FACTORS ASSOCIATED WITH RETENTION IN CARE FOR PERSONS LIVING WITH HIV IN
NON-URBAN WESTERN COLORADO

by

LUCY GRAHAM

B.A., University of Kansas, 1989

B.S.N., University of Kansas Medical Center, 1991

M.P.H., University of Northern Colorado, 1997

A thesis submitted to the

Faculty of the Graduate School of the

University of Colorado in partial fulfillment

of the requirements for the degree of

Doctor of Philosophy

College of Nursing

2016
This thesis for the Doctor of Philosophy degree by

Lucy Graham

Has been approved for the

College of Nursing

by

Paula Meek, Chair
Paul Cook, Advisor
Leli Pedro
Lucy Bradley-Springer

Date: August 19, 2016
Graham, Lucy (Ph.D., Nursing Science)

Factors Associated with Retention in Care for Persons Living with HIV in Non-Urban Western Colorado

Thesis directed by Associate Professor Paul Cook

**ABSTRACT**

The vast majority of people living with HIV are not retained in regular care, although retention in care is critical to reducing HIV-associated morbidity and mortality. Current research on retention in HIV care is heavily focused on urban populations. Informed by a theoretical framework and existing literature, we explored predictors of retention in care and viral suppression (HIV RNA PCR ≤ 200 copies/mL) among English- or Spanish-speaking people living with HIV in a predominately rural region of Colorado. Retention in care is defined as no missed visits (“no shows”). Through surveys and electronic medical record data, we obtained information on distance from participants’ residence to clinic, rurality, age, gender, race/ethnicity, education, HIV risk factor, country of origin, years living with HIV, health literacy, substance abuse, depression, coping, health locus of control, and the patient relationship with the health care team. Of 127 participants (mean age = 49 years; 65% male; 70% White), 48% attended or canceled in advance all HIV visits while 52% missed one or more visits after first entering care at the clinic. In this study, 97% of participants were virally suppressed based on one HIV viral load obtained closest to survey completion. Living farther from the clinic, health literacy, residing in a more rural versus urban area, HIV risk factors of heterosexual contact and injection drug use versus men having sex with men, and screening positive for depression decreased the
odds of being retained in HIV care. Denial and substance use coping mechanisms were also found to decrease the odds of being retained in care, however, only denial coping mediated the effects of health literacy, depression, and reporting heterosexual contact versus men who have sex with men as an HIV risk factor on retention in care. Understanding more about how to successfully retain people living with HIV in care over time is essential regardless of residence, but people living with HIV in rural areas require special considerations.

The form and content of this abstract are approved. I recommend its publication.

Approved: Paul Cook
ACKNOWLEDGEMENTS

I would like to acknowledge the tremendous mentorship and dedication I received from my committee members, Paula Meek, Lucy Bradley-Springer, Leli Pedro, and particularly Paul Cook, my advisor. I am grateful for their expertise throughout my journey. Dr. Cook’s ability to ask the right questions and point me in the right direction was uncanny and invaluable.

Additionally, I acknowledge COMIRB for their evaluation of my research and associated protocols. This research was approved as COMIRB #15-1537.

Last but not least, I acknowledge the patience and love I received from my husband, Paul, and my two sons, Aidan and Charlie. Without their support, I would never have had the strength to follow my passion and complete this academic marathon.
# TABLE OF CONTENTS

## CHAPTER

### I. INTRODUCTION
- Background .............................................................................................................................. 1
- Purpose .................................................................................................................................... 3
- Rationale .................................................................................................................................. 3
- Definitions ............................................................................................................................... 6
- Hypotheses/Research Questions .................................................................................. 9
- Limitations ........................................................................................................................... 10
- Implications for Nursing ................................................................................................ 11

### II. LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK
- Introduction ............................................................................................................................... 12
- Retention in HIV Care ............................................................................................................ 12
- Focused Review of the Rural HIV Literature ........................................................................ 21
- PubMed Search ...................................................................................................................... 23
- Discussion ............................................................................................................................... 32
- Conceptual Framework Guiding the Study ........................................................................... 33

### III. METHODS
- Design ................................................................................................................................... 42
- Variables ................................................................................................................................. 42
- Sample .................................................................................................................................. 44
- Setting ................................................................................................................................... 46
Procedures.......................................................................................................................................46

IV. RESULTS......................................................................................................................................62
Introduction.......................................................................................................................................62
Description of Sample and Univariate Analyses .................................................................62
Checks of Data Integrity........................................................................................................66
Bivariate Analyses................................................................................................................73
Hypotheses.......................................................................................................................................76
Multivariable Analysis............................................................................................................79
Mediation Analysis................................................................................................................82

V. DISCUSSION................................................................................................................................86
Introduction.......................................................................................................................................86
Graham’s Theoretical Framework..........................................................................................90
Limitations.......................................................................................................................................93
Future Recommendations....................................................................................................95
Conclusion.......................................................................................................................................97

REFERENCES....................................................................................................................................98

APPENDIX

A. Elsevier, Inc. Reprint Permission ............................................................................................110
B. Quality Assessment Table.........................................................................................................112
C. Wolters Kluwer Health Reprint Permission ..............................................................................114
D. Research Survey......................................................................................................................115
E. The Newest Vital Sign (Pfizer, Inc.) .........................................................................................125
F. Screening, Brief Intervention and Referral to Treatment.......................................................128
G. Patient Health Questionnaire.............................................................. 130
H. The Patient-Doctor Relationship Questionnaire-9.......................... 132
I. The Multidimensional Health Locus of Control Form C.................... 133
J. BriefCOPE.......................................................................................... 134
K. Rural-Urban Continuum Codes........................................................ 135
LIST OF FIGURES

FIGURE

1.1. Integration of the Interaction Model of Client Health Behavior and the Transactional Model of Stress and Coping..........................................................5

1.2. Rationale for the study ..................................................................................................................8

2.1. Retention in HIV care ................................................................................................................20

2.2. PubMed search results for retention in HIV Care for rural PLWH ......................... 23

2.3. The Interaction Model of Client Health Behavior .......................................................... 36

2.4. The Transactional Model of Stress and Coping ............................................................... 38

2.5. Graham’s Integrated Framework ......................................................................................... 39

2.6. The IMCHB and the TMSC integrated model ................................................................. 40

3.1. Mediation diagram ....................................................................................................................59

4.1. Mediation effects of denial coping on retention in care ............................................. 85

5.1. Predictor variables supported and not supported ...................................................... 91
LIST OF TABLES

TABLE

4.1. Demographics of Study Participants ................................................................. 63
4.2. Study Sample Demographics Compared to State and National Statistics ................................................................. 65
4.3. Independent t-test Results Comparing Participants to Non-participants .................................................................................... 66
4.4. Instrument Reliability Analysis ...................................................................... 71
4.5. Bivariate Analyses of Predictor Variables’ Relationship to Missed Visits ................................................................. 73
4.6. Bivariate Analyses of Predictor Variables’ Relationship to Viral Suppression ............................................................................. 75
4.7. Multivariable Logistic Regression of Significant Univariate Predictors to Missed Visits ................................................................. 79
4.8. Goodness of Fit of Multivariable Logistic Regression Model of Demographic Variables ................................................................. 80
4.9. Multivariable Logistic Regression Model of Significant BriefCOPE Subscales ............................................................................. 80
4.10. Goodness of Fit for Multivariable Regression of BriefCOPE Subscales .................................................................................... 81
4.11. Regression Model Inclusive of Significant Demographic and Instrument Subscales ............................................................................. 81
4.12. Tests of Coping as a Mediator of Significant Predictor Variables’ Effects on Retention in Care ................................................................. 83
CHAPTER I
INTRODUCTION

Background

More than 1.1 million people are currently living with human immunodeficiency virus (HIV) in the United States, and a staggering 50,000 new cases of HIV are reported each year according to the Centers for Disease Control and Prevention (CDC, 2013). HIV is now the most expensive sexually transmitted infection (STI) costing the healthcare industry an estimated $12.6 billion annually. Each new infection incurs an estimated lifetime cost of $304,500 (Owusu-Edisei et al., 2013). In 1996, combination therapy to treat HIV disease became available. As a result, HIV has become a manageable chronic disease with daily medication required to suppress the virus (Chesney, 2000). Viral suppression is essential to reduce HIV-associated morbidity and mortality (HIV-CAUSAL Collaboration, 2010). Regular HIV medical appointments are an important part of medication adherence resulting in viral suppression, not to mention enhanced longevity. Mugavero et al.’s research (2009; 2014) demonstrated a significantly increased risk of mortality in patients who missed medical visits compared with patients who kept appointments. However, most people living with HIV (PLWH) are not retained in care. In fact, just 39% of PLWH maintained regular medical care and 19% achieved viral suppression when the continuum of HIV care was initially analyzed for all PLWH in the United States (n=1,106,400; Gardner, McLees, Steiner, del Rio, & Burman, 2011). Viral suppression also significantly reduces the likelihood of HIV transmission (Cohen et al., 2011). Test and treat—the phrase used to reflect the recommended practice of initiating antiretroviral therapy (ART) as soon as possible
after HIV diagnosis—is supported in current HIV treatment guidelines as a way to prevent further spread of HIV and benefit individual health (Department of Health and Human Services, 2015). Retaining PLWH in care is a national concern and heavily emphasized in the U.S. National HIV/AIDS Strategy (White House Office of National AIDS Policy, 2010).

The majority of research on retaining PLWH in care has been generated from urban centers because the prevalence of HIV remains highest in these areas, and research centers are often located in large metropolitan areas. However, since 1985, there has been a steady migration of the disease to rural areas where close to 20% of PLWH currently reside (CDC, 2012). In comparison to urban and peri-urban counterparts, rural PLWH receive fewer annual outpatient healthcare visits (Wilson et al., 2011). Additionally, PLWH in rural areas struggle to stay in care due to large expanses of underserved areas, long travel distances to health care facilities, concerns about HIV-related confidentiality and stigma, and lack of providers with HIV expertise (National Rural Health Association, 2007).

Regardless of residence, the stress of coping with HIV may exacerbate immune system dysfunction in a disease that targets the immune system (Leserman, 2008). One recent review by Blashill, Perry, and Safren (2011) evaluated studies on stress, coping, and mental health and their affects on HIV treatment retention, adherence, and health outcomes. The authors concluded that not enough was known about how to intervene to improve the lives of PLWH who bear the burden of an increased prevalence of mental illness.
While primary care provider shortages exist across all areas of the United States (Department of Health and Human Services, 2010), non-urban areas are particularly affected (Ricketts, 2005). Nursing’s metaparadigm has emphasized the relationships between person, health, nurse, and environment (Fawcett, 1984), preparing nurses as integral leaders of HIV care retention efforts. However, effective intervention research is limited, especially in relation to health care providers’ roles in fostering better retention rates (Higa, Marks, Crepaz, Liau, & Lyles, 2012). Thus, more needs to be known about the relationships between the variables that affect retention in HIV care for PLWH in rural areas.

**Purpose**

The purpose of this research study was to explore relationships between demographic, social, and psychological variables, informed by theory and research, which affect retention in care for PLWH in rural western Colorado.

**Rationale**

Retaining PLWH in care is a critical aspect of HIV care with individual and public health implications at great cost to society regardless of residence designation, and much less is known about retention in care for rural PLWH. Even modest improvements in retention rates would reduce HIV-associated morbidity and mortality rates, save millions of dollars, and prevent numerous new infections. Reducing new infection rates by 10% would prevent an estimated 5,000 people from contracting HIV and save the United States more than $57 million annually ($12.6 billion spent annually on HIV / 1.1 million PLWH x 5,000 new infections prevented; Owusu-Edusei et al., 2013).
In searching for theories to guide retention in care research, no single health behavior theory adequately addressed the complicated issues that PLWH must routinely navigate to stay retained in care. However, an integration of the interaction model of client health behavior (IMCHB; Cox, 1982) and the transactional model of stress and coping (TMSC; Lazarus & Folkman, 1984 as cited in Glanz & Schwartz, 2008) provided the necessary comprehensiveness to guide retention research (Graham, 2015). Graham’s framework incorporated the complex individual demographic, psychological, and unique patient-provider variables found in the IMCHB, and infused stress and coping constructs important to the successful management of a chronic illness (see Figure 1.1). Note that the concepts in bold red are the variables of interest in this study.
Figure 1.1. Integration of the Interaction Model of Client Health Behavior and the Transactional Model of Stress and Coping.

Note. Italic print shows that concepts are from the TMSC. Regular print shows that concepts come primarily from the IMCHB. Underlined concepts are found in both the IMCHB and the TMSC. Bold print highlights where the proposed study variables are found. TMSC = Transactional Model of Stress and Coping; IMCHB = Interaction Model of Client Health Behavior. Adapted from Graham, L.J. (2015). Reprinted with permission (Appendix A). Copyright [2015] by Elsevier Inc.
Definitions

Health Literacy

Health literacy is the ability to understand and make meaningful use of basic health information and services in a way that informs decision-making (CDC, 2015). In this study, health literacy is a background variable (Figure 1.1).

Country of Origin

Birthplace is a demographic variable found in the background variable box (Figure 1.1). Foreign-born Latinos are a population of interest in this study as they are more likely to be diagnosed HIV late in the disease process. One group of researchers reported that 40% of new HIV infections diagnosed late in the disease process defined by progression to AIDS within one year were found in Puerto Ricans and other Latinos born in the United States, while late infections in Latinos born in Mexico or Central America were 55% and 58%, respectively (Garland, Andrade, & Page, 2010).

Rurality

Rurality is defined as the proximity or distance from metropolitan areas, and is measured by nine Rural-Urban Continuum Codes (RUCC) that consider proximity to urban areas along with county size (Vanderboom & Madigan, 2007). Rurality is a background variable in this study (Figure 1), specifically related to environmental resources, which considers geographic influences on health behavior.

Distance from Clinic

Distance from clinic is defined as the number of miles required to reach an outpatient HIV clinic. Similar to rurality, distance from clinic may be a geographic
influence on access to health care; thus, it is listed under the environmental resources subheading of the background variables box (Figure 1.1).

**Depression and Substance Use**

These can be affected by more than one subcategory of background variables (Figure 1.1). As such, they are listed at the bottom of the box. Criteria for each are described in more detail in Chapter 3.

**Patient-Provider Interaction**

As defined by Cox (1982), patient-provider interaction is the extent to which a provider emotionally supports, competently cares for, imparts understandable health information, and collaborates with patients to make meaningful health decisions. As shown in Figure 1.1, the patient-provider interaction influences a patient’s appraisal processes, which in turn influence individual perceptions that then affect coping processes, health behaviors, and ultimately health outcomes.

**Health Locus of Control**

Individual beliefs about what controls health decisions is termed health locus of control (Wallston, Stein, & Smith, 1994). In Figure 1.1, health locus of control is found in the dynamic variable box as a function of cognitive appraisal, specifically secondary appraisal.

**Coping Process**

Coping results from the mental appraisal of a stressor and consists of coping effort and meaning-based coping (Figure 1.1). The coping process involves problem management strategies and the emotional responses to stress. Meaning-based coping
incorporates strategies that help make sense of the process, and understanding of the stressor (Lazarus & Folkman, 1984 as cited in Glanz & Schwarz, 2008)

**Retention in HIV Care**

Many definitions exist but concisely, “retention refers to the consistency of service utilization after the initial care period” (Fleishman, Yehia, Moore, Korthuis, & Gebo, 2012, p. 249). In Figure 1.1, retention in HIV care is a health behavior.

**Viral Suppression**

Viral suppression means that 200 or fewer copies of HIV/mL are detected in blood samples generally measured using Real Time RNA-PCR technology (Department of Health and Human Services, 2015.) Viral suppression is a health outcome, fitting into health outcomes/adaptation (Figure 1.1). The overarching study rationale is best understood visually (see Figure 1.2).

*Figure 1.2. Rationale for the study.*

*Note.* PLWH = persons living with HIV; U.S. = United States; HIV = human immunodeficiency virus.
Hypotheses/Research Questions

Overarching Research Questions

1. Do health literacy, country of origin, rurality, distance from clinic, depression, substance abuse, patient-provider interaction, and health locus of control predict the likelihood of a PLWH being retained in HIV care and becoming virally suppressed?

2. Does the coping process mediate the effects between predictor variables and retention in HIV care?

Aims and Hypotheses

AIM 1. To determine if background variables such as health literacy, distance from clinic, rurality, and country of origin predict retention in HIV care and viral suppression in a rural outpatient HIV clinic.

H1. Greater distance from clinic will decrease the odds of being retained in HIV care and becoming virally suppressed.

H2. Rurality will decrease the odds of being retained in HIV care and becoming virally suppressed.

H3. Country of origin outside of the United States will decrease the odds of being retained in HIV care and becoming virally suppressed.

H4. Adequate health literacy scores will increase the odds of being retained in HIV care and becoming virally suppressed.

AIM 2. To determine if the patient-provider interaction predicts retention in HIV care and viral suppression.
**H5.** Higher scores on the Patient-Doctor Relationship Questionnaire will increase the odds of being retained in HIV care and becoming virally suppressed.

AIM 3. To evaluate if behavioral, psychological, and social factors predict retention in HIV care and viral suppression.

**H6.** Screening positive for substance use will decrease the odds of being retained in HIV care and becoming virally suppressed.

**H7.** Internal and doctor health loci of control will increase the odds of being retained in HIV care and becoming virally suppressed; chance and other people loci of control will decrease odds of being retained in HIV care and becoming virally suppressed.

**H8.** Screening positive on a depression screen will decrease the odds of being retained in HIV care and becoming virally suppressed.

AIM 4. To determine if the coping process has a mediating effect between predictor variables and retention in HIV care.

**H9.** Coping processes will significantly mediate the relationships between distance from clinic, rurality, country of origin, health literacy, the patient-provider interaction, substance abuse, health locus of control, depression, and retention in HIV care.

**Limitations**

This study consisted of a survey conducted at one point in time and a retrospective review of data found in patients’ medical records, thus it was unable to determine causality. It was also less powerful than a prospective study because much
of the data had already been collected; hence, there was less control of collection methods and no element of temporal sequencing to incorporate into the study (Portney & Watkins, 2009). Correlational studies do, however, allow for theory testing and provide insight into variables that support and lessen successful health outcomes (Portney & Watkins, 2009).

Potential threats to the validity of this study included the sample, instruments, and the study's setting. Selection bias may threaten internal validity. It is possible that PLWH not retained in regular care may be less likely to respond to a survey than those patients retained in regular care. Instrument reliability and validity was paramount to the success of this study and required careful review (Wood & Ross-Kerr, 2011). The central external threat to validity involved the geographic location of the study. PLWH in rural Colorado may not be representative of rural areas in other parts of the United States, which may limit generalizability of the findings.

**Implications for Nursing**

Nurses are the largest body of health care workers in the United States. As such, nurses are ideally suited to be leaders in the evolving health care system and to affect improvements in health care and health outcomes (Institute of Medicine, 2010). Identifying predictors of retention in HIV care informs nursing practice for PLWH in rural areas about important factors to consider in nursing care. Additionally, research-based evidence of important variables will allow nurses to design targeted quality improvement projects to enhance retention in HIV care in a variety of care settings. This study informs much needed nursing intervention research to determine the most effective ways to positively affect retention in HIV care in rural areas.
CHAPTER II
LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

Introduction
For the purposes of this study, a comprehensive review of the literature required delving into the concept of retention in HIV care and what that means, followed by a review of the rural literature that directly and indirectly related to retention in HIV care for PLWH in rural areas. “Theories guide both research and practice” (Walker & Avant, 2011, p. 40), but markedly little credit is given to them in the retention in HIV care literature. Therefore, a conceptual framework was developed from two existing theories to inform nursing research related to retention in HIV care.

Retention in HIV Care

Literature on the Concept of Retention in HIV Care

Background. Research on the phenomenon of retention in HIV care has been present in the literature from the early 2000s, but the number of published articles specifically related to this concept, separate from adherence to medications, increased significantly in 2009. A comprehensive meta-analysis that reviewed 28 U.S. studies on retention in care for PLWH between 1995 and 2009 (Marks, Gardner, Craw, & Crepaz, 2010) found that only 59% of the total sample \( n=75,655 \) were retained in care as defined by HIV health care visits averaged across time spans of 6 months for up to 3 to 5 years. These results differed from the national estimate of 39% based on all PLWH in the United States (Gardner et al., 2011). A more recent study by Yehia and colleagues (2012) compared three different measures of retention in 17,425 patients from 12 U.S. HIV clinics and determined a national estimate of retention to be 71-75%. All studies
were lower than the national goal of 90% (White House Office of National AIDS Policy, 2015). The reasons for variability in these results are complex and multi-faceted, but may be due to the lack of a clear consensus on what retention in care actually means, and how it is measured. A group of researchers in a quest for a “gold standard” for measuring retention in care evaluated six different measurements and determined that they all had merits and, in general, correlated with viral suppression. They concluded that a combination of measures might be beneficial, but that room existed for tailoring measurements to clinical situations (Mugavero et al., 2012).

While attention to this concept has grown, as evidenced by the recent increase in published studies in medical, public health, and behavioral science journals, there is a noticeable lack of published articles on retention in HIV care in nursing journals. Only two articles from 2009 to March 2015 were found in a professional nursing journal (Graham, 2015; Konkle-Parker, Amico, & Henderson, 2011). The national retention rates in HIV care conversations are becoming more noticeable, and nurses need to be involved in the dialogue. Patients report that integrated multidisciplinary care teams, which include nurses, are more satisfying and easier to access than more traditional models of care (Pillai, Kupprat, & Halkitis, 2009). An exploration of literature outside of the HIV realm revealed a study related to appointments missed by diabetic patients. The researchers found that improving patient education and enhancing nursing involvement in care delivery effectively benefitted the care continuum (Renders et al., 2001).

**Search strategy.** The CINAHL and PubMed databases were searched for articles published from 2009 to 2013. Relatively few articles were published on retention in
care before this time. Key words used were "HIV", "retention", "engagement", "adherence", "United States", "adults", and "patient compliance". Studies on exclusively pediatric populations were excluded, as retention issues are conceptually different than with adults and the population is markedly smaller. Only articles published in English and reporting on populations in the United States were included. Research was available from Africa and Asia, but the health care systems in those continents differ enough from the United States to alter the concept analysis. Therefore, only studies of U.S. populations were included to allow for better specificity of conclusions. Articles that focused solely on medication adherence were excluded, as the concept of retention in care shares similarities with adherence, but is an independent construct. One study evaluated adherence and retention and found that demographic variables similarly predicted adherence and retention, but behavioral characteristics differed between the two concepts (Murray et al., 2013). Dissecting the general concept of HIV care retention was done irrespective of residence designation to assure a large enough sample of relevant studies. Overwhelmingly, retention in care research has been generated in urban settings; therefore, restricting the studies to rural populations alone would have been insufficient to understand the complexities surrounding the concept of HIV care retention.

Ultimately, 29 quantitative and qualitative articles were included in the analysis; 24 were quantitative in design, and five used qualitative methods. Twenty-five studies were published in HIV-specific professional journals, while only one study was from a nursing journal. Most of the authors were physicians, but also included authors from psychology, education, public health, and nursing. The articles chosen were from peer-
reviewed journals. As predominantly quantitative studies were found, sample sizes ranged from a few hundred to more than 100,000.

**Results.** The literature review identified demographic, biological, behavioral, psychosocial, and health system variables that influence retention in HIV care. It also delineated the individual and community-level consequences of inadequate retention in HIV care.

**Demographic variables.** For PLWH, many individual characteristics affect retention in care—age, gender, race, HIV risk factor, health status, country of origin, education, housing, socioeconomic status, and insurance. Younger PLWH tend to be retained in care less consistently (Horstmann et al., 2010; Hu et al., 2012; Mugavero et al., 2009; Torian & Wiewel, 2011; Ulett et al., 2009; Yehia et al., 2012). Notably, men are less likely to remain in care compared to women (Fleishman et al., 2012; Yehia et al., 2012).

Several studies evaluated race with mixed results. Universally, the studies found that African-American PLWH were poorly retained in care (Horstmann et al., 2010; Hu et al., 2012; Mugavero et al., 2009; Sitapati et al., 2012; Torian & Wiewel, 2011; Yehia et al., 2012). The data for Latinos were conflicting. Fleishman et al.’s (2012) study reported better retention for Latinos than for Whites, while Hightow-Weidman et al. (2011) found that Latinos were more often retained in care than African-Americans. However, Hu et al. (2012) reported that Latinos were retained in care less often than Whites. This variation may have resulted from the populations studied. Hightow-Weidman et al. (2011) studied several hundred young men while Fleishman et al. (2012) studied nearly 23,000 men and women of all ages.
Reporting a risk factor other than men who have sex with men (MSM) was associated with poorer retention (Horstmann et al., 2010; Yehia et al., 2012). Health status, particularly mental health, also influenced retention rates. PLWH commonly cited depression and suicidality as significant health issues (Horstmann et al., 2010; Marks et al., 2010; Pecoraro et al., 2013). According to some reports, CD4+ T cell counts (the immune system laboratory test), were associated with retention in care. PLWH with higher CD4+ T cell counts, who are presumably healthier and with less disease symptoms, were retained in care less often (Ulett et al., 2009; Yehia et al., 2012). However, when CD4+ T cell levels dropped significantly, PLWH were more likely to be retained in care (Fleishman et al., 2012). Patients diagnosed before combination antiretroviral therapy was available were less often retained in care, as were those who had both an HIV and an AIDS diagnosis (Hu et al., 2012). One unique study evaluated intimate partner violence (IPV) and its association with care retention (Shafer et al., 2012). The nature of intimate partner violence itself, or even the threat of IPV, was associated with lower retention in care.

Foreign-born patients were less likely to stay retained in care (Hall et al., 2012), and undocumented PLWH in the United States were harder to keep in care due in part to fears of deportation, language barriers, and lack of ability to navigate the health care system (Dang et al., 2012). Patients with less education were in care less regularly (Horstmann et al., 2010), as were patients living in poverty (Horstmann et al., 2010; Shade et al., 2012) and those without insurance (Horstmann et al., 2010; Mugavero et al., 2009). PLWH who were incarcerated or recently released from prison were also less likely to be retained in care (Hu et al., 2012; Pecoraro et al., 2013). Unstable
housing and homelessness also contributed negatively to care retention (Marks et al., 2010; Pecoraro et al., 2013).

**Biologic variables.** Biologic variables were those reported in the literature pertaining to the genetics or physiology of the individual. These included issues with medication side effects, perceived state of health, and the well-known link between alcoholism and genetics. Overwhelming consensus was found related to the effects of alcohol and drug use, particularly injection drug use (IDU), on the ability of PLWH to remain in care (Horstmann, Brown, Islam, Buck, & Agins, 2010; Hu et al., 2012; Marks et al., 2011; Pecoraro et al., 2013; Sitapati et al., 2012; Torian & Wiewel, 2011; Ulett et al., 2009). Substance use was included as a behavioral characteristic as it can be biologic, behavioral, or both. Problems taking medications or issues with side effects were reported in only one study (Pecoraro et al., 2013). This was likely due to the many advances made in the last decade related to more tolerable antiretroviral medications. Not surprisingly, patients who did not feel sick were less often retained in care (Konkle-Parker et al., 2011; Sitapati et al., 2012).

**Behavioral variables.** Behavioral characteristics included alcohol and drug use, as mentioned above, as well as inadequate coping behaviors. Inadequate coping behaviors is a general category created to group attributes identified in the research, such as denial (Konkle-Parker et al., 2011; Pecoraro et al., 2013), forgetfulness (Pecoraro et al., 2013), being too busy, or letting work interfere with care adherence (Sitapati et al., 2012) were reasons to disconnect from care.

**Psychosocial variables.** Psychosocial variables included stigma, lack of support, and moving to a new location as reasons to drop out of care. Stigma is its own
area of interest and research in HIV health care, likely because HIV continues to be a disease negatively associated with sexual activity and drug use. Several studies reported stigma as a suppressive attribute to care retention (Dang, Giordano, & Kim, 2012; Pecoraro et al., 2013; Shade et al., 2012). Lack of social support was similarly suppressive. Patients who reported rejection by families or social networks were less engaged in their care (Dang, et al., 2012; Horstmann et al., 2010). Relocation was the final psychosocial attribute reported by patients in the reviewed studies (Konkle-Parker et al., 2011; Pecoraro et al., 2013).

**Health system variables.** On the level of the health care system, two main characteristics are related to HIV care retention—the culture of the health clinic, and the availability of support services. PLWH were found to be less likely to stay in care if their health clinics are culturally incompetent, inflexible in scheduling, or difficult to access (Pecoraro et al., 2013; Sitapati et al., 2012; Mugavero, Norton, & Saag, 2011) and much more likely to retain care if they expressed positive feelings about their health care providers (Marks et al., 2010; Pecoraro et al., 2013). Trust in the patient-provider relationship was reported to facilitate retention efforts (Marks et al., 2010; Shade et al., 2012; Smith et al., 2012) while lack of engagement with one’s provider significantly reduced retention (Horstmann et al., 2010). Not surprisingly, concerns about confidentiality at the clinic or specific care issues decreased retention (Shade et al., 2012). Perceived cultural competency of the clinic and staff influenced retention (Mugavero et al., 2011) and being satisfied with the care provided may greatly benefit retention (Dang et al., 2013). Research has supported providing care through an integrated team, which includes case management to help patients navigate the system.
and access needed housing and transportation assistance (Konkle-Parker et al., 2011; Mugavero et al., 2011).

**Consequences of inadequate retention in HIV care.** Two overarching groupings of consequences have been related to retention in HIV care—those that relate to the individual and those that relate to the community. At the individual level, research has demonstrated that as visit adherence decreases, the cumulative effects of unmanaged HIV infection in the body increases. Patients who did not keep medical appointments had an increased risk of mortality (Mugavero et al., 2012). Similarly, those patients not regularly engaged in health care were responsible for the largest percentage of patients with detectable viremia (Gardner et al., 2011). A study evaluating life expectancy and retention in care found significant differences in life expectancy between those in care versus those out of care (Losina et al., 2009).

At the community level, consequences of poor adherence to health care maintenance efforts are likely to result in increased transmission of HIV, increased community level viral load, and increased health care costs. Recent research and guidelines have emphasized the need to target energy toward retaining PLWH in care. Patients in care have been shown to be healthier and have lower viral loads, which decreases the community-level viral load and decreases transmissibility (Thompson et al., 2012), often referred to as positive prevention or treatment as prevention. Gardner and colleagues (2011) reported that among the greatest public health challenges facing the United States are the numbers of undiagnosed people, who unknowingly infect others, and the suboptimal retention efforts of PLWH in care. Out-of-care patients increase health care costs through utilization of emergency departments and increased
hospitalizations (Horstmann et al., 2010). However, work is being done to try to avert these consequences. One group of researchers designed an inexpensive intervention consisting of targeted retention messages and posted flyers about the importance of regular care in the clinic. They found improved rates of retention in younger patients and patients with detectable viral loads (Gardner et al., 2012). Another study of only women found that integrated care increased satisfaction with care and therefore increased retention in care (Pillai et al., 2009). The majority of studies call for research on effective interventions to mitigate these actual and potential consequences. See Figure 2.1.

![Diagram showing variables, behavior, and outcomes with focus on retention in HIV care.]

Figure 2.1. Retention in HIV care.

Note. HIV = human immunodeficiency virus
**Discussion.** Nurse researchers are well positioned to study this concept through a nursing lens, ascertaining how nurses can best affect person, health, and environment to improve health outcomes for PLWH and their communities. As more work evolves on best practice intervention methods to achieve better health outcomes, the involvement of nurse scientists is essential. Nurses in practice can independently assess, diagnose, and act to improve retention efforts in health care. However, unless these actions are formally incorporated from research to practice, and the results published, successes cannot be realized by the nursing community at large.

**Focused Review of the Rural HIV Literature**

After gaining a deeper understanding of the general concept of retention in HIV care, a focused review of the literature relating to PLWH in rural areas and HIV care retention provided more detail to inform this study.

**Search strategy.** Two electronic databases were searched, PubMed and CINAHL, to locate articles through a university-affiliated medical library. Key search words included: “HIV”, “rural”, “rural population”, “retention in care”, “treatment adherence”, “patient engagement”, and “United States”. The search term “compliance” was tried after these terms, but it did not yield additional articles. For this review, only studies published from 2003 to the present were eligible. Prior to 2003, primary emphasis was on palliative, not chronic, care. The literature review excluded pediatric populations as retention in care issues are expected to be different between pediatric and adult populations. Only publications in peer-reviewed journals were included. Qualitative, quantitative, and mixed-method designs were eligible for inclusion. The review focused on English language publications because the review was specific to
rural regions in the United States. Extensive variability exists in rural regions of other countries and continents. Additionally, review articles were removed to allow independent evaluation of original research.

A flow chart of the search terms and results provided visual explanation of the extraction process (see Figure 2.4). Attempts to minimize bias and error in the extraction process included careful adherence to inclusion criteria of research studies related to retention in HIV care of adults in the rural United States published in English-language, peer-reviewed journals from 2003 to 2013.
Figure 2.2. PubMed and CINAHL search results for retention in HIV care for rural PLWH literature review.

Note. PLWH = persons living with HIV. HIV = human immunodeficiency virus. U.S. = United States
After review of both database searches for duplicate articles, 23 citations remained eligible for review. Application of the eligibility criteria described above removed 10 articles that were conducted outside of the United States, leaving a total of 13 eligible articles. A more intensive review revealed three additional studies meeting exclusion conditions because the samples were exclusively urban. As a result, 10 publications met all of the inclusion criteria; eight included rural-only populations, and two included mixed urban/rural samples.

Of the 10 articles, authors of five studies evaluated adherence to HIV medications while five assessed retention in HIV care. Because the pool of articles was so small, the medication adherence articles were included in the review. The benefit of reviewing 10 articles rather than five was thought to add to the general synthesis of rural HIV literature. However, the constructs of medication adherence and retention in care are partially correlated, but distinct. Research has found that retention in HIV care is an independent predictor of survival (Giordano, Hartman, Gifford, Backus, & Morgan, 2009).

The majority of the studies used quantitative methods (n=9), but one applied a qualitative design. Most of the authors omitted discussion of a guiding theoretical or conceptual framework (n=8). In general, the studies sampled predominantly men, however, two studies included women exclusively. One study sampled a mixed older adolescent/adult population; the rest included only adults.

**Criteria to assess publication quality.** To minimize inter reviewer bias and errors, one independent reviewer—the author of this research—evaluated all studies. The PRISMA 2009 Checklist was used as a way to consistently assess methodological
soundness and study quality (Mohler, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009). These guidelines were developed to add structure to reviews in an effort to combat the pervasive inconsistencies found in many systematic and meta-analytic reviews. The checklist contains 27 reporting items to address when reviewing articles, providing specificity and guidance. Each study was evaluated against the checklist and results were pooled into a table (see Appendix B, Literature Review Quality Assessment Table). Not all checklist items were applicable to the current research, as several were specific to evaluation of meta-analytic or systematic reviews. As a result, items 1, 5, 7-9, 15, 17, and 22 were not used for the quality assurance process (see Appendix H for a list of the excluded items). The review of the literature consisted of original research only.

In general, the reviewed studies adequately addressed all components included in the PRISMA 2009 Checklist. Of course, each study had its own strengths and weaknesses, which were addressed in the data synthesis process. No authors discussed potential biases, but they all described limitations to their research studies. Risk of bias (items #12 and #20 of the PRISMA 2009 Checklist) was described as the assessment for risk or bias in the studies and its implications for data synthesis. These items may more appropriately assess a meta-analytic or systematic review rather than original research, but they were included in the interest of determining whether any authors addressed potential contributions to a review paper.

A language bias exists in this review because English language only articles were included. Publication bias was difficult to assess, but was of concern as it is known that positive studies are published more often than negative studies (Cochrane Collaboration, 2002). If this was present in the rural retention in HIV care literature in
the United States, then the review would be based on skewed information; therefore, conclusions must be interpreted with that possibility in mind.

Three aspects of critical reviews of the literature (usability, completeness, and consistency) provided another framework from which to assess quality (Wood & Ross-Kerr, 2011). Each selected study contributed to the general knowledge regarding adherence to HIV medications or retention in HIV care in rural U.S. adults, thus boosting applicability or usability, even if study-specific limitations influenced generalizability. Completeness refers to the comprehensiveness of the study (Wood & Ross-Kerr, 2011). The reviewed studies sufficiently addressed the components of the research process pertinent to their design. The third criterion, consistency, spoke to the logical progression of the elements of the study (Wood & Ross-Kerr, 2011). Each of the 10 studies reviewed included an abstract, introduction and/or background, purpose statement, definitions, sample, methods, analyses, results, discussion, and conclusion. Sections were clearly labeled and progressed logically. Thus, for the purposes of this research, the 10 studies individually passed the overall quality assessment and remained eligible for inclusion in a focused review of the literature.

Sample characteristics. Sample sizes varied widely in the reviewed studies. The smallest study sampled only 40 subjects, but was qualitative in design (Kempf et al., 2010). The largest study evaluated 100,375 subjects of mixed rural/urban residence from a large multi-state database (Hall et al., 2012). The largest rural-only sample was 1,782 from the Veterans Administration database and was predominantly male (Ohl et al., 2013). HIV still affects more males than females in the United States and this was reflected in the gender distribution of the study samples. However, research from the
last decade clearly included more women, even exclusively female samples, than in previous years.

The majority of the studies took place in the southeastern part of the United States (Amico et al., 2007; Kempf et al., 2012; Konkle-Parker et al., 2011; Mohammed et al., 2004; Reif, Golin, & Smith, 2005; Vyavaharkar et al., 2007). This made generalizability to other areas difficult, and was considered a limitation of the reviewed studies. African-Americans were more prevalent in the samples than other ethnicities, which is reflective of the HIV epidemic, particularly in the southern United States (CDC, 2013). In general, study participants reported living in poverty and most commonly reported a risk of HIV infection as either MSM or heterosexual sex, or, less often, IDU.

**Study designs.** Research methods were predominantly quantitative. Interestingly, all studies were descriptive in design, whether qualitative or quantitative. This spoke to the newness of the phenomenon of retention in HIV care in rural areas of the United States. Once there is a sufficient body of knowledge about the phenomenon, intervention studies can be designed to target identified sub-concepts that may affect retention rates. Of note, none of the authors employed a randomized control trial (RCT) design.

In general, sample sizes were appropriate to the selected study’s design. Most sample sizes in survey/interview studies \((n=7)\) were between 130 and 330. One study of 40 subjects was qualitative in design and the two studies with thousands of participants analyzed data from large, existing data sets. Convenience sampling dominated the sampling design. As a result, generalizability was not possible. Selection
bias was an important threat to internal validity of studies employing convenience sampling (Creswell, 2009).

**Results.** For this review, the synthesis of the 10 descriptive studies created a narrative, which described health-promoting and health-suppressing behaviors affecting medication adherence and retention in HIV care for adults living in rural areas in the United States.

The 10 studies described the phenomena of medication adherence and retention in HIV care in different ways. Five addressed only medication adherence, (Amico et al., 2007; Heckman, Catz, Heckman, Miller, & Kalichman, 2004; Mohammed et al., 2004; Ohl et al., 2013; Vyavaharkar et al., 2007) and five explored the barriers and facilitators to retention in HIV care (Hall et al., 2012; Kempf et al., 2010; Konkle-Parker et al., 2011; Reif et al., 2005; Shafer et al., 2012). Consensus from the 10 studies was that PLWH in rural areas did not take medications as required to control the virus (Amico et al., 2007; Heckman et al., 2004; Mohammed et al., 2004; Ohl et al., 2013; Vyavaharkar et al., 2007) and did not stay retained in care (Hall et al., 2012; Kempf et al., 2010; Konkle-Parker et al., 2011; Reif et al., 2005; Shafer et al., 2012).

**Results specific to medication adherence.** Suboptimal adherence to medications and health care maintenance is pervasive in both rural and urban populations. Ohl et al. (2013), in a study of more than 20,000 veterans, found that rural veterans had better medication adherence rates when pharmacy refill data were reviewed compared to their urban counterparts. Unfortunately, rural veterans were more likely to present with lower CD4+ T cell counts than were urban veterans.
Specific adherence rates were calculated from many of the rural samples, but measurement variability made determining an average adherence rate impossible. It was clear that medication adherence rates were low and a significant issue for rural populations in these samples. Ohl et al. (2013) reported that only 27%-35% of veterans in their study \(n=20,301\) were adherent to HIV medications at least 90% of the time throughout the first year of treatment. Vyawaharkar et al. (2007) discovered that 60% of their sample \(n=224\) was non-adherent to medication regimens in the previous month, which decreased to 25% when the sample reported on the previous 2 weeks. Specific research on self-reported recall of HIV medication adherence revealed that overreporting occurred less when 1-month recall time was used as opposed to 3 or 7-day recall periods when compared to data from medication event monitoring systems (MEMS; Lu et al., 2008). Amico and colleagues (2007) found that close to 48% of their sample \(n=151\) missed at least one dosage of medication in the previous 3 days. Mohammed and colleagues (2004) reported that 34.4% of their sample was non-adherent using 1-week recall \(n=273\). Participants \(n=329\) in Heckman et al.’s (2004) study reported 50% adherence rates in the previous week.

The researchers identified many health-promoting and health-suppressing behaviors affecting medication adherence. Ohl et al. (2013) found better adherence rates in patients who reported less alcohol and drug abuse. This was consistent across other studies evaluating adherence (Heckman et al., 2004; Mohammed et al., 2004). In their study of women living in rural areas of three southeastern states, Vyawaharkar et al. (2007) discovered that coping by denial and avoidance, as well as number of children, correlated to missing medication doses. In contrast to prior urban research,
Amico et al. (2007) did not find that side effects significantly contributed to missed doses in a mixed urban/rural population in Mississippi. Instead, participants blamed their non-adherence on running out of medications. Consistent with other studies (Heckman et al., 2004; Mohammed et al., 2004), high scores on depression screening tools were implicated in missed doses. Heckman et al. (2004) explored several factors of non-adherence and found that reasons for missed doses were often due to negative side effects, forgetfulness, and not having medications with them at the time they were due to be taken.

**Results specific to retention in HIV care.** Only one study calculated a rate for retention in care. Hall et al. (2012) found that only 44.8% of their sample \(n=100,375\) was retained in care as defined by at least two visits within a calendar year and spaced at least 3 months apart. As a comparison, a largely urban U.S. meta-analysis \(n=75,655\) calculated a retention rate of 59% when defined as medical visits averaged across time spans of 6 months for up to 5 years (Marks, Gardner, Craw, & Crepaz, 2010). Many health-promoting and health-suppressing behaviors influence retention in HIV care. Similar to the medication adherence literature described above, retention in HIV care was worse for patients reporting alcohol or drug abuse (Hall et al., 2012; Reif et al., 2004; Shafer et al., 2012). Shafer and colleagues (2012) found that 33% of their sample from rural Virginia \(n=251\) experienced intimate partner violence (IPV), and 69% had been threatened with IPV. IPV was associated with lower CD4+ T cell counts, higher HIV viral loads, and a higher number of missed visits. Even the threat of IPV was a significant contributor to poor engagement in care and health status. Hall and colleagues (2012) reported on birthplace, finding that US-born \(n=72,669\) and foreign-
born \((n=6,527)\) patients initiated care after diagnosis similarly, but that foreign-born patients were less likely to stay retained in care. Konkle-Parker, Amico, and Henderson (2011) studied personal and structural barriers and facilitators to PLWH retention in care in the southern United States. Urban studies have shown that structural barriers related to resources, support, and living situations were common reasons that PLWH were not in care. However, in their rural sample \((n=131)\), personal barriers including denial, disbelief, and active avoidance were cited more than 70% of the time as the reason PLWH were not in care.

In their qualitative study of women \((n=40)\) from rural Alabama, Kempf and colleagues (2010) discovered that the key facilitator to care retention for PLWH was the quality of the patient-provider relationship. Stigma surfaced as a major barrier to care. Comprehensive visits, flexible scheduling, appointment reminders, and transportation assistance were similarly important facilitators of retention in care. Reif, Golin, and Smith (2005) were the only researchers to survey HIV case managers about retention in care issues. Rural case managers reported more barriers to care than their urban colleagues, particularly related to stigma, transportation issues, and inadequate housing.

**Measurements.** Wide variability existed in outcome measurements. Adherence to HIV medications was assessed as missed doses in the previous 3 days (Amico et al., 2007), missed doses in the previous week (Heckman et al., 2004; Mohammed et al., 2004; Vyawaharkar et al., 2007), and pharmacy refill data (Ohl et al., 2013). Retention in care was defined as a greater than 6-month gap in health care (Konkle-Parker et al., 2011), no show rates/missed clinic visits (Kempf et al., 2010; Shafer et al., 2012), HIV
specific lab testing (CD4+ T cell count and HIV viral load) done at least two times a year at least 3 months apart (Hall et al., 2012), and with an adapted Barriers to Care survey instrument (Reif et al., 2005). The availability of laboratory data at specific time points was commonly used as a proxy for medical visits, especially in analyses of large data sets. This may not be an accurate proxy because PLWH may have blood work done and not see a medical provider, resulting in inflated retention in care rates. Inconsistencies in definitions complicated the ability to aggregate results; however, the research still contributed to a deeper understanding of medication adherence and retention in HIV care for adults living in rural areas.

Discussion

This literature review demonstrated inadequate adherence to medications and retention in HIV care in adults living with HIV in rural areas of the United States, despite the limitations of the studies. Conclusions were complicated by inconsistent measurements of medication adherence and retention in care, but the rates were low enough that even if they overrepresented the true rate, room for improvement exists. The U.S. National HIV/AIDS Strategy goal is to retain 90% of people living with HIV in regular medical care (White House Office of National AIDS Policy, 2015).

The majority of researchers used only one self-reported adherence measurement of less than 1 month, which may have resulted in over-reporting of actual rates (Lu et al., 2008). A recommendation for future research is to use more than one adherence measure when accuracy is important (Paterson, Potoski, & Capitano, 2002). Similarly, significant variability existed in definitions of care retention, affecting confidence in global conclusions. Analysis of common retention measures is thought to
be more robust if one measure of missed visits and one measure of kept visits are used (Mugavero et al., 2012). In all studies reviewed, measurement occurred through one method, reflecting a general weakness of the research. However, the consistent, low results support the conclusion that levels of HIV medication adherence and retention in care are suboptimal.

A collective strength of the studies reviewed was the breadth of descriptions of behaviors affecting HIV medication adherence and care retention for rural PLWH. Health-suppressing behaviors relating specifically to medication adherence included alcohol and drug use, coping by denial and avoidance, number of children, running out of medications, depression, not having medications when needed, and simply forgetting to take prescriptions. Alcohol, drug abuse, intimate partner violence, being foreign-born, poor coping skills (denial, disbelief, active avoidance), stigma, and inadequate housing influenced retention rates. Fewer health-promoting behaviors were described. Avoidance of alcohol and drugs was specifically discussed as enhancing medication adherence. The patient-provider relationship was found to be important in improving retention in HIV care. Patients who trusted their provider, had access to flexible scheduling, and received comprehensive visits, appointment reminders, and transportation assistance were better retained in care.

**Conceptual Framework Guiding the Study**

The review of studies in rural areas supported previous findings that medication adherence and retention in HIV care share similarities, but are independent constructs (Giordano et al., 2009; Murray et al., 2013). As such, theories specific to medication adherence behavior were not sought out to guide this research. Based on the literature
review, theoretical guidance needed to incorporate the complexities of individual characteristics on health behavior, inclusive of the influence of health care providers on those behaviors. Cox’s (1982) interaction model of client health behavior (IMCHB) is an excellent nursing framework because it includes demographic and psychological characteristics, the patient-nurse relationship, and explicitly designates adherence to treatment regimens as a health behavior. It did not, however, incorporate stress and coping mechanisms that affected retention in HIV care, an important construct identified in the research studies. Integration of the transactional model of stress and coping (TMSC; Lazarus & Folkman, 1984 as cited in Glanz & Schwarz, 2008) into the IMCHB added the necessary constructs to provide comprehensive guidance to HIV retention research (Graham, 2015).

**The Interaction Model of Client Health Behavior (IMCHB)**

The interaction model of client health behavior has informed a variety of studies since its inception, but none on HIV care retention (Ackerson, 2011; Cox, 1982; 2003; Cox, Miller, & Mull, 1987; Cox, et al., 2009; Cox & Roghmann, 1984; Robinson & Thomas, 2004). A search for the IMCHB and HIV returned one study that focused on condom use and sexual risk behavior (Abel & Chambers, 2004). Nurse scientists have reviewed the applicability of the IMCHB, deeming it a suitable model for health behaviors and outcomes research (Carter & Kulbok, 1995) and for use in diverse health care settings (Mathews, Secrest, & Muirhead, 2008).

The model describes three main categories involved in health behaviors (Cox, 1982). First is client singularity, or the demographic, experiential, emotional, and psychological aspects of individuals. Client singularity involves the generally fixed
variables including age, race, gender, social interactions, experience with health care, and environmental resources, such as geographic location and financial climate. It also uniquely encompasses the dynamic variables of individuals—motivation for healthy behaviors; knowledge, attitudes, and beliefs about health; and emotional responses to health experiences.

The model’s second category involves the patient-professional interaction, which includes professional competence, health professional delivery of information, the emotional support provided by health professionals, and whether or not health professionals supported patient-centered decision making.

The final category is listed as health outcomes, but received criticism because there are actually four health behaviors and one health outcome (Carter & Kulbok, 1995). The health behavior of specific interest to this study is adherence to the recommended care regimen, which is defined as the ability to comply with treatments that promote health (Cox, 1982; 2003; Mathews et al., 2008). Adherence to care regimens is conceptually consistent with being retained in HIV care.
Figure 2.3. The Interaction Model of Client Health Behavior


The Transactional Model of Stress and Coping (TMSC)

The transactional model of stress and coping (Lazarus & Folkman, 1984 as cited in Glanz & Schwarz, 2008) views stress and coping as a dynamic process that affects health status and quality of life. Initially, individuals evaluate stress through a primary cognitive appraisal process. During this process, individuals perceive their susceptibility to a stressor as well as the cause and severity of the stressor. Another consideration taken into account is whether or not the stressor affects their goals.
Secondary appraisal includes an individual’s perceived ability to manage associated emotions and outcomes, as well as their confidence, or coping self-efficacy, in doing so. Depending on these appraisals, there are several coping responses. Coping efforts dissect into meaning-based, problem-based, and emotion-based coping efforts. Meaning-based coping involves positive reframing of situations and experiences, updating goals, and searching personal and spiritual beliefs for explanations. Problem-based coping includes identifying information and realistic solutions as a way to cope. Emotion-based coping refers to shifting negative thoughts or feelings about a situation in an effort to cope. The sub-concepts of meaning-based coping (certain personality dispositions and social support) moderate the secondary appraisal and coping effort, as well as coping outcomes.

Stress and coping concepts are evident in the HIV literature. Stress was found to exacerbate HIV disease through its affect on the endocrine system, specifically the hypothalamic-pituitary-axis (Cole, 2008). Coping styles also appear to influence HIV disease progression. One group of researchers reviewed articles evaluating positive affect, finding meaning, spirituality, dispositional optimism, active coping efforts, personality, self-efficacy, emotional expression, and social support in relation to HIV disease. It was shown that active coping efforts, dispositional optimism, and spirituality had significant effects on slowing HIV disease progression (Ironson & Hayward, 2008). Another group of researchers determined that maladaptive coping dispositions, such as those that involve the inability to receive, process, and display emotions normally, were associated with immune dysfunction in PLWH (Temoshok et al., 2008). While few successful interventions targeting better coping and stress management were found in
the review of literature (Blashill, Perry, & Safren, 2011), one group of researchers found
that helping minority PLWH disclose their HIV status increased rates of retention in HIV
care (Wohl et al., 2011).

Figure 2.4. The Transactional Model of Stress and Coping.

Note. QOL = quality of life. Retrieved with permission and modified from
fittingpieces.org/research/learning-well-info/psychological-theories-on-human-
health-and-development/transactional-model-of-stress-and-adaptive-coping/ (Shattah,
behavior and transactional model of stress and coping as a tool for understanding
retention in HIV care across the lifespan. Copyright [2015] by Elsevier Inc. Reprinted
with permission.
Integration of the IMCHB and the TMSC

Graham’s (2015) conceptual framework integrated concepts from the Transactional Model of Stress and Coping into the Interaction Model of Client Health Behavior in a way that addressed both biobehavioral and system processes related to HIV care retention (see Figure 2.5).

Figure 2.5. Graham’s Integrated Framework

Figure 2.6 adds detail about the sub-concepts found within the integrated model. Walking through the model, it can be seen that background and dynamic variables influence perceptions of stress. The patient-provider relationship influences the way patients think about and perceive their stress. All of these experiences and perceptions affect coping skills, along with how individuals find meaning in their coping processes, problem-solving, and managing associated emotions. Health behaviors depend on the coping process and health outcomes, while adaptation depends on the health behaviors.

Figure 2.6. The IMCHB and the TMSC integrated model with descriptive detail

Note. IMCHB = Interaction Model of Client Health Behavior. TMSC = Transactional Model of Stress and Coping. Italic print shows that concepts are from the TMSC. Regular print means concepts come primarily from the IMCHB. Italicized print means concepts come from the TMSC. Underlined concepts are found in both the IMCHB and the TMSC. From Graham, L.J. (2015). Integration of the interaction model of client health behavior and transactional model of stress and coping as a tool for understanding retention in HIV care across the lifespan. Copyright [2015] by Elsevier Inc. Reprinted with permission.
This integrated conceptual framework informs the current study in that it addresses background, dynamic, patient-health care provider, coping variables and their associations with the health behavior of HIV care retention, and the health outcomes of HIV viral suppression.

While not all variables could be explored in this study, the selected variables were derived from the literature on the concept of retention in HIV care and the focused review of the rural literature. The integrated framework provided a cohesive structure to the relevant variables, which allowed for model testing and a variety of research.
CHAPTER III

METHODS

Design

This study fell under the auspices of exploratory research as a predictive correlational study design that was cross-sectional in nature (Portney & Watkins, 2009). The main outcome variable was retention in HIV care (yes/no), with a secondary categorical outcome variable of viral suppression (yes/no). As the outcome variables were binary, logistic regression was used for data analysis. Logistic regression allowed for the testing of statistical models to understand the strength and direction of relationships between variables. It did not determine causality (Plichta & Kelvin, 2013).

Variables

Demographic variables were captured as a way to describe the study’s sample, which included age, race, gender, risk factor, education, and years living with HIV. Independent variables included distance from an HIV clinic, rurality, country of origin, health literacy, current substance abuse, depression, patient-provider interaction, health locus of control, and the coping process. Dependent variables included retention in HIV care and viral suppression.

There has been no consensus on the right way to measure retention. Mugavero and colleagues (2012) evaluated six common methods to see if one was superior. The common measures were: (a) number of “no show” visits in a specified time period, (b) a no show rate, (c) proportion of scheduled visits over those actually attended, (d) the number of 4-month intervals with one visit, (e) a 6-month gap measure (equal to or more than 189 days between sequential visits), and (f) two visits separated by 90 or
more days in a 12-month period of time. All six measures were significantly associated with each other \((p < 0.0001)\). The authors found that each measure had its usefulness and none was better overall than the others. However, more recent research supports the use of missed visits as the best retention of care measure when compared to other standard measurements as missed visits better predict viral suppression, progression to AIDS, emergency department visits, and hospitalizations (Reveles et al., 2015), as well as all-cause mortality (Mugavero et al., 2014). As such, in this study, retention in HIV care was operationalized by evaluating the number of missed visits in an outpatient HIV clinic. Even one missed visit has been found to increase the odds of experiencing HIV-related morbidity and mortality (Park et al., 2007). Another study that examined missed visits by number, categories, and percent found a 71% increase in mortality when at least one visit was missed (Horberg et al., 2013). For this study, retention in care was defined as no missed visits. The variable was dichotomized into no missed visits or one or more missed visits.

A missed visit was defined as not keeping an appointment and not canceling in advance (a no show), which is consistent with previous definitions in the literature (Mugavero et al., 2012; Mugavero et al., 2014; Reveles et al., 2015). For this study, canceling in advance meant notifying the clinic at least 24 hours ahead of the scheduled appointment time.

The independent variables of distance from clinic, zip code of residence to determine RUCC, country of origin, patient-provider interaction, health locus of control, and coping process was obtained via a survey that occurred at one point in time and, thus, was cross-sectional in nature. Health literacy, substance use, depression, and viral
suppression data were obtained via the electronic medical record (EMR). A percentage of missed visits was calculated based on all visits attended at the clinic since a patient’s first appointment and involved EMR data and manual data abstraction if visits preceded 2012, the year the EMR was instituted. EMR data points, if more than one, were obtained from the visit closest to the survey date.

**Sample**

The sample was obtained from the pool of patients in an HIV primary and specialty care clinic in western Colorado. For the clinic in general, approximately 75% of patients are male and 25% are female; about 75% are Caucasian, 20% are Hispanic/Latino, and 5% are African-American, Native-American, or Other. About half of the participants report an HIV risk factor of MSM, 40% report HIV risk as heterosexual, and 8% report risk through IDU. Approximately 2% of patients report their risk as unknown or other. Patient ages range from 18 to 75 years of age, but the majority are 40 to 60 years of age.

**Sample Size**

Based on a power analysis using the statistical software program G*Power, version 3.1.9.2, it was determined that a minimum sample size of 102 participants would attain adequate power to achieve this study’s aims. An a priori α was set at .05, with β set at .20 for power at 80%, which has widely been considered the level required to protect against committing a Type II error (Portney & Watkins, 2009). Additionally, detection of a medium effect size was a reasonable expectation (Oliver & Bell, 2013); thus, an odds ratio of 1.9 was used in the power analysis as this corresponded to a medium Cohen’s $d$ effect size (Field, 2013). Very large samples are required to detect
small effect sizes; however, this was not possible in this study because the absolute number of PLWH served at this clinic was relatively small.

**Inclusion/Exclusion Criteria**

Eligible participants had a diagnosis of HIV with or without an AIDS diagnosis, were ages 18 or older, were English- or Spanish-speaking, were able to provide informed consent, and had a first visit more than 12 months before the start of the study to allow for at least 1 year of appointment opportunities. Patients residing in assisted living or other similar facilities, or who were incarcerated were excluded if they did not have control over scheduling their own medical appointments. Native speakers of other than English or Spanish were excluded as materials and translation services were only available in English and Spanish.

**Recruitment**

All PLWH in western Colorado who had at least one visit at the St. Mary’s Family Medicine HIV Clinic at least 12 months prior to the study’s initiation were invited to participate ($N=199$). The survey and a consent form were mailed to all eligible HIV-infected patients in the clinic. Patients were asked to return the survey in a pre-stamped and self-addressed envelope that was provided in the mailing. No incentives were offered as the host agency has a policy against the provision of incentives for research participants. A description of the demographics of respondents and non-respondents was performed to address sampling bias as a threat to validity as well as to assess the overall response rate.
Setting

The research was conducted in an outpatient HIV clinic nested within a family medicine residency clinic in western Colorado. The HIV clinic served approximately 240 PLWH from 22 counties of western Colorado, an area nearly the size of the state of Kentucky. Western Colorado includes rural, semi-rural and frontier counties, affluent ski resort towns, and two Native-American reservations. As a result, there is great disparity in the socioeconomic status of residents. Western Colorado is geographically diverse with limited, infrequent public transportation along the east-west I-70 corridor and no inter-community public transportation otherwise. High mountain passes, which are often impassable during the winter season, must be traversed on any road going into a large metropolitan area.

Procedures

Data Collection

Participants completed a self-administered survey via mail (Appendix D). First, the survey and consent form was mailed with a due date of 3 weeks after receipt. A month after the initial mailing, non-respondents were called and encouraged to complete the survey. Another copy of the consent and survey was mailed to non-responders 6 to 8 weeks after the initial mailing. Throughout the 3-month data collection period, patients were invited to consent and participate in the study while at the clinic for routine care.

Surveys requested information on education, years living with HIV, residential distance from clinic, and country of origin; they were also asked to complete the health locus of control, patient-health care team interaction, and coping process instruments.
Age, gender, race, HIV risk factor, zip code, health literacy, substance abuse screen, and depression screen were obtained via the EMR. Health literacy has been assessed on all patients at the clinic since 2008 using the screening tool described below. The resulting numeric value is entered into the EMR. Patients with weak health literacy receive an intervention at each visit to promote understanding of visit information, health education, and future recommendations. The dependent variables of missed visits and viral suppression were also obtained through the EMR and through manual data abstraction in situations where participants were patients prior to the EMR.

A bilingual English/Spanish research assistant was available to conduct the survey in person or over the telephone for participants with limited literacy in English or Spanish. All instruments were available in English and Spanish, but, not all participants were able to read. The consent process was witnessed by a staff member unaffiliated with the research for all illiterate participants and all participants completing the survey by telephone.

The Institutional Review Boards (IRB) at the University of Colorado–Denver and St. Mary's Hospital and Medical Center reviewed the study proposal and related materials. Due to the non-invasive nature of the proposed study, it met criteria for an expedited review (Wood & Ross-Kerr, 2011). Even so, caution was taken to ensure that participants received a robust informed consent form. Written and verbal informed consent were both available in English and Spanish. A unique identifier was created for each participant and that coded number was used instead of actual names. Data were stored on a password-protected laptop computer. All surveys and the master list of
patient names and corresponding numbers were stored in a locked file cabinet in a locked office in the HIV clinic at St. Mary’s Family Medicine.

**Variable Data Collection**

Descriptive variables included:

- **Age**: Exact age in years as of date on survey.
- **Race/Ethnicity**: Caucasian, African-American, Asian, Latino/a, and Native American
- **Gender**: Male, Female, Transgender
- **HIV risk factor**: MSM, heterosexual contact, IDU, and other.
- **Education**: Graduated high school—*yes/no*
- **Years living with HIV**: Number of years

Independent variables included:

- **Distance from clinic**: in exact miles.
- **Rurality**: designated by Rural Urban Continuum Codes (RUCC; Vanderboom & Madigan, 2007; Appendix K)
- **Country of origin**: Foreign-born - *yes/no*
- **Health literacy adequacy**: *yes/no*, assessed by The Newest Vital Sign tool (Appendix E), which has been in use in the clinic since 2008 (Pfizer Inc., 2011; Weiss et al., 2005). The Newest Vital Sign assesses the ability to understand words, numbers, and forms and is validated in both English and Spanish (Pfizer, Inc., 2011). A score of 4 or higher on a 6-item screen supported adequate health literacy (coded 1); a score of 3 or lower revealed inadequate health literacy (coded 0).
• Problematic alcohol use and/or substance abuse \( (\text{never/former} = 0, \text{current} = 1) \) using the screening, brief intervention, and referral to treatment (SBIRT) tool in use in the study clinic since 2008 (Babor et al., 2007; Appendix F).

• Depression—\textit{yes/no}, using the patient health questionnaire (Appendix G). Scores of 0-4 represented no or minimal depression; scores of 5 or higher were considered a positive screen as those revealed mild to severe depression (PHQ-9; Pfizer, Inc., 1999).

• Patient-Health care team Interaction—score from the Patient-Doctor Questionnaire-9, which was available in English and Spanish (Van der Feltz-Cornelius, Van Oppen, Van Marwijk, De Beurs, & Van Dyck, 2004; Appendix H).

• Health locus of control—score from the four subscales \textit{(internal, chance, doctor, and other people)} of the Multidimensional Health Locus of Control Form C (Wallston, Stein, & Smith, 1994; Appendix I).

• Coping process—score from the BriefCOPE, which was available in English and Spanish (Carver, 1997). When the BriefCOPE was adapted to Spanish, two of the 14 original scales did not converge, and the instrument was adapted to 12 scales and 24 items for use in research including English and Spanish-language participants (Perczek, Carver, & Price, 2000; Appendix J). More detail is provided in the Instruments Section.

Dependent variables included:

• Retention in HIV care—operationalized through total number of no show visits because patients initiated care at the clinic. No missed visits coded 0; \( \geq 1 \) missed visit coded 1. Patients who canceled a visit at least 24 hours in advance of an
appointment were not counted as a no show and that visit was removed from the denominator.

- Viral suppression—yes/no HIV RNA-PCR (viral load [VL]) lower than or equal to 200 copies/mL.

**Instruments**

**Multidimensional Health Locus of Control (MHLC).** The MHLC scales (Wallston, Wallston, & DeVellis, 1978) instrument was reviewed to measure concepts in Graham’s conceptual framework related to primary and secondary cognitive appraisal, specifically a person’s perceived control over outcomes and emotions. The MHLC scale, a widely used and well-validated instrument, measured beliefs about health behaviors and an individual’s feelings of control. A newer form of the MHLC scale, Form C (Wallston, Stein, & Smith, 1994), was developed to assess loci of control in patients living with chronic conditions. It measured four types of locus of control:

1. **Internal Locus of Control**—The belief that being healthy or sick stems from one’s own behaviors.

2. **Chance Locus of Control**—The belief that one’s health is a result of fate or chance.

3. **Doctor Locus of Control**—The belief that health results from the provider.

4. **Other People Locus of Control**—The belief that other people in one’s life have power over health behaviors.

These subscales are scored separately, but categorically one is internally focused and the other three are externally focused. Wallston and Wallston (1982) explained internal and external loci of control:
...although there has been quite a diversity of findings and conclusions, it has generally been the case that—compared to those persons espousing external locus of control expectancies—internals are more potent, competent, effective persons, likely to take responsibility for their actions and to take steps to change aversive life situations. (p. 67)

The tool consisted of 18 items that were answered with a 6-item Likert scale ranging from strongly disagree (1) to strongly agree (6. Psychometric testing demonstrated Cronbach’s alpha reliabilities of 0.85 for the internal subscale, 0.79 for chance, 0.71 for doctors, and 0.70 for other people. Additionally, the MHLC scale has been used in research related to a variety of aspects of HIV, but no studies related to HIV care retention were found.

When the MHLC-C was tested in a sample of mentally ill Spanish-speaking patients (De las Cuevas, Peñate, Betancort, & Cabrera, 2015), a confirmatory factor analysis supported the four subscales ($\chi^2(\text{df}) = 200.58(125)$; RMSEA (CI) = 0.039 (0.03–0.047); GFI = 0.994; CFI = 0.953). Cronbach's alpha reliabilities were 0.74 for the internal subscale, 0.65 for chance, 0.54 for doctors, and 0.48 for other, all lower than the English version. Two items (Item #2 and #18 in the instrument) loaded lower than 0.50 (0.30 and 0.35, respectively) and could have been considered for elimination, but were retained in this study.

**The Patient-Doctor Relationship Questionnaire–9 (PDRQ-9).** The PDRQ-9 in primary care was developed by Van der Feltz-Cornelius and colleagues (2004) from an existing scale that measured the therapeutic relationship between therapist and patient. The authors felt that a tool specific to the therapeutic aspect of the patient-doctor relationship was needed. The PDRQ-9 measured patients’ perceptions of their primary care providers as helpful, empathic, open, and effective. A recent review article
of 19 different instruments measuring the doctor-patient relationship found the PDRQ-9 to be short, easy to use, and well suited for use in primary care settings (Eveleigh et al., 2012). The PDRQ-9 is a 9-question instrument answered with a 5-item Likert scale ranging from not at all appropriate (1) to totally appropriate (5), with Cronbach’s alpha reliability of 0.94 published in the psychometric study based on 200 responses from patients of five primary care providers (Van der Feltz-Cornelius et al., 2004). The tool is available in English and Spanish and free for public use.

No studies were found that used this tool in HIV research. Team-based care has been the norm for patients of the western Colorado HIV clinic since its inception in 2000. As a result, the following sentence was inserted into the PDRQ-9 instructions: “When the questions say PCP or primary care provider, we are asking about the HIV care team that includes your physician, nurse, social worker, and health educator.” The PDRQ-9, translated into Spanish, was used in a sample of 451 patients from six community health centers in Madrid, Spain with a Cronbach’s alpha of 0.952 (Martín-Fernández, del Cura-González, Gómez-Gascón, Fernández-López, Pajares-Carabajal, & Moreno-Jiménez, 2010).

BriefCOPE. Coping process was measured using the BriefCOPE. The original BriefCOPE loaded 28 items and 14 scales from the original COPE instrument of 60 items and 15 scales (Carver, 1997). Response choices range from I didn’t do this at all (1) to I did this a lot (4). Scales for the BriefCOPE included Active Coping (α = .68), Planning (α = .73), Positive Reframing (α = .64), Acceptance (α = .57), Humor (α = .73), Religion (α = .82), Using Emotional Support (α = .71), Using Instrumental Support (α = .64), Self-
Distraction ($\alpha = .71$), Denial ($\alpha = .54$), Venting ($\alpha = .50$), Substance Use ($\alpha = .90$), Behavioral Disengagement ($\alpha = .65$), and Self-Blame ($\alpha = .69$).

The BriefCOPE was available in Spanish. Translations and back translations incorporated native Spanish speakers from several Spanish-language countries. English and Spanish versions of the BriefCOPE were tested together in a group of bilingual students (Perczek, Carver, & Price, 2000). Factor analysis revealed 12 factors with Eigenvalues greater than ‘1’ that accounted for 78% of the variance. Subscales included Active Coping ($\alpha = .80$ English; $\alpha = .72$ Spanish), Planning ($\alpha = .79$ English; $\alpha = .75$ Spanish), Positive Reframing ($\alpha = .76$ English; $\alpha = .78$ Spanish), Acceptance ($\alpha = .59$ English; $\alpha = .62$ Spanish), Humor ($\alpha = .85$ English; $\alpha = .81$ Spanish), Religion ($\alpha = .86$ English; $\alpha = .83$ Spanish), Using Emotional Support ($\alpha = .92$ English; $\alpha = .94$ Spanish), Self-Distraction ($\alpha = .59$ English; $\alpha = .64$ Spanish), Denial ($\alpha = .78$ English; $\alpha = .80$ Spanish), Substance Use ($\alpha = .93$ English; $\alpha = .93$ Spanish), Venting ($\alpha = .65$ English; $\alpha = .73$ Spanish), and Behavioral Disengagement ($\alpha = .57$ English; $\alpha = .74$ Spanish). Two scales, Behavioral Disengagement and Venting, did not converge. As a result, they were not used in this study (see Appendix 6). Interestingly, the BriefCOPE provided for public use via Dr. Carver’s Website (2007) omitted questions related to the use of instrumental support and self-blame scales. As a result, only 20 questions delivering 10 subscales were obtained from this study’s sample. Subscales included in this study were: self-distraction, active coping, denial, substance use, use of emotional support, positive reframing, planning, humor, acceptance, and religion.

A PubMed search of the BriefCOPE and HIV returned 58 articles, but none were specifically related to HIV care retention. However, the BriefCOPE has been used
widely in general health research and specifically in studies from the Coping with HIV/AIDS in the Southeast (CHASE) cohort (Mugavero et al., 2009).

**Analysis Strategies**

**Missing data.** Missing data were evaluated for any effect on the analyses. Using the survey, participants provided descriptive and demographic data, and then answered the 18 MHLC Form C questions, the 9 modified PDRQ-9 questions, and the 24 BriefCOPE questions. These 51 questions took approximately 10-15 minutes to complete. While the survey was relatively brief, which helped reduce missing data, some missing data were inevitable. Missing data were analyzed as follows (Bannon, Jr., 2013; Collins, Shafer, & Kam, 2001): Using SPSS commands Analyze—Descriptive Statistics—Frequencies, frequency tables were scanned for missing data by variable. From these tables, it was possible to categorize the amount of missing data. First, SPSS determined the proportion of missing data values per study participant. Then, the SPSS commands were used to see the proportion of study participants who had missing data values. Patterns of missing data were then evaluated.

For small samples, Bannon. (2013) recommended removing participants with fewer than 80% valid responses, if the total number was less than 5% of the overall sample. For larger samples, he supported removing participants with fewer than 80% valid responses if no more than 10% of the overall sample was affected. For participants who provided more than 80% of valid responses, but not 100%, SPSS performed multiple imputations, which is an inclusive, accurate, and effective way to handle missing data (Collins, Shafer, & Kam, 2001).
**Demographics.** All variables were analyzed descriptively to evaluate means, frequencies, distributions, and correlations before the first regression runs. Highly correlated variables were removed or consolidated and analyzed using SPSS, version 21.

**Analysis technique.** SPSS, version 21, was used to code and analyze data. Logistic regression was used to analyze results; the goal was to predict independent variable membership into categorical outcome groups (Field, 2013). Information obtained from the analyses included statistical significance of the model, fit of the model to the data, approximation of the amount of variance in the dependent variables as explained by the independent variables, adjusted odds ratios and associated confidence intervals, as well as the statistical significance of each adjusted odds ratio (Plichta & Kelvin, 2013).

Before testing each predictor variable, univariate and bivariate descriptive statistics were run to evaluate distributions of the criterion and predictor variables and to assess covariation between the variables. A series of logistic analyses were then run to test the relationship between each predictor variable and retention in HIV care, and, separately, the relationship between each predictor variable and viral suppression. Significant and non-significant relationships are described in more detail in Chapter 4. The relationships between the independent variables were evaluated to assess for multicollinearity, then each hypothesis was tested (Plichta & Kelvin, 2013). As a conceptual framework guided this study, forward block entry method was used and variables were entered in accordance with the framework as it reads from left to right, and allowed model building of the best predictors of retention in HIV care and viral
suppression. Goodness of fit was evaluated using the Hosmer and Lemeshow Chi-Square and the Nagelkerke $R^2$ statistics.

**Aim 1, hypothesis 1:** Greater distance from home to the clinic will decrease the odds of being retained in care and virally suppressed.

**Aim 1, hypothesis 2:** Rurality will decrease the odds of being retained in care and virally suppressed.

**Aim 1, hypothesis 3:** Country of origin outside of the United States will decrease the odds of being retained in care and virally suppressed.

**Aim 1, hypothesis 4:** Adequate health literacy will increase the odds of being retained in care and virally suppressed.

In SPSS under Analyze—Regression—Binary Logistic, the retention in care variable was moved into the Dependent Variable box and the predictor variable was moved into the Covariate box. The Methods box remained Enter, which was the default. Covariates were screened in the preliminary steps and included as appropriate. In the Options menu, the defaults of .05 to include a variable and .10 to exclude it were retained. Each variable was modeled with retention in care as the dependent variable and then again with viral suppression as the dependent variable.

**Aim 2, hypothesis 5:** Higher scores on the PDRQ-9 will increase the odds of being retained in care and virally suppressed. In SPSS under Analyze—Regression—Binary Logistic, the retention in care variable populated the Dependent Variable box and the PDRQ-9 score variable was added into the Covariate box. The Methods box remained Enter, which was the default. In the Options menu, the defaults of .05 to include a variable and .10 to exclude it were retained. Each variable was
modeled with retention in care as the dependent variable and then again with viral suppression as the dependent variable.

**Aim 3, hypothesis 6: Screening positive for substance abuse will decrease the odds of being retained in care and virally suppressed.** In SPSS under Analyze—Regression—Binary Logistic, the retention in care variable was placed into the Dependent Variable box and the substance use variable was entered through the Categorical option, which allows for categorical predictor variables. The Methods box remained Enter, which was the default. In the Options menu, the defaults of .05 to include a variable and .10 to exclude it were retained. Each variable was modeled with retention in care as the dependent variable and then again with viral suppression as the dependent variable.

**Aim 3, hypothesis 7: Internal and doctor health loci of control will increase the odds of being retained in care and virally suppressed; chance and other people loci of control will decrease the odds of being retained in HIV care and virally suppressed.** In SPSS under Analyze—Regression—Binary Logistic, retention in care variable was placed into the Dependent Variable box and the MHLC-C internal subscale score variable was added into the Covariate box and run. Then the doctor subscale score was added into the Covariate box and the analysis was run. The chance subscale score was entered next, followed by the other people subscale score. The Methods box remained Enter, which was the default. In the Options menu, the defaults of .05 to include a variable and .10 to exclude it were retained. Each variable was modeled with retention in care as the dependent variable and then again with viral suppression as the dependent variable.
Aim 3, hypothesis 8: Screening positive on a depression screen will decrease the odds of being retained in care and virally suppressed. In SPSS under Analyze—Regression—Binary Logistic, the retention in care variable was placed into the Dependent Variable box and the depression variable was added into the Covariate box. The Methods box remained Enter, which was the default. In the Options menu, the defaults of .05 to include a variable and .10 to exclude it were retained. The variable was then modeled with retention in care as the dependent variable and then again with viral suppression as the dependent variable.

Aim 4, hypothesis 9: Coping processes will significantly mediate the relationships between rurality, country of origin, the patient-provider interaction, health literacy, substance abuse, depression, health locus of control, and retention in HIV care. Baron and Kenney’s (1986) causal steps method was used to test for mediation. In this approach, variables are considered mediators when they affect variations in the mediating variable (path A), when the mediating variable affects variations in the outcome variable (path B), and when a previously significant relationship between predictor variable and outcome variable is no longer significant when paths A and B are controlled (path C; Figure 9). SPSS software now calculates the indirect effect, or the effect of mediation (paths A and B), with confidence intervals replacing regression equations and a Sobel test initially used to test the significance of the mediated effect (Field, 2013).
Figure 3.1. Mediation diagram


In SPSS under Analyze—Regression—PROCESS (a custom dialog box installed from http://www.afhayes.com/spss-sas-and-mplus-macros-and-code.html) – Model 4 – Options (select Effect size, Sobel test, Total effect model)—OK to run the analysis and test the mediation model (Hayes, 2016).

**Assumptions**

For logistic regression, the outcome variable must be dichotomous and independent, meaning each participant can only be in one of the two outcome groups (Grimm & Yarnold, 1995). Linearity, normal distribution, and homoscedasticity are not assumed, but multicollinearity between predictor variables must be assessed (Bannon, Jr., 2013).

- Assess for highly correlated variables. Initially, a correlation matrix was examined to look for insignificant and highly correlated relationships. Multicollinearity was addressed through this process.
• Errors must be normally distributed. The residuals in the model should be
normally distributed with a mean of about zero. It is not necessary for the
predictor variables to be normally distributed, except in the case of small
samples. Large samples can handle a lack of normal variable distribution due to
the central limit theorem.
• All predictor variables should be quantitative (measured at the interval level) or
categorical (with two categories).
• The predictor variables should have differences and not have variances of zero.
• Measurement error should be minimized; that is, the measurements should be a
good gauge of the variable.

Meeting these assumptions boosts confidence that the results from the sample model
are more like the population model. Not meeting these assumptions means that a
population model cannot be accurately estimated. However, statistical techniques can
be used to help meet the assumptions. For example, one or more predictor variables
can be removed from the analysis if significant multicollinearity is a concern.

The mediation model requires consideration of additional assumptions. The
dependent variable cannot cause the mediator variable (arrow B can not be reversed in
Figure 9), and there should be no measurement error in the mediator. Measurement
error in the mediator will cause an underestimation of the mediating effect and an
overestimation of predictor variable effects on the outcome variable. Structural
modeling accounts for this error, but it can be difficult to ascertain in regression
modeling (Baron & Kenny, 1986).
Error/Issue Monitoring

Missing data and assumptions of the analyses have been discussed at length. Corrections for unmet assumptions and missing data were performed before the logistic regression analysis was run. Beyond this, a significant problem arises if the minimum number of participants needed is not reached. In this study, the minimum required number of 102 participants was surpassed, with the total number of participants at 127.
CHAPTER IV

RESULTS

Introduction

The purpose of this research study was to explore relationships between demographic, psychosocial, and psychological variables, informed by theory and research, which affect retention in care for people living with HIV (PLWH) in rural western Colorado. The research questions guiding the study were:

1) Do health literacy, country of origin, rurality, distance from clinic, depression, substance abuse, patient-provider interaction, and health locus of control predict the likelihood of a PLWH being retained in HIV care and becoming virally suppressed?

2) Does the coping process mediate the effects between predictor variables and retention in HIV care?

Description of Sample and Univariate Analyses

Surveys were mailed to 199 eligible patients of the Western Colorado HIV Specialty Care Clinic. A total of 127 patients consented to participate in the study and either returned the survey by mail ($n=77$), completed a paper or iPad survey while in the clinic for a medical appointment ($n=44$), or completed the survey by telephone ($n=6$) for a 63.8% response rate. Data collection occurred from the end of October 2015 to the end of January 2016. Sample demographics are presented in Table 4.1. As can be seen in the table, the majority of participants completed the survey in English, were born in the United States, had lived with HIV for 1-15 years, drove 25 miles or less to the HIV clinic, lived in rural areas as designated by the Rural Urban Continuum Codes.
(RUCC), were 41 to 60 years of age, graduated from high school, were male, were White, reported an HIV risk factor of either MSM or heterosexual contact, had adequate health literacy, were not currently abusing substances or depressed, and had well-controlled HIV. However, significant percentages of participants were not health literate (30%), were actively abusing substances (39%), and screened positive for depression (31%). In terms of the dependent variable of keeping appointments, most participants had a history of missing at least one appointment in the HIV clinic without cancelling in advance.

Table 4.1

Demographics of Study Participants (n=127)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Result</th>
</tr>
</thead>
<tbody>
<tr>
<td>Language of survey</td>
<td>87% English 13% Spanish</td>
</tr>
<tr>
<td>Foreign-born</td>
<td>79% No 21% Yes</td>
</tr>
<tr>
<td>Years living with HIV</td>
<td></td>
</tr>
<tr>
<td>M = 14.3 (SD = 8.77)</td>
<td></td>
</tr>
<tr>
<td>Range: 1-35</td>
<td></td>
</tr>
<tr>
<td>1-5: 20%</td>
<td>21-25: 13%</td>
</tr>
<tr>
<td>6-10: 21%</td>
<td>26-30: 11%</td>
</tr>
<tr>
<td>11-15: 17%</td>
<td>31-35: 2%</td>
</tr>
<tr>
<td>16-20: 16%</td>
<td></td>
</tr>
<tr>
<td>Miles to care</td>
<td></td>
</tr>
<tr>
<td>M = 48.8 miles (SD = 57.1)</td>
<td></td>
</tr>
<tr>
<td>Range: 1-271</td>
<td></td>
</tr>
<tr>
<td>1-8: 38.6%</td>
<td>100-140: 15.7%</td>
</tr>
<tr>
<td>10-25: 15.7%</td>
<td>150-175: 4%</td>
</tr>
<tr>
<td>40-85: 22.9%</td>
<td>200-271: 3.1%</td>
</tr>
<tr>
<td>Rural Urban Continuum Codes (RUCC)</td>
<td></td>
</tr>
<tr>
<td>3: 50%</td>
<td>6: 5%</td>
</tr>
<tr>
<td>4: 13%</td>
<td>7: 16%</td>
</tr>
<tr>
<td>5: 14%</td>
<td>9: 2%</td>
</tr>
<tr>
<td>High School Graduate</td>
<td></td>
</tr>
<tr>
<td>20.5% No</td>
<td>79.5% Yes</td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>M = 48.7 years (SD = 11.87)</td>
<td></td>
</tr>
<tr>
<td>Range: 20-77</td>
<td></td>
</tr>
<tr>
<td>20-30: 6%</td>
<td>51-60: 38%</td>
</tr>
<tr>
<td>31-40: 21%</td>
<td>61-70: 11%</td>
</tr>
<tr>
<td>41-50: 21%</td>
<td>71-77: 3%</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>64.6% Male</td>
<td></td>
</tr>
<tr>
<td>34.6% Female</td>
<td></td>
</tr>
<tr>
<td>0.8% Transgender</td>
<td></td>
</tr>
</tbody>
</table>
Table 4.1 cont’d

<table>
<thead>
<tr>
<th>Variable</th>
<th>Result</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Race/Ethnicity</strong></td>
<td>White: 70%</td>
</tr>
<tr>
<td></td>
<td>Hispanic: 23%</td>
</tr>
<tr>
<td></td>
<td>Black: 3%</td>
</tr>
<tr>
<td></td>
<td>Native American: 3%</td>
</tr>
<tr>
<td></td>
<td>Asian: 1%</td>
</tr>
<tr>
<td><strong>HIV Risk Factor</strong></td>
<td>MSM sex: 45.7%</td>
</tr>
<tr>
<td></td>
<td>Heterosexual sex: 45.7%</td>
</tr>
<tr>
<td></td>
<td>IDU: 8.7%</td>
</tr>
<tr>
<td><strong>Health Literate</strong></td>
<td>30%: No</td>
</tr>
<tr>
<td></td>
<td>63%: Yes</td>
</tr>
<tr>
<td></td>
<td>7% missing data</td>
</tr>
<tr>
<td><strong>Current substance abuse</strong></td>
<td>61%: No</td>
</tr>
<tr>
<td></td>
<td>39%: Yes</td>
</tr>
<tr>
<td><strong>Screened positive for depression</strong></td>
<td>69%: No</td>
</tr>
<tr>
<td></td>
<td>31%: Yes</td>
</tr>
<tr>
<td><strong>Virally suppressed</strong></td>
<td>3%: No</td>
</tr>
<tr>
<td></td>
<td>97%: Yes</td>
</tr>
<tr>
<td><strong>Missed Visits</strong></td>
<td>$M = 1.64 \ (SD = 2.49); \text{Range: 0-11}$</td>
</tr>
<tr>
<td></td>
<td>48%: 0</td>
</tr>
<tr>
<td></td>
<td>52%: &gt;=1</td>
</tr>
</tbody>
</table>

*Note. M = mean; SD = standard deviation; HIV = human immunodeficiency virus; MSM = men who have sex with men; IDU = injection drug use.

Compared to PLWH in the state of Colorado and in the United States, the sample included fewer African-Americans, more Whites and Native Americans, and nearly the same percentages of Hispanics and Asians. Participants were more likely to be female and to report heterosexual sex as their risk factor for HIV infection compared to the state and the nation. Participants were slightly younger than PLWH in the state of Colorado overall, but much older than the average for PLWH throughout the United States. Not surprisingly, participants lived in much more rural counties compared to the general population of PLWH in Colorado (see Table 4.2).
Table 4.2

Study Sample Demographics Compared to State and National Statistics

<table>
<thead>
<tr>
<th></th>
<th>Western Colorado Sample of PLWH</th>
<th>State of Colorado(^a)</th>
<th>United States</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>70%</td>
<td>58.8%</td>
<td>31.6%(^a)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>23%</td>
<td>22.2%</td>
<td>21.4%(^a)</td>
</tr>
<tr>
<td>African-American</td>
<td>3%</td>
<td>16.4%</td>
<td>42.0%(^a)</td>
</tr>
<tr>
<td>Native American</td>
<td>3%</td>
<td>0.9%</td>
<td>0.3%(^a)</td>
</tr>
<tr>
<td>Asian/ Pacific Islander</td>
<td>1%</td>
<td>1%</td>
<td>1.2%(^a)</td>
</tr>
<tr>
<td>Males</td>
<td>64.6%</td>
<td>88.1%</td>
<td>76%(^b)</td>
</tr>
<tr>
<td>Females</td>
<td>34.6%</td>
<td>11.9%</td>
<td>20%(^c)</td>
</tr>
<tr>
<td>Transgender</td>
<td>0.8%</td>
<td>Not available</td>
<td>Data not uniformly collected. No direct comparison(^d)</td>
</tr>
<tr>
<td>MSM</td>
<td>45.7%</td>
<td>64.3%</td>
<td>55%(^e)</td>
</tr>
<tr>
<td>Heterosexual</td>
<td>45.7%</td>
<td>10.4%</td>
<td>25%(^e)</td>
</tr>
<tr>
<td>IVDU</td>
<td>8.7%</td>
<td>7%</td>
<td>14%(^e)</td>
</tr>
<tr>
<td>0-19 years old</td>
<td>0</td>
<td>0.5%</td>
<td>5%(^f)</td>
</tr>
<tr>
<td>20-39 years old</td>
<td>27%</td>
<td>20.6%</td>
<td>57%(^f)</td>
</tr>
<tr>
<td>40-59 years old</td>
<td>59%</td>
<td>63.9%</td>
<td>34%(^f)</td>
</tr>
<tr>
<td>60+ years old</td>
<td>14%</td>
<td>15%</td>
<td>5%(^f)</td>
</tr>
<tr>
<td>Urban</td>
<td>50%</td>
<td>95%</td>
<td>Not available</td>
</tr>
<tr>
<td>Rural/Frontier</td>
<td>50%</td>
<td>5%</td>
<td>Not available</td>
</tr>
</tbody>
</table>

Note. \(^a\) Colorado Department of Public Health and Environment (CDPHE, 2015); \(^b\) CDC, 2015: HIV among men in the United States; \(^c\) CDC, 2016: HIV among women; \(^d\) CDC, 2015: HIV among transgender people; \(^e\) CDC, 2016: HIV and AIDS in America: A snapshot; \(^f\) CDC, 2016: HIV among people aged 50 and over.

An independent \(t\)-test to assess differences between participants and non-participants was conducted on available variables (see Table 4.3). Compared to non-participants, participants were less likely to live in rural-designated RUCCs and were more likely to be older, female, and minority group members. No statistically significant differences were found between groups related to HIV acquisition risk factor, health literacy, or viral suppression. The results suggest potential sampling bias compared to the population of patients commonly seen by the clinic, who overall were likely to be even more rural than participants, as well as including a larger percentage
of men and younger patients. These factors may somewhat limit generalizability of results from this study, although the higher than expected proportion of minority group members in the current sample likely increases external validity of the results.

Table 4.3

*Indicates significance at the .05 level.

<table>
<thead>
<tr>
<th>Variable</th>
<th>M</th>
<th>SE</th>
<th>t</th>
<th>df</th>
<th>p</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>*RUCC</td>
<td>-.503</td>
<td>.246</td>
<td>-2.043</td>
<td>197</td>
<td>.042</td>
<td>-.988, -.017</td>
</tr>
<tr>
<td>*Age</td>
<td>4.875</td>
<td>1.672</td>
<td>2.916</td>
<td>197</td>
<td>.004</td>
<td>1.579, 8.172</td>
</tr>
<tr>
<td>*Gender</td>
<td>-.172</td>
<td>.062</td>
<td>-2.768</td>
<td>180</td>
<td>.006</td>
<td>-.294, -.049</td>
</tr>
<tr>
<td>*Race/Ethnicity</td>
<td>.636</td>
<td>.149</td>
<td>4.279</td>
<td>195</td>
<td>.000</td>
<td>.343, .929</td>
</tr>
<tr>
<td>HIV Risk Factor</td>
<td>-.120</td>
<td>.130</td>
<td>-.926</td>
<td>105</td>
<td>.357</td>
<td>-.377, .137</td>
</tr>
<tr>
<td>Health Literacy</td>
<td>.071</td>
<td>.075</td>
<td>.949</td>
<td>177</td>
<td>.344</td>
<td>-.077, .220</td>
</tr>
<tr>
<td>Viral Suppression</td>
<td>-.052</td>
<td>.036</td>
<td>-1.428</td>
<td>103</td>
<td>.156</td>
<td>-.124, .020</td>
</tr>
</tbody>
</table>

See *Note*.

**Checks of Data Integrity**

To ensure that the data were appropriate for analyses, several checks for data integrity were performed related to statistical power, test assumptions, missing data, and measurement tools.

**Statistical Power**

Based on a power analysis using the statistical software program G*Power, version 3.1.9.2, it was determined that a minimum sample size of 102 participants would provide adequate power to achieve the study's aims. An a priori α was set at .05.
with β set at .20 for power at 80%, which has been widely considered the level required to protect against committing a Type II error (Portney & Watkins, 2009). Additionally, detection of a medium effect size was a reasonable expectation (Field, 2013); thus, an odds ratio of 1.9 was used in the power analysis as this corresponded to a medium Cohen’s $d$ effect size (Oliver & Bell, 2013). A post hoc power analysis was performed using G*Power with the a priori settings, but using the known sample size of 127 to calculate actual power. The analysis revealed that the study was adequately powered at 90.6%, well above the 80% level that is generally considered acceptable (Portney & Watkins, 2009).

**Test Assumptions**

Binary logistic regression has fewer test assumptions than multiple linear regressions in that linearity, normal distribution, and homoscedasticity are not assumed; however, multicollinearity must be evaluated between predictor variables as significant multicollinearity weakens the overall regression model (Bannon, Jr., 2013). Nearly an equal number of participants fell into each dichotomous category of the primary dependent variable as seen in Table 4.1 (48% vs. 52%). Binary logistic regression has more power when the dependent variable has equal membership in each group, as found in this sample.

In this study, **RUCC** and **miles to care** were the most highly correlated variables, Kendall’s $\tau = .691$, $p < .001$, 95% CI [.642, .736]. Although .691 does not reach the .80—.90 level of multicollinearity that is commonly considered a cause for concern (Bannon, Jr., 2013), it was decided that the correlation was high enough that including both of these variables in the regression models would likely affect the results.
Collinearity diagnostics showed $VIF = 2.2$ and a tolerance = .45 between these two variables. Again these results were outside the usual thresholds for serious multicollinearity problems—$VIF$ greater than 2.5 and a tolerance less than .2 (Bannon, Jr., 2013), but were high enough to warrant further evaluation of collinearity. This was handled by evaluating predictors separately before placing them in the same equation; as described below, the predictors evaluated together were not significant, so the one predictor was dropped.

Each variable was regressed to the dependent variable of *missed visits*. Both variables were significant predictors of missed visits ($miles \text{ to care } p = .007; \text{RUCC } p = .009$). When regressed to *missed visits* together, however, neither were significant ($miles \text{ to care } p = .23; \text{RUCC } p = .40$). While the RUCC classification helps describe the sample and is thought to be one of the most precise Federal classification systems for identifying rural counties, what rurality means conceptually is more complex than simply grouping zip codes by population density and proximity to large metropolitan areas (Vanderboom & Madigan, 2007). Due to the RUCC’s collinearity with the *miles to care* variable and the complexity of what RUCC means as compared to actual miles required to reach medical care, the RUCC was dropped from further models and the *miles to care* variable was retained as a predictor variable in the logistic regression analyses.

**Missing Data**

Missing data were minimized in several ways. Participants completing the survey during clinic appointments could either complete the survey on paper or use an iPad, which minimized missing responses. Before leaving the clinic, the principal
investigator (PI) reviewed the participant’s answers and asked participants to answer questions that were unintentionally skipped or to choose just one response if more than one had been marked. For surveys returned in the mail, the PI contacted each participant via telephone when possible or during a clinic visit to obtain answers to any omitted questions. Three unique patients, all completing the survey in English, missed one different BriefCOPE question (different items for each participant); no other survey questions had missing data. EMR data were incomplete for one variable only—health literacy. Health literacy data were missing for 7.1% (n=9) of participants. In total, 12 participants or 9.4% of the sample missed one data element, but even these 12 respondents had valid responses to 98.5% of the data set, and 90.6% of participants had no missing data. No participant missed more than one data element. No missing data existed for either of the dependent variables, missed visits and viral suppression.

A \( \chi^2 \) Test was performed to compare the variable with the most missing data, health literacy, to the main dependent variable, missed visits. The health literacy variable was recoded and transformed to create a “missingness” variable on health literacy data. The \( \chi^2 \) test was not significant, \( \chi^2 = 0.84, p = .360 \), indicating that no relationship between missing health literacy data and missed visits existed. This indicated that health literacy data were missing at random with respect to the dependent variable (MAR), which was a desirable property suggesting a lack of bias in the results. However, an analysis of the relationship between missing health literacy cases and the secondary dependent variable, viral suppression, was significant, \( \chi^2 = 11.55, p = .001 \). Only four patients in the entire sample were not virally suppressed, and two of the four were missing health literacy data. The very small numbers may have
affected these results, and even though these results suggested data that were potentially missing not at random (MNAR), modern data imputation procedures are relatively robust to this problem as long as the correlation between missingness and the dependent variable is .40 or less (Collins, Shafer, & Kam, 2001). The calculated phi coefficient of association between the missing data in this sample and viral suppression was .30, thus multiple imputation was a supported method to handle significant biases related to missing data.

Furthermore, a missing values analysis in SPSS resulted in a non-significant Little’s MCAR value ($p=.570$) indicating that the data were missing completely at random. Even so, multiple imputation was performed and regression analyses included imputed data as multiple imputation, which was an appropriate and effective way to handle missing participant data where more than 80% but less than 100% of data was valid, such as in this study (Collins, Shafer, & Kam, 2001).

**Measurement Tools**

The level of internal consistency for each instrument scale or subscale, as well as the survey inclusive of all questions, were assessed through the reliability analysis function in SPSS. Details of all Cronbach’s alphas found in this study as compared to Cronbach’s alphas published in the literature are noted in Table 4.4.
Table 4.4

Instrument Reliability Analysis

<table>
<thead>
<tr>
<th>Survey Subscale</th>
<th>Cronbach’s α Western Colorado PLWH</th>
<th>Cronbach’s α from Literature</th>
</tr>
</thead>
<tbody>
<tr>
<td>PDRQ-9</td>
<td>.94</td>
<td>.94 English^a/ .95 Spanish^b</td>
</tr>
<tr>
<td>MHLC-C English Internal</td>
<td>.62</td>
<td>.85^c</td>
</tr>
<tr>
<td>MHLC-C English Chance</td>
<td>.79</td>
<td>.79^e</td>
</tr>
<tr>
<td>MHLC-C English Others</td>
<td>.53</td>
<td>.70^c</td>
</tr>
<tr>
<td>MHLC-C English Doctors</td>
<td>.47</td>
<td>.71^c</td>
</tr>
<tr>
<td>MHLC-C Spanish Internal</td>
<td>.69</td>
<td>.74^d</td>
</tr>
<tr>
<td>MHLC-C Spanish Chance</td>
<td>.88</td>
<td>.65^d</td>
</tr>
<tr>
<td>MHLC-C Spanish Others</td>
<td>.68</td>
<td>.48^d</td>
</tr>
<tr>
<td>MHLC-C Spanish Doctors</td>
<td>.50</td>
<td>.54^d</td>
</tr>
<tr>
<td>Cope: Self-distraction</td>
<td>.53</td>
<td>.71^e</td>
</tr>
<tr>
<td>Cope: Active</td>
<td>.76</td>
<td>.68^e</td>
</tr>
<tr>
<td>Cope: Denial</td>
<td>.60</td>
<td>.78 English/ .80 Spanish^f</td>
</tr>
<tr>
<td>Cope: Substance Use</td>
<td>.94</td>
<td>.90^e</td>
</tr>
<tr>
<td>Cope: Emotional Support</td>
<td>.81</td>
<td>.71^e</td>
</tr>
<tr>
<td>Cope: Positive Reframing</td>
<td>.68</td>
<td>.76 English/ .78 Spanish^f</td>
</tr>
<tr>
<td>Cope: Planning</td>
<td>.66</td>
<td>.73^e</td>
</tr>
<tr>
<td>Cope: Humor</td>
<td>.76</td>
<td>.73^e</td>
</tr>
<tr>
<td>Cope: Acceptance</td>
<td>.69</td>
<td>.85 English/ .81 Spanish^f</td>
</tr>
<tr>
<td>Cope: Religion</td>
<td>.79</td>
<td>.57^e</td>
</tr>
<tr>
<td>All questions plus MHLC-C English</td>
<td>.80</td>
<td>.59 English/ .62 Spanish^f</td>
</tr>
<tr>
<td>All questions plus MHLC-C Spanish</td>
<td>.62</td>
<td>.86 English/ .83 Spanish^f</td>
</tr>
</tbody>
</table>

Note. ^a Van der Feltz-Cornelius et al., 2004; ^b Martín-Fernández et al., 2010; ^c Wallston, Stein, & Smith, 1994; ^d De las Cuevas, Peñate, Betancort, & Cabrera, 2015; ^e Carver, 1997; ^f Perczek, Carver, & Price, 2000; PLWH = persons living with HIV; MHLC-C = multidimensional health locus of control, form C; PDRQ-9 = patient-doctor relationship questionnaire – 9.
A Cronbach’s alpha of 0.7 or higher is often regarded as an acceptable level of reliability (Bannon, Jr., 2013), but as these instruments were used in a new population, a value of 0.65 or higher was established a priori as evidence of scale reliability.

Six of 19 scales or subscales did not meet this threshold: the MHLC-C English Internal, Others, and Doctor subscales; the MHLC-C Spanish Doctor subscale; and the Self-distraction and Denial subscales of the BriefCOPE. The MHLC-C English Internal subscale and the BriefCOPE Denial subscale were close to the acceptable level at .62 and .60, respectively.

When all questions were considered together in the study sample, Cronbach’s alphas were excellent in participants who completed the survey inclusive of the MHLC-C English questions (.80) and nearly at threshold in the sample of participants who completed the survey inclusive of the MHLC-C Spanish questions (.62). The MHLC-C contains identical questions, however, the Spanish language instrument has a different Likert-type scale than the English version. The English version allows for responses of 1 to 6, but the Spanish instrument has a response scale from 1 to 5. Responses were standardized to allow for direct comparisons in the analyses.

While not all subscales or instruments met the 0.65 threshold, a meta-analysis on the reliability statistics of well-used instruments found that the average Cronbach’s alpha reported in behavioral research related to values and beliefs was only 0.7 (Peterson, 1994). Given this average, below-threshold results for measures in this study should not simply be dismissed, but warrant cautious consideration in the context of the research.
Bivariate Analysis

Each demographic and EMR predictor variable was independently evaluated through forced-entry logistic regression as a predictor of each dependent variable.

First, *missed visits* were selected as the dependent variable. The final imputation result was evaluated in all the analyses (see Table 4.5).

Table 4.5

*Bivariate Analyses of Predictor Variables’ Relationships to Missed Visits*

<table>
<thead>
<tr>
<th>Variable</th>
<th>$\chi^2$</th>
<th>p-value</th>
<th>OR</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Foreign-born</td>
<td>.18</td>
<td>.67</td>
<td>1.2</td>
<td>.511, 2.822</td>
</tr>
<tr>
<td>Years living with HIV</td>
<td>.22</td>
<td>.64</td>
<td>1.01</td>
<td>.970, 1.051</td>
</tr>
<tr>
<td>*Miles to care</td>
<td>7.204</td>
<td>.007</td>
<td>.991</td>
<td>.984, .997</td>
</tr>
<tr>
<td>*High School Graduate</td>
<td>7.45</td>
<td>.006</td>
<td>3.986</td>
<td>1.477, 10.756</td>
</tr>
<tr>
<td>Age</td>
<td>3.38</td>
<td>.066</td>
<td>.972</td>
<td>.943, 1.002</td>
</tr>
<tr>
<td>Gender</td>
<td>.056</td>
<td>.813</td>
<td>.918</td>
<td>.450, 1.869</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td>3.370</td>
<td>.066</td>
<td>1.281</td>
<td>.983, 1.668</td>
</tr>
<tr>
<td>*HIV Risk Factor</td>
<td>11.163</td>
<td>.001</td>
<td>2.853</td>
<td>1.542, 5.276</td>
</tr>
<tr>
<td>*Heterosexual Risk Factor</td>
<td>4.899</td>
<td>.027</td>
<td>2.318</td>
<td>1.101, 4.881</td>
</tr>
<tr>
<td>*IDU Risk Factor</td>
<td>6.659</td>
<td>.1</td>
<td>16.364</td>
<td>1.958, 136.731</td>
</tr>
<tr>
<td>*Health Literacy</td>
<td>10.042</td>
<td>.002</td>
<td>.276</td>
<td>.125, .612</td>
</tr>
<tr>
<td>Substance Use</td>
<td>1.66</td>
<td>.198</td>
<td>1.607</td>
<td>.780, 3.309</td>
</tr>
<tr>
<td>*Depression</td>
<td>6.49</td>
<td>.011</td>
<td>2.827</td>
<td>1.271, 6.289</td>
</tr>
</tbody>
</table>

**COPING SUBSCALES**

| Active                        | 3.616    | .057    | 1.233 | .994, 1.531  |
| *Denial                       | 8.55     | .003    | 1.412 | 1.121, 1.780 |
| Self-Distraction              | .568     | .451    | 1.078 | .886, 1.312  |
| *Substance Use                | 6.386    | .012    | 1.296 | 1.060, 1.585 |
| *Emotional                    | 4.858    | .028    | 1.226 | 1.023, 1.470 |
| Positive Reframing            | .000     | .996    | .999 | .816, 1.225  |
| Planning                      | .001     | .980    | 1.003 | .819, 1.228  |
| Humor                         | .592     | .442    | 1.076 | .893, 1.298  |
| Acceptance                    | 2.307    | .129    | .836 | .664, 1.053  |
| Religion                      | 1.152    | .283    | 1.091 | .931, 1.279  |

**MHLC-C SUBSCALES**

| Internal                      | 1.553    | .213    | 1.254 | .878, 1.791  |
| Doctor                        | 1.645    | .200    | .789 | .548, 1.134  |
| Others                        | .275     | .600    | 1.099 | .773, 1.562  |
| Chance                        | .487     | .485    | 1.134 | .797, 1.613  |

**PDRQ-9 SCALE**

| Note. *p < .05; OR = odds ratio; CI = confidence interval; HIV = human immunodeficiency virus; IDU = injection drug use; MLHC-C = multidimensional health lock so control, form C, PDRQ-9 = patient doctor relationship questionnaire-9.
Results for demographic variables revealed that participants who lived farther away from a healthcare facility, did not graduated from high school, had an HIV risk factor of heterosexuality or IDU as compared to MSM, had low health literacy, and screened positive for depression were more likely to miss medical visits.

Survey instruments were then evaluated using forced-entry logistic regression to test for scales and/or subscales that predicted missed visits. It was found that participants who reported coping through denial, substance abuse, or emotional coping were more likely to miss visits than those who used other types of coping behaviors (see Table 4.5). A parallel analysis was performed with the four MHLC-C subscales and the PDRQ-9. Health locus of control was not found to significantly affect the odds of missing medical visits, nor did the patient’s relationship with the health care team as measured by the PDRQ-9 (see Table 4.5).

We then repeated the forced-entry logistic regression models with each variable considered independently as a predictor of the dichotomous outcome of viral suppression (< 200 copies/mL; yes/no). This analysis returned only one significant predictor, the Others subscale of the MHLC-C (Table 4.6).
Table 4.6

*Bivariate Analyses of Predictor Variables’ Relationship to Viral Suppression*

<table>
<thead>
<tr>
<th>Variable</th>
<th>$\chi^2$</th>
<th>$p$</th>
<th>OR</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Foreign-born</td>
<td>.034</td>
<td>.853</td>
<td>1.244</td>
<td>.124, 12.456</td>
</tr>
<tr>
<td>Years with HIV</td>
<td>.852</td>
<td>.356</td>
<td>.939</td>
<td>.820, 1.074</td>
</tr>
<tr>
<td>Miles to care</td>
<td>.655</td>
<td>.418</td>
<td>.989</td>
<td>.963, 1.016</td>
</tr>
<tr>
<td>High School graduate</td>
<td>1.909</td>
<td>.167</td>
<td>4.125</td>
<td>.553, 30.788</td>
</tr>
<tr>
<td>Age</td>
<td>.780</td>
<td>.377</td>
<td>.962</td>
<td>.883, 1.048</td>
</tr>
<tr>
<td>Gender</td>
<td>.436</td>
<td>.509</td>
<td>.515</td>
<td>.072, 3.692</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td>3.261</td>
<td>.071</td>
<td>1.876</td>
<td>.948, 3.715</td>
</tr>
<tr>
<td>HIV risk factor</td>
<td>.170</td>
<td>.680</td>
<td>.704</td>
<td>.133, 3.728</td>
</tr>
<tr>
<td>Health literacy</td>
<td>2.440</td>
<td>.118</td>
<td>.161</td>
<td>.016, 1.593</td>
</tr>
<tr>
<td>Substance use</td>
<td>.223</td>
<td>.637</td>
<td>1.617</td>
<td>.220, 11.870</td>
</tr>
<tr>
<td>Depression</td>
<td>.063</td>
<td>.802</td>
<td>.746</td>
<td>.075, 7.402</td>
</tr>
<tr>
<td>Active Coping</td>
<td>1.809</td>
<td>.179</td>
<td>.686</td>
<td>.396, 1.188</td>
</tr>
<tr>
<td>Denial Coping</td>
<td>.114</td>
<td>.735</td>
<td>1.097</td>
<td>.643, 1.871</td>
</tr>
<tr>
<td>Self-distraction Coping</td>
<td>.349</td>
<td>.555</td>
<td>1.198</td>
<td>.658, 2.181</td>
</tr>
<tr>
<td>Substance use Coping</td>
<td>.027</td>
<td>.868</td>
<td>1.042</td>
<td>.639, 1.701</td>
</tr>
<tr>
<td>Emotional Coping</td>
<td>.240</td>
<td>.624</td>
<td>1.140</td>
<td>.675, 1.924</td>
</tr>
<tr>
<td>Positive reframing Coping</td>
<td>.140</td>
<td>.709</td>
<td>1.123</td>
<td>.612, 2.060</td>
</tr>
<tr>
<td>Planning Coping</td>
<td>.609</td>
<td>.435</td>
<td>.806</td>
<td>.469, 1.385</td>
</tr>
<tr>
<td>Humor Coping</td>
<td>.577</td>
<td>.448</td>
<td>1.206</td>
<td>.744, 1.955</td>
</tr>
<tr>
<td>Acceptance Coping</td>
<td>1.589</td>
<td>.207</td>
<td>.708</td>
<td>.413, 1.212</td>
</tr>
<tr>
<td>Religion Coping</td>
<td>.245</td>
<td>.621</td>
<td>1.120</td>
<td>.715, 1.754</td>
</tr>
<tr>
<td>MHLC-C Internal</td>
<td>.291</td>
<td>.590</td>
<td>1.315</td>
<td>.486, 3.563</td>
</tr>
<tr>
<td>MHLC-C Doctor</td>
<td>1.087</td>
<td>.297</td>
<td>.649</td>
<td>.288, 1.463</td>
</tr>
<tr>
<td>*MHLC-C Others</td>
<td>3.978</td>
<td>.046</td>
<td>3.406</td>
<td>1.021, 11.355</td>
</tr>
<tr>
<td>MHLC-C Chance</td>
<td>3.541</td>
<td>.060</td>
<td>2.779</td>
<td>.958, 8.056</td>
</tr>
<tr>
<td>PDRQ-9</td>
<td>1.880</td>
<td>.170</td>
<td>.919</td>
<td>.814, 1.037</td>
</tr>
</tbody>
</table>

*Note. *$p < .05$; OR = odds ratio; CI = confidence interval; HIV = human immunodeficiency virus; MLHC-C = multidimensional health locus of control, form C, PDRQ-9 = patient doctor relationship questionnaire-9.

Compared to people with other types of locus of control attributions, participants who believed that other people had power over their health behaviors were more than three times more likely to have HIV viral loads greater than 200 copies/mL (unsuppressed). Cronbach’s alphas for the MHLC-C Others subscale in this
study were not as robust as those for other subscales. The English Others subscale had a Cronbach’s alpha of .53, while the Spanish Others subscale had a Cronbach’s alpha of .68. As noted above, alphas this low are not uncommon in research, but they do suggest that further investigation is warranted to elucidate if the association remains significant in other samples or whether this was a random finding. The associated $R^2$ was 0.148, thus only 14.8% of the variance in viral load was explained by the Others Subscale. The fact that only one of many variables was a significant predictor of viral suppression, with no correction for inflated alpha across multiple tests in this exploratory study, also suggested that the single finding related to locus of control might be a Type II error. The Hosmer and Lemeshow test demonstrated that the model was a good fit, $\chi^2 = 3.624$, $df = 8$, $p = .889$, and as only one variable was significant, no further analyses were performed.

**Hypotheses**

In general, this study’s hypotheses were addressed by results from the bivariate analyses presented above. One hypothesis required additional analysis for mediation effects.

**Hypothesis 1**

**Greater distance from home to the clinic will decrease the odds of being retained in care and virally suppressed.**

Greater distance from home to the clinic slightly, yet significantly, decreased the odds of being retained in care in this study, $OR = .991$, $p = .007$, 95% CI = .984-.997, but it had no effect on viral suppression, $OR = .989$, $p = .42$, 95% CI = .963-1.02.

**Hypothesis 2**
Rurality will decrease the odds of being retained in care and virally suppressed.

Rurality as defined by the RUCC classification system independently decreased the odds of being retained in care, $OR = .74$, $p = .009$, 95% CI = .59-.93, but had no effect on viral suppression, $OR = .62$, $p = .34$, 95% CI = .23-1.66.

Hypothesis 3

Country of origin outside of the United States will decrease the odds of being retained in care and virally suppressed.

Being foreign-born did not decrease the odds of being retained in care, $OR = 1.2$, $p = .67$, 95% CI = .51-2.82 or virally suppressed, $OR = 1.24$, $p = .85$, 95% CI = .12-12.46, in this sample.

Hypothesis 4

Adequate health literacy will increase the odds of being retained in care and virally suppressed.

Adequate health literacy as ascertained by the Vital Signs screening tool (Pfizer, Inc., 2011) significantly decreased the odds of missed visits, $OR = .28$, $p = .002$, 95% CI = .13-.61, thereby increasing retention in care, but had no effect on viral suppression, $OR = .16$, $p = .12$, 95% CI = .02-1.59.

Hypothesis 5

Higher scores on the PDRQ-9 will increase the odds of being retained in care and virally suppressed.
Higher scores on the PDRQ-9, meaning higher satisfaction with the health care team, did not significantly increase the odds of being retained in care, $OR = .98, p = .56$, 95% CI = .92-1.05, or virally suppressed, $OR = .92, p = .17$, 95% CI = .81-1.04.

**Hypothesis 6**

**Screening positive for substance abuse will decrease the odds of being retained in care and virally suppressed.**

Screening positive for active substance abuse did not significantly decrease the odds of being retained in care, $OR = 1.61, p = .20$, 95% CI = .78-3.31 or virally suppressed, $OR = 1.62, p = .64$, 95% CI = .22-11.87.

**Hypothesis 7**

**Internal and doctor health loci of control will increase the odds of being retained in care and virally suppressed; chance and other people loci of control will decrease the odds of being retained in HIV care and virally suppressed.**

None of the MHLC-C subscales were found to significantly affect the odds of being retained in care. However, participants scoring higher on the Others locus of control subscale were found to have a 71% decrease in the odds of being virally suppressed, $OR = 0.29, p = .046$, 95% CI = 1.02-11.36.

**Hypothesis 8**

**Screening positive on a depression screen will decrease the odds of being retained in care and virally suppressed.**

Screening positive for depression significantly increased the odds of missing clinic visits, $OR=2.83, p = .01$, 95% CI=1.27-6.23, but did not affect the odds of being virally suppressed, $OR = .75, p = .80$, 95% CI = .08-7.40.
**Multivariable Analysis**

A combined logistic regression model to predict *missed visits* was created using the forward stepwise likelihood ratio option as a way to ascertain the best predictors of missing clinic visits. We included all predictors that had significant univariate relationships to missed visits, entered them in a single step, and allowed the multivariable stepwise logistic regression procedure to select among them on the basis of the percent of variance explained. In the first model, the *high school graduation* variable fell out (Table 4.7).

Table 4.7

**Multivariable Logistic Regression of Significant Univariate Predictors to Missed Visits**

<table>
<thead>
<tr>
<th>Step</th>
<th>Variable</th>
<th>$R^2$</th>
<th>$\chi^2$</th>
<th>$p$-value</th>
<th>OR</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Miles to care</td>
<td>.109</td>
<td>6.889</td>
<td>.009</td>
<td>.988</td>
<td>.980, .997</td>
</tr>
<tr>
<td>2</td>
<td>Health literacy score</td>
<td>.201</td>
<td>10.501</td>
<td>.001</td>
<td>.224</td>
<td>.091, .554</td>
</tr>
<tr>
<td>3</td>
<td>Depression (yes/no)</td>
<td>.262</td>
<td>6.477</td>
<td>.011</td>
<td>3.372</td>
<td>1.322, 8.596</td>
</tr>
<tr>
<td>4</td>
<td>Heterosexual (vs. MSM)</td>
<td>.313</td>
<td>5.111</td>
<td>.024</td>
<td>2.692</td>
<td>1.141, 6.353</td>
</tr>
<tr>
<td>5</td>
<td>IDU (vs. MSM)</td>
<td>.355</td>
<td>6.833</td>
<td>.009</td>
<td>19.110</td>
<td>2.092, 174.561</td>
</tr>
</tbody>
</table>

*Note.* OR = odds ratio; CI = confidence interval; HIV = human immunodeficiency virus; MSM = men who have sex with men; IDU = injection drug use.

The overall $R^2$ of .36 showed that 36% of the variance in missed visits was explained by this model. Perhaps more relevant to clinical practice, a classification table analysis revealed that the model also predicted missed visits 74.2% of the time correctly. Most of the explained variance (20.1%) was attributed to the first two
predictor variables, *miles to care* and *health literacy*. The Hosmer and Lemeshow test showed no significant difference between the model and the data, indicating a good fit (see Table 4.8).

Table 4.8

*Goodness of Fit of Multivariable Logistic Regression Model of Demographic Variables*

<table>
<thead>
<tr>
<th>Step</th>
<th>$\chi^2$</th>
<th>df</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>0.000</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>0.001</td>
<td>1</td>
<td>0.969</td>
</tr>
<tr>
<td>3</td>
<td>4.515</td>
<td>8</td>
<td>0.808</td>
</tr>
<tr>
<td>4</td>
<td>2.541</td>
<td>8</td>
<td>0.960</td>
</tr>
<tr>
<td>5</td>
<td>5.427</td>
<td>8</td>
<td>0.731</td>
</tr>
</tbody>
</table>

The forward stepwise likelihood ratio method was also used to regress the *active, denial, substance abuse, and emotional* subscales of the BriefCOPE to *missed visits*. The *active* and *emotional* subscales dropped out of the model (Table 4.9).

Table 4.9

*Multivariable Logistic Regression Model of Significant BriefCOPE Subscales*

<table>
<thead>
<tr>
<th>Step</th>
<th>Variable</th>
<th>$R^2$</th>
<th>$\chi^2$</th>
<th>$p$-value</th>
<th>OR</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Denial</td>
<td>.099</td>
<td>8.550</td>
<td>.003</td>
<td>1.412</td>
<td>1.121, 1.780</td>
</tr>
<tr>
<td>2</td>
<td>Substance Use</td>
<td>.146</td>
<td>4.435</td>
<td>.035</td>
<td>1.255</td>
<td>1.016, 1.550</td>
</tr>
</tbody>
</table>

*Note.* OR = odds ratio; CI = confidence interval.
The total variance explained by this model, with two coping subscales included, was 15%. The model predicted missed visits 67% of the time correctly and goodness of fit was shown by the Hosmer and Lemeshow test (see Table 4.10).

Table 4.10

_Goodness of Fit for Multivariable Regression of BriefCOPE Subscales_

<table>
<thead>
<tr>
<th>Step</th>
<th>( \chi^2 )</th>
<th>( df )</th>
<th>( p )</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>3.385</td>
<td>3</td>
<td>.336</td>
</tr>
<tr>
<td>2</td>
<td>2.647</td>
<td>6</td>
<td>.852</td>
</tr>
</tbody>
</table>

Regressing miles to care, HIV risk factor, depression, and health literacy to the two significant BriefCOPE subscales explained 38% of the variance, \( R^2 = .382 \), so the BriefCOPE added just 2% to the amount of variance explained by the first model shown in Table 4.11. Nevertheless, the Hosmer and Lemeshow test showed a good fit, \( \chi^2 = 9.315, df = 8, p = .316 \). These results suggested that the BriefCOPE subscales provided a small incremental gain in the ability to predict missed visits, above and beyond what was attributable to demographic variables.
Table 4.11

Regression Model Inclusive of Significant Demographic and Instrument Subscales

<table>
<thead>
<tr>
<th>Variable</th>
<th>$\chi^2$</th>
<th>p-value</th>
<th>OR</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coping—substance use</td>
<td>2.712</td>
<td>.100</td>
<td>1.235</td>
<td>.961, 1.587</td>
</tr>
<tr>
<td>Coping—denial</td>
<td>1.047</td>
<td>.306</td>
<td>1.160</td>
<td>.873, 1.540</td>
</tr>
<tr>
<td>Miles to care</td>
<td>5.910</td>
<td>.015</td>
<td>.989</td>
<td>.981, 998</td>
</tr>
<tr>
<td>HIV Risk Factor</td>
<td>10.278</td>
<td>.001</td>
<td>3.311</td>
<td>1.593, 6.884</td>
</tr>
<tr>
<td>Depression</td>
<td>4.555</td>
<td>.033</td>
<td>2.923</td>
<td>1.092, 7.826</td>
</tr>
<tr>
<td>Health literacy</td>
<td>5.360</td>
<td>.021</td>
<td>.322</td>
<td>.123, .840</td>
</tr>
</tbody>
</table>

Note. OR = odds ratio; CI = confidence interval; HIV = human immunodeficiency virus.

Mediation Analysis

Hypothesis 9

Coping processes will significantly mediate the relationships between rurality, country of origin, the patient-provider interaction, health literacy, substance abuse, depression, health locus of control and retention in HIV care.

Hypothesis 9 required testing the mediating effects of coping behaviors on retention in care. Only those predictor variables that were found to have significant direct effects on retention in care as defined by missed visits in the multivariable analyses were analyzed. Using PROCESS software that was available at no cost to add functionality to SPSS regression analysis (Hayes, 2016), mediation was tested. Specifically, the BriefCOPE subscales of denial and substance abuse were tested as potential mediators of the demographic risk factors miles to care, health literacy, depression, heterosexual risk factor, and IDU risk factor. PROCESS computations could
not measure actual effect sizes because the outcome variable was dichotomous, which is a limitation of current statistical procedures. However, PROCESS can determine the presence of mediating effects based on whether or not the confidence intervals of the indirect effects cross zero (see Table 4.12).

Table 4.12

Tests of Coping as a Mediator of Significant Predictor Variables’ Effects on Retention in Care

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mediator</th>
<th>Indirect Effect</th>
<th>95% BCa CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>*Health literacy</td>
<td>Denial Coping</td>
<td>-.325</td>
<td>-.826, -.035</td>
</tr>
<tr>
<td>Health literacy</td>
<td>Substance Abuse Coping</td>
<td>-.16</td>
<td>-.57, .008</td>
</tr>
<tr>
<td>Miles to care</td>
<td>Denial Coping</td>
<td>-.001</td>
<td>-.004, .001</td>
</tr>
<tr>
<td>Miles to care</td>
<td>Substance Abuse Coping</td>
<td>-.009</td>
<td>-.003, .000</td>
</tr>
<tr>
<td>IDU risk factor</td>
<td>Denial Coping</td>
<td>-.038</td>
<td>-.404, .338</td>
</tr>
<tr>
<td>IDU risk factor</td>
<td>Substance Abuse Coping</td>
<td>.114</td>
<td>-.293, .854</td>
</tr>
<tr>
<td>*Heterosexual risk factor</td>
<td>Denial Coping</td>
<td>.206</td>
<td>.012, .577</td>
</tr>
<tr>
<td>Heterosexual risk factor</td>
<td>Substance Abuse Coping</td>
<td>-.155</td>
<td>-.517, .024</td>
</tr>
<tr>
<td>*Depression</td>
<td>Denial Coping</td>
<td>.204</td>
<td>.004, .61</td>
</tr>
<tr>
<td>Depression</td>
<td>Substance Abuse Coping</td>
<td>.165</td>
<td>-.006, .541</td>
</tr>
</tbody>
</table>

Note. IDU = injection drug use; a 95% bootstrapped confidence interval; *Effect present.

As seen in Table 4.12 denial coping was a significant mediator for the effects of health literacy, heterosexual risk factor as compared to MSM, and screening positive for depression. Neither of the BriefCOPE subscales mediated the effects of other predictor variables. No mediating effects were seen for substance abuse coping with any predictor variables. All direct and indirect effects of the relationships for the variables mediated by denial coping are diagrammed in Figure 4.1. The Cronbach’s alpha of the
denial coping subscale was 0.60 in this sample, which was higher than what Carver (1997) published in his psychometric study of the instrument (0.54). However, this result was still lower than generally accepted standards for Cronbach’s alpha, and further testing is therefore needed to validate these findings.
Figure 4.1. Mediation effects of denial coping on retention in care.  

Note. BCa CI = bootstrapped confidence interval; HIV = human immunodeficiency virus
CHAPTER V
DISCUSSION

Introduction

Retaining people living with HIV (PLWH) in regular care is a priority of the National HIV/AIDS Strategy (White House Office of National AIDS Policy, 2015), not only to reduce HIV-related morbidity and mortality but also to prevent further HIV transmission (Cohen et al., 2011; Department of Health and Human Services, 2015). To the best of our knowledge, this study is the first to look at predictors of retention in care for PLWH in a predominately rural region in the western United States. Informed by existing literature and a theoretical framework, this study sought to answer two important questions:

1. Do health literacy, country of origin, rurality, distance from clinic, depression, substance abuse, patient-provider interaction, and health locus of control predict the likelihood of a PLWH being retained in HIV care and virally suppressed?

2. Does the coping process mediate the effects between predictor variables and retention in HIV care?

In this study, health literacy, residing in a more rural versus an urban area, living farther away from the clinic, and screening positive for depression decreased the odds of being retained in HIV care. Not graduating from high school and HIV risk factors of heterosexual contact and IDU versus MSM also reduced the odds of being retained in care. During further analyses, education level dropped out and the five variables that reduced the odds of being retained in care, in order of amount of variance explained,
were distance from clinic, health literacy, depression, heterosexual versus MSM risk factor for HIV, and IDU versus MSM as an HIV risk factor. Surprisingly, in this sample, being foreign-born or currently abusing substances were not associated with retention in care, which was different from other studies that focused on rural populations (Hall et al., 2012; Reif et al., 2005; Shafer et al., 2012).

The patient-provider relationship was found to be paramount to successful retention in care in one rural study (Kempf et al., 2010), but was not significant in this study. However, a ceiling effect undoubtedly confused the results, as this study’s sample was extremely satisfied with their relationships with the health care team as evidenced by an average response of 4.6 out of 5 per question on the Patient Doctor Relationship Questionnaire-9.

No studies on rural PLWH were found that included HIV risk factor or race/ethnicity variables, however, the non-rural HIV retention in care research found that a risk factor of MSM was less associated with being retained in care (Horstmann et al., 2010; Yehia et al., 2012), which was the opposite of what was discovered in this study. This study’s sample included far less reported MSM risk than state or national averages, which may explain why a heterosexual risk factor was significant compared to a risk factor of MSM. Race/ethnicity have been significant in many other non-rural studies (Fleishman et al., 2012; Hightow-Weidman et al., 2011; Horstmann et al., 2010; Hu et al., 2012; Mugavero et al., 2009; Sitapati et al., 2012; Torian & Wiewel, 2011; Yehia et al., 2012), but did not affect retention in care in this sample, in spite of an overrepresentation of minority patients compared to the general patient population.
Previous research on PLWH in rural areas reported transportation issues as a major contributor to retention in care (Kempf et al., 2010; Reif et al., 2005). Distance from the HIV clinic was the largest predictor of missing medical visits in this study. Distance from the clinic in western Colorado was more complicated than the number of miles between a patient’s home and the clinic, however. Public transportation was often not available so a personal vehicle was required. Weather can make travel to an appointment dangerous or impossible as road closures due to winter storms or rockslides are not uncommon.

After distance from the HIV clinic, health literacy was found to be the next most significant predictor of retention in care. Beckman and colleagues (2011) found an indisputable link between low health literacy and poor health outcomes in their systematic review of 96 studies. Phillips and Arya (2016) made a connection between low health literacy in the United States and the HIV epidemic. Health literacy specifically related to HIV and care retention has not been studied, but Dawson-Rose and colleagues (2016) found that a trusting relationship between patient and provider was foundationally essential before health literacy issues could successfully be addressed. A recent systematic review of health literacy interventions for PLWH (Perazzo, Reyes, & Webel, 2016) identified only six studies, most focusing on medication adherence. In general, the authors concluded that the interventions studied did not significantly improve the outcomes of interest. Studies that measured a gain in knowledge and behavior skills after receiving HIV-specific education, however, did predict medication adherence.
Depression has been linked to poor retention in HIV care in the non-rural literature (Horstmann et al., 2010; Marks et al., 2010; Pecoraro et al., 2013), but has not been isolated in the literature on PLWH in the rural United States. In this study, depression predicted missing clinic visits. This study’s sample accessed a clinic where behavioral health was integrated into every appointment. Even so, depression was reported in nearly one-third of the participants. A paucity of current intervention research was found in the literature related to depression and retention in HIV care. Gardner and colleagues (2016) conducted an experiment randomizing PLWH who received care at six different clinics to either a “usual care” or an “enhanced personal contact” group. Only those with lower levels of depression benefitted from the enhanced contact; it had no significant effect on PLWH exhibiting higher levels of depression. Gardner et al.’s study focused solely on urban patients.

In this study, denial, emotional, and substance abuse coping styles independently reduced the odds of being retained in care. However, when tested together, only denial and substance abuse coping remained significant. The more adaptive coping styles had no effect on retention in HIV care. Denial and substance abuse coping were not nearly as strong as the other variables already discussed when modeled together. Still, denial coping was found to mediate effects of health literacy, depression, and reporting heterosexual contact versus MSM as an HIV risk factor on retention in HIV care. Konkle-Parker, Amico, and Henderson’s (2011) study of 131 rural PLWH in the southeastern United States found that 70% of their sample reported denial, disbelief, and active avoidance as reasons for dropping out of care. This study
confirmed that the construct of denial was important, yet it merits further research to better understand how it affects retention in care.

Health locus of control did not influence retention in HIV care in this study. The MHLC-C instrument was the most problematic in terms of reliability with the lowest Cronbach’s alphas in general. Future research should explore a more reliable tool to measure the construct of health beliefs and locus of control before disavowing the contribution that health beliefs may have on retention in HIV care.

Only one variable predicted viral suppression. A health belief that other people have power over one’s health behaviors decreased the odds of being virally suppressed. Of note, 97% of this study’s sample was virally suppressed. However, the others subscale of the MHLC-C had below threshold reliability statistics. This finding may have been a random event, but warrants further investigation.

**Graham’s Theoretical Framework**

The study did not support all of the predictor variables tested in the analyses, but did support many (see Figure 5.1). Country of origin, substance abuse, the patient-provider relationship, and health locus of control (used to operationalize cognitive appraisal) were not found to be significant predictors of retention in care. As described above, only the others subscale of the MHLC-C was significant in bivariate analyses when regressed to viral suppression, but instrument limitations weakened any definitive interpretation. Nevertheless, health literacy, distance from clinic, rurality, depression, and aspects of coping did affect retention in care. High scores on the Patient-Doctor Relationship Questionnaire-9 prohibited the discrimination necessary to find relevancy in this study, but the patients’ relationships with their clinicians and staff
has been a well-supported concept in both the rural and urban literature. In this highly satisfied sample, qualitative or mixed methods research may better discern the specific aspects of the patient-provider relationship that most affect retention in care.

Figure 5.1. Predictor variables supported in current study (red bold) and not supported (line through variable).


Surprisingly, because these variables have been repeatedly supported in the existing literature, country of origin and current substance abuse did not increase the odds of missing clinic appointments in this study. Most participants not born in the United States were born in Mexico or Central or South America. This study’s sample attended a clinic with bilingual/bicultural English-Spanish staff that communicates with
Spanish-language patients in their native tongue without need for translation technology. Further research is needed to explore how this may influence retention in care. Sampling bias may have affected the substance abuse findings. It is unknown whether substance abuse affected non-respondents’ inclinations to participate in research, attend clinic visits, or stay virally suppressed. A qualitative study by Yehia and colleagues (2015) asked patients who were retained in care and those who were not retained in care about barriers to care retention and then categorized the responses into low, medium, and high tertiles. Substance abuse as a barrier was in the medium tertile range for both groups of patients. In contrast, depression was in the high tertile range for both retained and not retained patients. Substance abuse may not ultimately be as strong a predictor as depression, but it should remain as a background variable in the theoretical model.

The Multidimensional Health Locus of Control, Form C instrument was weak in certain subscales and in its Spanish version in this study’s sample. Future research may need to incorporate a more reliable instrument or one that better captures the construct of interest, if one exists, or design an instrument to measure the construct of cognitive appraisal. The dynamic variables should be explored more to determine their usefulness in predicting behaviors and outcomes; it is premature to consider omitting or amending these variables.

While coping was supported as an independent predictor and a mediator of retention in this study, the magnitude of effects were either low or unknown. Operationalizing coping is difficult, but continued use of the BriefCOPE as well as consideration of other coping instruments in future studies is recommended. Keeping
the study limitations in mind, this study supported the use of Graham’s framework, but continued testing of the model for clinical relevancy and refinement of certain constructs is needed.

**Limitations**

Results should be interpreted with the study’s limitations in mind. This study included only PLWH in a predominately rural region of western Colorado. As such, it may not be representative of rural areas in other parts of the United States, which may limit generalizability of the findings. Additionally, this exploratory study consisted of a survey conducted at one point in time and a retrospective review of data found in patients’ medical records, thus it was unable to determine causality. Internal threats to validity were less concerning as this was a one-group, one-time period, non-experimental, cross-sectional design. As there was no repeat testing and the study was not longitudinal, history, maturation, attrition, testing effects, and regression toward the mean were not applicable.

However, potential sampling bias may have been present compared to the population of patients commonly attended to by the clinic, who overall were likely to be younger and male, and to have lived in more rural areas than this study’s participants. These factors may limit generalizability of results from this study, although the higher than expected proportion of minority group members in the sample likely increased external validity of the results. Furthermore, it is possible that PLWH not retained in regular care were less likely to respond to a survey request than those patients retained in regular care, indicative of selection bias. Experimental bias was possible if the patients who completed the survey did so in a way that was not honest or was thought
to provide information perceived as what the researchers wanted. We attempted to mitigate this bias by providing clear instructions encouraging honesty and assuring confidentiality of data through the use of randomly selected numeric identifiers.

The predominant threat to construct validity concerned how the independent and dependent variables were operationalized. In this study, the main variables operationalized were health locus of control, the patient-health care team relationship, coping, and retention in HIV care. Well-studied, well-validated instruments were selected to measure the independent variables. Even so, several subscales did not perform as well as expected. Instrument reliability was weaker than the .65 threshold in the overall survey that included the Spanish MHLC-C questions (α = .62) and in 6 of the 19 subscales of the MHLC-C and the BriefCOPE. However, given that the average Cronbach’s alpha reported in behavioral research related to values and beliefs was only 0.7 (Peterson, 1994), further research is needed on these instruments specific to PLWH to better understand their overall value to clinical research.

While the PDRQ-9 instrument showed high reliability in this sample as evidenced by a Cronbach’s alpha of .94, the patient-provider relationship surprisingly had no association with either missed visits or viral suppression. Likely, a ceiling effect obscured any ability to find associations. This study’s sample was highly satisfied with the health care team as seen by an average rating per question of 4.6 out of 5.

Selecting the number of missed visits as a measure of retention in HIV care was consistent with the latest research in the field. However, this study’s sample was highly virally suppressed (97%), making analyses specific to this outcome difficult. Only one viral load measurement was obtained in the study. In a recent study, Marks and
colleagues (2016) found that using just one viral load measurement overestimated the number of patients with sustained viral suppression by 16%. They also found that stable suppression was less likely among PLWH who missed greater than or equal to one visit. Thus, the percentage of patients in this sample who sustained their viral suppression may, in fact, have been much lower.

Ensuring appropriate statistical power, reviewing data before analysis to ensure they met the assumptions of the statistical tests, and ensuring data and protocol integrity to reduce issues related to reliability and variance, mitigated threats to statistical conclusion validity.

**Future Recommendations**

Based on results from this and previous studies that have shown the problems related to clinic access, telemedicine could have an important role in retaining patients in care. Pamvir and colleagues (2015) reviewed the use of telemedicine technologies to provide care for patients with a variety of infectious diseases, including HIV. Outcomes were comparable to traditional office visits and accessibility increased. What is not known yet is the cost-effectiveness of telemedicine. Concerns about reimbursement and privacy have stymied the broader adoption of telemedicine in the United States, but Canada has successfully improved physician access through a telemedicine network. Future research on the use of telemedicine to keep rural PLWH retained in care and how it affects health outcomes to include a cost-effectiveness analysis would contribute significantly to current evidence, policy, and clinical practice.

For rural populations, it makes sense that telemedicine could also support patients with depression as a way to promote HIV care retention. While that has not yet
been studied, Vahia and colleagues (2015) tested the feasibility of using telepsychiatry for neurocognitive testing of older Latinos living in rural areas of the United States. Telepsychiatric assessments were equally effective when compared to in-person assessments. Future research using telepsychiatry with and without telemedicine to keep rural PLWH retained in care is a worthwhile pursuit.

Health literacy was found to be an important predictor of retention in care in this study, but more research is urgently needed to determine useful interventions to help patients with low health literacy stay retained in HIV care. Nurses are at the forefront of this research with several articles dedicated to the topic of health literacy available online in the *Journal of the Association of Nurses in AIDS Care*.

This is the first known study to report higher odds of missing health care visits when a reported HIV risk factor was heterosexual contact as compared to MSM. Inclusion of HIV risk factors in future research targeting rural PLWH is needed to determine if this finding is isolated to this study or merits further exploration as a rural phenomenon.

Finally, identifying coping styles and targeted interventions to address maladaptive coping styles, particularly denial coping, may help PLWH stay in care, especially if they have low health literacy, depression, or a reported HIV risk factor of heterosexual contact. Research that quantifies the mediating effect size of coping between known predictor variables and retention in care will help focus intervention research. Using the BriefCOPE in a larger sample of rural PLWH may result in better reliability statistics, but other instruments that measure the construct of coping should be tested in rural PLWH.
Conclusion

This study contributed new information on predictors of retention in HIV care for rural populations. Findings indicated that distance from health care, health literacy, depression, HIV risk factors of heterosexual contact and IDU as compared to MSM, and denial and substance abuse coping predicted missing clinic visits. Denial coping, but not substance abuse coping, mediated the effects of health literacy, depression, and a risk factor of heterosexual contact on retention in HIV care. Education level, race/ethnicity, age, gender, years living with HIV, active substance abuse, being foreign-born, health locus of control, and the patient-provider relationship did not predict whether or not a patient was retained in care. In general, this study supported Graham’s framework as a valuable model to guide retention in HIV care research, however, some of the constructs of the framework are complicated, making measurement challenging. Nurse scientists have an obligation to support the necessary work to meet the goals outlined in the National HIV/AIDS Strategy, and are well suited to conduct innovative research focused on retention in care for rural PLWH.
References


APPENDIX A

ELSEVIER, INC. REPRINT PERMISSION
**Step 3: Order Confirmation**

Thank you for your order! A confirmation for your order will be sent to your account email address. If you have questions about your order, you can call us at 1-855-236-3415 Toll Free, M-F between 8:00 AM and 6:00 PM (Eastern), or write to us at info@copyright.com. This is not an invoice.

**Confirmation Number:** 11538615  
**Order Date:** 02/11/2016  
**If you paid by credit card, your order will be finalized and your card will be charged within 24 hours. If you choose to be invoiced, you can change or cancel your order until the invoice is generated.**

**Payment Information**  
Lucy Graham  
lucy-graham@ucdenver.edu  
+1 (970)266-4628  
**Payment Method:** n/a

**Order Details**

**The Journal of the Association of Nurses in AIDS Care : JANAC**

<table>
<thead>
<tr>
<th>Order detail ID:</th>
<th>Permission Status:</th>
<th>Permission type:</th>
<th>Type of use:</th>
</tr>
</thead>
<tbody>
<tr>
<td>69612476</td>
<td>Granted</td>
<td>Republish or display content:</td>
<td>Thesis/Dissertation</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Publisher:</th>
<th>Requestor type:</th>
</tr>
</thead>
<tbody>
<tr>
<td>ELSEVIER INC.</td>
<td>Author of requested content</td>
</tr>
</tbody>
</table>

**Order License Id:** 3006021473756

<table>
<thead>
<tr>
<th>ISSN:</th>
<th>Format:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1033-3290</td>
<td>Electronic</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Volume:</th>
<th>Number of images/photos requested:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Issue:</th>
<th>Title or numeric reference of the portion(s):</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Figures 2-4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Start page:</th>
<th>Title of the article or chapter the portion is from:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Integration of the interaction model of client health behavior and transactional model of stress and coping as a tool of understanding</td>
</tr>
</tbody>
</table>

**Notes:** This item will be invoiced or charged separately through CCC’s RightsLink service. More information $0.00
APPENDIX B
QUALITY ASSESSMENT TABLE

<table>
<thead>
<tr>
<th>PRISMA Checklist Section/Topic</th>
<th>PRISMA Number</th>
<th>Ref 1</th>
<th>Ref 2</th>
<th>Ref 3</th>
<th>Ref 4</th>
<th>Ref 5*</th>
<th>Ref 6</th>
<th>Ref 7</th>
<th>Ref 8</th>
<th>Ref 9</th>
<th>Ref 10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract/Structured summary</td>
<td>2</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Introduction/ Rationale</td>
<td>3</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Introduction/ Objectives</td>
<td>4</td>
<td>N</td>
<td>Y</td>
<td>N</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Methods/ Eligibility criteria</td>
<td>6</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Methods/ Data collection process</td>
<td></td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Methods/ Data items</td>
<td>10</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Methods/ Risk of bias in individual studies</td>
<td>11</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Methods/ Summary measures</td>
<td>12</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Methods/ Synthesis of results</td>
<td>13</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Methods/ Additional Analyses</td>
<td>14</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Results/ Study characteristics</td>
<td>15</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Results/ Risk of bias within studies</td>
<td>16</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Results/ Results of individual studies</td>
<td>17</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Results/ Synthesis of results</td>
<td>18</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Results/ Additional analysis</td>
<td>19</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Discussion/ Summary of evidence</td>
<td>20</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Discussion/ Limitations</td>
<td>21</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>Discussion/ Conclusions</td>
<td>22</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
</tbody>
</table>

* Qualitative study. Checklist topics evaluated as related to qualitative design.
Ref = Reference.
Based on PRISMA 2009 Checklist (Mohler, Liberati, Tetzlaff, Altman, and The PRISMA Group, 2009) with modifications. Items 1, 5, 7-10, 15, 17, 22 excluded as specific to meta-analysis or systematic review. Excluded item descriptions:
Item 1: Title
Item 5: Methods/ Protocol and registration
Item 7: Methods/ Information sources
Item 8: Methods/ Search
Item 9: Methods/ Study selection
Item 15: Methods/ Risk of bias across studies
Item 17: Results/ Study selection
Item 22: Results/ Risk of bias across studies
Reference number key:


APPENDIX C

WOLTERS KLUWER REPRINT PERMISSION

Thank you for placing an order with Wolters Kluwer Health. If payment has been submitted, please disregard this notice.

<table>
<thead>
<tr>
<th>License No:</th>
<th>3433650303636</th>
</tr>
</thead>
<tbody>
<tr>
<td>License Date:</td>
<td>21/Jul/2014</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>License Type:</th>
<th>Journal/Magazine</th>
</tr>
</thead>
<tbody>
<tr>
<td>Publication:</td>
<td>Advances in Nursing Science</td>
</tr>
<tr>
<td>Identifier of Original Work:</td>
<td>00012272-198210000-00007</td>
</tr>
<tr>
<td>Title:</td>
<td>An interaction model of client health behavior: theoretical prescription for nursing.</td>
</tr>
<tr>
<td>Author/Editor:</td>
<td>Cox, Cheryl; RN, PhD</td>
</tr>
<tr>
<td>Order Amount:</td>
<td>115.00 USD</td>
</tr>
</tbody>
</table>

| Sub Total:           | 115.00 USD |
| Tax:                 | 0.90 USD   |
| Total Amount Due:    | 115.00 USD |
APPENDIX D

RESEARCH SURVEY

Please complete the survey below. Thank you!

Please complete all questions.

Last Name __________________________

First Name __________________________

Country you were born in ______________________

Years living with HIV ______________________

(In numbers, not words)

Miles you drive to the HIV clinic ______________________

(In numbers, not words)

Highest grade completed in school ______________________

You will read nine statements that a person can make about his/her Primary Care Provider or PCP. When the questions say PCP, we are asking about your HIV care team that includes your doctor, nurse, social worker, and health educator. Please choose the appropriateness of each statement for your PCP by marking one number per statement. Thank you!

Not at all appropriate - 1

Somewhat appropriate - 2

Appropriate - 3

Mostly appropriate - 4

Totally appropriate - 5
My PCP helps me

My PCP has enough time for me

I trust my PCP

My PCP understands me

My PCP is dedicated to me

My PCP and I agree on the nature of my medical symptoms

I can talk to my PCP

I feel content with my PCP’s treatment

I find my PCP easily accessible

Following are some ways of coping with difficult situations. Think of a difficult situation you had to face during the past year. We want to know how you coped with that difficult situation.

I didn’t do this at all - 1

I did this a little bit - 2

I did this a medium amount - 3

I did this a lot - 4

I turned to work or other activities to take my mind off things

I concentrated my efforts on doing something about the situation I’m in.

I said to myself "this isn’t real."

I used alcohol or other drugs to make myself feel better.
I got emotional support from others.

I gave up trying to deal with it.

I took action to try to make the situation better.

I refused to believe that it has happened.

I said things to let my unpleasant feelings escape.

I used alcohol or other drugs to help me get through it.

I tried to see it in a different light, to make it seem more positive.

I tried to come up with a strategy about what to do.

I got comfort and understanding from someone.

I gave up the attempt to cope.

I looked for something good in what is happening.

I made jokes about it.

I did something to think about it less, such as going to movies, watching TV, reading,

daydreaming, sleeping, or shopping.

I accepted the reality of the fact that it has happened.

I expressed my negative feelings

I tries to find comfort in my religion or spiritual beliefs.

I learned to live with it.

I thought hard about what steps to take.

I prayed or meditated.

I made fun of the situation.
Each item below is a belief statement about your medical condition with which you may agree or disagree. In this case, medical condition refers to HIV. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you agree or disagree with that statement. The more you agree with a statement, the higher will be the number you circle. The more you disagree with a statement, the lower will be the number you circle. Please make sure that you answer EVERY ITEM and that you choose ONLY ONE number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

1. Strongly disagree
2. Moderately disagree
3. Slightly disagree
4. Slightly agree
5. Moderately agree
6. Strongly agree

If my condition worsens, it is my own behavior which determines how soon I will feel better again.

As to my condition, what will be will be.

If I see my doctor regularly, I am less likely to have problems with my condition.

Most things that affect my condition happen to me by chance.

Whenever my condition worsens, I should consult a medically trained professional.
I am directly responsible for my condition getting better or worse.

Other people play a big role in whether my condition improves, stays the same, or gets worse.

Whatever goes wrong with my condition is my fault.

Luck plays a big part in determining how my condition improves

In order for my condition to improve, it is up to other people to see that the right things happen.

Whatever improvement occurs with my condition is largely a matter of good fortune.

The main thing which affects my condition is what I myself do.

I deserve the credit when my condition improves and the blame when it gets worse.

Following doctor’s orders to the letter is the best way to keep my condition from getting worse.

If my condition worsens, it's a matter of fate.

If I am lucky, my condition will get better.

If my condition takes a turn for the worse, it is because I have not been taking proper care of myself.

The type of help I receive from other people determines how soon my condition improves.
Por favor conteste todas las preguntas.

Appellido ____________________________

Primer Nombre ____________________________

El país dónde nació ____________________________

Años que vivir con el VIH ____________________________

(Con números, no con palabras)

Distancia que viajó hacia la clínica en millas ____________________________

(Con números, no con palabras)

El grado más alto que ha cumplido ____________________________

Las siguientes son algunas declaraciones que una persona puede hacer sobre su médico.

Cuando las declaraciones dicen Médico, preguntamos sobre su equipo de atención para el VIH que incluye su médico (a), su enfermera, trabajador social, y su educador de salud. Por favor escoja la opción que aplica más a cada declaración para su Médico. Solamente escoja una opción para cada declaración.

Cada opción se explica abajo.

Gracias!

Nada Apropiado - 1

Algo Apropiado - 2

Apropiado - 3

Bastante Apropiado - 4

Muy Apropiado - 5
Mi médico me ayuda.

Mi médico tiene suficiente tiempo para mí.

Creo en mi médico.

Mi médico me entiende.

Mi médico se dedica a ayudarme.

Mi médico y yo estamos de acuerdo sobre la naturaleza de mis síntomas.

Puedo hablar con mi médico.

Me siento contento con el tratamiento de mi médico.

Siento a mi médico fácilmente accessible.

Las siguientes son algunas maneras de enfrentarse y adaptarse a situaciones difíciles.

Piense en una situación difícil que Usted tuvo que enfrentar en el año pasado.

Estamos interesados en saber cómo Usted se enfrentó y adaptó a esa situación difícil.

No hice esto en lo absoluto - 1
Hice esto un poco - 2
Hice esto con cierta frecuencia - 3
Hice esto con mucha frecuencia – 4

Yo me enfoqué en el trabajo u otras actividades para distraer mi mente

Yo concentré mis esfuerzos para hacer algo acerca de la situación en la que estaba.

Yo me dije a mí mismo(a), esto no es real.
Yo usé alcohol u otras drogas para sentirme mejor.

Yo recibí apoyo emocional de otras personas.

Yo me di por vencido(a) de tratar de lidiar con esto.

Yo tomé acción para poder mejorar la situación.

Yo rehusé creer que esto hubiera pasado.

Yo dije cosas para dejar escapar mis sentimientos desagradables.

Yo usé alcohol u otras drogas para que me ayudaran a pasar por esto.

Yo traté de verlo con un enfoque distinto para que pareciera más positivo.

Yo traté de crear una estrategia para saber que hacer.

Yo recibí apoyo y comprensión de alguien.

Yo dejé de hacerle frente a la situación en la que estaba.

Yo busqué algo bueno en lo que estaba pasando.

Yo hice bromas acerca de esto.

Yo hice algo para pensar menos en esto, como ir al cine, ver T.V., leer, soñar despierto(a), dormir, o ir de compras.

Yo acepté la realidad de que esto haya pasado.

Yo expresé mis pensamientos negativos.

Yo traté de encontrar apoyo en mi religión o mis creencias espirituales.

Yo aprendí a vivir con esto.

Yo pensé mucho cuales eran los pasos a tomar.

Yo recé o medité.

Yo hice gracia de la situación.
Las siguientes frases expresan lo que las personas piensan y/o hacen en asuntos de salud. Ecogiendo una de las opciones que están al frente de cada afirmación, dé su opinión, de acuerdo con los siguientes criterios:

1 = Totalmente de acuerdo
2 = De acuerdo en su mayor parte
3 = En duda
4 = En desacuerdo en su mayor parte
5 = Totalmente en desacuerdo

No existen respuestas correctas o erradas; lo que importa es su opinión. Por favor conteste todos.

1. Totalmente de acuerdo
2. De acuerdo en su mayor parte
3. En duda
4. En desacuerdo en su mayor parte
5. Totalmente en desacuerdo

Si yo estuviera enfermo, la recuperación rápida va a depender en mi comportamiento. No importa lo que yo haga; si fuera para estar enfermo, enfermo de todas maneras. Para mí, la mejor manera de evitar enfermedades es hacer consultas regulares con un medico.

Muchas cosas que afectan mi salud ocurren por casualidad.

Todas las veces que no me siento bien de salud, consulto un medico.

Yo puedo controlar mi salud.
Si estoy enferma o con salud, mi familia tiene mucho que ver con eso.

Cuando enfermo, normalmente yo soy el culpable.

La suerte es muy importante para recuperarme de una enfermedad.

Quienes controlan mi salud, son los médicos.

Mi salud es principalmente una cuestión de suerte y azar.

La principal cosa que afecta mi salud, es lo que yo mismo hago.

Si yo me cuidara bien, puedo evitar enfermedades.

Cuando sano de una enfermedad, es porque las personas cuidaron bien de mí. (mi médico, mi esposa, la enfermera, los amigos, la familia, etc.)

No importa lo que yo haya, siempre es posible que esté enfermo.

Si fuera por mi destino, yo tendría salud.

Si yo hiciera las cosas bien, podría mantenerme saludable.

Para tener salud, solo tengo que obedecer a mi médico.
APPENDIX E

THE NEWEST VITAL SIGN (Pfizer, Inc.)

Why Does an Ice Cream Label Work as a Predictor of the Ability To Understand Medical Instructions?

A patient’s ability to read and analyze any kind of nutrition label requires the same analytical and conceptual skills that are needed to understand and follow a provider’s medical instructions. The skills, which are known as health literacy, are defined as the understanding and application of words (prose), numbers (numeracy), and forms (documents).

The use of an ice cream label is especially relevant as recent research in the American Journal of Preventive Medicine (November 2006) has shown that poor comprehension of food labels correlated highly with low-level literacy and numeracy skills. However, the study found that even patients with better reading skills could have difficulties interpreting the labels.

Whether reading a food label or following medical instructions, patients need to:
- remember numbers and make mathematical calculations.
- identify and be mindful of different ingredients that could be potentially harmful to them.
- make decisions about their actions based on the given information.

**PROSE LITERACY:**

Clinical example: The patient has scheduled some blood tests and is instructed in writing to fast the night before the tests. The skill needed to follow this instruction is Prose Literacy.

Ice cream label example: The patient needs this skill to read the label and determine if he can eat the ice cream if he is allergic to peanuts.

**NUMERACY:**

Clinical example: A patient is given a prescription for a new medication that needs to be taken at a certain dosage twice a day. The skill needed to take the medication properly is Numeracy.

Ice cream label example: The patient needs this same skill to calculate how many calories are in a serving of ice cream.

**DOCUMENT LITERACY:**

Clinical example: The patient is told to buy a glucose meter and use it 30 minutes before each meal and before going to bed. If the number is higher than 200, he should call the office. The skill needed to follow this instruction is Document Literacy.

Ice cream label example: The patient needs this skill to identify the amount of saturated fat in a serving of ice cream and how it will affect his daily diet if he doesn’t eat it.
### Nutrition Facts

<table>
<thead>
<tr>
<th>Amount per serving</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Calories</td>
<td>250</td>
</tr>
<tr>
<td>Fat Cal</td>
<td>120</td>
</tr>
<tr>
<td>%DV</td>
<td></td>
</tr>
<tr>
<td>Total Fat</td>
<td>13g</td>
</tr>
<tr>
<td>Sat Fat</td>
<td>9g</td>
</tr>
<tr>
<td>Cholesterol</td>
<td>28mg</td>
</tr>
<tr>
<td>Sodium</td>
<td>55mg</td>
</tr>
<tr>
<td>Total Carbohydrate</td>
<td>30g</td>
</tr>
<tr>
<td>Dietary Fiber</td>
<td>2g</td>
</tr>
<tr>
<td>Sugars</td>
<td>23g</td>
</tr>
<tr>
<td>Protein</td>
<td>4g</td>
</tr>
</tbody>
</table>

*Percentage Daily Values (DV) are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.

**Ingredients:** Cream, Skim Milk, Liquid Sugar, Water, Egg Yolks, Brown Sugar, Milkfat, Peanut Oil, Sugar, Butter, Salt, Carrageenan, Vanilla Extract.
1. If you eat the entire container, how many calories will you eat?  
   **Answer:** 1,000 is the only correct answer

2. If you are allowed to eat 60 grams of carbohydrates as a snack, how much ice cream could you have?  
   **Answer:** Any of the following is correct: 1 cup (or any amount up to 1 cup), half the container. Note: If patient answers “two servings,” ask “How much ice cream would that be if you were to measure it into a bowl?”

3. Your doctor advises you to reduce the amount of saturated fat in your diet. You usually have 42 g of saturated fat each day, which includes one serving of ice cream. If you stop eating ice cream, how many grams of saturated fat would you be consuming each day?  
   **Answer:** 33 is the only correct answer

4. If you usually eat 2,500 calories in a day, what percentage of your daily value of calories will you be eating if you eat one serving?  
   **Answer:** 10% is the only correct answer

READ TO SUBJECT: Pretend that you are allergic to the following substances: penicillin, peanuts, latex gloves, and bee stings.

5. Is it safe for you to eat this ice cream?  
   **Answer:** No

   **(Ask only if the patient responds “no” to question 5):** Why not?  
   **ANSWER CORRECT?**  
   yes  
   no  
   **Answer:** Because it has peanut oil.

**Interpretation**

Number of correct answers:

**Score of 0-1 suggests high likelihood (50% or more) of limited literacy. Score of 2-3 indicates the possibility of limited literacy. Score of 4-6 almost always indicates adequate literacy.**
SCREENING, BRIEF INTERVENTION AND REFERRAL TO TREATMENT

St. Mary's Hospital and Medical Center
2635 N 7th Street, Grand Junction, CO 81502

Federal Regulations (42 CFR part 2) prohibits you from making disclosure of this information without specific written consent of the person to whom it pertains, or as otherwise permitted by such regulations. A general authorization for the release of medical or other information in NOT

CONFIDENTIAL
Screening, Brief Intervention and Referral to Treatment Brief Screen

Pre-screen Questions

1. Have you smoked cigarettes or used other tobacco products in the past 3 years? Yes □ No □
Type, amount, frequency: _____________________________________________________________

2. On average, how many days a week do you drink alcohol? ______

3. On a typical day when you drink, how many drinks do you have? ______
Acceptable limits:
Women: 3 per day/ 7 per week
Men: 4 per day/ 14 per week

What are you drinking and what size is each drink?
________________________________________________________

4. What is the maximum number of drinks you had on any given day in the past month? ______

5. Do you use prescription drugs for reasons other than prescribed, more frequently than prescribed, or any illicit drugs?
Yes □ No □
Substance/Route: ________________________________________________________________

_____

APPENDIX F
<table>
<thead>
<tr>
<th>Substance</th>
<th>Score</th>
<th>Risk Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tobacco Products</td>
<td>0-3 Low</td>
<td>27+ High</td>
</tr>
<tr>
<td></td>
<td>4-26 Moderate</td>
<td></td>
</tr>
<tr>
<td>Alcoholic Beverages</td>
<td>0-10 Low</td>
<td>27+ High</td>
</tr>
<tr>
<td></td>
<td>11-26 Moderate</td>
<td></td>
</tr>
<tr>
<td>Cannabis</td>
<td>0-3 Low</td>
<td>27+ High</td>
</tr>
<tr>
<td></td>
<td>4-26 Moderate</td>
<td></td>
</tr>
<tr>
<td>Cocaine</td>
<td>0-3 Low</td>
<td>27+ High</td>
</tr>
<tr>
<td></td>
<td>4-26 Moderate</td>
<td></td>
</tr>
<tr>
<td>Amphetamine type Stimulants</td>
<td>0-3 Low</td>
<td>27+ High</td>
</tr>
<tr>
<td></td>
<td>4-26 Moderate</td>
<td></td>
</tr>
<tr>
<td>Inhalants</td>
<td>0-3 Low</td>
<td>27+ High</td>
</tr>
<tr>
<td></td>
<td>4-26 Moderate</td>
<td></td>
</tr>
<tr>
<td>Sedatives or Sleeping Pills</td>
<td>0-3 Low</td>
<td>27+ High</td>
</tr>
<tr>
<td></td>
<td>4-26 Moderate</td>
<td></td>
</tr>
<tr>
<td>Hallucinogens</td>
<td>0-3 Low</td>
<td>27+ High</td>
</tr>
<tr>
<td></td>
<td>4-26 Moderate</td>
<td></td>
</tr>
<tr>
<td>Opioids</td>
<td>0-3 Low</td>
<td>27+ High</td>
</tr>
<tr>
<td></td>
<td>4-26 Moderate</td>
<td></td>
</tr>
<tr>
<td>Other-Specify</td>
<td>0-3 Low</td>
<td>27+ High</td>
</tr>
<tr>
<td></td>
<td>4-26 Moderate</td>
<td></td>
</tr>
</tbody>
</table>
# PATIENT HEALTH QUESTIONNAIRE (PHQ-9)

## NAME: ___________________________ DATE: ________________

Over the last 2 weeks, how often have you been bothered by any of the following problems?

(use *'s* to indicate your answer)

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Several days</th>
<th>More than half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Little interest or pleasure in doing things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. Feeling down, depressed, or hopeless</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. Trouble falling or staying asleep, or sleeping too much</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4. Feeling tired or having little energy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5. Poor appetite or overeating</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7. Trouble concentrating on things, such as reading the newspaper or watching television</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8. Moving or speaking so slowly that other people could have noticed. Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9. Thoughts that you would be better off dead, or of hurting yourself</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

**Add columns:**

TOTAL: ______________________

(Hospital professional: For interpretation of TOTAL, please refer to accompanying scoring card.)

10. If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

- Not difficult at all
- Somewhat difficult
- Very difficult
- Extremely difficult

---

Copyright © 1999 Pfizer Inc. All rights reserved. Reproduced with permission. PRIME-MDC is a trademark of Pfizer Inc.

A26613B 10/01-2005
PHQ-9 Patient Depression Questionnaire

For initial diagnosis:

1. Patient completes PHQ-9 Quick Depression Assessment.
2. If there are at least 4 √'s in the shaded section (including Questions #1 and #2), consider a depressive disorder. Add score to determine severity.

Consider Major Depressive Disorder
- if there are at least 5 √'s in the shaded section (one of which corresponds to Question #1 or #2)

Consider Other Depressive Disorder
- if there are 2-4 √'s in the shaded section (one of which corresponds to Question #1 or #2)

Note: Since the questionnaire relies on patient self-report, all responses should be verified by the clinician, and a definitive diagnosis is made on clinical grounds taking into account how well the patient understood the questionnaire, as well as other relevant information from the patient. Diagnoses of Major Depressive Disorder or Other Depressive Disorder also require impairment of social, occupational, or other important areas of functioning (Question #10) and ruling out normal bereavement, a history of a Manic Episode (Bipolar Disorder), and a physical disorder, medication, or other drug as the biological cause of the depressive symptoms.

To monitor severity over time for newly diagnosed patients or patients in current treatment for depression:

1. Patients may complete questionnaires at baseline and at regular intervals (e.g., every 2 weeks) at home and bring them in at their next appointment for scoring or they may complete the questionnaire during each scheduled appointment.
2. Add up √'s by column. For every √: Several days = 1; More than half the days = 2; Nearly every day = 3
3. Add together column scores to get a TOTAL score.
4. Refer to the accompanying PHQ-9 Scoring Box to interpret the TOTAL score.
5. Results may be included in patient files to assist you in setting up a treatment goal, determining degree of response, as well as guiding treatment intervention.

Scoring: add up all checked boxes on PHQ-9

For every √ Not at all = 0; Several days = 1; More than half the days = 2; Nearly every day = 3

Interpretation of Total Score

<table>
<thead>
<tr>
<th>Total Score</th>
<th>Depression Severity</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-4</td>
<td>Minimal depression</td>
</tr>
<tr>
<td>5-9</td>
<td>Mild depression</td>
</tr>
<tr>
<td>10-14</td>
<td>Moderate depression</td>
</tr>
<tr>
<td>15-19</td>
<td>Moderately severe depression</td>
</tr>
<tr>
<td>20-27</td>
<td>Severe depression</td>
</tr>
</tbody>
</table>

PHQ9 Copyright © Pfizer Inc. All rights reserved. Reproduced with permission. PRIME-MD © is a trademark of Pfizer Inc.
APPENDIX H

THE PATIENT-DOCTOR RELATIONSHIP QUESTIONNAIRE – 9

Instruction:
You will read nine statements that a person can make about his/her PCP. Please choose the appropriateness of each statement for your PCP by marking one number per statement. The meaning of the numbers is as follows:

1 - not at all appropriate 2 - somewhat appropriate 3 - appropriate 4 - mostly appropriate 5 - totally appropriate

1. My PCP helps me
2. My PCP has enough time for me
3. I trust my PCP
4. My PCP understands me
5. My PCP is dedicated to help me
6. My PCP and I agree on the nature of my medical symptoms
7. I can talk to my PCP
8. I feel content with my PCP’s treatment
9. I find my PCP easily accessible
APPENDIX I

THE MULTIDIMENSIONAL HEALTH LOCUS OF CONTROL - FORM C

Instructions: Each item below is a belief statement about your medical condition with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you agree or disagree with that statement. The more you agree with a statement, the higher will be the number you circle. The more you disagree with a statement, the lower will be the number you circle. Please make sure that you answer EVERY ITEM and that you circle ONLY ONE number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

1. If my condition worsens, it is my own behavior which determines how soon I will feel better again.
2. As to my condition, what will be will be.
3. If I see my doctor regularly, I am less likely to have problems with my condition.
4. Most things that affect my condition happen to me by chance.
5. Whenever my condition worsens, I should consult a medically trained professional.
6. I am directly responsible for my condition getting better or worse.
7. Other people play a big role in whether my condition improves, stays the same, or gets worse.
8. Whatever goes wrong with my condition is my own fault.
9. Luck plays a big part in determining how my condition improves.
10. In order for my condition to improve, it is up to other people to see that the right things happen.
11. Whatever improvement occurs with my condition is largely a matter of good fortune.
12. The main thing which affects my condition is what I myself do.
13. I deserve the credit when my condition improves and the blame when it gets worse.
14. Following doctor's orders to the letter is the best way to keep my condition from getting any worse.
15. If my condition worsens, it's a matter of fate.
16. If I am lucky, my condition will get better.
17. If my condition takes a turn for the worse, it is because I have not been taking proper care of myself.
18. The type of help I receive from other people determines how soon my condition improves.
APPENDIX J

BRIEFCOPE

These items deal with ways you've been coping with the stress in your life since you found out you were going to have to have this operation. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

1. I've been turning to work or other activities to take my mind off things.
2. I've been concentrating my efforts on doing something about the situation I'm in.
3. I've been saying to myself "this isn't real."
4. I've been using alcohol or other drugs to make myself feel better.
5. I've been getting emotional support from others.
6. I've been giving up trying to deal with it.
7. I've been taking action to try to make the situation better.
8. I've been refusing to believe that it has happened.
9. I've been saying things to let my unpleasant feelings escape.
10. I've been getting help and advice from other people.
11. I've been using alcohol or other drugs to help me get through it.
12. I've been trying to see it in a different light, to make it seem more positive.
13. I've been criticizing myself.
14. I've been trying to come up with a strategy about what to do.
15. I've been getting comfort and understanding from someone.
16. I've been giving up the attempt to cope.
17. I've been looking for something good in what is happening.
18. I've been making jokes about it.
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
20. I've been accepting the reality of the fact that it has happened.
21. I've been expressing my negative feelings.
22. I've been trying to find comfort in my religion or spiritual beliefs.
23. I've been trying to get advice or help from other people about what to do.
24. I've been learning to live with it.
25. I've been thinking hard about what steps to take.
26. I've been blaming myself for things that happened.
27. I've been praying or meditating.
28. I've been making fun of the situation.
APPENDIX K

RURAL-URBAN CONTINUUM CODE (Vanderbroom & Madigan, 2007)

1 = Urban Core Census Tract (CT)
2 = CT strongly tied to urban core
3 = CT weakly tied to urban core
4 = Large town CT
5 = CT strongly tied to large town
6 = CT weakly tied to large town
7 = Small town CT
8 = CT strongly tied to small town