nonadherent to ART.

Further, a Wald statistic and its significance were computed. According to the Wald criterion, both gender and social support reliably predict adherence to ART. The chi-square Wald statistics for social support (z = 21.452) was statistically significant (p = .001) (p < .05). Thus, the null hypothesis that there is no relation between social support and adherence to ART was rejected, concluding that there is a significant relation between social support and adherence to ART in people living with HIV. Table 9 shows the regression coefficients, Wald statistics, odds ratio, and 95% confidence intervals for odds ratios both for gender and social support.

Table 9

								% Cł xp(B)
Variable	В	SE	Wald	df	Sig.	Exp(B)	Lower	Upper
Gender	1.320	.514	6.585	1	.010	3.743	1.366	10.258
ISEL	.058	.012	21.452	1	.000	1.059	1.034	1.086
Constant	-3.922	1.307	9.004	1	.003	.020		

Social Support as a Predictor for Adherence to ART (ART) (N = 354)

Note. Variable entered on Step 1: Gender, ISEL-Interpersonal Evaluation List composite (undimensional) score.

Prediction success of the full model was impressive with an overall success rate of 94.9%. However, the results are interpreted with caution given

the low base of nonadherent respondents in this study. The Hosmer and Lemeshow goodness-of-fit test result was not significant (p = .788), which indicated that the data fit the model.

In regard to adherent relative to nonadherent, if one unit of social support increases, then the log-odds (b) of an increase in adherence would increase by .059. An Exp (b) = 1.059 for social support indicates that for a one-unit increase in social support, the odds for a positive outcome in adherence are 1.059. A Nagelkerke R-square estimate of variance indicated that the full model accounted for 24.2% of variance.

Hypothesis 2: There is a significant relation between the subscales of social support and adherence to ART.

A direct logistic regression analysis was performed to assess the relation between the four predictors of tangible support, emotional support, informational support, and belonging support with the outcome variable, that is, adherence to ART in the previous 4 days. A model was fitted with all four interpersonal support scales and gender. A Hosmer and Lemeshow goodness-of-fitness test was not significant, so it was concluded that the data fit the model.

The result of the test of the full model with the four dimensions of social support and gender as predictors of adherence to ART was statistically reliable, $\chi^2(5, N = 354) = 39.360, p = .0001, (p < .05)$, indicating that the five dimensions of social support predicted adherence to ART. The model, consisting of the four dimensions of social support, as a set, significantly predicted adherence to ART.

However, tangible (p = .006) and emotional (P= .015) dimensions of support were statistically significant while informational and belonging support were not. Further, the Wald statistic for the predictor tangible support was 7.468 and was statistically significant (p = .006; p < .05). Consequently, the null hypothesis was rejected, and it was concluded that there is a significant relation between tangible support and adherence. The Wald statistic for the predictor emotional support was 5.952. With an alpha level of p = .015 (p < .05). Thus, the null hypothesis stating that emotional support was not statistically different from zero was rejected, and it was concluded that there is a relationship between emotional support and adherence to ART. However, there was no significant statistical evidence to support that there was a relation between informational and belonging support with adherence to ART in the previous 4 days (Table 10). Table 10

							95% CI for Exp(B)	
Variable	В	SE	Wald	df	Sig.	Exp(B)	Lower	Upper
Gender	.989	.538	3.383	1	.066	2.688	.937	7.710
Tangible	.189	.069	7.468	1	.006	1.208	1.055	1.384
Emotional	.156	.064	5.952	1	.015	1.169	1.031	1.326
Informational	051	.073	.489	1	.484	.950	.823	1.097
Belonging	056	.069	.664	1	.415	.946	.827	1.082
Constant	-3.184	1.373	5.374	1	.020	.041		

Dimensions of Social Support as Predictors of Adherence to ART (ART) (N = 354)

Note. Variables entered on Step 1: gender, tangible, emotional, informational, belonging support.

In regards to adherent relative to nonadherent, if one unit of emotional support increased, then the log-odds (b) of an increase in adherence to ART would increase by .156 units. Exp(b) = 1.169 for emotional support implies that, for a one-unit increase in emotional support, the odds for a positive outcome in adherence are 1.169, given that all the other variables in the model are held constant.

Further, if one unit of tangible support increased, then the log-odds of an increase in adherence to ART would increase by .189 units. An Exp. (b) = 1.208 for tangible support implies that, for a one-unit increase in informational support, the odds of a positive outcome in adherence are 1.208, given that all the other variables in the model are held constant. The *p* values showed that variables informational (*p* = .485) and belonging (*p* = .415) were not significant.

A Nagelkerke R-square estimate of variance indicated that the model accounted for 30.8% of variance. The model predicted 94.1% of the cases correctly. However, the results are interpreted with caution, given the low number of participants who were nonadherent.

Hypothesis 3:_There is a significant relation between CSE and adherence to ART.

Two direct logistic regression analyses were performed to assess (a) the relation between CSE (composite) and adherence to ART and (b) the relation between the subscales of CSE—Meaning Based Coping (MBC_, Problem Management Coping (PMC), and Seek Social Support (SSS)—and adherence to ART.

The first model was fitted to assess the relation between CSE and adherence to ART. The model was statistically reliable χ^2 (2, *N* = 354) = 11.365, *p* = .003, (*p* < .05). Controlling for gender, the chi-square Wald statistic for CSE was 6.099 and significant (*p* =.01, (*p* < .05); therefore, the null hypothesis stating that there is no statistically significant relation between CSE and adherence to ART was rejected. Thus, it was concluded that there is a significant relation between CSE and adherence to HIV ART.

Another model was fitted to assess the relation between the subscales of CSE and adherence to ART. The model was statistically reliable χ^2 (4, *N* = 354) = 8.536, *p* = .041, (*p* < .05). However, only the MBC relation with adherence to ART was statistically significant (*p* = .020). The chi-square Wald statistic for MBC was 5.402. Another model run without MBC was not statistically reliable, thus confirming that MBC was the only statistically reliable predictor of adherence to ART among the three subscales of CSE.

Further, the results show that, if one unit of CSE increases, then the logodds (b) of adherence would increase by .059. The results suggest that an individual living with HIV is more likely to adhere to the ART regimen if he or she can find meaning in a negative event and keep away from unpleasant thoughts and emotions. An Exp(b) = 1.061 for the predictor MBC shows that for a one-unit increase in CSE, the odds of a positive outcome in adherence are 1.061 (Table 11).

							95% for E	
Variable	В	SE	Wald	df	Sig.	Exp(B)	Lower	Upper
MBC	.059	.025	5.404	1	.020	1.061	1.009	1.115
PMS	.062	.064	.949	1	.330	1.064	.939	1.207
SSS	046	.046	.989	1	.320	.955	.873	1.045
Constant	.072	1.039	.005	1	.945	1.074		

Subscales of Coping Self-Efficacy (CSE) and Adherence to ART (N = 354)

Note. Variables entered on Step 1: MBC = Meaning-Based Coping; PMS = Problem-Management Coping; SSS = Seek Social Support.

The Hosmer and Lemeshow test result was not significant, indicating that the data fit the model. A Nagelkerke R-Square estimate of variance indicated that the model accounted only for 7% of the variance while it accurately predicted 94.6% (overall percentage) of the cases correctly.

Hypothesis 4: There is a significant relation between social support and CSE in people living with HIV.

A linear model was fitted to determine the relation between social support (ISEL) and demographic variables as predictors and CSE as the outcome. The *F* test showed that the prob (F) <.0001; therefore, the fitted model was significant. Thus, the null hypothesis was rejected, and it was concluded that there is a relation between social support and CSE. The ISEL at t < .0001 (*t* <.05) was significant to be used for prediction. R-square = .132, indicating that ISEL explains about 13.2% of the variation in CSE. A coefficient for variable ISEL =

.298 indicates that, for every unit increase in ISEL, CSE would increase by .298 units, with a confidence interval (CI) of .210-.386 (Table 12).

Table 12

	Constant	Age	Gender	Religion	Marital Status	Social Support
Unstandardized coefficients						
В	68.112	54 1	-2.614	-3.100	168	.298
SE	7.122	1.081	2.024	1.341	.723	.045
Standardized coefficients						
Beta		027	067	116	012	.333
Т	9.563	500	-1.292	-2.311	-,232	6.654
Sig.	.000	.617	.197	.021	.817	.000
95% CI for B						
Lower bound	54.103	2.667	-6.595	-5.737	-1.589	.210
Upper bound	82.120	1.585	1.366	462	1.254	.386
Correlations						
Zero-order		028	077	122	018	.335
Partial		027	069	123	012	.336
Part		025	065	115	012	.332

Relation between Social Support and Coping Self-Efficacy (CSE)

Note. Dependent variable: Coping Self-Efficacy total.

The multiple regression results suggest that men and women living with HIV who perceive social support would be available are also likely to believe in their ability to find meaning in negative events by focusing on the positive side and engaging in activities that can impede unpleasant thoughts and emotions and to seek support from family and friends. Hypotheses 5: There is a significant relation between social support (subscales) and CSE.

Standard multiple regressions were performed between CSE as the outcome variable with all four dimensions of social support—tangible, emotional, informational, and belonging—entered in the model simultaneously as predictor variables.

R for regression was significantly different from zero, F(4, 354) = 14.237, p < .001. Thus, it is concluded that there is a significant relation between measures of support (subscales) and CSE. Three of the predictors contributed significantly to the prediction of CSE. The three predictors of emotional, informational, and belonging support contributed about 14% of the variation in CSE. The variable of tangible support (t = .508) was not significant as a predictor variable for CSE. The remaining variables, emotional (t = .003), informational, (t = 003), and belonging (t = .044), were statistically significant, hence predictor variables for CSE. A coefficient for emotional support of .852 indicates that, for every unit increase in emotional support, CSE would increase by .852, a coefficient for informational support of .766 indicates that, for every unit increase in emotional support, CSE would increase by .766.

The multiple regression results suggest that men and women living with HIV who perceive that emotional, informational, and belonging support would be available are also likely to believe in their ability to regulate emotions, manage problems, and seek social support from friends, family, and community.

Hypothesis 6: Coping self-efficacy is a mediator of the relation between social support and adherence to ART.

Several logistic regression analyses were performed to determine whether CSE is a mediator of the relation between social support and adherence to ART. First, the analyses consisted of three separate regression analyses: social support predicting adherence to ART, CSE predicting adherence to ART, and social support predicting CSE. As indicated in Hypotheses 1, 3, and 4, the separate regression results showed significant relations among the variables, as had been hypothesized.

Two regression analyses were performed: analysis of social support predicting adherence to ART controlling for CSE and analysis of CSE predicting adherence controlling for social support. To conduct a mediation hypothesis, each of these two regression analyses is required to be significantly related to the outcome variable (Baron & Kenny, 1986), in this case, adherence to ART. Results of social support as a predictor of adherence indicated that social support was predictive of adherence to ART (p < .001, chi-square, Wald statistic 17.295) when controlling for CSE. The results for CSE as a predictor of adherence to ART indicated that CSE was not predictive of adherence to ART (p= .408) when controlling for social support. Essentially, lack of significance nullifies the mediation analysis. Given the lack of significance of the partial effect of CSE on adherence to ART the null hypothesis that CSE is not a mediator was not rejected.

Summary of Findings

Social support and coping self-efficacy were predictive of adherence to ART. The composite measure of social support accounted for roughly 24.2% of the total variance in adherence to ART. Tangible and emotional dimensions of support were the strongest predictor variables for adherence to ART among the four dimensions of social support. Tangible support recorded an odds ratio of 1.208, and emotional support recorded an odds ratio of 1.169, which means that for every 1 unit increase in emotional and tangible support on a scale of 0-3, the odds of adherence would increase by 1.208 and 1.169.

CSE only accounted for a small amount of the variance (7%) in adherence to ART, which means that although beliefs have a significant relations with behavior (adherence to ART), they are probably other variables that contribute to adherence Among the subscales of CSE only meaning-Based Coping was a statistically significant predictor of adherence to ART, however it still only accounted, when controlling for the effects of social support, CSE was no longer statistically significant, which nullified CSE as a mediator between social support and adherence to ART. The findings indicate that the statistics do not demonstrate that the effects of social support on adherence to ART are mediated by CSE. It is probable that other psychological variables not considered in this study are the mechanism through which social support influences adherence to ART.

Social support was predictive of CSE, accounting for 13.2% of variance in CSE. Furthermore, emotional, informational, and belonging types of support

were statistically significant predictors of CSE, but tangible support was not. A model with these three dimensions of support (without tangible support) accounted for about 14% of variation in the CSE. People who perceived social support to be available are also likely to believe in the ability to cope with life stressors.

Gender was a predictor of adherence to ART, such that a larger proportion of women was adherent to ART than males.

CHAPTER V

DISCUSSION

The purpose of this study was to delineate social and psychological factors that influence adherence to ART in patient's prescribed HIV medication. As ART is increasingly becoming available in Kenya and reports of high adherence to ART among Kenyans begin to be reported, few studies have examined the factors influencing adherence to ART. This study addressed this gap in reports by examining the relationships between individuals' perceptions of availability of social support, their beliefs in coping self-efficacy, and their adherence to ART in Kenya. Understanding the possible factors influencing adherence to ART is critical to ensuring improved interventions in order to optimize ART health benefits in people living with HIV.

The respondents were drawn from nine comprehensive care and treatment centers managed by a major healthcare provider serving populations in the Central Province and the metropolitan city of Nairobi, Kenya. The majority of the respondents in this study were women, which reflect both the national and the metropolitan city of Nairobi distribution of people living with HIV. The *Kenya AIDS Indicators Survey of 2007* (KAIS) reported that more women were infected with HIV (8.7%) as compared to men (5.6%), such that 3 out of 5 HIV infected Kenyans are women (NASCOP, 2008). HIV prevalence is particularly high among women in Nairobi, Kenya. Prevalence estimates for the metropolitan city of Nairobi indicate that 10.7% of women live with HIV as compared to 6.7% of men (NASCOP, 2008). Thus, it is not surprising that the majority of respondents

in this study were women, as they are disproportionately affected by the HIV pandemic in Kenya.

The data from this study demonstrate that a greater proportion (70.3%) of respondents were in the age range of 31-50. This finding also mirrors the national AIDs indicators, which show HIV prevalence estimates to be greater within this age bracket than in any other (NASCOP, 2008). Additionally, the smaller proportion of older people (51-64 years) in this study may result from higher mortality rates noted before the introduction and scaling-up of ART protocol in Kenya. The World Health Organization (WHO, 2006) mortality sheet for Kenya indicated that HIV was the number one cause of death in Kenya in 2002 (WHO, 2006), which may have affected the age bracket in 2002 and earlier years. Perhaps a sizable proportion died of HIV prior to the introduction of ART in 2003 (WHO, 2006).

When reflecting on the fewer number of younger respondents (18-30) in this study, these findings may represent the individuals recently infected but who may not have qualified for HIV medication. To qualify for treatment, the Kenya Ministry of Health and WHO recommend that an individual either have a CD4 cell count less of than 200 or have an AIDS defining illness, known as an *opportunistic infection* (NASCOP, 2008).

In this study, a larger number of women were unemployed when compared to men. Conversely, the Kenya Ministry of Health report of 2003 reported that higher proportions of females (68.6%) than males (56.6%) were employed in Kenya in 2003 (Central Bureau of Statistics, 2004). This difference

may be accounted for the fact that this study included the formal, informal, and farming sectors; however, it is not clear whether the Central Bureau of Statistics of Kenya considered the informal and farming sectors as forms of employment.

Adherence to ART

Based upon the data from this study a larger proportion of the respondents were adherent to ART. This high adherence to ART in Kenya reflects findings from a previous meta-analysis that examined adherence to ART across sub-Saharan Africa. Overall the data from the meta-analysis of patients' self-reports indicated that a pooled estimate of 77% was adherent to ART (Mills et al., 2006). Similarly, Byakika-Tusiime et al. (2005), in a self-reported adherence to ART study, found favorable levels of adherence to ART in Uganda. Adherence to ART among the respondents could have been the result of psychosocial resources provided to them.

Social Support

Overall, respondents in this study perceived social support to be available if needed as measured by ISEL. The construct of ISEL investigates individuals' perceptions of availability of multi-dimensional functional social support if needed (Cohen & Hoberman 1983).

This high perception of availability of social support (emotional, tangible informational and belonging) among the respondents may suggest that the individuals living with HIV and prescribed ART in Kenya have networks that are providing or are perceived to provide this support. The present access to ART and care both at clinical settings and other social contexts, implies that

individuals seeking or needing ART and care find it much easier today than it was the case 7 years ago in Kenya. As Withington and Kesler (1986) have argued, individuals' perceptions that support would be available if needed, rather than the objective support behavior of received support is most strongly linked to recipients' well-being.

The findings of high perceptions of social support mirrors the care and treatment services provided to respondents, which may be directly fostering beliefs that support would be available when needed. The respondents in this study were among men and women accessing free comprehensive care and treatment provided by Nazareth Hospital, a faith-based healthcare organization, through its nine centers. The care and treatment provided to patients include HIV voluntary counseling and testing; post test counseling; ART; treatment of opportunistic infections related to HIV/AIDS, active referral to peer support groups; palliative care, home based care, nutrition and transport to the poor seeking services at their sites. Every individual accessing ART is assigned a "buddy" to provide him or her with needed support. In this buddy system, two individuals "buddies" operate together as a single unit so that they are able to monitor and help each other in performing difficult or challenging tasks. These interventions may add up to heighten perceptions that tangible, emotional, informational, and belonging support would be made available if needed.

Coping Self-Efficacy

The study finding that the respondents had moderate coping self-efficacy suggest that people living with HIV in Kenya engage in positive cognitive and behavioral efforts to regulate distressing emotions, to persist in problem solving strategies, and to seek social support from friends, family, or community. As Lazarus and Folkman (1984) postulated in stress, appraisal and coping processes, coping self-efficacy may foster evaluation of stressful situations and assessment of coping resources, which may produce psychological adjustment to HIV/AIDS disease and behavioral outcome.

Coping-self-efficacy is either belief in individuals' ability to regulate distressing emotions, or the perceived ability to find solutions to problems causing distress. This emotion-focused form of coping may facilitate individual's confidence in stopping unpleasant thoughts, stopping themselves from being upset, or keeping themselves from feeling sad. Such an objective could be accomplished through reflection or visualization of pleasant events or places or activities (Chesney et al., 2006). Individuals may decide to focus on "the brighter part" of their life or find new meaning in the encounter, which may foster adaptation. Others may use positive comparisons, such as telling themselves, "I realized I am alive and others like me died or are worse off."

Consistent with the notion of Simoni et al (2002) that spiritual coping fosters psychological adaptation; it is likely that men and women living with HIV in this study relied to a great extent on spirituality as a form of coping with stressors. In this study, respondents' belief in prayer and meditation as a form of coping with their stressors underscore the importance of spiritual coping resources in form spirituality and spiritual care and fellowship among believers. Moreover, the findings may identify the role of faith based organizations in fighting HIV/AIDS in Kenya.

In Kenya, faith based organizations have the most extensive network and outreach to the most remote and poorest communities as well as those living in urban cities such as Nairobi. Faith-based organizations can provide care, treatment and general spiritual support. As a result, these organizations may be effective conduits through which individuals coping self-efficacy would be optimized.

In summary, respondents' confidence in their ability to regulate emotions may contribute to healthful behaviors and general well-being. The meaningbased forms of coping may mitigate the effect of stressors and allow individuals to adapt to living with HIV. Furthermore, they may create the positive states conducive for problem-focused coping. Conversely, a lack of meaning-based coping may lead to questions with no answers, which can cause psychological distress.

Respondents in this study may have engaged in this form of coping to deal directly with problems causing emotional or psychological distress. Individuals' belief in their ability to engage in strategies to reduce or eliminate the problem (e.g. "find solutions to your most difficult problems" or "break an upsetting problem down into smaller parts") may have positively influenced strategies used to solve their problems.

Respondents' belief that they can manage problems may have fostered a "planful way" of coping, whereby, they carefully consider various alternatives, weigh those alternatives, make choices among the alternatives, and act upon their preferences (Lazarus & Folkman, 1984). These beliefs may have an impact in what people feel, think, and how they act. In this study, these beliefs may be influencing men and women living with HIV to regulate their emotions and to work hard to find solutions to problems they encounter daily.

Respondents in this study may have focused on altering their individual attitudes and interpretation of events construed as negative. For example, treatment preparation sessions before initiation of ART among the respondents in this study could have promoted or enhanced their skills needed to remain adherent to ART.

Consistent with the Lazarus and Folkman theory on problem-focused forms of coping, data from this study demonstrated that respondents engaged inward or outward strategies to deal with stressors. Outward-directed strategies may focus on combating and overcoming external barriers. Belief in respondents' ability to tap resources external resources and seek help from friends, family, and community to cope with problem are examples of outward-directed strategies to manage problems (e.g., "get friends to help you with things you need" or "get emotional support from friends/family" or "get emotional support from community organizations").

Findings from Study Hypotheses

Social Support and Adherence to ART

The findings in this study supporting significant relationships between social support and adherence to ART underscore the importance of social resources in optimizing adherence to ART in people living with HIV in Kenya. Tangible and emotional forms of social support appear to be the strongest predictors of adherence to ART. The findings in this study support findings from previous studies, the theory of social support, and interventions being implemented by Nazareth Hospital to foster adherence to ART in Kenya. Social support was predictive of adherence to ART among men and women living with HIV in the United States (Gonzalez et al., 2004). These findings are consistent with the study by Murphy et al. (2004) of the factors associated with nonadherence to ART in patients living with HIV/AIDS. Their research showed social support fostered adherence to ART. Conversely, a perception of lack of emotional support has been reported to be associated with self-reported nonadherence (Simoni et al., 2002).

In its nine sites, Nazareth Hospital's comprehensive care and treatment approach is an intervention program that may be providing a positive impact on adherence to ART. Availability of individual and group counseling, creation of support groups for youth, discordant couples, widows/widowers, and children support groups are forms of social resources being leveraged by the hospital to improve adherence to ART. Sharing of experiences and learning from one another techniques to adhere to treatment may enhance adherence to ART.

Patients are provided with treatment preparation sessions prior to receipt of HIV medication (ART). Comprehensive instruction and training is a form of informational support that may explain adherence to ART. Additionally, newly diagnosed individual are guided in identifying confidant with whom to share their most private worries and concerns, who may be the first individuals to disclose HIV status. Respondents' confidants provide emotional, informational, and belonging support, all of which may foster adherence to ART.

Nazareth community team of nurses, social workers and community health workers provide expert support and early follow-up to individuals experiencing difficulties which may increase critical quality information that may be needed. Furthermore, food supplements, money for transport to the clinic to the neediest on ART serve as form of material support that may be perceived as available when needed.

Individuals who perceived that they would not have a "hard time finding someone" to help them out or would easily find material assistance such as money and "find someone" to look after their house or children were also likely to adhere to ART.

The findings of this study indicate that increasing social support among men and women living with HIV may result to higher adherence to ART. For example, for every one-unit increase in emotional support on a scale of 4, the odds of a positive outcome in adherence are 1.169 in the sample, given that all the other variables in the model are held constant. It is evident that the tangible and emotional dimensions of social support were the strongest predictor

variables for adherence to ART among the four dimensions of social support. The model accounted for 30.8% of the estimated variance in adherence to ART.

The comprehensive care and treatment approach, which includes provision of social resources through mobilization of resources, is likely to be effective in fostering adherence to ART. Furthermore, it indirectly impacts the morbidity, mortality, and health of men and women living with HIV in Kenya.

.

Social Support and Coping Self-Efficacy

The findings of significant relationship between social support and CSE lend support for the transactional model of stress and coping. When men and women living with HIV perceive social support to be available, they are more likely to believe in their ability to cope with HIV-related or unrelated stressors. Thus, perceptions of availability of social support likely foster a secondary appraisal as theorized (Lazarus and Folkman, 1984). In the secondary appraisal, individuals under stress are likely to gain perceived control over outcomes, or perceived control over emotions given the availability of social resources relevant to stressors being experienced. Additionally, the availability of social resources to men and women living with HIV probably bolsters their belief to cope with HIV/related and unrelated stressors.

Findings from this study indicate that the composite measure of social support (ISEL) explain about 13.2% of the variation in the measure of CSE using multiple regression analysis. The findings of a significant relation is consistent with the theories of perceived self-efficacy (Bandura, 1997; Lazarus & Folkman, 1984), which posit that perceptions of availability of social support and belief in one's ability to do certain things are closely intertwined. Perceptions of availability of support may enhance belief in the self to confront problems or regulate emotions and vice versa.

This study's findings are also consistent with previous research that showed a significant relation between social support and self-efficacy (Simoni et al., 2004; Chesney et al., 2000). Significant relations between these variables

point to possible interplay between perceptions of support and CSE; thus, it is a two-way street. An individual's perception of social support, based on past supportive experiences, may bolster belief in his or her capabilities (coping selfefficacy) to seek social support. Still, these perceptions may indicate an effort to find meaning in a negative situation or to deal with problems causing stress. Individuals' coping self-efficacy may prompt them to establish social ties that may generate functional social support, giving rise to their perception that support would be available if needed.

Further, findings in this study support three of the four sub-hypotheses. Whereas emotional, informational, and belonging types of social support were significant predictors of coping self-efficacy, tangible support was not. A model with these three significant dimensions of support accounted for about 14% of variation in the CSE.

Perhaps the experience of being loved despite one's short-comings or weaknesses (emotional support), receiving of credible, trustworthy and critical information (informational support), or experience of belongingness such having confidants, family members, friends, or social group to engage in activities that distract a person from ruminations of negative thoughts of past, present experiences or fears of the future, may bolster individuals belief in their ability to confront HIV-related and HIV-unrelated stressors. In addition, a multidimensional measure of social support, such as ISEL used in this study, is critical to understanding the needed resources for a target population.

Coping Self-Efficacy as a Predictor of Adherence to ART

The findings of this study also demonstrate a significant relation between CSE and adherence to ART during the previous 4 days. Although the relation accounted for a small proportion of variance (7%) in adherence to ART, individuals' beliefs in their capabilities appear to influence their adherence to ART behavior. Individuals' belief in their abilities to perform difficult tasks influence how they feel, think, and motivate themselves to act (Bandura, 1997). Thus, threats, sense of loss of health, or challenges that confront efficacious men and women living with HIV in Kenya are unlikely to cause discourage them from losing confidence in their capabilities. Instead, CSE may result in reduced stress and increased attention and substantial commitment to a life-long adherence to ART in such individuals. These findings are relevant and consistent with the construct of CSE. Interventions to increase CSE among men and women living with HIV on ART are needed.

Coping Self-Efficacy as a Mediator of Support and Adherence

This study did not find sufficient evidence to support the notion that CSE is a mediator between social support and adherence to ART. The lack of support may indicate that other variables qualify as mediators, such as treatment efficacy, efficacy to adhere, internal locus of control, or self-esteem.

Limitations

As with any study there are several limitations to the present study. First, this study used a cross-sectional design to investigate adherence to HIV medication at only one point in time. A longitudinal study design, which involves taking multiple measures over a defined length of time, could possibly give more information about changes that occur in individuals' in terms of needs over time. A cross-sectional study design therefore may not have detected changes in this type of social support needed to ameliorate stressors.

This being a descriptive correlational study, no cause and effect can be inferred as it is not controlled and randomized. This means that findings of significant relations between social support and adherence to ART; significant relations between social support and coping-self efficacy; and significant relations between coping self-efficacy and adherence, do not suggest the direction of influences. It is possible that individuals who adhere to treatment enhance their coping self-efficacy, or coping self-efficacy fosters their perceptions of availability of support.

This study relied on respondents' self-reports on adherence to ART, which may result to underreporting of non-adherence or result to over-estimating adherence to ART. It is possible that a more objective measure of adherence -such as a medication event monitoring system (MEMS), pill count, viral load, or CD4 count— would have yielded different results. These additional measures could have also been used to further validate the outcome of this study as

measures of self-report of adherence due to patients' overestimating adherence or underreporting nonadherence.

This study also used a convenience sample of willing patients who were prescribed HIV medication and were being served in one of the nine comprehensive care and treatment centers under the umbrella of a major healthcare provider. This sampling method limits the degree to which the findings of the present study can be generalized to other populations in Central Province and the metropolitan city of Nairobi, let alone the rest of Kenya or Africa. To make findings generalizable, it would be essential to randomize the sample selection and include different locations and more providers of HIVtreatment and care centers because differing quality of services may influence levels of adherence to ART and perceptions of social support and CSE among people living with HIV. However, as indicated in the result section, the sample in this study was reflective of the national demographic characteristics of Kenya, which means that the results from the sample are reliable despite the fact that a convenient sampling methods was used in this study

Finally, the low base of nonadherent respondents in this study limits the interpretation of cases predicted correctly as nonadherent. To delineate factors explaining nonadherence, it is critical to have an adequate sample size of those who have difficulty adhering to ART. Therefore, the results are interpreted with caution.

Study Implications

These findings may influence clinical practice as it provides evidence of the positive role of an individual's support, coping strategy, self-efficacy on adherence to ART. Healthcare providers have a reason to retain and promote strategies whose objectives are to increase provision of social support to patients prescribed to ART as these strategies have direct relations with adherence to ART. Furthermore, the strategies are likely to improve physical and mental health of patients prescribed to ART.

Clearly, a link exists between objective functional social support, coping self-efficacy, and health and healthful outcomes. The findings in this study lend support to the theories of stress, appraisal, coping (Lazarus and Folkman, 1984; Bandura, 1997) as well as the construct of functional perceptions of availability of social support (Cohen & Hoberman; Cohen & Wills, 1985). Although the goal of the present study was not to test theories, the findings of a significant relation between social support and adherence are consistent with the theory of social support. This is important as theories and empirical findings tend to reinforce one another. In this study, emotional and tangible types of social support and coping self-efficacy are predictors of adherence, with positive implications on health of people living with HIV.

The study has implications on future research as it creates the basis for longitudinal studies in resource constrained settings and in cultural settings similar to those identified in this study.

CHAPTER VI SUMMARY AND CONCLUSIONS

This study sought to identify psychological and social factors that may be influencing adherence to ART among men and women living with HIV in Kenya. Most research studies that have investigated psychosocial factors predicting adherence focused on populations in North America. Findings from such studies may not be globally generalizable in particular to people living with HIV in the Sub-Saharan Africa due to socio-economic, cultural, and/or political differences which exist between North America and any other region. Moreover, recent findings of high adherence to ART among men and women living with HIV in the Sub-Saharan Africa (Mills et al., 2006) left unanswered questions about the plausible explanation of such a phenomenon. Thus, this study forms the first building blocks of an understanding of possible psychosocial determinants of adherence to ART in Africa.

This study was designed within the framework of the theory of stress, appraisal, and coping, concept of social support and perceptions of self-efficacy. The measures of perceptions that social support would be available and coping self-efficacy were significantly associated with adherence to ART. The results lead to the conclusion that adherence to ART among people living with HIV could be influenced to some extent by the resources which they perceive to be available if needed. Individuals' perceptions that such resources would be

available when required are likely to be associated with individuals' confidence in their ability to regulate emotional and psychological distress, and to manage problems (coping self-efficacy). Thus, this study underscored the importance of providing social support to men and women living with HIV, both to enhance their belief to cope with HIV-related and unrelated stressors, and to improve and to sustain their adherence to ART in Kenya.

The findings that emotional and tangible types of supports are significantly associated with adherence and not informational and belonging types of support lend support to the use of a multi-dimensional measure of social support. A composite (undimensional) may not be able to demonstrate whether all subscales of social support are equally important in predicting the outcome.

The findings of social support and coping self-efficacy determinants of adherence to ART underscore the comprehensive approach to HIV treatment and care undertaken by Nazareth Hospital. Clearly, patients' perceptions of availability of social support and their belief in coping with life stressors informs program planners and designers some of the factors to monitor, measure, and compare in striving to understand adherence to ART. This is true in Kenya and most likely the overarching strategy to the populations in the Sub-Saharan Africa.

Finally, the results from this study provide support for the continued development of policies addressing psychosocial interventions. The findings lend support to President's Emergency Plan for Relief PEPFAR and the Kenya National Strategic Framework approach that support programs that include social support in addition to ART. As a result, this study answers a "so what?" question.

People living with HIV perceive that social support was available through the hospital system. As a result, when social support was used, people living with HIV were empowered and adhered to ART, fostering their quality of life. Their health status improved, longevity of lige increased, and life was enjoyed. It is evident that simple compliance to governmental requirements of financial accountability and transparency of use of funds without indicators that measure quality of life is not adequate. Findings that social support influences adherence to ART supports that programmatic goals have been and will continue being achieved as is likely evidenced in its impact on health and lives of men, women, and children infected and affected with HIV.

The inference of the positive impact of adherence on those infected and affected with HIV is based on consistent empirical demonstration of the effect of adherence to ART on mortality, morbidity, and health of people living with HIV. Their adherence to ART has been shown to slow disease progression, reduce in incidences of opportunistic infections, and significantly extend their survival time (Collier et al., 1996; Palella et al., 1998). In terms of health, adherence to ART in men and women living with HIV in Kenya is likely to improve their clinical health and their immune functioning (Kelly et al., 1998; Montaner et al., 1998). Importantly too, it can be concluded that ART adherence as a result of the positive perceptions of availability of social support, is likely minimize risk of transmissible drug resistant strains.

Findings that men and women living with HIV adhered to ART likely will contribute to the achievement of strategic goal of reducing HIV-related mortality

in Kenya by 90% by the end of 2010. HIV Death and morbidity reduction is likely to have positive impact HIV disease in Kenya and in the Sub-Saharan Africa. The impact is likely to reduce the growth of children being orphaned as a result of HIV-related mortality and reduce numbers of vulnerable children as a result of improved health and reduced morbidity in men and women living with HIV.

,

Future Studies

A longitudinal study is needed to determine the role of social support on adherence to ART over a period of time. In addition, insightful understanding of the trigger of emotional or psychological distress and the appropriate resources for patients to cope with such stressors would expand the relevant body of knowledge. Future research may also seek to contrast and compare adherence outcomes across different healthcare providers. In Kenya, healthcare services are largely provided by public, faith-based, or private healthcare institutions. It is probable that healthcare providers engage different strategies to foster and sustain adherence to ART with differing results. The differences in results may facilitate in establishing foundations for best-practices through which providers can learn to improve care and treatment, not only in people living with HIV but also other chronic illnesses and conditions.

Future research may compare adherence to HIV medication across different measures to validate the accuracy of self-reported measures. Such measures consist of medication event monitoring system (MEMS), pill count, CD4 count, viral loads measured periodically may enhance providers and researchers conclusion on the accuracy of self-reported measures of adherence to ART. Findings may contribute to our understanding on use and maintenance of self-report measure of adherence which is relatively most cost efficient method.

As noted earlier on, the sample size of the non-adherent in this study was very small to make any reliable conclusion of individuals who were non-adherent. Future research could be focused on individuals who have difficulties in adhering to HIV medication. Psychological illnesses, such as depression, use of substances, and alcohol, could be factored in as correlates of non-adherence to ART. Understanding of impediments of adherence to ART could help in designing interventions that overcomes these barriers and puts on track individuals experiencing difficulties to adhere to ART.

Despite reported high adherence to ART in this study and other recent studies focusing on population in the Sub-Saharan Africa, knowledge of factors influencing adherence and interventions not only to foster adherence but also sustain adherence in the long-term are needed. The experience of ART in Africa is still novel and so it is not clear if patients who are currently adherent continue being adherent in future. Consequently, studies are needed to ensure long-term adherence to ART in Kenya and in the Sub-Saharan Africa.

Researchers may want to establish whether attitudes of others after disclosure of one's HIV-status enhances or impedes adherence to ART. It is probable that patients who disclose their status are likely not to hide from others their HIV medications when taking them. Reluctance to disclose HIV status could be a barrier to adherence, especially during social occasions. For instance, it is unclear whether more advanced disease status is a cause or an effect of lower self-efficacy for treatment adherence. Other research could be directed specifically toward individuals who have difficulties in adhering to treatment in order to determine the factors associated with nonadherence and capture predictors of nonadherence.

.

- Abramson, L. Y., Metalsky, I. G., & Alloy, L. B. (1989). Hopelessness depression: Theory-based subtype of depression. *Psychological Review*, *962*(2), 358-372.
- Baron, R. M., & Kenny, D. A. (1986). The moderator mediator variable distinction in social psychological research: Conceptual, strategic and statistical considerations. *Journal of Personality and Social Psychology*, *51*, 1173-1182.
- Bottonari, K. A., Roberts, J. E., Ciesla, J. A., & Hewitt, R. G. (2005). Life stress and adherence to ART among HIV-positive individuals: A preliminary investigation. *AIDS Patient Care and STDs, 19*(11), 719-728.
- Byakika-Tusiime, J., Oyugi, J. H., Tumwikirize, W. A., Katabira, E. T., Mugyenyi,
 P. N., & Bangsberg, D. R. (2005). Adherence to HIV ART in HIV+
 Ugandan patients purchasing therapy [Abstract]. *International Journal of STD AIDS*, *16*, 41.
- Bandura, A. (1997). *Self-Efficacy: the exercise of Control.* New York, NY: W.H. Freeman and Company.
- Catz, S. L., Kelly, J. A., Bogart, L. M., Benotsch, E. G., & McAulife, T. L. (2000). Pattems, correlates, and barriers to medication adherence among persons prescribed new treatments for HIV disease. *Health Psychology, 19*(2), 124-133.
- Center for Disease Control and Prevention. (2007). *Title of the page accessed*. Retrieved from http://www.cdc.gov/hiv.htm

Central Bureau of Statistics. (2004). Kenya Demographic Health Survey 2003. Nairobi, Kenya: Ministry of Health.

Chapman, D. W., & Carter, J. F. (1979). Translation procedures for crosscultural use measurement instruments. *Education and Policy Analysis, 1* (3), 71-76.

Chesney M.A, Chambers D.B., Taylor J.M., Johnson L.S., Folkman S. (2003).
 Coping effectiveness training for men living with HIV: Results from a randomized clinical trial testing a group-based intervention.
 Psychosomatic Medicine, 65(6):1038–1046.

- Chesney, M. A., Ickovics, J. R., Chambers, D. B., Gifford, A. L., Neidig, J., & Wu,
 A. W. (2000). Self-reported adherence to antiretroviral medications
 among participants in HIV clinical trials: AACTG Adherence Instruments. *AIDS Care, 12*(3), 255-266.
- Chesney, M. A., Neilands, T. B., Chambers, D. B., Taylor, J. M., & Folkman, S. (2006). A validity and reliability study of coping Self-Efficacy Scale. *British Journal of Health Psychology, 11*(Pt. 3), 421-437.
- Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd Ed.) Hillsdale, NJ: Earlbaum.
- Cohen, S. & Hoberman, H. (1983). Positive events and social supports as buffers of life change stress. Journal of Applied Psychology, 13, (2), 99-125.
- Cohen, S., & McKay, G. (1984). Positive events and social support as buffers of life change stress on health. In A. Baum, J. E. Singer, & S. E. Taylor

(Eds.), *Handbook of psychology and health* (Vol. 4). Hissdale, NJ: Erlbaum.

- Cohen, S., Mermelstein, R. K., & Hoberman, H. M. (1985). Measuring the functional components of social support. In I. G. Sarason (Ed.), *Social support: Theory, research and applications* (pp. 73-94). Netherlands: Dordrecht.
- Cohen, S., Underwood, L. G., & Gottlieb, B. H. (Eds.). (2000). Social *support* and intervention: A guide for health and social scientists. New York, NY: Oxford University Press.
- Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin, 98*(2), 310-357.
- Collier, A. C., Coombs, R. W., Schoenfeld, D. A., Basset, R. L., Timpone, J., Baruch, A., . . . Corey, L. (1996). Treatment of human immunodeficiency virus infection with saquinavir, zidovudine, and zalcitabine. *New England Journal of Medicine, 334*, 1011-1017.
- DiMatteo, M. R. (2004). Social support and patient adherence to medical treatment: A meta-analysis. *Health Psychology, 23*(2), 207-218.
- Flaherty, A. J., Gaviria, M. F, Pathak, D., Mitchell, T., Wintrob, R., Richman, J., &
 Birz, S. (1988). Developing instruments for cross-cultural psychiatric
 research. *Journal of Nervous and Mental Disease*, *176*(5), 257-263.
- Frazier, P. A., Tix, P. A., & Barron, K. E. (2004). Testing moderator and mediator effects in counseling psychology research. *Journal of Counseling Psychology*, *51*(1), 115-134.

Gonzalez, J. S., Penedo, F. J., Antoni, M., Durán, R. E., McPherson-Baker, S.,
Ironson, G., Schneiderman, N. (2004). Social support, positive states of
mind, and HIV treatment adherence in men and women living with
HIV/AIDS. *Health Psychology, 23*(4), 413-418.

- Green, B. & Salkind, N.J. (2004). Using SPSS for Windows and Macintosh Analyzing and Understanding Data, (4th Ed.), Upper Saddle River, NJ, Pearson Prentice Hall.
- Guillemin, F., Bombardier, C., & Beaton, D. (1993). Cross-cultural adaptation of health-related quality of life measures: Literature review and proposed guidelines. *Journal of Clinical Epidemiology*, *12*, 1417-1432.
- Hammer, S. M., Saag, M. S., Schechter, M., Montaner, J. S. G., Schooley, R. T., Jacobsen, D. M, . . . Volberding, P. A. (2006). Treatment for adult HIV infection: 2006 recommendations of the International AIDS Society-USA panel. *Journal of the American Medical Association, 296*(7), 827-843.
- Hutchinson, C. (1999). Social support: Factors to consider when designing studies that measure social support. *Journal of Advanced Nursing, 29*(6), 1520-1526.
- Igreja, I., Zuroff, D. C., Koestner, R., Saltaris, C., Brouillette, M.-J., & Lalonde, R. (2000). Social motives, social support, and distress in gay men differing in HIV status. *Journal of Research in Personality, 34*, 287-304.
- Kelly, J. A., Otto-Salaj, L., Sikkema, K. J., Pinkerton, S. D., & Bloom, F. R. (1998). Implication of HIV treatment advances for behavioral research on

AIDS: Protease inhibitors and new challenges in HIV secondary prevention. *Health Psychology*, *17*(4), 310-319.

- Knobel, H., Guelar, A., Carmona, A., Espona, M., González, A., López-Colómes,
 J. L., Díez, A. (2001). Virologic outcome and predictors of virologic failure of highly active therapy containing protease inhibitors. *AIDS Patient Care and STDs*, *15*(4), 193-199.
- Langford, C.P.H., Bowsher, J., Maloney, J.P., & Lillies, P.P. (1997). Social support: a conceptual analysis. *Journal of Advanced*, 25 (1), 95-100
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping.* New York, NY: Springer.
- Leserman J, Ironson G, O'Cleirigh C, Fordiani JM, Balbin E. (2008). Stressful life events and adherence in HIV. *AIDS Patient Care STDS*, 22(5):403-11.
 - Lu, M., & Wilson, I. B. (2008). Optimal recall period for self-reported HIV medication adherence [Abstract]. *AIDS and Behavior*, *12*(1), 94.
- Maneesriwongul, W., & Dixon, J. (2004). Instrument translation: A methods review. *Journal of Advanced Nursing*, *48*(2), 175-186.
- Mills, E. J., Nachega, J. B., Buchan, I., Orbinski, J., Attaran, A., Singh, S.,
 Bangsderg, D. R. (2006). Adherence to ART in sub-Saharan Africa and
 North America: A meta-analysis. *Journal of the American Medical*Association, 296, 679-690.
- Montaner, J. S., Reiss, P., Cooper, D., Vella, S., Harris, M., Conway, B., Lange, J. M. (1998). A randomized, double-blind trial comparing combinations of

nevirapine, didanosine, and zidovudine for HIV-infected patients. *Journal* of the American Medical Association, 279, 930-937.

- Munro, B. H (2005). *Statistical Methods for Health Care Research* (5 Ed.), New York, Lippincott Williams & Wilkins.
- Murphy, D. A., Marelich, W. D., Hoffman, D., & Steers, W. N. (2004). Predictors of antiretroviral adherence. *AIDS Care*, *16*(4), 471-484.
- National AIDS and STD Control Programme. (2001). Clinical *guidelines on ART*. Nairobi: Ministry of Health.
- National AIDS and STD Programs. (2008). Kenya AIDS Indicator Survey. Nairobi: Ministry of Health.
- National AIDS Control Council. (2005). Kenya national strategic plan 2005/6-2009/10 (pp. 1-57). Nairobi: Ministry of Health.
- Ncama, B. P., McInerney, P., Nicholas, P., Corless, I., Bhengu, B. R., McGibbon,
 C., & Davis, S. (2004, July). Social support and medication adherence in
 HIV disease in South Africa. Paper presented at the International
 Conference on AIDS (15th), Bangkok, Thailand. (Abstract no.
 WePeB5769)
- Oyugi, J. H., Byakika-Tusiime, C., MPH, E., D., K., & Cissy, MB. *Oyugi, J. H., Byakika-Tusiime, K., & Cissy, MB. (2009). Multiple* validated measures of adherence indicate high levels of adherence to generic HIV ART in a resource-limited setting. *Journal of Acquired Immune Deficiency Syndromes, 46*(10), 1616.

Palella, F. J., Delaney, K. M., Moorman, A. C., Loveless, M. O., Fuhrer, J.,
Satten, G. A., Holmberg, S. D. (1998). Declining morbidity and mortality among patients with advanced human immunodeficiency virus infection.
HIV outpatient study investigators. *New England Journal of Medicine, 338*(13), 853-860. Retrieved from http://ejournals.ebsco.com.
ezproxy.shu.edu/Article.asp

- Paterson, D. L., Swindells, S., Mohr, J., Brester, M., Vergis, E. N., Squier, C., ...
 Singh, N. (2000). Adherence to protease inhibitor therapy and outcome in patients with HIV infection. *Annals of Internal Medicine*, *133*, 21-30.
- Portney, L.G. & Watkins, M.P. (2000). *Foundations of Clinical Research Applications to Practice*. Upper Saddle River, NJ: Prentice Hall
- Samet, J. H., Libman, H., Steger, K. A, Dhawan, R. K., Chen, J., Shevitz, A. H., Craven, D. E. (1992). Compliance with zidovudine therapy in patients infected with human immunodeficiency virus, type 1: A cross-sectional study in a municipal hospital clinic. *American Journal of Medicine, 92*(5), 495-502.
- Schwarzer, R., Dunkel-Schetter, C., & Kemeny, M. (1994). The multidimensional nature of received social support in gay men at risk of HIV infection and AIDS. American Journal of Community Psychology, 22(3), 319-339.

Schwarzer, R., Renner, B. (2000). Social-cognitive predictors of health behavior: Action self-efficacy and coping self-efficacy. *Health Psychology*, Vol 19(5), 487-495.

- Siegel, K., & Scrimshaw, E. W. (2005). Stress, appraisal, and coping: A comparison of HIV-infected women in the pre-HAART and HAART eras. *Journal of Psychosomatic Research, 58*(3), 225-233.
- Simoni J. M., Frick P.A., Huang, B. (2006). A longitudinal evaluation of a social support model of medication adherence among HIV-positive men and women on antiretroviral therapy. *Health psychology*, 25(1),74-81.
- Simoni, J. M., Frick, P. A., Lochkart, D., & Liebovitz, D. (2002). Mediators of social support and antiretroviral adherence among an indigent population in New York City. *AIDS Patient Care and STDs, 16*(9), 431-438.
- Tabachnick, B. G. & Fidell, L.S. (2001). *Using Multivariate Statistics* (4th Ed.), Boston, Allyn and Bacon.
- Thorkildsen, T. A. (2005). Fundamentals of measurement in applied research. New York, NY: Pearson.
- Tix, A. P., & Frazier, P. A. (1998). The use of religious coping during stressful life events: Main effects, moderation, and mediation. *Journal of Consulting* and Clinical Psychology, 66(2), 411-422.
- United Nations Program on HIV/AIDS & World Health Organization. (2005). Epidemic updates: December, 2005. Geneva: Authors.
- Ware, N. C., Idoko, J., Kaaya, S., Biraro, I. A., Wyatt, M. A., Agbaji, O., . . .
 Bangsberg, D. R. (2009). Explaining adherence success in sub-Saharan
 Africa: An ethnographic study. *PLoS Medicine*, 6(1), e11.

- Weiminberg, M. A., & Friendland, G. (1998). Public health implications of ART and HIV drug resistance. *Journal of the American Medical Association, 279*, 1977-1983.
- Wethington, E., & Kessler, R. C. (1986). Perceived support, received support, and adjustment to stressful life events [Abstract]. *Journal of Health and Social Behavior, 27*, 89.
- Williams, A. B., Fennie, K. P., Bova, C. A., Burgess, J. D., Danvers, K. A., & Dieckhaus, K. D. (2006). Home visits to improve adherence to highly active ART: A randomized controlled trial. *Journal of Acquired Immune Deficiency Syndromes, 43*(3), 314-321. Retrieved from http://www.medscape.com/viewpublication/878_index
- Yerly, S., Kaiser, L., Race, E., Bru, J.-P., Clavel, F., & Perin, L. (1999). Transmission of antiretroviral-drug resistant HIV-1 variants. *Lancet, 354*, 729-733.

APPENDICES

Appendix A: List of Abbreviations

AIDS	Acquired Immunodeficiency syndrome
ART	ART
HIV/AIDS	Human immunodeficiency virus/Acquired immunodeficiency
	Syndrome
KNASP	Kenya National Strategic Plan 2005/6-2009/10
NRTI	Nucleoside/nucleotide reverses transcriptase inhibitor
NNRTI	Non-nucleoside/nucleotide reverse transcriptase inhibitor
Ol	Opportunistic infection
PI	Protease inhibitors
PLH	People living with HIV
РМТСТ	Prevention of mother to child transmission
STI	Sexually transmitted infection
TMSC	Transactional Model of Stress and Coping
UNAIDS	Joint United Nations Program on HIV/AIDS
VCT	Voluntary testing and counseling
WHO	World Health Organization

Appendix B: Survey Tools

DEMOGRAPHIC SURVEY

Demographic characteristics

Date/	Participants code
District code	Duration of Interview
(Mark response by ticking) Demographics, socio-cultural survey 1. Age 18-30 31-40 41-50 51-64 2. Gender Female 3. Religion	
 Muslim Catholic 4. Marital Status Never married Married ivorced 	Protestant African
 Separated Widowed 5. Educational level None Primary Secondary Vocational University/College Post graduate 6. Employment status 	
 Employed Formal Sector Informal Farming Not employed 	

Interpersonal Support Evaluation List (ISEL) – General Population

This scale is made up of a list of statements each of which may or may not be true about you. For each statement check "definitely true" if you are sure it is true about you and "probably true" if you think it is true but are not absolutely certain. Similarly, you should check "definitely false" if you are sure the statement is false and "probably false" is you think it is false but are not absolutely certain.

1. There are several people that I trust to help solve my problems.

____definitely true (3) _____definitely false (0)

____probably true (2) ____probably false (1)

2. If I needed help fixing an appliance or repairing my car, there is someone who would help me.

____definitely true (3) ____definitely false (0) ____probably true (2) ___probably false (1)

3. Most of my friends are more interesting than I am.

- ____definitely true (3) ____definitely false (0)
- ____probably true (2) ____probably false (1)

4. There is someone who takes pride in my accomplishments.

____definitely true (3) _____definitely false (0)

____probably true (2) ____probably false (1)

5. When I feel lonely, there are several people I can talk to.

_____definitely true (3) _____definitely false (0)

____probably true (2) ____probably false (1)

6. There is no one that I feel comfortable to talking about intimate personal problems.

_____definitely true (3) _____definitely false (0)

____probably true (2) ____probably false (1)

7. I often meet or talk with family or friends.

____definitely true (3) ____definitely false (0) ____probably true (2) ____probably false (1)

8. Most people I know think highly of me.

____definitely true (3) _____definitely false (0)

____probably true (2) ____probably false (1)

9. If I needed a ride to the airport very early in the morning, I would have a hard time finding someone to take me.

____definitely true (3) ____definitely false (0) ____probably true (2) ____probably false (1)

10. I feel like I'm not always included by my circle of friends.

____definitely true (3) _____definitely false (0)

____probably true (2) ____probably false (1)

11. There really is no one who can give me an objective view of how I'm handling my problems.

_____definitely true (3) _____definitely false (0)

____probably true (2) ____probably false (1)

12. There are several different people I enjoy spending time with.

____definitely true (3) _____definitely false (0)

____probably true (2) ____probably false (1)

13. I think that my friends feel that I'm not very good at helping them solve their problems.

____definitely true (3) ____definitely false (0) ____probably true (2) ____probably false (1)

14. If I were sick and needed someone (friend, family member, or acquaintance) to take me to the doctor, I would have trouble finding someone.

____definitely true (3) _____definitely false (0)

____probably true (2) ____probably false (1)

15. If I wanted to go on a trip for a day (e.g., to the mountains, beach, or country), I would have a hard time finding someone to go with me.

____definitely true (3) _____definitely false (0) ____probably true (2) ____probably false (1)

16. If I needed a place to stay for a week because of an emergency (for example, water or electricity out in my apartment or house), I could easily find someone who would put me up.

_____definitely true (3) _____definitely false (0) _____probably true (2) ____probably false (1)

17. I feel that there is no one I can share my most private worries and fears with. ______definitely true (3) ______ definitely false (0)

_____definitely frue (c) _____definitely false (d) _____probably true (2) _____probably false (1)

18. If I were sick, I could easily find someone to help me with my daily chores.

_____definitely true (3) _____definitely false (0)

____probably true (2) ____probably false (1)

19. There is someone I can turn to for advice about handling problems with my family.

_definitely true (3) ____definitely false (0) ____probably true (2) ____probably false (1)

20. I am as good at doing things as most other people are.

_definitely true (3) _____definitely false (0)

____probably true (2) ____probably false (1)

21. If I decide one afternoon that I would like to go to a movie that evening. I could easily find someone to go with me.

_definitely true (3) ____definitely false (0)

probably true (2) probably false (1)

22. When I need suggestions on how to deal with a personal problem, I know someone I can turn to.

definitely true (3) definitely false (0)

____probably true (2) ____probably false (1)

23. If I needed an emergency loan of \$100, there is someone (friend, relative, or acquaintance) I could get it from.

____definitely true (3) ____definitely false (0) _probably true (2) ____probably false (1)

24. In general, people do not have much confidence in me.

_definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

25. Most people I know do not enjoy the same things that I do.

_definitely true (3) _____definitely false (0) _probably true (2) ____probably false (1)

26. There is someone I could turn to for advice about making career plans or changing my job.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

27. I don't often get invited to do things with others.

_definitely true (3) _____definitely false (0)

____probably true (2) ____probably false (1)

28. Most of my friends are more successful at making changes in their lives than I am.

_____definitely true (3) _____definitely false (0)

____probably true (2) ____probably false (1)

29. If I had to go out of town for a few weeks, it would be difficult to find someone who would look after my house or apartment (the plants, pets, garden, etc.).

____definitely true (3) _____definitely false (0) probably true (2) probably false (1)

30. There really is no one I can trust to give me good financial advice.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

31. If I wanted to have lunch with someone, I could easily find someone to join me.

____definitely true (3) ____definitely false (0) ____probably true (2) ____probably false (1)

32. I am more satisfied with my life than most people are with theirs.

_____definitely true (3) _____definitely false (0)

____probably true (2) ____probably false (1)

33. If I was stranded 10 miles from home, there is someone I could call who would come and get me.

____definitely true (3) ____definitely false (0) ____probably true (2) ____probably false (1)

34. No one I know would throw a birthday party for me.

____definitely true (3) _____definitely false (0)

____probably true (2) ____probably false (1)

35. It would me difficult to find someone who would lend me their car for a few hours.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

36. If a family crisis arose, it would be difficult to find someone who could give me good advice about how to handle it.

____definitely true (3) ____definitely false (0) ____probably true (2) ____probably false (1)

37. I am closer to my friends than most other people are to theirs.

_____definitely true (3) _____definitely false (0)

____probably true (2) ____probably false (1)

38. There is at least one person I know whose advice I really trust.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

39. If I needed some help in moving to a new house or apartment, I would have a hard time finding someone to help me.

____definitely true (3) ____definitely false (0) ____probably true (2) ___probably false (1)

40. I have a hard time keeping pace with my friends.

____definitely true (3) ____definitely false (0)

____probably true (2) ____probably false (1)

This scale is from the following:

Cohen, S., & Hoberman, H. (1983). Positive events and social supports as buffers of life change stress. *Journal of Applied Social Psychology, 13*, 99-125.

Cohen, S., Mermelstein, R., Kamarck, T., & Hoberman, H. (1985). Measuring the functional components of social support. In I. G. Sarason & B. R. Sarason (Eds.), *Social support: Theory, research, and application*. The Hague, Holland: Martinus Nijhoff.

Coping Self-Efficacy Scale

When th	ings ar					ou're ha an do the			now col	nfident or
Cannot do at all			_	N	Aoderate certain can do	•				Certain can do
0	1	2	3	4	5	6	7	8	9	10
	1	1	1			1		1	1	

For each of the following items, write a number from 0 - 10, using the scale above.

When things aren't going well for you, how confident are you that you can:

1.	Keep from getting down in the dumps.		99
2.	Talk positively to yourself.		99
3.	Sort out what can be changed, and what can not be changed.		99
4.	Get emotional support from friends and family.		99
5.	Find solutions to your most difficult problems.		99
6.	Break an upsetting problem down into smaller parts.		99
7.	Leave options open when things get stressful.		99
8.	Make a plan of action and follow it when confronted with a problem.		99
9.	Develop new hobbies or recreations.		99
10.	Take your mind off unpleasant thoughts.		99
11.	Look for something good in a negative situation.		99
12.	Keep from feeling sad.	<u> </u>	99
13.	See things from the other person's point of view during a heated argume	nt	99
14.	Try other solutions to your problems if your first solutions don't work.		99
15.	Stop yourself from being upset by unpleasant thoughts.		99

please go on to next page

When th	iings ar					vou're ha an do the				nfident or
Cannot do at all				Ν	Ioderate certain can do	•				Certain can do
0	1	2	3	4	5	6	7	8	9	10
L_		_1_								

When things aren't going well for you, how confident are you that you can:

16.	Make new friends.		99
17.	Get friends to help you with the things you need.		99
18.	Do something positive for yourself when you are feeling discouraged.		99
19.	Make unpleasant thoughts go away.		99
20.	Think about one part of the problem at a time.	<u></u> n	99
21.	Visualize a pleasant activity or place.		99
22.	Keep yourself from feeling lonely.		99
23.	Pray or meditate.		99
24.	Get emotional support from community organizations or resources.		99
25.	Stand your ground and fight for what you want.		99
26.	Resist the impulse to act hastily when under pressure.		99

Chesney MA, Neilands TB, Chambers DB, Taylor JM, Folkman S. A validity and reliability study of the coping self-efficacy scale. Br J Health Psychol 2006 Sep; 11(3): 421-37. http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1602207.

We appreciate copies of manuscripts or conference presentations generated from the use of this scale to help us stay current with its use and to assess its validity and reliability in other populations.

Please address correspondence to Margaret A. Chesney, PhD, Deputy Director, National Center for Complementary and Alternative Medicine, National Institutes of Health, 31 Center Drive, Room 2B11, MSC2182, Bethesda, MD 20892-2182, USA (e-mail: chesneym@mail.nih.gov).

			L0702(000)/00-00-00
A	CTG ADHERENCE FOLI	LOW-UP QUESTIONNA	JRE
	NIAID ADULT AIDS	CLINICAL TRIALS GROUP	Page 1 of 5
Patient Number		Date of Patient Visit	
		mn	nm dd yy
Protocol Number	0 0 0	Institution Code	
Form Week		Key Operator Coc	te et

FOR OFFICE USE ONLY - TEAR OFF SHEET

INSTRUCTIONS TO THE STUDY PERSONNEL: The ACTG ADHERENCE FOLLOW-UP QUESTIONNAIRE SHOULD BE GIVEN TO THE SUBJECT PRIOR TO THE CLINICAL EXAM. The subject must be able to read at the sixth-grade level at a minimum to complete the questionnaire without additional assistance.

It is important to be familiar with the content and format of the guestionnaire before giving it to study participants. At the first visit, please begin by telling the participant:

- The purpose of this form is to learn about potential influences of treatment adherence.
- .
- Please answer all questions honestly; you will not be "judged" based on your responses. If you do not wish to answer a question, please draw a line through it. When completed, the form will be quickly reviewed to make sure you didn't mistakenty skip questions (without crossing them out); your specific responses to questions will not be reviewed. Please feel free to ask if you need any of the questions explained to you. 6

For question *A," review with the subject what treatment they are receiving and complete the worksheet together. You should then briefly go over the format of the questions and how to complete them.

The guestionnaire is very brief and should take no more than 5 minutes to complete. Before giving the subject the questionnaire, please fill out the header(s) and DETACH THIS PAGE.

Each question is in the same general format and contains several items. Note that the subject is always asked to make a */* next to the appropriate category. Drug names and abbreviations of the most common anti-HIV drugs have been included on the worksheet for reference and use.

Collect the completed questionnaire before the clinical exam. Before going on, review the questionnaire for omissions. If the participant missed any of the questions, point this out and encourage him/her to complete the omissions,

For data keying, if the subject did not answer a question, enter *-1," Do not leave any fields blank,

PLEASE COMPLETE THE FOLLOWING ITEMS AFTER SUBJECT COMPLETES THE QUESTIONNAIRE OR AFTER YOU ASCERTAIN THAT THIS IS NOT POSSIBLE:

•	How was the questionnaire completed?	1-Self administered by the study participant 2-Face-to-face interview that you conducted 3-Both self-administered and interview 4-Not completed 9-Other, specify	
	If Other, specify [30]:		<u> </u>
	a. If you answered "4-Not completed," please	indicate the reason why : 1-Subject refused 2-Subject missed clinic v 3-There was not enough 9-Other reason, specify	
	If Other, specify [30]:		

07-17-68/10-09-00/12-19-00

			02(000)/00-00-00
A		LOW-UP QUESTIONNAIR	
	NIAID ADULT AID:	3 CLINICAL TRIALS GROUP	Page 2 of 5
Patient Number		Date of Patient Visit	
		mmm	do yy
Protocol Number	0 0 0	Institution Code	
Form Week		Key Operator Code	

THIS PAGE IS TO BE COMPLETED BY THE SUBJECT AND STUDY PERSONNEL TOGETHER.

INSTRUCTIONS: Complete this worksheet with the subject. Drug names and abbreviations of the most common anti-HIV drugs have been included for your reference and use. Use the abbreviations indicated (i.e., "APV" for Amprenavir).

A. You are currently taking the following study drugs at the frequency and doses listed:

	Study Regimen	
Study Drug Name/Dose	# Pills Each Time (Pills Each Dose)	# Times Per Day (Doses Per Day)
الهوري والمستقل المرابي والمستقل المتعاد المروق المستقل والمتعين		
nound ^{ant} , <u>and an</u> , <u>an</u> an		

Abacavir/ABC/Ziagen/1592U89	FTC/coviracil/emtricitabine
Alovudine/CL-184824	Indinavir/IDV/Crixivan
Amprenavir/Agenerase/APV/141W94/VX-479	Interleukin-2/IL-2
Atevirdine mesylate U-87201E	Lamivudine/3TC/Epivir
Azidouridine/AzdU/azido-2',3'-dideoxyundine	Lopinavir/Ritonavir (LPV/RTV)Kaletra/ABT-378r
ZT/ZDV/Zidovudine/Retrovir	Lovinde/Lotrane
D4/RST4	Netfinavir/NFV/Viracept
Combivir (3TC/ZDV)	Nevirapine/NVP/Viramune
HT/Stavudine/Zerit	Rilonavir/RTV/Norvir
IdC/Zalcitabine/HIVID	Saquinavir soft gel/FTV/Fortovase
Idl/Didanosine/Videx	Saguinavir(HGC)/SQV/Invirase/R031-8959
XV/delavirdine mesylate/Rescriptor	T-20/pentaluside
favirenz/EFV/Sustiva/DMP266	Trizivir (3TC/ABC/ZDV)
Fiuorouridina/935U83	

07-17-98/10-09-00/12-19-00

	QL0702(000)/00-00-00
	ACTG ADHERENCE FOLLOW-UP QUESTIONNAIRE Page 3 of 5
Patient Number	Date of Patient Visit
	mmm dd w

The answers you give on this form will be used to plan ways to help other people who must take pills on a difficult schedule. Please do the best you can to answer all the questions. If you do not wish to answer a question, please draw a line through it. If you do not know how to answer a question, ask your study nurse to help. Thank you for helping in this important study.

SUBJECT ONLY continue here.

The next section of the questionnaire asks about your HIV study medications that you took over the last four days. Drug codes and abbreviations of the most common anti-HIV drugs have been included for your reference and use on page 2.

(B^C Most people with HIV have many pills to take at different times during the day. Many people find it hard to always remember their pills:

doses

doses

doses

doses

doses

doses

doses

- Some people get busy and forget to carry their pills with them. Some people find it hard to take their pills according to all the instructions, such as "with meals" or "on an empty stomach," "every 8 hours," "with plenty of fluids." Some people decide to skip pills to avoid side effects or to just not be taking .
- . pills that day.

We need to understand how people with HIV are really doing with their pills. Please tell us what you are actually doing. Don't worry about telling us that you don't take all your pills. We need to know what is really happening, not what you think we "want to hear."

1. The next section of the questionnaire asks about the anti-HIV study medications that you may have missed taking over the last four days. Please complete the table below. using one line for each study drug you are taking, and using the abbreviations on the previous page. If you did not miss any doses, write a zero (0) in the box. Note that the table asks about DOSES, not PILLS.

PLEASE REPORT THE DOSE(S) AS BEING MISSED.					
		HOW MANY DOSES DID YOU MISS			
	Step 1	Step 2	Step 3	Step 4	Step 5
	Names of your anti-HIV study drugs	Yesterday	Day before yesterday (2 days ago)	3 days ago	4 days ago

doses

doses doses

doses

doses

doses

doses

doses doses

doses

doses

doses

IF YOU TOOK ONLY A PORTION OF A DOSE ON ONE OR MORE OF THESE DAYS,

07-17-96/10-09-00/12-19-00

	QLC	702(000)/00-00-00
	ACTG ADHERENCE FOLLOW-UP QUESTIONNAIRE	Page 4 of 5
Patient Number	Date of Patient Visit	
		n dd vv

The following questions pertain to the study regimen on page 2.

If you took only a <u>portion</u> of a dose on one or more of these days, please report the dose(s) as being <u>missed.</u>

B. During the past 4 days, on how many days have you missed taking all your doses?

(Check	one box)
None	٥
One day	1
Two days	2 🗖
Three day	s 3 🗋
Four days	40

C. Most anti-HIV medications need to be taken on a schedule, such as "2 times a day" or "3 times a day" or "every 8 hours." How closely did you follow your specific schedule over the last four days?

Never	Some Of	About Half	Most Of	All Of
	The Time	Of The Time	The Time	The Time
				Ģ

D. Do any of your anti-HIV medications have special instructions, such as "take with food" or "on an empty stomach" or "with plenty of fluids"?

Yes No

If Yes, how often did you follow those special instructions over the last four days?

Never	Some Of	About Haif	Most Of	All Of
	The Time	Of The Time	The Time	The Time
Ģ				□

E. Some people find that they forget to take their pills on the weekend days. Did you miss any of your anti-HIV medications last weekend - last Saturday or Sunday?



F. When was the last time you missed any of your medications?

(Checi	k one box)
Within the past week	5
1-2 weeks ago	4□
2-4 weeks ago	3
1-3 months ago	2
More than 3 months ago	10
Never skip medications	₀⊡

If you Never miss your study medications, please STOP. Otherwise, please continue by answering the next set of questions.

97-17-98/10/09-00/12-19-00

		QL0702(000)/00-00-00
Patient Number	ACTG ADHERENCE FOLLOW-UP QUESTIONNAIRE	

G. People may miss taking their study medications for various reasons. Here is a list of possible reasons why you may miss taking your medications. How often have you missed taking your study medications because you: (Check of Check o (Check one)

Please check one box for each question.	Never	Rarely	Sometimes	Often
1. Were away from home?	D	Ç		Ū
2. Were busy with other things?	Ģ	Ģ	2	r C
3. Simply forgot?	Ď	ģ	Ĺ,	ů
4. Had too many pills to take?	Ď	Ċ	ģ	Ļ,
5. Wanted to avoid side effects?	Ď	ċ	ģ	
Did not want others to notice you taking medication?	Ç	ļ	Ļ	ģ
7. Had a change in daily routine?	Q		Ę	ņ
8. Feit like the drug was toxic/harmful?	Ď	ò	Ć	Ļ
9. Fell asleep/slept through dose time?	Ď		ģ	, ,
10. Felt sick or ill?	ů	Ċ	Ć	
11. Feit depressed/overwhelmed?	Ď	ò	Ć	3
 Had problem taking pills at specified times (with meals, on empty stomach, etc.)? 			Ĺ,	
13. Ran out of pills?	D	Ģ	D	
14. Fell good?	å	¢	ģ	ļ

Thank you very much for completing these questions. The information that you provided will help with the development of better drug regimens for all subjects with HIV.

Language: **E** English

07-17-98/10-09-00/12-19-00

Date Form Keyed: (DO NOT KEY) / /

KISWAHILI VERSION OF SURVEY TOOLS ACTG – MASWALI ENDELEVU KWA TAFITI ZA ACTG

TIBA ZA MAJARIBIO KWA MTU ALIYEATHIRIKA KWA UGONJWA WA UKIMV	VI KUPITIA
NIAID	
Namba ya Mgonjwa	
Tarehe ya Mahudhurio ya Mgonjwa	
mmm	dd
Namba ya Makubaliano O O O	
kimu ya Nyumba	
Stakabadhi ya Juma	

Namba ya Mhudumu Mkuu

UKURASA HUU UTAKAMILISHWA NA MTU HUSIKA NA PASONELI ANAYEJIFUNZA PAMOJA

MAAGIZO: Kamilisha jedwali hili na mtu husika. Majina ya dawa na mfupisho wa dawa za ukimwi zinazopatikana zimeshahusishwa kwa marejeo na kwa matumiziyako. Tumia ufupisho ulioneshwa (i.e. "APV" kifupi cha Amprenavir)

A. Umekuwa ukisoma dawa kama zinavyoonyeshwa mara kwa mara pamoja

na vipimo hapa chini:-

Kujifunza Taratibu					
# Kipimo cha tembe za mara kwa mara	# Mara ngapi kwa siku (Kipimo kila siku)				

Tembe dhidi ya Virus vya Ukimwi (Anti-HIV Drugs)

Abacavir/ABC/Ziagen/1592U89	FTC/coviracil/emtricitabine
Alovudine/CL-184824	Indinavir/IDV/Crixivan
Amprenavir/Agenerase/APV/141W94/VX-479	Interleukin-2/IL-2
Atevirdine mesylate U-87201E	Lamivudine/3TC/Epivir
Aziduridine/AzdU/azido-2',3'-dideoxyuridine	Lopinavir/Ritonavir (LPV/RTV) Kaletra/ABT-
	378r
AZT/ZDV/Zidvudine/Retrovir	Loviride/Lotrene
CD4/RST4	Nelfinavir/NFV/Viracept
Combivir (3TC/ZDV)	Nevirapine/NVP/Viramune
d4T/Stavudine/Zerit	Ritonavir/RTV/Norvir
ddC/Zalcitabine/HIVID	Saquinavir soft gel/FTV/Fortovase
ddl/Didanosine/Videx	Saquinavir(HGC)/SQV/Invirase/R031-8959
DLV/delavirdine mesylate/Rescriptor	T-20/pentafuside
Efavirenz/EFV/Sustiva/DMP266	Trizivir (3TC/ABC/ZDV)
Flurouridine/935U83	

ACTG UAMINIFU WAKUFUATA ORDH	IA YA MASWALI
Namba ya Mgonjwa Tarehe ya mahudhurio ya Mgonjwa	

145

mm dd y

Majibu utakayojaza katika fomu hii yatatumiwa kupanga njia za kusaidia watu wengine ambao hulazimika kutumia dawa ama tembe wakiwa katika mazingira yenye ratiba ngumu .Tafadhali fanya uwezavyo kujibu maswali yote. Iwapo hutaki kujibu swali tafadhali likate kwa mstari.Iwapo haujui jinsi ya kulijibu swali muulize tabibu kwa ufafanuzi zaidi.

Asante kwa kushiriki kwako katika zoezi hili muhimu.

KWA MHUSIKA TU endelea hapa:-

Sehemu nyingine ya orodha ya maswali yanahusu somo lihusulo njia mbalimbali zinazochangia kuleta maambukizi ya virusi vya ukimwi ikiwa ni pamoja na matumizi wa dawa ambazo ulipata kuzitumia katika siku nne zilizopita. Kiasi cha dawa pamoja na vifupisho vya aina mbalimbali za dawa za kawaida zitumikazo dhidi ya virusi vya UKIMWI zimewekwa ili kukusaidia uweze kufanya marejeo mara kwa mara utumiapo ukurasa wa pili.

Watu wengi wenye virusi vya UKIMWI kila siku humeza tembe za aina mbalimbali kwa nyakati tofauti. Watu wanaratiba ngumu kiasi cha kuwa wafanya washindwe kukumbuka mara kwa mara kuzimeza tembe zao.

- Baadhi ya watu hujishughulisha na mambo mengi kiasi cha kujisahahu kuzibeba tembe zao.
- Baadhi ya watu hupata ugumu wa kuzitumia tembe zao kwa kulingana na maelekezo na masharti yaliiyotolewa kumeza kabla ya kula au baada ya kula ama pamoja na chakula ama bila ya kula chochote ama kila baada ya masaa 8 ama pamoja na maji mengi.
- Baadhi ya watu huamua kutozimia tembe husika kwa lengo la kukwepa kupata madhara yatokanayo na matumizi ya tembe ama dawa hizo.

Tunapasika kujua jinsi ambavyo watu walio na virusi vya UKIMWI wanavyozichukulia dawa. Tafadhali wewe utuambie kile hasa unachokifanya kuhusiana na matumizi ya tembe zako. Usiwe na shaka unapotuambia kwamba wewe humezi tembe zako zote. Tunataka kupata hakika ya kiutafiti juu ya kile hasa kinachofanyika kuhusiana na matumizi ya hizi dawa. Hatuna nia ya kukutaka wewe utuambie sisi kile unachofikiria kuwa *tungependa kukijua na kukisikia toka kwako*. Yaani usijibu kwa nia ya kutufurahisha sisi, la hasha, bali jibu kadiri ya ukweli halisi na mang'amuzi yako juu ya jambo unaloulizwa.

1. Sehemu hiyo nyingine ya fomu za maswali inalenga kutaka kujua juu ya utafiti juu ya dawa zitumizako dhidi ya virusi vya UKIMWI ambazo unaweza ukawa ulizikosa ama uliziruka kuzitumia ndani ya siku nne zilizopita. Tafadhali

kamilisha kwa kulijaza jedwali lifuatalo hapo chini, ukitumia vyumba ama safu husika kujaza kuingizia vifupisho vitokavyo kwenye ukurasa uliopita. Iwapo hukukosa kutumia kiasi cha dawa, andika sufuri (0) katika sanduku. Tanbihi kwamba jedwali lauliza juu ya kiasi chochote cha dawa, na siyo kiasi cha tembe.

IWAPO ULITUMIA <u>SEHEMU</u> TU YA KIASI CHA DAWA AU NYINGI ZA SIKU HIZI, TAFADHALI RIPOTI KIASI CHA DAWA <u>ULICHOKIKOSA</u>

Hatua ya 1	NI VIASI VIPI VYA DAWA UMEKOSA						
	Hatua ya 2	Hatua ya 3	Hatua ya 4	Hatua ya 5			
Majina ya tafiti juu ya tembe zitumikazo dhidi ya virusi vya UKIMWI	Jana	Juzi (Siku mbili zilizopita)	Siku tatu zilizopita	Siku nne zilizopita			
	Kiasi cha dawa	Kiasi cha dawa	Kiasi cha dawa	Kiasi cha dawa			
	Kiasi cha dawa	Kiasi cha dawa	Kiasi cha dawa	Kiasi cha dawa			
	Kiasi cha dawa	Kiasi cha dawa	Kiasi cha dawa	Kiasi cha dawa			
	Kiasi cha dawa	Kiasi cha dawa	Kiasi cha dawa	Kiasi cha dawa			
	Kiasi cha dawa	Kiasi cha dawa	Kiasi cha dawa	Kiasi cha dawa			
	Kiasi cha dawa	Kiasi cha dawa	Kiasi cha dawa	Kiasi cha dawa			
	Kiasi cha dawa	Kiasi cha dawa	Kiasi cha dawa	Kiasi cha dawa			

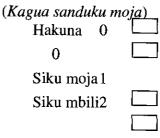
ACTG FUATA KIMAKINI ORODHA YA MASWALI YAFUATAYO

Namba ya Mgonjwa Tarehe ya Ziara ya Mgo	onjwa					Τ		
		 		I	<u>n</u> mr	<u>n</u>	 	
				dd		w		

Maswali yafuatayo yanaendana na taratibu zilizoko nyuma kwenye ukurasa wa pili.

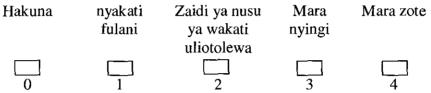
Iwapo ulitumia <u>sehemu</u> tu ya kiasi cha dawa mara moja au mara nyingi katika siku za hivi karibuni, tafadhari taja ama ripoti kiasi hicho *ulichokikosa ama ulichokiruka*kukitumia.

B. Ndani ya siku nne zilizopita ,ni siku ngapi umekosa kumeza kiasi cha dawa ulichotakiwa kukimeza?



Siku tatu 3 3 Siku nne 4 4

C. Sehemu kubwa ya dawa zitumikazo dhidi ya virusi vya UKIMWI inapaswa kutumika kwa mpango maalumu: Kama vile, *mara mbili kwa siku*, *kila baada ya masaa* 8.Je, wewe ulikuwa makini kwa kiwango gani katika kuufuatilia mpango huo ndani ya siku nne zilizopita?



D. Je, kuna masharti ama maelezo yoyote yale katika dawa uzitumiazo dhidi ya virusi vya UKIMWI yenye maagizo maalumu kama vile, tumia *kabla ya kula* au *baada ya kula* ama *pamoja na chakula* ama *bila ya kula chochote* ama *kila baada ya masaa 8* ama *pamoja na maji mengi* ?

Ndiyo		Hapana
1	2	

Iwapo Ndiyo, ni mara ngapi umekuwa ukifuata maagizo hayo katika kipindi kisichozidi siku nne zilizopita?



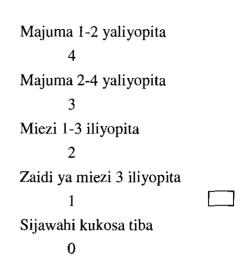
E. Baadhi ya watu hujikuta wamejisahahu kumeza tembe zao kwa kadiri ya maelekezo. Je, umewahi kukosa kuzimeza tembe zako mwishoni mwa wiki iliyopita , yaani katika siku za Jumamosi au Jumapili iliyopita?

Image: NdiyoImage: Hapana12

F. Kwa mara ya mwisho ni lini ulitokea kukosa ama kuruka kutumia tiba zako?

(Kagua saduku moja) Ndani ya Juma lililopita 5

147



Iwapo **hujawahi** kukosa kuchukua tiba za majaribio, tafadhali USIENDELEE (ACHA KUJIBU MASWALI HAYO). Vinginevyo,, tafadhali endelea kuyajibu maswali mengine yafuatayo huko mbele.

FUATA KWA MAKINI ORODHA YA MASWALI YA ACTG

Namba ya Mgonjwa Tarehe ya Ziara ya Mgonjwa		
		<u>mmm</u>
	bb	

G. Watu wanaweza kukosa kutumia tiba za majaribio na utafiti kutokana na sababu mbalimbali. Hapa zimeorodheshwa baadhi ya sababu zinazoweza kujitokeza mara kwa mara kukukosesha wewe kutumiawa tiba hizo. Hii ni kwa vile wewe :-

Tafadhali kagua moja ya sanduku kwa kila swali.	<u>Hakuna</u>	<u>Mara</u> chache	Pengine	<u>Mara kwa</u> mara
1. Upombali na nyumbani?				$\overline{\Box}$
2. Unatingwa na mambo mengi ya kufanya?				□ 3
3. Ulijisahau tu.	ũ			
4. Ulikuwa na tembe nyingi za kumeza?				3
5. Ulitaka kuepuka madhara ya dawa?			$\frac{2}{\Box}$	3 □ 3
6. Hukutaka wengine kukuona ukitibiwa?				
7. Ulikuwa na mabadiliko katika ratiba ya kila siku?		\square	\square	\square

 8. Ulihisi dawa zilikuwa na sumu yeny kuleta madhara makubwa? 9. Ulipitiwa na usingizi wakati wa kumeza kiasi cha dawa uliyoelekezwa? 10. Ulikuwa mgonjwa? 11. Ulipatwa na huzuni na maumivu? 				
12. Ulishindwa kutumia tembe kwa kufuata maagizo yanayoambana nazo (pamoja na	0 □ 0	1 □ 1	2 □ 2	3 \square 3
chakula, kabla ya mlo n.k.) 13. Uliishiwa tembe? 14. Ulihisi uko salama kiafya?			$\begin{array}{c} \Box\\ 2\\ \Box\\ 2\end{array}$	

Ahsante sana kwa kukamilisha maswali haya

Habari uliyoitoa itasaidia katika jitihada za kuboresha dawa kwa ajili ya tiba dhidi ya virusi vya UKIMWI kwa watu wote.

INTERPERSONAL SUPPORT EVALUTION LIST (ISEL) <u>KUUNGA MKONO STAKABADHI YA KUTATHIMINI MAHUSIANO BAINA</u> <u>YA WATU: (ISEL INTERPERSONAL</u> SUPPORT EVALUATION – GENERAL POPULATION)

Kila mojawapo ya maelezo thibitisha "ni kweli kabisa" iwapo una uhakika ni kweli kukuhusu na "ni kweli kwa kiasi fulani" iwapo unafikiria ni kweli kukuhusu na "ni kweli kwa kiasi fulani" iwapo unafikiria ni kweli lakini huna uhakika kabisa. Vivyo hivyo, sharti uthibitishe "si kweli kabisa" iwapo una hakika maelezo si kweli na "si kweli kwa kiasi fulani" iwapo una fikiri si kweli lakini iwapo huna uhakika kabisa.

- 1. Kuna watu kadha ambao ninawaamini kuwa wanaweza kunisaidia katika kutatua shida zangu.
- _____ ni kweli kabisa (3) ______ sikweli kabisa (0). _____ ni kweli kwa kiasi fulani(2) ______si kweli kwa kiasi fulani (1) 2. Ikiwa ningetaka usaidizi wa kutengeneza chombo kama gari, baisekeli, simu, au radio kuna mtu ambaye angenisaidia. _____ ni kweli kabisa (3) ______si kweli kabisa (0) ni kweli kwa kiasi fulani (2) si kweli kwa kiasi fulani (1)3. Wengi kati ya marafiki zangu hupendeza na kuvutia zaidi kuliko mimi. _____ ni kweli kabisa (3) si kweli kabisa (0) _____ ni kweli kwa kiasi fulani(2) si kweli kwa kiasi fulani (1) 4. Kuna mtu ambaye hufurahia ushindi wangu. _____ ni kweli kabisa (3) _____si kweli kabisa (0) _____ ni kweli kwa kiasi fulani (2) ______ si kweli kwa kiasi fulani (1) 5. Ninapojisikia upweke, kuna watu kadhaa ninaoweza kuzungumza nao. _____ ni kweli kabisa (3) _____si kweli kabisa (0) _____ ni kweli kwa kiasi fulani (2) ______ si kweli kwa kiasi fulani (1) 6. Sina mtu ambaye ninajisikia kuwa huru naye kumweleza mambo yangu binafsi. _____ ni kweli kabisa (3) _____si kweli kabisa (0)
 - _____ ni kweli kwa kiasi fulani (2) ______si kweli kwa kiasi fulani (1)

7. Mara kwa mara mimi hukutana au kuong	ea na familia au na marafiki.
ni kweli kabisa (3)	si kweli kabisa (0)
ni kweli kwa kiasi fulani (2)	si kweli kwa kiasi fulani (1)
8. Wengi kati ya ninaowajua huzungumza n	nazuri juu yangu.
ni kweli kabisa (3)	si kweli kabisa (0)
ni kweli kwa kiasi fulani (2)	si kweli kwa kiasi fulani (1)
9. Ikiwa nataka kwenda mjini, au popote m	apema asubuhi ningepata shida kumpata
mtu wa kunisaidia.	
ni kweli kabisa (3)	si kweli kabisa (0)
ni kweli kwa kiasi fulani (2)	si kweli kwa kiasi fulani (1)
10. Daima najihisi kutengwa na kundi la mai	rafiki zangu.
ni kweli kabisa (3)	si kweli kabisa (0)
ni kweli kwa kiasi fulani (2)	si kweli kwa kiasi fulani (1)
11. Kwa hakika hakuna mtu anayeweza kuni	ipa maoni halisi juu ya namna
ninavyotatua shida zangu.	
ni kweli kabisa (3)	si kweli kabisa (0)
ni kweli kwa kiasi fulani (2)	si kweli kwa kiasi fulani (1)
12. Kuna watu wengi hapa na pale ambao na	furahia kuwa pamoja nao.
ni kweli kabisa (3)	si kweli kabisa (0)
ni kweli kwa kiasi fulani (2)	si kweli kwa kiasi fulani (1)
13. Nafikiria rafiki zangu huona kama mimi s	siwezi kuwasaidia kutatua shida zao.
	si kweli kabisa (0)
ni kweli kwa kiasi fulani (2)	si kweli kwa kiasi fulani (1)
14. Ningepata taabu kumpata mtu (rafiki, jam	iii, au mtu ninayemjua) wa kunipeleka
hospitalini iwapo ningekuwa mgonjwa.	
ni kweli kabisa (3)	si kweli kabisa (0)
ni kweli kwa kiasi fulani (2)	si kweli kwa kiasi fulani (1)

- 15. Iwapo ningependa kusafiri kuelekea popote pale kama kwenye mabulundisho, au sherehe zingenezo, ningekuwa na wakati mgumu kumpata mtu au watu wa kuandamana name.
- _____ ni kweli kabisa (3) ______ si kweli kabisa (0)
- _____ ni kweli kwa kiasi fulani (2) _____si kweli kwa kiasi fulani (1)
 - 16. Ikiwa ningetapata dharula kama kuchomeka kwa ngoma langu, ningempata mtu wa kunikaribisha kwake nyumbani kwa muda wa wiki moja.
 - ______ni kweli kabisa (3) _______si kweli kabisa (0)
 - _____ni kweli kwa kiasi fulani (2) ______si kweli kwa kiasi fulani (1)
 - 17. Nahisi sina mtu wa kumshirikisha mambo ya kuhofisha au wasiwasi wa binafsi.
 - _____ ni kweli kabisa (3) ______ si kweli kabisa (0)
 - _____ ni kweli kwa kiasi fulani (2) ______ si kweli kwa kiasi fulani (1)
 - 18. Iwapo ningekuwa mgonjwa, ningepata kwa urahisi mtu wa kunisaidia kuzifanya kazi zangu ndogondogo za kila siku.
 - _____ ni kweli kabisa (3) ______si kweli kabisa (0) ______si kweli kwa kiasi fulani (2) ______si kweli kwa kiasi fulani (1)
 - 19. Kuna mtu ninayeweza kumwendea kwa ushauri jinsi ya kutatua matatizo ya kijamii.
 - _____ ni kweli kabisa (3) ______ si kweli kabisa (0) ______ si kweli kwa kiasi fulani (2) ______ si kweli kwa kiasi fulani (1)
 - 20. Ninafanya mambo vizuri sawa tu na wengine.
 - ______ni kweli kabisa (3) ______si kweli kabisa (0)
 - _____ ni kweli kwa kiasi fulani (2) ______si kweli kwa kiasi fulani (1)
 - 21. Ikiwa naamua kwenda matembezi jioni, ningempata kirahisi mtu wa kuandamana nami.
 - _____ ni kweli kabisa (3) ______ si kweli kabisa (0) ______ si kweli kwa kiasi fulani (2) ______ si kweli kwa kiasi fulani (1)
 - 22. Ninapohitaji mashauri kuhusu masuala yangu binafsi, daima najua ni nani wa kumwendea.

ni kweli kabisa (3)	si kweli kabisa (0)
ni kweli kwa kiasi fulani (2)	si kweli kwa kiasi fulani (1)
23. Iwapo ningehitaji mkopo wa dharur	a wa shilingi elfu moja kuna mtu awe rafiki,
jamaa au mtu ninayemjua ambaye ar	ngenikopesha.
ni kweli kabisa (3)	si kweli kabisa (0)
ni kweli kwa kiasi fulani (2)	si kweli kwa kiasi fulani (1)
24. Kwa kawaida watu hawaniamini.	
ni kweli kabisa (3)	si kweli kabisa (0)
ni kweli kwa kiasi fulani (2)	si kweli kwa kiasi fulani (1)
25. Watu wengi ninaowajua hawafurahi	i memba vala vala ninevovafurahia
e i	
ni kweli kabisa (3)	si kweli kabisa (0)
ni kweli kwa kiasi fulani (2)	si kweli kwa kiasi fulani (1)
26. Kuna mtu ninaweza kumtegemea kul	husiana na kazi zangu ama mipango yangu ya
kimaisha.	
ni kweli kabisa (3)	si kweli kabisa (0)
ni kweli kwa kiasi fulani (2)	si kweli kwa kiasi fulani (1)
27. Sialikwi mara kwa mara kujumuika	na wengine.
	si kweli kabisa (0)
ni kweli kwa kiasi fulani (2)	
•	ı vizuri zaidi katika kurekebisha maisha yao
kuliko mimi.	
ni kweli kabisa (3)	si kweli kabisa (0)
ni kweli kwa kiasi fulani (2)	si kweli kwa kiasi fulani (1)
29. Ikiwa ningesafiri kwenda nje ya mji	wangu kwa majuma machache ingenkuwa
	goma langu, chumba change, mimea,
bustani, ng'ombe, kondoo, vifaranga	
ni kweli kabisa (3)	si kweli kabisa (0)
ni kweli kwa kiasi fulani (2)	si kweli kwa kiasi fulani (1)

	a kuamini anipe ushauri mwema wa kifedha
ni kweli kabisa (3) ni kweli kwa kiasi fulani (2)	si kweli kabisa (0) si kweli kwa kiasi fulani (1)
	riki naye, ikiwa ningependa kungana na mtu
katika chakula cha mchana.	
ni kweli kabisa (3)	si kweli kabisa (0)
ni kweli kwa kiasi fulani (2)	si kweli kwa kiasi fulani (1)
32. Ninaridhika zaidi na maisha yangu	kuliko wengine.
ni kweli kabisa (3)	si kweli kabisa (0)
	si kweli kwa kiasi fulani (1)
33. Ikiwa mkasa ungenipata ndani ya k	ilomita kumi toka nyumbani kwangu,
ningepata mtu wa kunisaidia.	
ni kweli kabisa (3)	si kweli kabisa (0)
ni kweli kwa kiasi fulani (2)	si kweli kwa kiasi fulani (1)
34. Hakuna yeyote nimjuaye angeniano	lalia sherehe ya siku ya kuzaliwa kwangu.
ni kweli kabisa (3)	si kweli kabisa (0)
ni kweli kwa kiasi fulani (2)	si kweli kwa kiasi fulani (1)
35. Ingekuwa vigumu kumpata mtu am	baye angeniazimisha gari, baiskeli, au
chombo chochote kinginecho kwa n	nasaa machache.
ni kweli kabisa (3)	si kweli kabisa (0)
ni kweli kwa kiasi fulani (2)	si kweli kwa kiasi fulani (1)
36. Ikiwa familia ingepatwa na shida, i	ngekuwa vigumu kumpata mtu wa kutoa
ushauri mzuri juu ya namna ya kuka	biliana na shida hiyo.
ni kweli kabisa (3)	si kweli kabisa (0)
ni kweli kwa kiasi fulani (2)	si kweli kwa kiasi fulani (1)
37. Mimi ninahusiana vizuri, na kwa ka	aribu zaidi, na marafiki zangu kuliko watu
wengi wanavyo na marafiki zao.	
ni kweli kabisa (3)	si kweli kabisa (0)
ni kweli kwa kiasi fulani (2)	

- 38. Walau kuna mtu ambaye mimi ninamjua, ambaye ninamwamini kwa kiasi kikubwa.
- _____ ni kweli kabisa (3) ______si kweli kabisa (0)
- _____ ni kweli kwa kiasi fulani (2) ______si kweli kwa kiasi fulani (1)
- 39. Ikiwa ningehitaji uzaidizi wa kuhamia nyumba au chumba kipya, ningekuwa na wakati mgumu wa kumpata mtu wa kunisaidia.
- ______ni kweli kabisa (3) ______si kweli kabisa (0) ______si kweli kwa kiasi fulani (2) ______si kweli kwa kiasi fulani (1)

40. Ni vigumu kufanya mambo viliyo kama marafiki zangu.

- _____ni kweli kabisa (3) ______si kweli kabisa (0)
- _____ ni kweli kwa kiasi fulani (2) ______si kweli kwa kiasi fulani (1)

KUJIPIMIA KADIRI YAKO (CSE)

Wakati mambo hayaendi vizuri, ama wakati una shinda unauhakika gani unaweza kufanya mambo haya?

(0-3) Huwezi kufanya lolote (4-6) kwa kiasi Fulani (7-10) Unaweza kufanya jambo lolote bila shida

1 2 3 4 5 6 7 8 9 10

Kwa maswali yaliyopo hapa andika nambari 0-10 ukitumia kipimo kilipo hapa juu.

Kama mambo hayaendi vizuri, unajiamini kuwa unaweza kuyapatia ufumbuzi?

- 1. Jizuie kuwa na hisia za chini _____
- 2. Waza mazuri juu yako_____
- 3. Tofautisha shida zenye suluhisho na zile ambazo hazina suluhisho._____
- 4. Pata usaidizi kutoka kwa familia au marafiki_____
- 5. Tafuta suluhisho za matatizo magumu yako_____
- 6. Vuja vuja tatizo lako katika vipengee mbalimbali_____
- 7. Kutafuta njia mbalimbali za kutatua shida zako wakati wa dhiki_____
- 8. Panga mpango wa kupambana na matatizo na kuweza kufuata mpango huo
- 9. Tafuta njia zingine za kujiburudisha_____
- 10. Epukana na mawazo yanayohofisha_____
- 11. Jaribu kuwaza au kuona lililo nzuri unapozingirwa na mambaya_____
- 12. Epukana na yale yanayoweza kukuhuzunisha_____
- 13. Jaribu kuelewa musimamo wa mwenzako wakati wa ubishi mkali_____
- 14. Jaribu kutumia mbinu zingine kutafuta suluhisho la matatizo ikiwa ile iliyotumika awali haileti mafanikio_____
- 15. Jizuie kukasirishwa na mawzo yasiyopendeza_____

- 16. Fanya urafiki na watu wapya_____
- 17. Pata marafiki wakusaidie mahitaji yako_____
- 18. Fanya chochote halisi wakati kufa moyo_____
- 19. Ondoa mawazo potofu_____
- 20. Fikiria kila kipengee cha shida fulani kwa wakati wake_____
- 21. Waza au dhania jambo au mahali pazuri_____
- 22. Jiepushe kuhisi upweke_____
- 23. Omba Mungu au tafakari_____
- 24. Pata usaidizi wa kuinua hisia zako kutota kwa jamii yako au marafiki_____
- 25. Simama imara na upiganie jambo unalolitaka_____
- 26. Jizuie kufanya lolote kwa haraka wakati wa mkazo_____

KIKUYU VERSIONS CIURIA CIA GUTUIRIA KANA MURUARU NIARAHUTHIRA NDAWA NA KINYI

Namba ya muruaru..... Tariki..... Tariki

Ciuria iria irumiriire nicikonainie na uhoro uria uri karatathiini ga keeri.

Onania ati ndwanyuire ndawa ta uria wathiriirwo angikorwo no gacunji ga githimo wahuthirire muthenya umwe kana makiria ma muthenya umwe.

B. Thiini wa mithenya ina ni mithenya iigana utaahuthirire ndawa kuringana na ithimo iria wathiriirwo?

- Hatiri
- Muthenya umwe
- Mithenya iiri
- Mithenya itatu
- Mithenya ina

C. Ndawa nyingi cia mukingo ciagiriire kunyuagwo na mutaratara ta maita meeri kana matatu o muthenya, kana o thuutha wa mathaa manaana. Ukoreetwo ukirumirira mutaratara waku wa kunyua ndawa atia mithenya ina mihituku?

- Ndikoreetwo ngiurumirira
- Rimwe na rimwe
- Ta nuthu ya ihinda riria riathanirire
- Kaingi
- Ta uria njathiriirwo

D. Niwathiriirwo unyuanagirie ndawa ciaku na irio, kana utariite, kana na maai maingi?

- Ii
- Aaca

Angikorwo macookio maaku ni "Ii"-ri, thiini wa mithenya ina mihituku ni maita maigana ukoreetwo ugiika ta uria wathiriirwo?

- Ndikoreetwo ngirumirira
- Rimwe na rimwe
- Ta riita rimwe kana meeri
- Kaingi
- Ta uria njathiriirwo

E. Andu amwe nimariganagirwo nikunyua ndawa muthiaini wa wiki – Jumamothi na Mwambiririo. Niuragararire kunyua ndawa ciaku muthiaini wa wiki?

- Ii
- Aaca

F. Ni ri uterigiite kunyua ndawa ciaku?

- Kiumia kihituku
- Kiumia kimwe kana igiri hituku
- Ciumia igiri kana inya hituku
- Mweri umwe kana itatu mihituku
- Makiria ma mieri itatu mihituku
- Ngoreetwo nginyua o ta uria njathiriirwo

Ciuria iria irumiriire ciagiriire nigucookio **ni muruaru uria utakoreetwo akinyua ndawa ciake ta uria aathiriirwo**. Muruaru uria ukoreetwo akinyua ndawa ciake na mutaratara uria mwathirire ndaagiriirwo nigucookia ciuria ici.

Namba ya muruaru..... Tariki..... Tariki

G. Andu nimakoragwo na itumi mwanya mwanya iria maheanaga ciakuaga kunyua ndawa ciao ta uria maathiriirwo. Ni maita maigana wanaaga kunyua ndawa ciaku ni undu:

Ikira tiki haria haringaine na icookia riaku

	Ndiri ndaaga	Ti kaingi	Rimwe na rimwe	Kaingi
1. Ndwari mucii				
2.				
Warumbunyanagia				
na maund <u>u mang</u> i				
3. Wariganiirwo				
4. Wari na ndawa				
mithemba miingi				
wagiriirwo				
nikumeria				
5. Niwendaga				
gwithema mathiina				
maria meeragwo				
ati nimoimanaga				
na muthemba wa				

·····	T	T	T	······································
ndawa iria				
wathiriirwo unyue				
6. Ndwendaga				
andu aria angi				
moone ukihuthira			l	((
ndawa	·			
7. Niwagaruriire				
uria umenyereete				
guikaraga o				
muthenya				
8. Niwaiguaga ta				
ndawa				
ingiagwikire uuru		[
9. Niwacungire				
riria wanyuaga				
ndawa				
10. Niwaruarire				
11. Niwatangikire				
ngoro				
12. Niwagiire na				
thiina kunyua		1		
ndawa na				
mutaratara				
(hamwe na irio,				
utariite, kana na				
maai maingi)				
13. Ndawa ciaku		<u> </u>		<u> </u>
niciathirire				
14. Niwaiguire ta		<u>├</u> ── ~── <u>─</u> ─ <u>─</u> ─	├── ≁──────────────────────────────────	╞──────┤
uhoneete				
	L	L	L	L

Ni wega muno ni undu wa gucookia ciuria ici. Macookio maaku nimeguteithiriria kwagiria mutaratara wa kuhuthira ndawa uria aruaru a mukingo maagiriirwo nikurumirira.

INTERPERSONAL SUPPORT EVALUATION LIST (ISEL)

GITHIMI GIA GUTUIRIA UTEITHIO URIA MURUARU ARAHEEO NI ANDU MWANYA MWANYA

Githimi giiki kiri na maundu mwanya mwanya maronania uria wee utarii kana utatarii. Ikira tiki undu uria wonaniriirio "ni uhoro wa ma," angikorwo niuringaine na uria uratarii; na "no gukorwo ni ma," undu uria uui ni wa ma no ndungiuga uguo ugwatiirie. Ika o ta guo na njira ya gwikira tiki undu uria wonaniriirio "ni maheeni," angikorwo niuui na ma ni wa maheeni, na "no gukorwo ni maheeni," angikorwo niuui ni wa maheeni no ndungiuga uguo ugwatiirie.

1. He na andu ndihokeete mandeithie mathiinaini maria ndi na mo.

ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

2. Ingikorwo ngihaariria kindu kana ngithondeka ngaari, kana muithikiri, ndingiaga mundu ungindeithia.

ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

3. Aingi a araata aakwa nimakenagirirwo uria matarii gukira uria nii mwene ngenagirirwo uria ndarii

____ ni uhoro wa ma (3) ____ ni maheeni (0) ___ no gukorwo ni ma (2) ____ no gukorwo ni maheeni (1)

4. Ni hari mundu ukenagio ni uhootani wa maundu maria ngoretwo ngirua kana ngigeria gukinyira utuuro-ini wakwa ni uhoro wa ma (3) ni maheeni (0)

$\underline{\qquad}$ ni unoro wa ma (3)	$_$ ni maneeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

5. Ni hari andu ingiaria nao ingiigua bata wa kwaria na mundu

1 1 (0)	
ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	no gukorwo ni mahaani (1)
IIO gukotwo III IIIa (2)	no gukorwo ni maheeni (1)

6. Hatiri mundu ingiteereta naake mathiina maakwa mathinii kana makwa kiumbe.

ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

7. Kaingi ninjemanagia kana ngaaria na andu a mucii kana araata.
 _____ni uhoro wa ma (3) _____ni maheeni (0)

__ no gukorwo ni ma (2) __ no gukorwo ni maheeni (1)

8. Andu aingi aria njuui nimeinjiragia wega

ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

9. Nothike muno ingikoona mundu wa kuundwara handu njititwo cai kana or undu ta ucio

ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

10. Ninyonaga kaingi ta araata aakwa matendaga menye maundu maingi ma thinii ma gakundi gaitu ni uboro wa ma (3)

$__$ m unoro wa ma (3)	ni maneeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

11. Hatiri o na u unginjiira uria ndiragiana na mathiina maakwa atekuongerera cumbi

ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

12. Nihari andu mwanya mwanya aria ngenaga gukorwo hamwe nao

ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

13. Nyonaga ta araata aakwa meciiragia ta itangihoota kumateithia ta uria kwagiriire mathiinaini maao

ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

- 14. Ingikorwo ndi muruaru ri, no thiinike ingikoona mundu ta muraata, mundu wa mucii,kana mundu tuyaine ungindwara kuri ndagitaari kana thibitari
 _____ ni uhoro wa ma (3)
 _____ ni maheeni (0)
 - ____ no gukorwo ni ma (2) ____ no gukorwo ni maheeni (1)
- 15. No thiinike ingikoona mundu wa guthii hamwe nanii riria ingienda nguceera handu kana guceerera andu

ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

16. No nyone mundu unginyiita ugeni kwa ihinda na njira huthu ingikorwo ndina ugwati ta a kuhirirwo ni nyumba

ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

17. Hatiri mundu ingiteereta naake maundu maria marandanga na maranguoyohia

____ ni uhoro wa ma (3) ____ ni maheeni (0)

no gukorwo ni ma (2)	no gukorwo ni maheeni ((1))
			,

18. No nyone o narua mundu wa kundeithia maundu mucii ingiruara.

ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

19. He mundu ungindaara mathiinaini maria ingikorwo namo na andu a mucii wakwa.

ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

20. No hoote gwika wega maundu o ta andu aria angi.

ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

21. No nyone mundu wa gutwarana na nii ingitua ati nindirenda guthii kuona thenema hwaiini kana mung'etho.

ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

22. Ninjuui mundu ungindaara ingikorwo ndi na thiina wakwa kiumbe.

ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

23. He mundu ta muraata, mundu wa mucii, mundu tuyaine, ungingombera ciringi ta ngiri imwe ingibatario ni mbeeca hi na hi.

ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

24. Andu aingi ni aria matainjihokeete.

ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

25. Ninjuui andu aingi matikenagio ni maundu maria menyereete gwika.

······	
ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

26. No nyone mundu ungindaara ingibatario niguthuura kana gucenjia wira.

ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

- 27. Ti kaingi njitagwo ngeeke maundu hamwe na andu aria angi.
 - ____ ni uhoro wa ma (3) ____ ni maheeni (0)
 - ____ no gukorwo ni ma (2) ____ no gukorwo ni maheeni (1)

28. Araata aakwa aingi nimooi kugarurira maundu utuuro-ini wao kungira.

ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

29. No ngorwo na thiina kuona mundu unginjikariria mucii ingikorwo nindirathii iceera kwa ihinda.

____ ni uhoro wa ma (3) ____ ni maheeni (0) ____ no gukorwo ni ma (2) ____ no gukorwo ni maheeni (1)

30. Hatiri mundu ungindaara maunduini makonii muhuthirire kana wethi mwega wa mbeeca.

ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

31. No nyone o narua mundu ungienda kurianira na nii irio cia miaraho.

ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

32. Ninjiganiire na utuuro wakwa makiria ma andu aria angi.

ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	_ no gukorwo ni maheeni (1)

33. No nyone wa gukaira ingikorwo nemereirwo gukuhi na mucii.

ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

34. Gutiri o na umwe wa andu aria njuui ungihaaririria thiguku ya gukunguira muthenya uria ndaciarirwo.

ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

35. No ngorwo na thiina kuona mundu ungingwatia ngaari kana muithikiri wake kwa ihinda.

ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

36. No ngorwo na thiina kuona mundu ungihe mataaro meega kungigia na thiina mucii.

ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

37. Ningwatanagira wega na araata aakwa gukira andu aria angi.

ni uhoro	wa ma (3)	ni maheeni (0)

___ no gukorwo ni ma (2) ___ no gukorwo ni maheeni (1)

38. He mundu njuui ndihokeete mataaro maake muno.

ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

39. No nyone thiina ngikoona mundu wa kundeithia angikorwo niguthaama ndirathaama.

ni uhoro wa ma (3)	ni maheeni (0)
no gukorwo ni ma (2)	no gukorwo ni maheeni (1)

- 40. Nihuumagio ni araata aakwa riria tureeka maundu twi hamwe.
 - ____ ni uhoro wa ma (3) ____ ni maheeni (0)
 - ____ no gukorwo ni ma (2) ____ no gukorwo ni maheeni (1)

Coping Self-Efficacy Scale

Riria maundu maku matarathii wega kana riria uri na mathina ri, uri na umiriru kana uuma ati no uhote gwika maundu maya?

			8		
1					1

Thiinii wa undu uria uguthoma haha muhuroini ri, andika namba imwe kuma kibugu kinya ikumi na mutaratara ta uyu: Angikowro ndungihota undu ucio-ri, andika namba imwe kuma kibugu kinya ithatu (0-3); Angikorwo no uhote gwika undu ucio gicuji kiigana una ri, andika namba inya kinya ithathatu (4-6); Angikorwo uri na umiriru na uuma hatati nganja no uhote gwika undu ucio ri, andika mugwanja kinya ikumi (7-10).

Hindi iria maundu matrathii wega ri, uri na umiriru ati niukuhota gwika maudu ta maya:

- 1. Gwithema maundu maria matumaga mundu aigue ari na ihooru kana kieha
- 2. Guitikia na kinyi ati maundu maku timoru uguo maroneka mahuana
- 3. Guthurania na kumenya maundu maria mundu angihota guthondeka na maria mundu atangihota ori ori
- 4. Gwetha uteithio uria uhoragiria ngoro kuma kuri arata na andu a mucii
- 5. Gwetha kihonia kia mathiina maria maritu muno muno
- 6. Kugayukania undu munene uria ugiaga mundu thiinii wa tucunji kana tukundi tunini tunini
- 7. Gutigia mweke wa guika kana kurora maundu na njira ingi maundu marituha muno
- 8. Banga mutaratara wa uria ubatii gwika na urumirire mubango ucio riria thina ukuhithukiire
- 9. Ambiria gukuria maundu mageni ma kuhurukia meciria
- 10. Eheria matarania moru kuma meciria-ini maku
- 11. Rora undu mwega thiinii wa undu uria uria muuru
- 12. Witheme kuigua ihooru
- 13. Kuona maundu uria mundu kana andu aria angi monaga undu muna riria kuri na ngarari hiu kana ngucanio
- 14. Geria kihonia gia thiina kingi angikorwo kihonia kiambere gitirahingia itaanya
- 15. Witheme marakara maria maumanaga hari maudu maria matakenagia meciria
- 16. Thondeke urata na andu angi
- 17. Ira arata aku maguteithie na indo iria ungikorwo ubatarite
- 18. Gwika undu wa gukuongera hinya riria ungiigua ugiite hinya ngoro-ini yaku
- 19. Eheria meciria matari mega
- 20. Thugunda undu kana gicunji kia undu umwe thinii wa ihinda rimwe
- 21. Ona na meciria maku undu ungigukenia kana wone handu hega
- 22. Gwithema kuigua wimutiganirie
- 23. Hoya Ngai kana uthungunde iguru ria Ngai
- 24. Etha uteithio uria umagiria mundu kuma kuri andu aria mugwatanagira nao
- 25. Wirugumie na kinyi iguru ria uria urenda na kuruirira undu kana maundu ta macio
- 26. Gwithema gwika maundu hinahi riria uhatikitwo na hinya ni maundu maingi

Appendix C: Nazareth Hospital Acceptance Letter



P.O. BOX 49682-00100 NAIROBI, KENYA EAST AFRICA

NAZARETH HOSPITAL

TEL: 254 - 020 - 6750945 254 - 020 - 2017401 FAX: 254 - 020 - 2017402 Email nazcom@wananchi.com "Witnessing Christ through a heating Ministry, offering holistic care".

24th March 2009

Father Thomas M. Kamau Holy Rosary Church Hawthrone, NY 10532 U.S.A

Dear Father,

RE: RESEARCH - ACCEPTANCE.

We acknowledge receipt of your letter dated March 5th 2009 on the above referenced issue. The Hospital Management has considered your request and you have been allowed to carry on with your research.

You will be required to have a letter of approval from the Ministry of Health and Ethics Research Committee from a recognized university, also a letter from Seton Hall University for our documentation. There is also Research fee of Ksh. 5,000/- payable to the hospital.

Wishing you the best as you prepare to start you research.

Yours faithfully,

Dr. Janies Nyabanda MEDICAL OFFICER INCHARGE.

Naxansth Hospital 90. C. 33ca 59682. Naischi - Konya.

Appendix D: Moi University's Institutional Research and Ethics Committee Approval



INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE (IREC)

MOI TEACHING AND REFERRAL HOSPITAL P.O. BOX 3 ELDORET Tel: 33471*82/*3 REC) MOI UNIVERSITY SCHOOL OF MEDICINE P.O. BOX 4606 ELDORET Tel: 33471/2/3

25th August, 2009

Reference: IREC/2009/101 Approval Number: 000424

Rev. Thomas Matenjwa Kamau, 170 Bradhurst Avenue, Hawthorne, NEW YORK 10532.

Dear Rev. Kamau,

RE: FORMAL APPROVAL

The Institutional Research and Ethics Committee have reviewed your research proposal titled:

"Psychosocial Correlates of Adherence to Antiretroviral Therapy in People Living with HIV in Kenya".

Your proposal has been granted a Formal Approval Number: FAN: IREC 000424 on 25th August, 2009. You are therefore permitted to continue with your study.

Note that this approval is for 1 year; it will thus expire on 24th August, 2010. If it is necessary to continue with this research beyond the expiry date, a request for continuation should be made in writing to IREC Secretariat two months prior to expiry date.

You are required to submit progress report(s) regularly as dictated by your proposal. Furthermore, you must notify the Committee of any proposal change (s) or amendment (s), serious or unexpected outcomes related to the conduct of the study, or study termination for any reason. The Committee expects to receive a final report at the end of the study.

Yours Sincerely,

Dean

PROF D. NGARE CHARMAN INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE cc: Director - MTRH Dean - SOM Dean - SPH

SOD



Appendix E: Seton Hall University Institutional Review Board Approval



October 8, 2009

Rev. Fr. Thomas Kamau 170 Bradhurst Avenue Hawthome, NY 10532

Dear Rev. Kamau,

The Seton Hall University Institutional Review Board has reviewed and approved as submitted under expedited review your research proposal entitled "Psychological Correlates of Adherence to Antretroviral Therapy (ART) in People Living with HIV in Kenya". The IRB reserves the right to recall the proposal at any time for full review.

Enclosed for your records are the signed Request for Approval form, the stamped Recruitment Flyers, and the stamped original Consent Forms. Make copies only of these stamped forms.

The Institutional Review Board approval of your research is valid until August 24, 2010. During this time, any changes to the research protocol must be reviewed and approved by the IRB prior to their implementation.

According to federal regulations, continuing review of already approved research is mandated to take place at least 12 months after this initial approval. You will receive communication from the IRB Office for this several months before the anniversary date of your initial approval.

Thank you for you cooperation.

In harmony with federal regulations, none of the investigators or research staff involved in the study took part in the final decision.

Sincerely,

very J. Rugels, M.D.

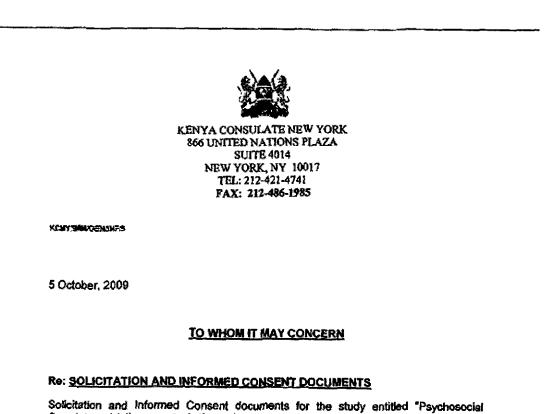
Mary F. Ruzicka, Ph.D. Professor Director, Institutional Review Board

cc: Dr. Valerie Olsen

Presidenti Hall + 400 South Orange Avenue + South Orange, New Jeney 07079-2641 + Tel: 973.313.6314 + Fax: 973.275.2361

A HOME POR THE MIND, THE HEART AND THE SPIRIT

Appendix F: Flyer and Recruitment Form



Correlates of Adherence to Antiretroviral Therapy (ART)" refers.

We have read the original English versions of the solicitation and informed consent documents and compared them to their Kiswahili and Kikuyu versions. We hereby certify that the Kiswahili and Kikuyu versions are accurate and complete translations of the original English language text.

Thank you.

allminero Charles Muendo

CONSUL

ł

VOLUNTEERS on HIV Treatment

are needed for a study examining factors influencing one's ability to take HIV medication as needed

- The research will examine the social support and life challenges that influence how an individual takes the medications required on HIV treatment.
- ✓ The study will require a 45 minute session where the volunteer will complete surveys that ask questions about social support, life challenges, and the ability to take prescribed medications.
- ✓ The session is held in a private room and will be confidential.
- ✓ Participation in the study is voluntary.

If you are interested and would like to help, please pick-up a recruitment form beneath this flyer and write your contact information.

When you have finished, please put the form in the Research Study Drop-box. You can ask for assistance from the clinic staff of Comprehensive Treatment and Care Center of Nazareth Hospita.

If you have questions, please contact me:

Thomas Kamau

Seton Hall University Institutional Review Board

Doctoral Candidate, Seton Hall University, USA

Telephone Number: 0720-224496

01

~

\$

OCT 08 2009 Approval Date WIRUTIRI thiinii wa kurora uria uteithio wa mucii na mathina mangi mangiteithia kana maremithie andu aria marahuthira ndawa cia murimu wa mukingo.

- Utuiria uyu ukurora uria uteithio wa andu ta a mucii na arata uteithagiriria kunyua dawa cia mukingo uria ta uria mundu akoragwo athiriirwo ni ndagitari wake.
- Ukurio wirutire ta ndagika mirongo ina na ithano gucokia ciuria ikonii uteithio wa andu a mucii na arata ona kana kuuma ikundi mwanya mwanya.
- Ugacokia ciuria uri thiinii wa nyumba njega ina hitho.
- Kunyitanira thiinii wa utuitia uyu ni wa wirutiri,

Angikorwo in ukwenda kunyitanira thiinii wa utitia uyu ri, oya bomu imwe iria iri haha muhuro, umiyurie, na umitige thiinii wa ithanduku riria ukuonio haria. Ukungikorwo uri na kiuri uria umwe wa aria maraguthondeka guku thibitari ya Nazareth.

Ungikorwo na kiuria ri, ni ukurio na gitio uhurire thimu:

Thomas Kamau Murutwo wa Yunibaciti Seton Hail, USA.

Namba ya thimu ni: 0720-224496

Seton Hall University Institutional Review Board 3CT 08 2009

Expiration Date AUG 24 2010

Approval Date

MNAOMBWA Kujitolea Katika Utafiti wa Utumianji wa dawa za

Ukimwi . Utafiti huu unatufuta kujua jinsi usaldizi wa kijamii na vikwazo vingine zaweza kudhili utumianiji wa dawa za ukimwi vilivyo.

- Lengo la utafiti huu ni kungalia kwa makini uhusiano wa usaidizi wa kijamii and vikwazo ambazo zaweza kuelezeza utumiaji wa dawa za ukimwi.
- ✓ Utafiti huu utatumia kama dakika arobaini na tano kusoma na kujibu maswahili katika dodoso nne.
- Mahojiano hayo yakuwa katika chumba au vyumba ambavyo vimetayarishwa vilivyo kuhakisha siri yako.
- Kushiriki katika utafiti huu ni huru

Ikiwa ungetaka kushiriki na kusaidia, tafadhali chukua fomu hapa chini ya tangazo hii au ulize usaidizi kwa wale wanakutumikia hapa, ili uljaze vilivyo.

Utakapomaliza, tafadhali weka fomu hiyo kwenye kisanduku maluum hapa chumbani au umpatie wenye kufanya kazi hapa. Wakuguzi wa Hospitali ya Nazareth watakusaidia iwapo utapata shinda yeyote au una Swahili kuhusu utafiti huu

iwaop una maswali mengine, tafadhali waweza kunipigia simu:

Thomas Kamau

Mwanafunzi wa masomo ya juu, Seton Hall University, USA

Nambari ya Simu: 0720-224496

Seton Hall University Institutional Review Board

OCT 08 2909

Expiration Date AUG 24 2019

Approval Date

174

Appendix G: Informed Consent Form



Consent Form

introduction

The Principal Investigator, Thomas M Kamau, is a doctoral Candidate in Health Sciences, Department of Graduate Programs in Health Sciences at Seton Hall University, South Orange, New Jersey, USA. His research seeks to explore and explain the "psychosocial correlates of adherence to antiretroviral therapy in people living with HIV/AIDS in Kenya". The purpose of this study is to learn about a person's potential influences to take medication of treatment of HIV as instructed. The survey will take you about 45 minutes to complete.

If you agree to participate in this study, you be will asked to complete each of the survey questionnaires on your. If you have any question, please feel free to ask any of the Research Assistants or the Principal Investigator. Please answer all questions honestly; you will not be "judged" based on your responses as there is no "right or wrong answer".

The purpose of this form is to obtain your written consent to participate in this study.

Procedures

You will be asked to complete four survey questionnaires; (1) Demographic Questionnaire, which will ask you about your personal characteristics for example, your age bracket, gender, level education, employment status and so on. (2) In the Adherence to medication questionnaire (5) items, you be will asked, for example, "How many days have you missed taking all your doses?" (3) Interpersonal Support Evaluation List. You will be asked to indicate to each item, for example, "There are several people that I trust to help solve my problems" if it is "definitely true" 3, "probably true" 2, "probably false", 1, or "definitely false" 0. (4) Coping Self-Efficacy: On a scale of 0-10, your will be asked how confident or certain you are that you can do certain things, for example "Talk positively to yourself", "develop new hobbies or recreations".

Voluntary nature and right to withdraw

Your participation is voluntary. If you do choose to participate, but prefer not to answer certain questions, or withdraw from the study, you are free to do so at any time and for any reason.

There is not penalty if you decline to participate, withdraw, or refuse to answer any question.

Confidentiality and Anonymity

The informed consent forms will be kept separately and confidentially. Other data collected information collected in this study will be confidential and will be kept anonymous. All responses will be stored in a USB memory key and kept in a locked secure site for at least three years. Only the Principal Investigator will have access to it.

> School of Health and Medical Sciences Department of Graduate Programs in Health Sciences Tel: 973.275.2076 + Pax: 973.275.2171 400 South Orange Avenue + South Orange, New Foraet 07079 + shint shu.edu

To ensure your anonymity, no personal identifiers will be recorded on any of the questionnaires on which your responses will appear. Your name, birth-date, national identification card or number, address, telephone, email address or any other identifying information, will not appear anywhere on your response sheet record. Instead you will be assigned a code for the purposes of analyzing data. You will not be identified in any description or publication of this research.

Risks

This study has minimal risk. The foreseeable risk or discomforts include being questioned on your perception about others' supportiveness or your behavior to adhere to HIV medication, which you may feel are private to you.

There are no costs to you or your party. You will receive \$7.00 to cover your transportation cost whether you do complete or do not complete answering the questions.

Benefits

There is no direct benefit to you from this study. Nevertheless, the results from this study may help in understanding what works and what does not in the adherence to medication for HIV. Furthermore, the results are likely to enhance approaches in the planning and designing programs to enhance adherence to treatment in people living with HIV.

You will be given a copy of the signed and dated informed Consent Form. Your consent to participate is indicated by completing the questionnaires and or when you return your responses to the researcher. Please be assured that this form will not be linked to your answers.

If you have questions during the course of the study, you may contact the following:

Thomas M Kamau, Investigator, Telephone Nazareth Hospital Tel...254-020-6750945 Institutional Research and Ethics Review (IREC), Moi University Tel.33471/2/3 Department of Graduate Programs in Health Sciences, Tel.1-973-275-2076 Institutional Review Board (IRB), Seton Half University Tel. 1-973-313-6314

I have read or had read to me the information sheet for the study. I understand that if I decide to be involved in the study I will complete four survey tools or be interviewed by the investigator or by a research assistant for about forty five minutes.

I understand that I am free to withdraw from the study at any time. I am also aware of the fact that if I decide not to participate in the study this will not affect my normal health care and rights in any way.

Any questions or concerns about the study will be answered.

I have read this information and agree to take part in this study

Signature.....
Date
Principal Investigator /Research Assistant
Name
Signature
Date

SETON HALL UNIVERSITY.

Fomu va uthibitisho (Kiswahili Consent Form)

Utangulizi

Thomas M Kamau, mwenye utafiti huu, ni mwanachuo katika idara ya afya na utibabu, chuo kikuu cha Seton Hall, New Jersey. Anatafiti kuhusu "mambo ya kijamii na kimawazo yanayoyathiri uzingatiaji wa tiba kwa Wakenya wanaoshi na virusi vya ukimwi". Unaombwa kushiriki katika mahojiano ambayo yatachukua takribani dakika arobaini na tano.

Endapo utakubali kushiniki katika utafiti huu, utamua jinsi ya kujibu maswahili kakika dodoso ya utafiti huu. Utakuwa na fursa ya kufanya uamuzi iwapo utandika majibu yako kwenye karatasi,au nitakuhonji na kunakili majibu yako kwenye karatasi ya maswali.

Sababu ya fomu hii ni kuonyesha hiari yako ya kushiriki katika utafiti huu. Hakuna majibu yalio sahihi(mazuri) na yasiokuwa sahihi(mabaya). Kinachohilajiwa ni ukweli wa vile mambo yanavyotendeka kwako au unavyoyaona.

Mpangilio

Ninakuomba kujibu maswali katika dododoso nne; (1) Demografia (mambo yayokuhusu). Kwa mfano, yaweza kuwa "kama umeoa au kuohwewa" "kiwango cha masomo" na megineyo. (2) Uzingatiaji wa tiba la ukimwi- mfano wa maswali ni kama "ni mara ngapi umekuwa ukifuata maagizo ya utumiaji wa dawa katika kipindi kisichozidi siku nne zilizopita?". (3) Dododoso la uzaidizi wa kijamii lautiza maswali kuhusu maoni yako kuhusu vite unavyohisia juu usaidizi wa kijamii ijapo utakuwa na haja. Kwa mfano, Kama unaamini kuna watu kadha ambao unawaamini kuwa wanaweza kukusaidia katika kutatua shida zako" jibu laweza kuwa "*ni kweli kabisa" (3) , ni kweli kwa kiasi Fulani*"(2, "si *kweli kwa kiasi futani " au "sikweli kabisa" (0).* (4) Dodoso la nne la chunguza imani yako juu ya uwezo wako wa kukabiana na shinda za zote ambazo waweza kupata. Kwa mfano nitakuliza, "Wakati mambo hayaendi vizuri, ama wakati una shinda unauhakika gani unaweza " "kujipa moyo" au "kujizula kua na huzuni"

Haki ya kukataa au kusitisha

Kushiriki kwako katika utafiti huu ni kwa hiari, hwapo utaamua kushiriki, lakini upendelee kulojibu maswali mengine, uko huru kufanya hivyo.Pia uko huru kusitisha mahojiano wakati wowole. Hakuna adhabu kwa kutoshiriki au kujitoa katika utafiti. Basi, unaweza kukataa kujibu swali lolole au kujitoa kabisa katika utafiti huu wakati wowote na kwa sababu yoyole.

KUJITAMBULISHA NA KUHIFADHI SIRI

Majibu yote yatawekwa sehemu iliyofungiwa chini ya mwongozo wa ulafiti huu ...Jina lako,au habari zingine za utambulisho, nambari yako ya simu, anwani au anwani ya barua pepe hazitaonekana mahala popote kwa nakela ya mahojiano au majibu yako. Dala zitakazopatikana katika utafiti huu, zitakuwa ni siri. Ishara Fulani zitatumia ili, wewe kama mhusika, majibu yako yausiweze kufahamika na yeyote iwe kwa maelezo au machapisho ya baadaye.

> School of Health and Medical Sciences Department of Graduate Programs in Health Sciences Tel: 975.275 2076 + Fax: 973.275.2171 400 South Orange Avenue + South Orange, New Jerney 07079 + Jans.shu.adu

MADHARA

Madhara kwako kama mshiriki kwa utafiti huu ni machache.Utautizwa kuhusu ufahamu na mienendo yako kuhusu uzingatiaji wa tiba ya virusi vya ukimwhi na maoini yako kuhusu uzaidizi wa kijamit. Ijapokuwa,tunatumaini kuwa utakuwa radhi kuongelea kuhusu ukifahamu habari yoyote utayotoa ni ya siri. Hakuna malipo yoyote utakayotakiwa kutoa.Utapata shilingi mia tano (dollar \$7, Ksh. 500) kwa anjili ya gharama ya nauti ya matatu.

Falda ya utafiti

Ingawapo hakuna moja kwa moja faida kwa kushiriki katika utafit huu, matokeo ya utafiti huu ni rahisi uwa na faida kubwa kwa watu waishio na Virusi via ukimwi ambao wanazitumia au wataopata tiba la ukimwi. Maoini utakayotoa ya uwezo wa kusaidia katika mipango ya baadaye.

Uko huru kuuliza maswali yoyole kabla ya kuweka sahihi kwenye fomu ambayo nakupatia.I wapo una maswali pindi utafiti utakuwa ukiendelea, unaweza kuwasikana na watuatao:

lwapo ulakubali kushiriki taladhali weka sahihi kwenye formu mbili za uthibitisho kisha mimi nitaweka sahihi. Taladhali hiladhi moja yapo ya fornu hii na kisha kulregesha ingineyo ya fornu.

Unahakikishwa kuwa fomu hii haitakuwa pamajo na karatasi yenye majibu yaliomo kwa dodoso, hivyo hakuna anayweza kutambua majibu yako.Data itawekwa miaka mitalu.

Thomas M Kamau, Investigator, Telephone Nazareth Hospital Tel...254-020-6750945 Institutional Research and Ethics Review (IREC), Moi University Tel.33471/2/3 Department of Graduate Programs in Health Sciences, Tel.1-973-275-2076 Institutional Review Board (IRB), Seton Hall University Tel. 1-973-313-6314

Nimesoma au nimesomewa karatasi ya habari kuhusu utafiti.Naelewa kuwa lwapo nilaamua kushidikishwa katika utafiti huu, nitajibu maswahili yenye katika dodoso nne abazo zatumika kwenye utafiti huu. Naelewa kuwa niko huru kusitisha mahojiano ya utafiti wakati wowote.Naelewa pia kuwa iwapo nitaamua kutoshiriki katika utafiti huu, haita athiri huduma za afya yangu kwa njia yeyote.

Ukiwa na swali lotelote, tafadhali uliza mtafiti mkuu au mmoja wa wafiti wasaidizi. Maswali yoyote kuhusu utafiti huu yatajibiwa wakati wowote na wasimamizi wa utafiti huu.

Nakubali kushiriki katika ulafiti huu

Sahihi.....

Tarehe......

Mtafiti Mkuu au Mtafiti Mzaidizi,

Sahihi,	

Tarehe.....

Appendix H: Training Protocol for Research Assistants

Training Protocol for the Research Assistants Study Title: "Psychosocial correlates of Adherence to Antiretroviral Therapy in People Living with HIV in Kenya"

October 2009

Introduction:

Principal Investigator, contacts, the study, the study venue, and other housekeeping issues

Roles and responsibilities

- Recruitment of research participants: Select and schedule participants who meet the inclusion criteria for the signing of the informed consent and the administration of the survey tools
- b. Preparation of the venue (rooms) in the sites for the research and ensure adequate stationeries for the research.
 Ensure rooms provide a private environment where respondents can feel free to respond to the questionnaires
- c. Issue and sign the informed consent forms
- d. Facilitate the administration of the survey tools
- e. Respond to questions, address issues of concern and consult the investigator for issues
- f. Collect completed and or uncompleted questionnaires and submit them to the principals investigator

The purpose of the research

The objective of this study is to explore if there is a relationship between an individual's perception of social support, coping self-efficacy, and the ability to adhere to ART in people living with HIV in Kenya.

Significance

The proposed research has the potential of progressing knowledge of, and the ability of

advancing treatment adherence in people living with HIV. The findings are expected to

have significant clinical benefits for people living with HIV, for_ those providing care and

treatment, and for the public health at large. Clearly, adherence to ART carries clinical

benefits on individuals living with HIV evident in their improved health, reduced

opportunistic infections, and reduced mortality. Healthcare providers too stand to gain.

They may use the___ findings to design or strengthen approaches for maintaining high

treatment adherence in people living with HIV.

Participant's Bill of Rights

- (a) Brief review of the ethical principles
- (b) Participants' right to know:
 - (i) Purpose of the study,
 - (ii) Procedures involved in the investigation,
 - (iii) Benefits of participating in the study
 - (iv) How their privacy will be preserved, (confidentiality and anonymity),
 - (v) Their right to withdraw from the study,
 - (vi) Investigator's right to remove individuals from the study, etc.

Procedures of respondents' identification

Respondent will self-identify themselves through their staff at the center. To ensure that subjects will feel free to decline to participate or not in the study the following procedures will be observed. Display flyers and recruitment forms in each of the nine HIV Comprehensive Care and Treatment Centers, where people living with HIV seek services. (Give them flyers to read). The flyer states why the study is being conducted, why a participant is being recruited, procedures involved, and eligibility (inclusion) criteria and exclusion criteria. The flyer indicates that participation in the study is voluntary, that informed consent will be needed before administration of the survey tools, that eligible participant have the right to decline to participate in the study without penalties. Interested participants will be requested to either complete recruitment forms placed in an eye-catching site in the centre or if not literate request the staff at the clinic to do so on his/her behalf. Please see a sample of the recruitment forms. These recruitment forms will be used to obtain contact information such as names addresses and telephone contacts. All completed forms will be dropped at the drop-box located at the designated location in each of the centers. The staff at the clinic will hand-over these contacts to the Principal Investigator.

Inclusion and exclusion criteria

An equitable number of men and women living with HIV who are:

- Between 18 years and 65 years old. Eighteen years is the legal age at which a person in Kenya can give informed consent.
- (2) Able to communicate in Kiswahili, Kikuyu, or English as determined by selfreport.
- (3) Able to read and write either English Kiswahili, or Kikuyu.
- (4) Prescribed to antiretroviral therapy.
- (5) Seeking treatment and care at any of the nine Nazareth Hospital's

Comprehensive Care and Treatment Centers located in the Metropolitan Province of Nairobi and the Central province of Kenya. There are nine sites.

How to recruit participants by phone

Potential participant's contact information to schedule a volunteer for a session which will

require them to sign the informed consent and complete the administration of the survey

tools. The following is the recommended telephone script. Exercise: (Role play)

Good morning/afternoon/or evening! May I speak to......I am.....I have called because you provided your contact information to be contacted about Thomas Kamau's study. This research is to determine what helps an individual living with HIV to adhere to HIV treatment (medication). Remember the research information you will provide will remain anonymous and confidential. You are at liberty to accept or decline to take part in the study. Your decision will not affect in any way the treatment and care being provided to you. If you agree to be in the study, you are asked to choose time and date convenient to you to read and sign your informed consent and to complete the survey tools. The following time slots are still open: Dates......Days......Time...... It will take you about forty-five minutes to complete survey tools. Do you have any question or need clarification about this study? Thank you so much

Or Kiswahili

Habari ya asubuhi, mchana, au jioni! Mimi ni.....Nimekupigia simu hii kwa sababu ulikubali kushiriki katika utafiti unaongozwa na mtafiti Thomas Kamau. Lengo la utafiti huu nikutafuta mambo yanayoweza kumsaidia wagonjwa wanaotumia dawa za uikimwhi kuzitumia kulingana na maagizo ya daktari.Yote utakatotoa katika utafiti huu yakuwa siri. Uko huru kukubali au kukataa kushiriki. Hatua yako haitakuwa na uhusiano na matibabu unayopata kwa sasa. Ikiwa umekubali kushiriki katika utafiti huu, ninakuomba uniambie siku na saa inayokufaa ili uweze kuhonjiwa.

Kwa sasa chagua: Tarehe.....Siku.....Saa...... Maswali yote yatatumia kama dakika arobaini na tano. Je, Uko na swali lolote kuhusu utafiti huu? Ahsante sana.

Or kikuyu

Urimwega kiroko, muthenya, kana hwaini! Nii njitagwo......Ndakuhurira thimu ino tondu niwonanirie ati no wende kunyitanira thiinii wa utuiria uria uratongorio ni Thomas Kamau. Mwerekera wa utuiria uyu ni kwenda kumenya undu uria uteithagia arwaru kuhuthira ndawa cia murimi wa ukimwi. Ririkana ati maria mother ukauga magakorow mari ma thiri. Itua riaku kunyitnira thinii wa undu uyu ritingihota guthukia utungati uria uheagwo ni thibitari. Angikorwo niwetikira kunyitanira thiinii wa undu uyu ri, ni ukurio unjire muthenya na mathaa maria ukoneka. Uguthura muthenya na mathaa mariku:

Mweri......Muthenya.....Mathaa. Hihi uri na kiuria oro giothe iguru nia utuiria uyu? Niwega muno.

Procedures of issuing and signing of informed consent

Introduction: Welcome the participant and introduce yourself upon showing up for informed consent and completing the survey tools. Briefly explain the purpose of the study. Tell the respondent that the administration of the four survey tools will take about forty-five minutes and that before the administration of the survey tools they will need to read carefully the informed consent document and if interested to take part in the study to sign two forms.

Presentation of the informed consent forms to participants

An informed consent will be sought from every respondent. Informed Consent. Participants will be explained their right to decline to participate in the study. They also will be informed of the right not to answer any question, to withdraw from the study or to seek clarification at any time during the administration of the survey. The informed consent will be issued to each respondent and read out.

Components of an informed consent (go through the informed consent document)

Brief explanation of the voluntary nature of the study, anonymity, confidentiality, risks, benefits and participants right to decline to answers any question at anytime for any reason or to withdraw from the study without any penalty. No personal identifiers such as names, birth-date, addresses, and email or telephone numbers will be attached to participants' responses on the questionnaire. If a respondent agrees to participate in the study, he or she will be asked to sign an informed consent.

Note that a participants signing of the consent form can't deprive of his or her right to withdraw from the research.

If a participant chooses to take part in the study, ask them to sign the forms and retain of the copies.

<u>Procedures of administration of the survey tools</u> Introduction

Respondent should be encouraged to answer all questions honestly. Emphasize to them that no one will be "judged" based on his/her responses as there is no "right or wrong answer". Explain to the respondents about the purpose, procedures, and duration of the study. Tell them why they are being recruited, procedures involved in the study, discomforts that they might face and their right not to answer any question for any reason or to withdraw from the study at any time during the study. Assure them that strict confidentiality will be maintained.

DEMOGRAPHIC SURVEY: This is a brief questionnaire that is aimed to record participant personal information that will be aggregated or summed to draw some conclusions about the sample. Note carefully that the survey does not ask for any personal identifiers such as names, identification numbers of cards but general information. Such information as you can (see the sample forms) include age bracket, gender, marital status, level of education, employment status etc.

INTERPERSONAL SUPPORT EVALUATION LIST (ISEL): The Interpersonal Support Evaluation (ISEL) was designed to provide a measure of perception of social support. This is a forty item survey tools. Please see the copies of this survey questionnaire in English, Kiswahili, and Kikuyu languages. ISEL is a measure of respondents' perception of availability of social support if needed. It consists of 40 items classified under four dimensions that measure emotional, informational, material support and belongingness. Each of these four dimensions of perceived social support consists of a list of 10 statements. The items are Likert-type statements. Participants are asked to indicate their level agreement to each statement. A respondent either states that the statement is "definitely true" 3, "probably true" 2, "probably false", 1, or "definitely false".

<u>COPING SELF-EFFICACY (CSE)</u> - is a 26-item questionnaire that measures belief in one's ability to cope with stressors (negative life events). The CSE is a 26item measure that measures an individual's belief that he or she can perform behaviors important to adaptive coping by sorting out what is controllable and what is uncontrollable. On a scale of 0-10, participants are asked to indicate how confident they are that they can do certain things when things are not going on well. For example, "when things are not going on well with you, how confident are you that you can talk positively to yourself" or "sort out what can be changed and what cannot be changed" or "get emotional support from friends and family. The scale ranges from 0 ("cannot do at all"), 5 ("moderately certain I can do"), and 10 ("certain can do").

ADULT CLINICAL TRIAL GROUP ADHERENCE QUESTIONNAIRE: ACTG

Adherence questionnaire- is a 5 item tool that measures a patient's adherence to doses, pills, timings, and dietary instructions. This instrument also measures patients' reasons for any missed medication or dietary requirement. It has been widely used in adherence studies and found to be reliable measure of self-reported adherence to antiretroviral therapy.

Please be available to the participants to answer any question that they may have. Remember if they wish not to answer any question they are free to do so at any time.

Questions and Discussions.

Invitation to participate in HIV Treatment Adherence Study

Thomas Kamau is a PhD Candidate, Department of Graduate Programs in Health Sciences, School of Medical Education and Health Sciences, Seton Hall University, South Orange, New Jersey, USA.

The purpose of his doctoral research is to understand what helps or maintains HIV treatment adherence among men and women living with HIV in Kenya. Specifically, the study aims at establishing whether an individual's perception of availability of social support and belief in his or her ability to cope with life challenges has a relationship with his or her ability to take HIV medication as needed.

The survey will take about forty five minutes (45) to complete responding to all the questionnaires.

If you are interested to take part in the study, please pick-up a recruitment form beneath this flyer and give your contact information or ask for assistance from your staff at the clinic. When you have completed writing the contacts, please drop the form at the designated drop-box.

You will be contacted by either the Principal Investigator or a Research Assistant for scheduling and signing of informed consent and administration of the survey tools.

If you agree to participate in this study, you will sign informed consent form. Your participation is voluntary. If you do choose to participate, but prefer not to answer certain questions, or withdraw from the study, you are will be free to do so at any time and for any reason. There is not penalty if you decline to participate, withdraw, or refuse to answer any question.

You will be asked to complete four survey questionnaires; (1) Demographic Questionnaire, which will ask you about your personal characteristics. (2) Adherence to medication questionnaire: You be will asked, for example, "*How many days have you missed taking all your doses?*" (3) Interpersonal Support Evaluation List: You will be asked to indicate to each item, for example, "*there are several people that I trust to help solve my problems*" if it is "*definitely true*" *3*, "*probably true*" *2*, "*probably false*", *1, or "definitely false*" *0*. (4) Coping Self-Efficacy: On a scale of 0-10, your will be asked how confident or certain you are that you can do certain things, for example "Talk positively to yourself", "develop new hobbies or recreations".

To ensure your anonymity, no personal identifiers will be preserved on any of the questionnaires on which your responses will appear. Instead you will be assigned a code for the purposes of analyzing data. Thus, you will not be identified as a person in any description or publication of this research.

All responses will be stored in a USB memory key and kept in a locked secure site for at least five years. Only the principal research will have access to it.

190

.