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Health Literacy, Depression, Anxiety, and Posttraumatic Stress Disorder as Predictors of Biological Markers of Immune Functioning in Youth and Young Adults with HIV

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Health Literacy, Depression, Anxiety, and Posttraumatic Stress Disorder as Predictors of Biological Markers of Immune Functioning in Youth and Young Adults with HIV

by

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A dissertation submitted in partial fulfillment
of the requirements for the degree of
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DEDICATION

To my parents, sister, and friends for providing unconditional patience and support through my journey of graduate school. You always remind me how much I am loved and appreciated.

A special thank you to my dear friend Lorraine for always lending a listening ear and a sound voice of reason. You taught me to not take myself too seriously and to wear life like a loose garment. I could have never made it without you by my side. I am so grateful that one day at a time, I get to trudge the road of happy destiny with you.

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ABSTRACT

Human immunodeficiency virus (HIV) is a virus that affects the body's immune system (Centers for Disease Control [CDC], 2016a). HIV is a worldwide epidemic and disproportionately impacts youth in the United States. Youth living with HIV (YLWH) face significant mental health problems, namely depression, anxiety, and posttraumatic stress disorder (PTSD) with rates of these disorders discrepant from those in the general population. In addition to psychological difficulties, health literacy is another factor that influences individuals with HIV and is a priority of research with adolescents (Kalichman et al., 2000; Manganello, 2008). The *National HIV/AIDS Strategy: Update 2020* (White House Office of National AIDS Policy, 2015**)** identified youth, ages 13 to 24 years, as a key population needing broad support not only for HIV prevention but also engagement in care including improving mental health and health literacy. The current study explored the extent to which YLWH were health literate in addition to the extent to which they exhibited psychological symptoms of depression, anxiety, and posttraumatic stress disorder. Furthermore, the study examined the extent to which health literacy and psychological symptoms were associated with health outcomes.

A total of 145 YLWH between the ages of 13 and 25 years participated in the study. Participants completed the Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977), Generalized Anxiety Disorder-7 Item Scale (GAD-7; Spitzer, Kroenke, Williams, & Lowe, 2006), Primary Care-PTSD Screen (PC-PTSD; Prins et al., 2003), and Brief Estimate of Health Knowledge and Action-HIV Version (Osborn, Davis, Bailey, & Wolf, 2010). Of the 145 participants, 103 completed the CES-D, 144 completed the GAD-7, 131 completed the PC-

PTSD, and 102 completed the BEHKA-HIV. In addition, participants' biological markers of immune functioning (i.e., CD4 count and viral load) were obtained from medical abstraction.

Results indicated the sample reported high levels of symptoms of depression, anxiety, and PTSD. Thirty-five percent of participants screened positive for depressive symptoms, 26% screened positive for anxiety symptoms, and 21% screened positive for PTSD symptoms. Participants had a moderate amount of HIV knowledge and the majority reported taking their medications under most conditions. Age was a significant predictor of CD4 count and viral load such that increasing age was associated with worse immune system functioning. Educational attainment was a significant predictor of CD4 count and to a lesser extent viral load indicating that greater education was associated with better immune system functioning. There was an interaction between mode of transmission and psychological symptoms. For perinatally infected youth, greater psychological symptoms were associated with a decline in CD4 count. The same decline was not seen for behaviorally infected youth. Health literacy (knowledge and action) added significantly to the explanation of the variance in viral load. Decreasing action scores were statistically associated with an increased likelihood of having a detectable viral load.

These findings point to the need for prevention and intervention mental health services for YLWH. Future research should determine prevention and intervention strategies for mental health issues with YLWH in particular. Additionally, health literacy is an important factor that should be addressed by practitioners working with YLWH. More research needs to be conducted to determine the best way to measure health literacy in YLWH and how to intervene with improving health literacy.

CHAPTER ONE:

INTRODUCTION

Statement of the Problem

Human immunodeficiency virus (HIV) is a worldwide epidemic that gradually destroys the body's ability to fight infections and cancers by damaging the immune system (National Institutes of Health [NIH], 2012). HIV disproportionately impacts youth in the United States (Centers for Disease Control [CDC], 2017). In 2015, youth and young adults accounted for approximately 22% of all new HIV diagnoses despite only representing 17% of the United States population (CDC, 2017). Health literacy has appeared in the literature as a factor that is related to positive health outcomes for individuals living with HIV (Kalichman et al., 2000). Additionally, youth living with HIV (YLWH) face significant mental health problems, namely depression, anxiety, and posttraumatic stress disorder with rates of these disorders discrepant from those in the general population. For example, the CDC (Pratt & Brody, 2014) reported a rate of depression of 5.7% in the general population of youth aged 12-17 years compared to 37% in YLWH (Murphy et al., 2001). Given these concerning statistics, the *National HIV/AIDS Strategy: Update 2020* (White House Office of National AIDS Policy, 2015**)** identified youth, ages 13 to 24 years, as a key population needing broad support not only for HIV prevention but also engagement in care including improving mental health and health literacy.

Critical Issues related to YLWH

Health literacy. Traditionally the definition of health literacy refers to the ability to read and perform mathematical tasks required in a medical setting (e.g., reading prescription bottles, measuring the correct dosage; AMA Ad Hoc Committee on Health Literacy, 1999). More recent definitions have expanded to include outcomes of health literacy rather than the act of reading health material (Berkman, Davis, & McCormack, 2010). Ratzan and Parker (2010) were the first to expand the basic definition to include "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions," a definition later used in the Institute of Medicine's (IOM; 2004) report titled "Health literacy: A prescription to end confusion" and *Healthy People 2010.* Other definitions take a more dynamic approach and recognize that the specific health issue, health care providers, and health care system all interact to influence an individual's health literacy (Baker, 2006).

Studies of adults living with HIV have shown a robust relationship between health literacy and objectively measured treatment adherence (Kalichman et al., 2009), self-reported treatment adherence (Kalichman et al., 1999; Osborn et al., 2007), HIV-related knowledge (Kalichman & Rompa, 2000; Wolf et al., 2004), and self-reported biological indicators (Kalichman et al., 2000). To date, there have only been two studies measuring the relationship between health literacy and adherence to medication regimen in youth and young adults (i.e., Murphy et al., 2010; Navarra, Neu, Toussi, Nelson, & Larson, 2014) and neither of these studies found significant results. However, it is important to recognize that both studies assessed health literacy by measuring the number of health-related words participants could read and neither

study assessed HIV-specific health literacy. Additionally, the sample of participants in the study conducted by Murphy and colleagues (2010) only included individuals who were engaging in at-risk behaviors (e.g., unprotected sex, alcohol/drug use). The study conducted by Navarra and colleagues (2014) included only 50 participants and the sample size likely was too small for enough power to detect statistical differences. Given these limitations, there is a need for further research in this area.

Psychological disorders. YLWH face significant mental health problems, namely depression, anxiety, and posttraumatic stress disorder. The CDC (Pratt & Brody, 2014) reported that from 2009-2012 5.7% of youth aged 12-17 years and 7.4% of individuals aged 18-39 years experienced moderate or severe depressive symptoms in the two weeks prior to completing a questionnaire of depression symptoms. However, statistics regarding the prevalence of depression in YLWH reveals rates of depression varying from 15% (Martinez et al., 2009) to 37% (Murphy et al., 2001). Regarding anxiety, rates in YLWH ranged from 4% for males with perinatally acquired HIV specifically (Brown et al., 2015) to 17% of an entire sample of YLWH (Martinez et al., 2009). These rates are consistent with those found in the general population of 13 to 18 years olds (Marikangas et al., under review); however, anxiety is one of the most common mental health disorders making it an important area to study. YLWH may also be at increased risk for PTSD due to past traumatic experiences or interpreting receiving the diagnosis of HIV as a traumatic event (O'Cleirigh et al., 2008). Rates indicated 13.3% of YLWH met criteria for PTSD and 20% had posttraumatic stress symptoms (Radcliffe et al., 2007). The average number of 5.6 traumatic events reported in YLWH (Radcliffe et al., 2007; Radcliffe et al., 2011) is considerably greater than the average of 1 to 4.2 reported in other studies of youth and young adults (Jaycox et al., 2004; Zatzick et al., 2006). Overall, the research looking at

mental health problems in YLWH indicates that these youth suffer from a variety of difficulties including depression, anxiety, and PTSD.

Health outcomes. Antiretroviral therapy (ART) is the term used to refer to treatment for HIV (World Health Organization [WHO], 2016a). Standard ART consists of at least three antiretroviral (ARV) drugs that prevent the replication and progression of the virus. ART is currently the most effective treatment for HIV and has reduced HIV-related morbidity and mortality (Panel on Antiretroviral Guidelines for Adults and Adolescents, 2015). ART helps to improve an individual's health by increasing CD4 T-cells and decreasing viral load (Mutwa et al., 2014), two biological markers of immune functioning. CD4-cells and T-cells refer to the same type of white blood cell that protects an individual's body from infection and is an indicator of immune system functioning. Viral load (VL) refers to the amount of HIV RNA in an individual's blood (Health and Human Services, 2015a). The goal of any HIV treatment is to increase CD4 count and decrease VL.

Treatment adherence is a critical issue for YLWH in order to reduce their VL and increase their CD4 count, maintain optimal immune functioning, and live a long, healthy life (Paterson et al., 2000); however, many YLWH have suboptimal rates of medication adherence and thus poorer health outcomes than those who adhere to their medications (Hosek, Harper, & Domanico, 2005). Some barriers to treatment adherence include forgetting, striving for normalcy, side effects, and the large number of pills (Hanghoj & Boisen, 2014; Kourrouski et al., 2009). Additionally, mental health symptoms such as those associated with anxiety, depression, and PTSD show relationships with biological markers (Radcliffe et al., 2011; Walsh et al., 2017) and treatment adherence (Murphy et al., 2010).

Conceptual Framework

Nutbeam (2000) created a model for health promotion, which contends that health actions (i.e., education, social mobilization, and advocacy) lead to different levels of health outcomes. These actions lead to outcomes such as health literacy, which then lead to health and social effects such as reduced morbidity and disability, enhanced quality of life, and equity. Manganello (2008) created a framework specifically for adolescent health literacy drawing heavily from an ecological approach. In this model, individual characteristics of adolescents predict health literacy, which then influences health behaviors. Family and peer influences as well as mass media, the education system, and the health system also influence these relationships. In the case of YLWH, the high incidence of risk-taking behaviors, low socioeconomic status of many youth, and racial/ethnic minority status all are associated with the low health literacy of this population. However, what this framework leaves out are the psychological factors that have an influence on health outcomes. As such, this study examined the relationships between health literacy and health outcomes as well as psychological symptoms and health outcomes in YLWH.

Purpose of the Current Study

Currently, there is a dearth of research on YLWH especially in terms of the relations between health literacy, psychological symptoms, and health outcomes. When health literacy has been studied in YLWH, researchers have relied on patients' ability to read health related words. There have been no studies that have examined health literacy in terms of knowledge about one's health condition (e.g., definitions of HIV specific terms) and specific actions individuals take regarding their health condition (e.g., taking medications when tired). Because researchers have not found a relationship between health literacy and health outcomes in YLWH, alternative ways

to measure health literacy in YLWH may be more appropriate. As such, one of the purposes of this study was to determine the extent to which YLWH exhibited health literacy utilizing an HIV-specific measure of health literacy. Given the importance of health outcomes (i.e., CD4 count and viral load), this study also determined the extent to which health literacy was associated with health outcomes. Additionally, given the disproportionate amount of mental health issues experienced by YLWH, it was important to understand the degree to which YLWH reported various mental health symptoms and the extent to which psychological symptoms were associated with health outcomes. The specific research questions for this study are presented below.

Research Questions

1) To what extent do youth and young adults with HIV ages 13-25 years report psychological symptoms of depression, anxiety, and PTSD?
2) To what extent do youth and young adults with HIV ages 13-25 years demonstrate health literacy?
3) To what extent are health literacy and health outcomes (i.e., CD4 count and viral load) associated after controlling for demographic variables? It was hypothesized that increasing health literacy would be associated with better immune functioning.
4) To what extent are psychological symptoms and health outcomes (i.e., CD4 count and viral load) associated after controlling for demographic variables? It was hypothesized that more mental health symptoms would be associated with worse immune functioning.

Importance of the Current Study to School Psychology

Health literacy is an individual's ability to gather and process health-related information and understand the information in order to make informed health decisions (Ratzan & Parker,

2000). In the Institute of Medicine's (2004) review entitled, *Health Literacy: A Prescription to End Confusion,* health literacy was further conceptualized as being "based on the interaction of individuals' skills with health contexts, the health-care system, the education system, and broad social and cultural factors at home, at work, [at school], and in the community" (p. 5). This definition highlights the interactions between various systems. The report further highlights the role of the educational system in promoting health literacy. According to the School Health Policies and Practices Study (CDC, 2015), 78.2% of schools follow health education standards. Regarding HIV in particular, only 41.4% require students receive instruction on HIV prevention. These statistics indicate there is much room for growth regarding the provision of appropriate health education. As such, one of the objectives of *Healthy People 2020* is increasing the number of schools that provide comprehensive school health education specifically in the area of HIV/AIDS and STD infections (Office of Disease Prevention and Health Promotion [ODPHP], 2016).

Pediatric school psychology is a subspecialty of school psychology that is focused on promoting children's health through interdisciplinary communication and collaboration (Power & Bradley-Klug, 2013). Approximately 10-30% of youth are suffering from a chronic health condition (Shaw, Glaser, Ster, Sferdenschi, & McCabe, 2010). Children with a chronic health condition are those with "long-term physical, emotional, behavioral, and developmental disorders that require prescription medications and/[or] medical or educational services" (National Association of School Nurses [NASN], 2012, p. 1), such as HIV. Given the unique training pediatric school psychologists have in systems-level consultation and collaboration and pediatric health issues, they are in the ideal position to serve as the liaison between the many systems in which children with chronic health conditions interact (e.g., family, school, health

system, community agencies). In order for children to optimize their academic, social-emotional, behavioral, and health potential it is imperative this cross-system communication exists. The IOM (2004) places an emphasis on this collaboration as well.

This study attempted to establish relationships between health literacy, psychological symptoms, and health outcomes. Although the relationships that were explored in this study were not causal in nature, this investigation had the ability to identify potential areas where pediatric school psychologists can intervene with YLWH. Specifically, increasing health literacy and providing mental health services to decrease psychological symptoms and promote well-being are areas where pediatric school psychologists have expertise and will be able to impact YLWH.

Contributions to the Literature

To our knowledge, this study is the first to utilize an HIV-specific measure of health literacy with YLWH. Thus, the reliability of this measure for use with YLWH in addition to the extent to which YLWH exhibit health literacy are novel contributions to the literature. Additionally, the literature base regarding YLWH and health literacy is limited. There are only two studies that examine the health literacy of YLWH (i.e., Murphy et al., 2010; Navarra, Neu, Toussi, Nelson, & Larson, 2014) and how health literacy relates to health outcomes in this population. However, both of these studies utilized basic or functional health literacy measures and did not utilize an HIV-specific health literacy measure. Therefore, this study contributes to the empirical literature for YLWH by examining the extent to which YLWH exhibit HIV-specific health literacy and how this relates to health outcomes. Another contribution to the literature is that this study examined psychological symptoms of YLWH. This study first considered the extent to which YLWH reported psychological symptoms of depression, anxiety, and PTSD, and then examined the extent to which these psychological symptoms were related to

health outcomes. Additionally, the interactions between mode of transmission and psychological symptoms as well as mode of transmission and health literacy were explored as they relate to health outcomes.

Definition of Key Terms

Youth living with HIV (YLWH). YLWH is used to refer to individuals 13 to 25 years old who are infected with HIV.

CD4 cell count. CD4-cells and T-cells refer to the same type of white blood cell that protects an individual's body from infection and is an indicator of immune system functioning. The CDC (1993) created a classification system for HIV-infected adults and adolescents based on CD4 cell count. Individuals with 500 or more cells/μL are classified as *asymptomatic or acute HIV*, those with a CD4 count between 200 and 500 cells/μL are in the *symptomatic* category, and those with less than 200 cells/μL are classified as having *AIDS-indicator conditions*.

Viral load. Viral load (VL) refers to the amount of HIV RNA in an individual's blood (HHS, 2015a). An individual with less than 20-75 copies/mL of HIV RNA in a blood sample is said to have an undetectable viral load (HHS, 2015a). For the current study, a viral load of less than 20 copies/mL of HIV RNA in a blood sample was used to determine an undetectable viral load.

Health outcomes. Health outcomes is a term used to refer to both CD4 count and viral load.

Health literacy. Health literacy refers to one's ability to make informed health decisions based on their understanding and processing of health related information (Ratzan & Parker, 2010). It is comprised of three different levels that allow for increasingly more autonomy and decisional capacity (Nutbeam, 2008). Basic/functional literacy includes basic skills in reading

and writing. Communicative/interactive literacy is using reading and writing skills as well as social skills to make decisions in everyday life and use the information to adapt to different situations. Critical literacy is applying cognitive and social skills to critically analyze information and to use this information to increase autonomy and decisional capacity. For this study, health literacy refers to one's knowledge about HIV as well as their health-related behaviors regarding treatment adherence.

CHAPTER TWO:

REVIEW OF THE LITERATURE

This chapter begins with an overview of human immunodeficiency virus (HIV) including its prevalence, transmission, and treatment as they relate to youth. Models of health literacy as well as measures of health literacy will then be reviewed. Important biologic markers of immune functioning will be presented in addition to how they relate to health literacy. A discussion of the psychological impact of HIV on youth with a specific focus on depression, anxiety, and posttraumatic stress disorder ensues followed by the impact of psychological problems on health outcomes. The chapter concludes with a summary of the literature and how the proposed study addresses many of the current gaps.

Human Immunodeficiency Virus (HIV) in Youth

Human immunodeficiency virus (HIV) is a worldwide epidemic that continues to spread throughout many countries (World Health Organization [WHO], 2016b). HIV gradually destroys the body's ability to fight infections and cancers by killing and damaging the cells of the body's immune system (National Institutes of Health [NIH], 2012). Youth in the United States, as well as other countries, are increasingly affected by the HIV epidemic. Advances in the treatment of HIV with antiretroviral medications (ART) have significantly extended the life of youth living with HIV (YLWH; Rangel et al., 2006). Due to ART and other new medications the death rates among people with HIV have decreased 79% since 1995 (U.S. Department of Health and Human Services [HHS], 2011). Early diagnosis and treatment (i.e., ART) is effective in reducing the risk

of developing acquired immunodeficiency syndrome (AIDS; i.e., the final stage of HIV infection when the immune system is damaged beyond repair and vulnerable to infections and diseases) as well as preventing transmission; however, there is still no cure for HIV (CDC, 2015).

Prevalence. In the United States more than 1.2 million people are living with HIV and youth are disproportionately impacted (CDC, 2016a). Despite youth only representing 17% of the United States population, in 2014 there were approximately 9,731 new HIV diagnoses among those aged 13 to 24 years, accounting for nearly 22% of new HIV infections (CDC, 2017). Of the new diagnoses, young gay and bisexual males accounted for 80% (CDC, 2017). In the annual *HIV Surveillance Report*, the CDC (2014) reported the estimated rate of diagnoses of HIV infection for youth and young adults ages birth to 24 years from 2010 through 2014. The rate of HIV infection for individuals birth to 19 years decreased while the rates for those aged 20 to 24 years remained stable (CDC, 2014). Despite these positive statistics suggesting the decrease or stabilization of the rate of HIV infection, YLWH face several challenges. At the end of 2012, over 40% of youth ages 18 to 24 years living with HIV were unaware of their status, the highest rate of undiagnosed HIV in any age group (CDC, 2017). Additionally, only 78% of youth ages 13 to 24 years were linked to care within 3 months of diagnosis, representing the lowest rate of any age group, and only 52% were retained in HIV care at the end of 2012 (CDC, 2017). Given these staggering statistics, the *National HIV/AIDS Strategy: Update 2020* (White House Office of National AIDS Policy, 2015) identified youth, ages 13 to 24, as a key population needing broad support not only for HIV prevention but also engagement in care and treatment adherence.

Transmission. There are many misperceptions about the ways in which HIV can be transmitted; however, only certain bodily fluids make transmission of the virus possible (CDC, 2016b). A person who has HIV can transmit the virus through blood, semen, pre-seminal fluid,

rectal fluids, vaginal fluids, and breast milk (CDC, 2016b). In order for HIV transmission to occur, these fluids have to come in contact with mucous membranes found in various body parts (i.e., rectum, vagina, penis, and mouth) or be injected directly into the bloodstream (via needle or syringe). The five modes of transmission for HIV include sexual contact, sharing needles or other drug injection paraphernalia, before or during birth from mother to child, breastfeeding, and transfusion of blood or blood products (American Psychological Association [APA], 2010). The most recent *HIV Surveillance Report* (2014) indicated that from 2010 through 2014, the number of HIV infections due to male-to-male sexual (MSM) contact increased from 27,031 per 100,000 to 29,418 among male adults and adolescents. There were decreases in the number of HIV infections due to other causes such as injection drug use (from 2,115 per 100,000 to 1,590), MSM contact *and* injection drug use (from 1,562 to 1,217), or heterosexual contact (from 4,111 to 3,285). Among male and female adults and adolescents, approximately 94% of HIV infections in 2014 were due to MSM contact and heterosexual contact, indicating less transmission via other methods such as drug use. There also has been a reduction in HIV transmission from mother to child (APA, 2010). This can be attributed to 1) the efficacy of certain ART (i.e., AZT/ZDV) for reducing perinatal transmission and 2) recommendations by CDC (Branson et al., 2006) and the American College of Obstetricians and Gynecologists (ACOG; 2014) that all pregnant mothers be tested for HIV. Adhering to AZT reduces the risk of passing HIV from mother to child to 1-2% (APA, 2010). Despite these positive medical advances, in 2014 there was an estimated 127 youth younger than 13 years of age who were perinatally infected with HIV (CDC, 2014).

Treatment. The term antiretroviral therapy (ART) is used throughout the literature to refer to medications that treat HIV (WHO, 2016a). Standard ART consists of at least three

antiretroviral (ARV) drugs that prevent the replication and progression of the virus. Usually the three ARV drugs come from two different classes (Health and Human Services [HHS], 2015b). The different classes of ARV drugs refer to the point in the virus' life-cycle the drug attacks; taking a combination of ARV drugs from different classes decreases one's viral load and the likelihood the virus is able to replicate in one's body. The different classes of ARV drugs are: Nucleoside/Nucleotide Reverse Transcriptase Inhibitors (NRTIs), Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs), Protease Inhibitors, Fusion or Entry Inhibitors, and Integrase Inhibitors. NRTIs were approved in 1987 as the first class of antiretroviral drugs. These drugs prolonged patients' lives for 6 to 18 months (de Bethune, 2009). In 1995, Protease Inhibitors were approved and opened the door for ART by allowing an individual to take medications from two different classes, thus minimizing virus replication. Subsequently, in 1996, NNRTIs were introduced and furthered the effectiveness of ART by addressing drug resistance and poor combination therapy treatments (de Bethune, 2009).

ART is currently the most effective treatment for HIV and has reduced HIV-related morbidity and mortality (Panel on Antiretroviral Guidelines for Adults and Adolescents, 2013). Mutwa and colleagues (2014) conducted a longitudinal study of 123 Rwandan children aged 15 years and younger who had never been treated with ART. Following 12 months of ART (i.e., two NRTIs and one NNRTI), the children experienced a significant increase in CD4 T-cells and 76% of patients had a viral load < 40 copies/mL, indicating an undetectable status. Children also had improved nutritional status as measured by weight- and height-for-age (Mutwa et al., 2014).

The information on the prevalence, modes of transmission, and treatment for HIV provide the context for HIV in the youth population. The remainder of the chapter will review

the literature regarding the variables of interest, namely health literacy, symptoms of psychological disorders, and health outcomes.

Health Literacy

Models of health literacy. Traditionally the definition of health literacy referred to the ability to read and perform mathematical tasks required in a medical setting (e.g., reading prescription bottles, measuring the correct dosage; AMA Ad Hoc Committee on Health Literacy, 1999). However, more recent definitions have expanded to include outcomes of health literacy rather than the act of reading health material (Berkman, Davis, & McCormack, 2011). Ratzan and Parker (2010) were the first to expand the basic definition to include "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions," a definition later used in the Institute of Medicine's (IOM; 2004) report entitled, "Health literacy: A prescription to end confusion" and *Healthy People 2010.* Other definitions take a more dynamic approach and recognize that the specific health issue, health care providers, and health care system all interact to influence an individual's health literacy (Baker, 2006).

Nutbeam (2000) created an outcome model for health promotion (Figure 1), which contends that health promotion actions (i.e., education, social mobilization, and advocacy) lead to different levels of health outcomes. At the most immediate level, health promotion actions lead specifically to health promotion outcomes including health literacy, social action and influence, and healthy public policy and organizational practice. The intermediate health outcomes are healthy lifestyles, effective health services, and healthy environments. Ultimately, this leads to health and social outcomes to include reduced morbidity, disability, avoidable mortality, quality of life, and equity.

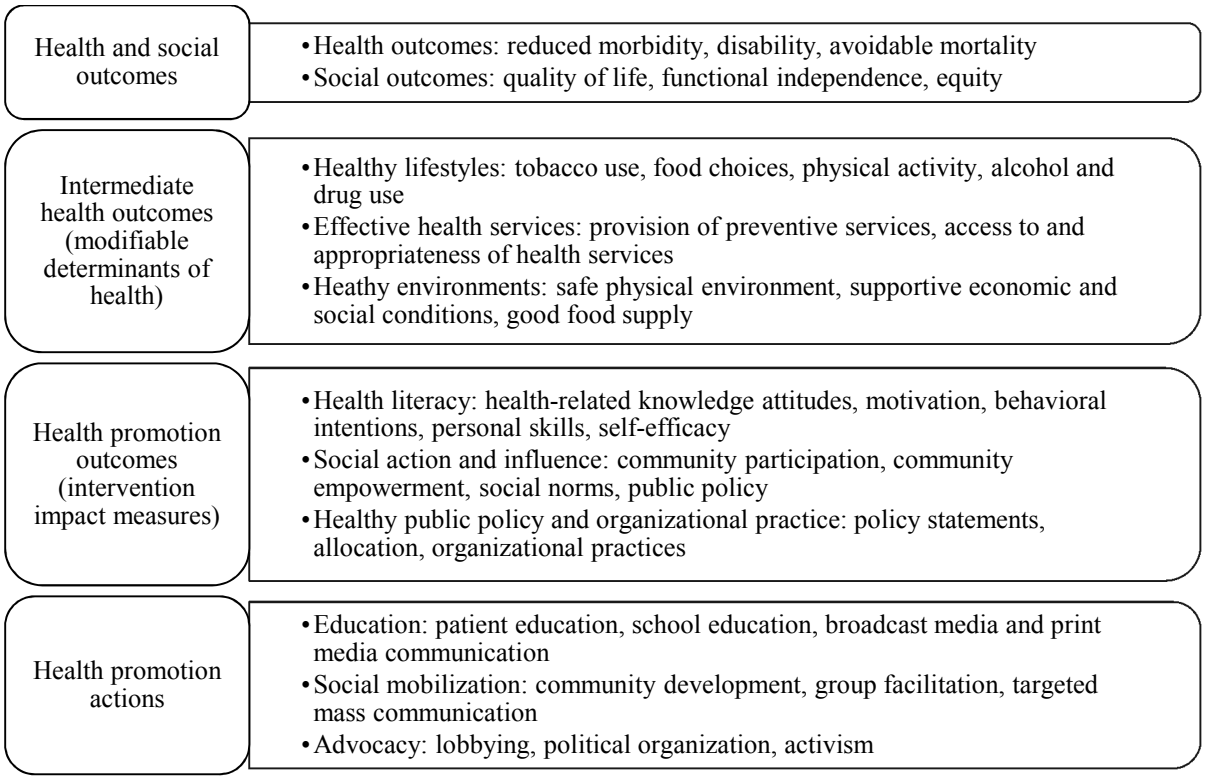

Figure 1. Outcome model for health promotion. (adapted from Nutbeam, 2000).

When it comes to increasing health literacy, Nutbeam (2008) identified three different types of health literacy that allow for increasingly more autonomy and decisional capacity. Basic/functional literacy includes basic skills in reading and writing. Communicative/interactive literacy is using reading and writing skills as well as social skills to make decisions in everyday life and use the information to adapt to different situations. Critical literacy is applying cognitive and social skills to critically analyze information and to use this information to increase autonomy and decisional capacity. Most of the literature relies on measures of basic/functional health literacy.

In the first article to address adolescent health literacy, Manganello (2008) created a framework (Figure 2) drawing heavily on an ecological approach. In this model, individual characteristics of adolescents predict health literacy, which then influences health behaviors.

Family and peer influences as well as mass media, the education system, and the health system also influence these relationships. In the case of YLWH, the high incidence of risk-taking behaviors, low socioeconomic status of many youth, and racial/ethnic minority status all are associated with the low health literacy of this population. However, what this framework leaves out is one's mental health. As such, the present study expanded on this model by examining the extent to which symptoms of psychological disorders as well as health literacy predict health outcomes.

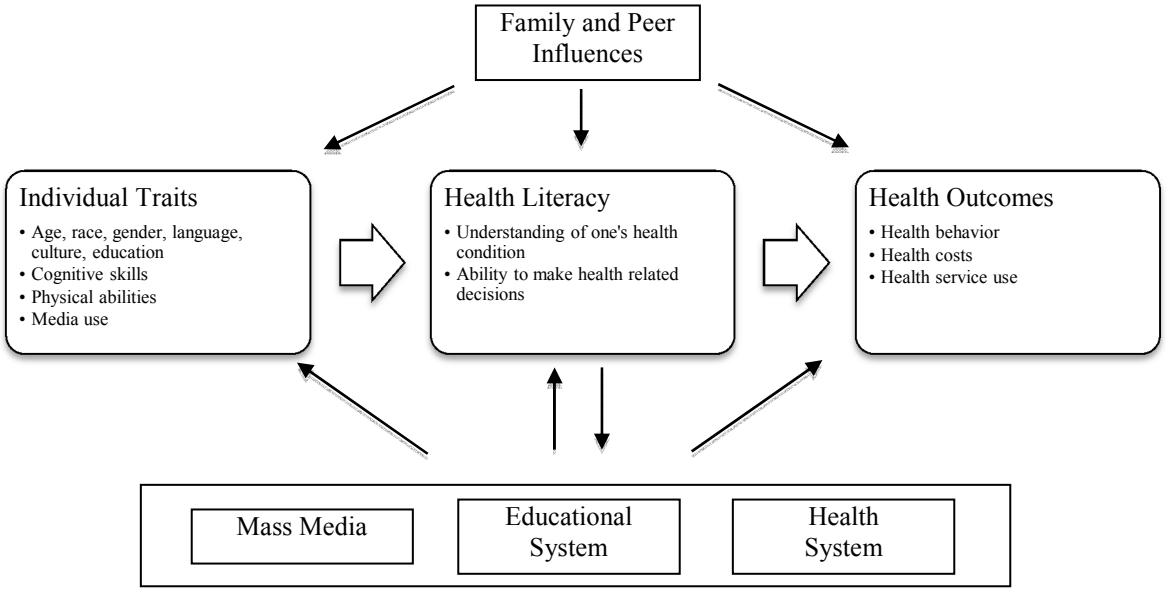

Figure 2. Framework for studying adolescent health literacy (adapted from Manganello, 2008).

Measures of health literacy. In addition to establishing a framework for adolescent health literacy, Manganello (2008) identified four goals for future research regarding adolescents and health literacy. Specifically, she urged researchers to develop tools to measure health literacy in the adolescent population beyond that of basic literacy in the medical setting, study predictors of health literacy in the adolescent population, examine the relationship between health literacy

and health outcomes, and develop interventions to improve health literacy among adolescents. Although in the adult literature, researchers are encouraged to move beyond that of scale development and identifying predictors of health literacy (Weiss, 2015), these areas have been understudied in the adolescent population (Manganello, 2008). As such, the current study contributed to this area of research by identifying the extent to which YLWH exhibited health literacy and the extent to which health literacy was associated with health outcomes. In order to do this, it is important to understand the current measures of health literacy as well as their benefits and drawbacks.

General measures. In the adult literature there are two main measures of health literacy that are used to measure basic/functional health literacy: the Rapid Estimate of Adult Literacy in Medicine (REALM; Murphy, Davis, Long, Jackson, Decker, 1993) and the Test of Functional Health Literacy in Adults (TOFHLA; Parker, Baker, Williams, Nurss, 1995). The REALM (Murphy et al., 1993) is a measure of basic health literacy used to screen patients for low reading levels in the medical setting and patients are asked to read a list of 66 words related to body parts, illnesses, and medical terms. Similarly, The TOFHLA (Parker et al., 1995) is a measure of functional health literacy in which patients are asked to apply literacy and numeracy skills when reading and comprehending health-related materials. The Newest Vital Sign is a measure of communicative health literacy (NVS; Weiss et al., 2005) and was designed to be a quick, screener of functional health literacy. The NVS displays an ice cream nutritional label and 6 questions that require the patient to use both reading comprehension and numeracy skills. Manganello (2008) argued that health literacy measures need to be created for adolescents in order to move the health literacy research agenda forward. She and her colleagues developed the

Health Literacy Assessment Scale for Adolescents (HAS-A; Manganello, 2015). The HAS-A measures Communication, Confusion, and Functional Health Literacy.

HIV-specific measures. Although broad measures of health literacy are useful, Mackert and colleagues (2015) suggested researchers also use disease-specific measures of health literacy to assess health literacy of individuals within a domain (i.e., HIV). A review of the literature revealed two HIV-specific measures of health literacy. The HIV-Related Health Literacy Scale (HIV-HL; Ownby, Waldrop-Valverde, Hardigan, Caballero, Jacobs, & Acevedo, 2013) is a computer-administered measure of health literacy for individuals living with HIV and assesses patients' reading comprehension and listening comprehension by including a video simulation of a doctor giving directions to a patient about taking a new medication and how to deal with the side effects. Although Ownby and colleagues created the measure to be completed on a computer/tablet in order to ease the burden on the clinicians and researchers, many clinics do not have sufficient resources to purchase the quantity of tablets necessary for use in clinical practice.

The Brief Estimate of Health Knowledge and Action- HIV Version (BEHKA-HIV; Osborn, Davis, Bailey, & Wolf, 2010) is an HIV-specific measure of health literacy and was used as the measure of health literacy in this study. The BEHKA-HIV is a 10-item measure made up of two factors: Knowledge and Action. The questions measuring Knowledge ask about the definition of key medical terms associated with HIV treatment (i.e., CD4 count and viral load) and whether treatment is supposed to cause these to go up or down in addition to the names of medications the patient it taking. Questions measuring Action ask about whether a patient takes medications under certain conditions (e.g., tired, feeling down or low, feeling good). Thus, this measure assesses both HIV-related knowledge and the ability to make decisions regarding medications in everyday life, an important aspect of the definition of health literacy (Ratzan &

Parker, 2010). The BEHKA-HIV was validated with a sample of adults with a mean age of 40.1 years. The Cronbach's alpha for the knowledge subscale was .73 and .79 for the action subscale. Scores on the BEHKA-HIV were significantly associated with self-reported medication adherence. Patients who scored 4-5 (marginal) on the BEHKA-HIV were 2.6 times more likely and patients who scored 0-3 (low) were 11.4 times more likely to be non-adherent to treatment compared to those who scored 6-8 (adequate).

Although there are several measures of health literacy, few of these have been validated with adolescents and none of the HIV-specific measures have been used with adolescents. Despite these drawbacks, HIV knowledge and action are two areas that are very important for adolescents especially as they transition to taking charge of their own healthcare and being responsible for their own health outcomes.

Psychological Symptoms in YLWH

Much research has been conducted on barriers to treatment adherence and predictors of treatment adherence. Many studies report "forgetting" to be a common barrier and mental health issues have also been raised as predictors of treatment adherence. However, the relationship between health outcomes and various symptoms related to psychological disorders such as depression, anxiety, and posttraumatic stress disorder (PTSD) needs to be explored further. Given that the research is correlational in nature, it does not shed light on directionality of the relationships. Individuals with psychological difficulties may be at increased risk for developing HIV due to engaging in risky sexual behaviors or intravenous drug use (O'Cleirigh, Hart, James, 2008). Conversely, individuals with HIV may develop psychological symptoms (e.g., depression, anxiety, PTSD) as a result of the news of being diagnosed with a chronic health condition or the stress related to strict adherence to a medical regimen (O'Cleirigh et al., 2008).

Brown and colleagues (2015) conducted one of the largest studies on psychological symptoms among YLWH. They examined the prevalence of psychological symptoms in 2,032 YLWH with an average age of 20.14 years. The majority of the sample was male (67%) and African American (68%) followed by White (13%), Mixed (11%), Other (6%), Asian/Pacific Islander (1%), and Native American (1%). The Brief Symptom Inventory (BSI) was used to measure psychological symptoms. The BSI yields an overall Global Severity Index (GSI) in addition to subscales of anxiety, somatization, obsessive compulsive, depression, hostility, phobic anxiety, paranoid, psychoticism, and interpersonal sensitivity. Eighteen percent of the participants scored significantly above the threshold on the GSI indicating great distress. The presence of psychological symptoms was significantly higher in youth with behaviorally acquired HIV (21%) compared to perinatially acquired HIV (11%). In addition, males and females with behaviorally acquired HIV scored significantly higher on all of the subscales of the BSI compared to those with perinatally acquired HIV with the exception that there were no differences between females who were behaviorally and perinatally infected on the depression and phobic anxiety subscales. Among those who were behaviorally infected, there were significantly more mental health problems in those who were not taking ART compared to those who were. This study presented data indicating not only the wide range of mental health problems YLWH experience, but also the alarming rates at which they do. Three of the most commonly occurring disorders screened for in medical and mental health clinics are depression, anxiety, and posttraumatic stress disorder. For example, the American Academy of Pediatrics (2016) recommends screening for depression starting as early as 11 years of age. The following sections will review these disorders.

Depression. Depression is the most commonly studied psychological disorder across the HIV adolescent and young adult literature. Major depressive disorder is a constellation of symptoms that affect one's mood (American Psychiatric Association, 2013a). Individuals can experience a range of symptoms including feeling sad, loss of pleasure in activities, changes in body weight, changes in sleep patterns, little energy, psychomotor changes, sense of worthlessness or guilt, inability to focus or make decisions, and suicidal thoughts/ideation. From 2009-2012, the CDC (Pratt & Brody, 2014) reported 5.7% of youth aged 12-17 years and 7.4% of individuals aged 18-39 years experienced moderate or severe depressive symptoms in the two weeks prior to completing a questionnaire of depression symptoms. These numbers are in stark contrast to the literature on YLWH.

Reaching for Excellence in Adolescent Care and Health (REACH) is a network of 16 sites throughout the United States that were formed through the National Institutes of Health and the Health Resources and Services Administration in order to better understand YLWH (Rogers et al., 1998). The REACH study only includes YLWH who were infected through sexual contact and drug use and thus does not include those who were perinatally infected. In the first study to report findings from the REACH project, Murphy and colleagues along with the Adolescent Medicine HIV/AIDS Research Network (2000) examined the effect of stressful life events, social support, and adaptive coping on anxiety and depression. Life events, satisfaction with social support, and coping were assessed through interview and measures specifically developed for the REACH study. The Center for Epidemiologic Studies Depression Scales (CES-D; Radloff, 1977) was used to measure depression and the physiologic anxiety and worry/oversensitivity subscales from Reynolds and Richmond's (1978) Manifest Anxiety Scale were used to measure anxiety. Participants included 230 YLWH (mean age = 16.9 years, 77%

female, 74% Black). Eighteen percent of the sample reported at least moderately elevated anxiety scores and 17% of participants scored 1 standard deviation above the mean for depression. Those youth who experienced greater distressing life events were more likely to score higher on the anxiety and depression scales compared to those with fewer distressing life events. Additionally, greater satisfaction with social support and adaptive coping were associated with lower levels of depression.

In a subsequent analysis of data from the REACH project, Murphy and colleagues (2001) sought to examine factors that were associated with medication adherence in YLWH including depression and health anxiety. Patients' biological markers were obtained in addition to asking patients about medication adherence. Patients were first asked what medications they were taking and if they responded correctly they were asked how often they had taken them in the past month ranging from *none of the time* to *all of the time*. Depression was measured using the CES-D (Radloff, 1977) and anxiety was measured using a 4-item scale developed for the REACH study. Participants included 161 YLWH with a mean age of 17.5 years. The majority of participants were female (73%) and African American (73%). Viral load was significantly associated with self-reported medication adherence and identification of medications indicating these were reasonable estimates of adherence. Depression was significantly associated with both medication identification and self-reported adherence. Ninety-one percent of participants who were not depressed identified their medications compared to 74% of depressed participants. Additionally, 57% of non-depressed participants reported taking their medication *all of the time* compared to 38% of depressed patients. Regarding the overall sample, 37% of the sample met criteria for depression. This study sheds light not only on the large percentage of the sample that is considered depressed but also on the relationship between depression and health outcomes.

Martinez, Hosek, and Carleton (2009) reported findings from data collected through routine diagnostic interviews conducted at a clinic for YLWH. Participants included 174 youth with an average age of 21 years. Seventy-nine percent of the participants were African American, 11% Hispanic, 5% White, and 5.6% Mixed. The Client Diagnostic Questionnaire (CDQ) was administered to all participants followed by a diagnostic clinical interview using criteria from the DSM-IV (American Psychiatric Association, 2000). The results indicated 15% of the sample met criteria for major depressive disorder. Additionally, the role of exposure to violence was also included as a variable in this study. Participants who had experienced a physical assault during childhood were more likely to meet the criteria for depression at the time they were interviewed.

Data obtained from the same clinic in which this study was conducted indicated 23.5% of YLWH had a positive depression screen (Walsh et al., 2017). Participants were 115 YLWH who ranged in age from 11-25 years (M = 19.65) and 68% were African American. The Patient Health Questionnaire (Kroenke & Spitzer, 2000) was administered to screen for depression. Patients screened positive if they had a score greater than 9 (scores ranged from 0 to 27) or endorsed the critical item relating to self-harm and suicidal thoughts. Patients who acquired HIV through behavioral means (i.e., sexual contact) were more likely to endorse thoughts of self-harm or suicide compared to those who acquired HIV perinatally. Depression risk did not differ by age, gender, race, ethnicity, or sexual orientation. Furthermore, participants who endorsed feeling down depressed or hopeless and those who reported little interest or pleasure in normal activities nearly every day had significantly lower CD4 counts (Walsh et al., 2017).

According to the studies reviewed, rates of depression vary from 15% (Martinez et al., 2009) to 37% (Murphy et al., 2001). These percentages are much greater than the 5.7-7.4%

recorded for the general adolescent population. Additionally, depression is correlated with biological markers as well as medication adherence. As such, depression is a very important disorder that needs to continue to be studied in YLWH.

Anxiety. Generalized anxiety disorder is marked by excessive worry or anxiety in which the individual finds it difficult to control (American Psychiatric Association, 2013a). Individuals also experience such symptoms as restlessness, fatigue, difficulty staying focused, irritability, tension, and difficulties with sleep. Martinez and colleagues (2009) reported 17% of the YLWH in their sample met diagnostic criteria for generalized anxiety disorder. When looking specifically at anxiety in the study conducted by Brown and colleagues (2015), the percentages differed when considering gender. The percentage of participants who were above the threshold for anxiety ranged from 4% and 18% for males with perinatally acquired and behaviorally acquired HIV, respectively, to 6.1% and 16% for females with perinatally acquired and behaviorally acquired HIV, respectively.

Merikangas and colleagues (under review) reported a lifetime prevalence rate of 25.1% of 13 to 18 year olds having an anxiety disorder (i.e., PTSD, obsessive-compulsive disorder, and specific phobia) and 5.9% having a *severe* anxiety disorder. The percentages appear to be consistent with those found in studies of YLWH; however, anxiety disorders represent the most common mental health disorders (Merikangas et al., 2010) thus they remain an important area of research.

Posttraumatic stress disorder. According to the DSM-V (American Psychiatric Association, 2013a), posttraumatic stress disorder (PTSD) comprises a set of symptoms following the experience of at least one traumatic event. The symptoms include exposure to a trauma, presence of intrusive symptoms (e.g., involuntary memories of the event), avoidance of

things related to the trauma (e.g., avoiding people that bring about memories associated with the trauma), negative thoughts or feelings (e.g., feeling fear or horror), and changes in arousal and reactions (e.g., angry outbursts, heightened startle response). The reviewed studies use the DSM-IV criteria versus that of the DSM-5. There are a few noteworthy differences between the DSM-IV and DSM-5. Specifically, the DSM-IV had three symptom clusters (i.e., re-experiencing, avoidance/numbing, and arousal), whereas the DSM-5 has four symptoms clusters after dividing the avoidance/numbing cluster into two distinct categories (i.e., avoidance and persistent negative thoughts and feelings). The criteria is lowered for children age 6 years or younger and the criteria for a traumatic event is more explicitly with regard to whether it was experienced directly, witnessed, or experienced indirectly (American Psychiatric Association, 2013b).

YLWH may be at increased risk for PTSD due to past traumatic experiences or interpreting receiving the diagnosis of HIV as a traumatic event (O'Cleirigh et al., 2008). The first study examining YLWH and trauma sought to determine the impact of the HIV diagnosis for these youth (Radcliffe et al., 2007). The sample consisted of 30 youth with a mean age of 21.4 years. The majority were African American (83%) and male (70%). The Traumatic Events Screening Inventory (TESI; Ribbe, 1996) and Posttraumatic Stress Disorder Checklist-Civilian Version (PCL-C; Weathers, Litz, Hermana, Huska, & Keane, 1993) were administered to participants to measure history of trauma and posttraumatic stress symptoms. One-hundred percent of participants reported at least one traumatic event with the mean being 5.6 traumatic events. Over half of the participants (59%) reported getting diagnosed with HIV as the worst trauma they had experienced and 13.3% met the DSM-IV criteria for PTSD as a result of this diagnosis whereas 20% experienced posttraumatic stress symptoms. In response to other

traumatic stressors (e.g., sexual abuse, family violence) 23.3% experienced posttraumatic stress symptoms and 23.3% met criteria for PTSD.

In a subsequent study of male YLWH who had been diagnosed with HIV through sexual intercourse, Radcliffe and colleagues (2011) examined the relationships among trauma and physical and emotional health in a sample of 40 individuals ages 16 to 24 years (M = 20.4 years). All youth identified as African American except one who identified as multiracial. Seventy-five percent of the sample identified as homosexual and the remaining individuals identified as bisexual (25%). Participants completed the Traumatic Events Screening Inventory (Ribbe, 1996) to measures their lifetime history of traumatic events. Posttraumatic stress symptoms (PTSS) were measured using the Posttraumatic Stress Scale- Civilian Version (PCL-C; Weathers et al., 1993). The Beck Depression Inventory (BDI-II; Beck, Steer, & Brown, 1996) measured depressive symptoms and the Sexual Behavior Scale (SBS; Jemmott, Jemmott, Fong, & McCaffree, 1999) measured sexual risk behaviors. Participants' CD4 count and viral load in addition to comorbid STIs were extracted from medical records. A little over half of the participants (55%) endorsed the diagnosis of HIV as being the worst trauma they had experienced in their life. Forty-six percent of the participants endorsed symptoms of depression that fell in the mild range or greater and the mean score on the PCL-C was 41.77 indicating moderate level of PTSS. The subscale on the PCL-C measuring avoidance was related to viral load after controlling for time since diagnosis and whether the youth was taking ART such that the more avoidance the participants reported, the higher their viral load. No other correlations between depressive symptoms, lifetime traumas, and PTSS with biological markers of HIV were significant. Although there were few significant relationships between variables, the results of this study shed light on the high number of traumatic events experienced by YLWH.

Additionally, the sample used by Radcliffe and colleagues (2011) only included behaviorally infected males. Thus, more research needs to be conducted with perinatally infected youth.

The limited body of literature relating to PTSD and YLWH revealed that these youth may experience PTSS to a greater extent than either clinical or community samples. The average number of 5.6 traumatic events reported in these studies (i.e., Radcliffe et al., 2007; Radcliffe et al., 2011) is considerably greater than the average of 1 to 4.2 reported in other studies of youth and young adults (Jaycox et al., 2004; Zatzick et al., 2006). Additionally, a sample of YLWH indicated 28% of the sample met criteria for PTSD (Martinez et al., 2009). Thus PTSD and PTSS are important variables to consider when studying YLWH. Additionally, the reviewed studies had relatively small sample sizes of 30 (Radcliffe et al., 2007) and 40 (Radcliffe et al., 2011). Future studies need to examine PTSD and PTSS at a larger scale.

Overall, the research looking at mental health problems in YLWH indicates that these youth suffer from a variety of symptoms of depression, anxiety, and PTSD. These disorders also show relationships with biological markers (Radcliffe et al., 2011; Walsh et al., 2017) and treatment adherence (Murphy et al., 2010). However, more research needs to be conducted to determine how psychological symptoms are related to these important biological markers in YLWH.

Health Outcomes

Biological indicators. There are numerous biological indicators that measure the extent to which an individual's immune system is functioning optimally. Viral load (VL) refers to the amount of HIV RNA in an individual's blood (HHS, 2015a). An individual with less than 20-75 copies/mL of HIV RNA in a blood sample is said to have an undetectable viral load (HHS, 2015a). This is desirable as it is evidence that the individual's immune system is not working as

hard to fight HIV. CD4-cells and T-cells refer to the same type of white blood cell that protect an individual's body from infection and is another indicator of immune system functioning. The CDC (1992) created a classification system for HIV-infected adults and adolescents based on CD4 cell count. Individuals with 500 or more cells/μL are classified as *asymptomatic or acute HIV*, those with a CD4 count between 200 and 500 cells/μL are in the *symptomatic* category, and those with less than 200 cells/μL are classified as having *AIDS-indicator conditions*. A higher VL is associated with a decline in CD4 cells as well as increased risk of transmission. Thus, the goal of any HIV treatment is to increase CD4 count and decrease VL.

Importance of treatment adherence for health outcomes. Treatment adherence is a critical issue not only for people living with HIV, but also for public health. With high levels of medication adherence to antiretroviral therapy (at least 80-90%), most people can reduce the amount of virus in the body to undetectable levels. This is an important outcome for patients because, with viral suppression, people with HIV can live long, healthy lives. From a public health perspective, risk of HIV transmission is reduced dramatically with lower levels of the virus in the body. Despite the benefits, adherence to treatment in youth is a problem with overall suboptimal rates (Hosek, Harper, & Domanico, 2005). As a population, youth are less likely to be tested for HIV, access and remain in care, and achieve viral suppression (CDC, 2013). Additionally, youth who are not adherent to medication present an increased risk of transmission of the disease, higher viral loads (further progression of the disease), and decreased quality of life (Brown et al., 2015; MacDonell et al., 2013), while YLWH who adhere to treatment can lead relatively normal, healthy lives. As the numbers of YLWH increases it is important to address treatment adherence in this population.

Treatment adherence also is critical in order for YLWH to achieve an undetectable viral load, reduce their risk for becoming resistant to different drug therapies, and increase survival (Chandwani, 2012). Whereas the criterion of 80% is traditionally used to describe treatment adherence for most chronic health conditions, for YLWH, treatment adherence of 95% or greater is needed in order to sustain the benefits noted above (Paterson et al., 2000). In a study of 81 patients (mean age 40.7 years), 78% of those who adhered to treatment 95% or more of the time had VL < 400 copies/mL, compared to 39% of those who adhered 80% to 94.9% of the time and 20% of those with less than 80% adherence (Paterson et al., 2000). A VL >400 copies/mL indicates virologic failure, thus a smaller percentage of patients who adhered to ART 95% or more of the time experienced virologic failure. When measuring changes in CD4 lymphocyte count, patients with 95% or greater adherence had a mean increase of 83 cells/mm^3 compared to a 6 cell/mm^3 mean increase in those with less than 95% adherence. Patients who adhered 95% or more of the time also spent significantly less days hospitalized compared to those with less than 95% adherence (Paterson et al., 2000).

Kahana and colleagues (2013) conducted a meta-analysis of 37 studies measuring ART adherence and clinical outcomes in youth and young adults. The aggregate sample included 5,344 individuals who ranged in age from newborn to 25 years. The majority of studies involved individuals who were perinatally infected (78.38%), 16.22% of the studies were with individuals who were behaviorally infected, and 5.41% of the studies had a mixed sample. Overall 67.58% of the sample was treatment adherent and all of the studies used at least an 85% cut-off point to define adequate adherence. The effect sizes for the relationship between treatment adherence and VL < 400, VL < 100, and continuously-measured VL were 0.35, 0.51, and 0.71, respectively. The large effect for continuously-measured VL compared to VL < 400 or VL < 100 is likely due

to the continuous nature of the data which allows for a broader range compared to the categorical outcomes (Kahana et al., 2013). Thus, treatment adherence relates to improved biological indicators of HIV (Chandwani, 2012; Kahana et al., 2013).

Although studies have found adherence rates to vary by assessment method (e.g., 82.6% for caregiver report, 60.9% for pharmacy refill report, and 76.1% for appointment maintenance data; Burack, Guar, Marone, & Petrova, 2010), there is consensus that overall adherence rates in the pediatric population are suboptimal (Simoni et al., 2007; Steele & Grauer, 2003; Vreeman, Wiehe, Pearce, Nyandiko, 2008).

Relationship of health literacy with treatment adherence and health outcomes. Several studies have been conducted, particularly in a lab run by Kalichman and colleagues, showing the relationship between health literacy and objectively measured treatment adherence, self-reported treatment adherence, HIV-related knowledge, and self-reported biological indicators in adults living with HIV. To date, there have only been two studies measuring the relationship between health literacy and adherence to ART in youth and young adults (i.e., Murphy et al., 2010; Navarra, Neu, Toussi, Nelson, & Larson, 2014) suggesting the need for further research in this area.

Kalichman and colleagues (1999) conducted one of the first studies investigating adherence to ART in a sample of 318 adults living with HIV. Seventy percent of the participants were male and the majority was African American (65%) with a mean age of 39.1 years. Health literacy was measured using the TOFHLA (Parker et al., 1995). Treatment adherence was measured by self-reported adherence to medications in the previous 2 days. Participants were considered nonadherent if they reported <100% adherence. Participants were also asked to give a self-report of their CD4 count and viral load. Twenty percent of the sample missed at least one

dose of ART in the previous 2 days. Participants' years of education and health literacy were the only variables with significant independent associations with treatment adherence. Income level, ethnic background, and HIV disease progression did not account for the relationships. Those with less education were 3 times more likely to be nonadherent than those with high school education and those with lower literacy were almost 4 times more likely to be nonadherent. Further examination of the relationships indicated among participants with less than a high school education, the relationship between health literacy and adherence was not significant. However, among those with 12 or more years of education, the relationship between health literacy and adherence was significant. Participants with lower health literacy reported missing doses due to being confused about the medication regimen, experiencing negative side effects, having a depressed mood, and wanting to cleanse their body. As such, it appears particularly important to assess health literacy as education level may not be enough to predict adherence, especially among those with higher educational attainment.

To further establish the relationship between health literacy and treatment adherence, Kalichman and colleagues (2009) examined the relationship between health literacy and objectively measured treatment adherence through unannounced telephone-based pill counts. Health literacy was measured using the TOFHLA (Parker et al., 1995). One hundred forty-five adults living with HIV receiving ART participated in the study (mean age = 44.5 years, mean education = 11.5 years, 65% male, 93% African American). Overall, the median adherence found was 71% of pills taken and the median score on the TOFHLA was 90%. Consistent with Kalichman's original study (1999), participants with lower health literacy were less likely to take their medications with 80% adherence, 85% adherence, and 90% adherence. Health literacy predicted adherence at the 85% level over and above demographic variables (e.g., age, years of

education, income, ethnicity, employment status) and health characteristics (e.g., HIV-related symptoms, CD4 count, viral load), emotional distress, internalized stigma, and social support, and alcohol use (Kalichman et al., 2009). This study further supports the robust nature of the relationship between health literacy and adherence.

In addition to health literacy being related to treatment adherence, health literacy has also been shown to relate to one's health status, awareness and understanding of one's HIV disease status, and HIV disease and treatment-related knowledge (Kalichman & Rompa, 2000). Participants included 339 adults living with HIV (67% male, 78% African American, mean age = 40.2 years, mean education = 12.7 years). Health literacy was measured using the TOFHLA (Parker et al., 1995). Participants' awareness and understanding of HIV-related health status was measured by asking whether they knew their most recent CD4 count and viral load in addition to whether they understood what CD4 count and viral load are and what they mean. HIV disease treatment-related knowledge was measured using 14-items that measured knowledge of HIV disease processes, how the virus can be transmitted, medication management, and viral load. Twenty-five percent of participants had low health literacy as measured by the TOFHLA. Results indicated that higher health literacy was associated with lower viral load and higher CD4 counts. Those with higher health literacy were more likely to have undetectable viral loads and CD4 cell counts >300 cells/mm. Participants with higher health literacy were more likely to know their CD4 count and viral load. Those who did know their viral load were more likely to understand its meaning if they had higher health literacy. Additionally, participants with lower health literacy knew less about HIV and its treatment compared to those with higher health literacy even after controlling for years of education. This study expanded the body of literature by including HIV-related knowledge and biological markers. HIV-related knowledge is another

variable that is important to measure when working with individuals with HIV as this study shows it relates to biological markers, which are important indicators of health status.

Kalichman and colleagues (2000) conducted a similar study to further support the evidence for a relationship between health literacy and knowledge and understanding of one's HIV-disease status. Two hundred and ninety-four adults living with HIV participated in the study. The majority was male (78%) and African American (70%). The mean age was 39.7 years and mean number of years of education was 13.0. They completed the same measures as in the study conducted by Kalichman and Rompa (2000). Specifically, the TOFHLA (Parker et al., 1995) measured health literacy, questions regarding CD4 count and viral load measured knowledge and understanding of HIV-related health status, and participants' health status was measured by assessing HIV-related symptoms, whether they had been diagnosed with AIDS case-defining conditions, most recent CD4 count and viral load, medications, and how often they see their doctor. Eighteen percent of participants had low health literacy according to the TOFHLA. Participants with higher health literacy were more likely to have an undetectable viral load and know their CD4 cell counts and viral load. Of the participants who knew their CD4 count, those with higher health literacy were more likely to know the meaning of CD4 count. Participants with higher health literacy were also more likely to understand the meaning of viral load. Additionally, this study found participants with lower health literacy were more likely to believe if they are taking their medications they are less likely to transmit HIV and can, therefore, have unprotected sex if their viral load is undetectable. Those with lower health literacy also reported being able to relax more when practicing unprotected sex compared to those with higher health literacy. These findings provide further support for the relationship

between health literacy and disease-related knowledge. They also suggest health literacy is associated with specific health behaviors that increase the risk of HIV transmission.

Similar results were found in a study that used the REALM (Murphy et al., 1993) as the measure of health literacy (Wolf et al., 2004). Participants were 157 adults living with HIV who completed the REALM and were asked several questions regarding their understanding of CD4 count and viral load as well as the name of medications they are taking and the recommended regimen. The majority were male (74.5%), Black (59.2%), and had a range of educational levels (37.4% less than high school, 32.9% high school graduate, 29.7% some college). The mean age was 37 years. Descriptive statistics indicated 31% of participants did not know the names of at least one of their medications, 58% were unable to accurately state their medication regimen, 53% did not know what CD4 count was, and 47% did not know what viral load was. Additionally, 52% of participants read at a 9th grade or higher reading level according to the REALM. Participants with lower health literacy were less likely to be able to explain the meaning of CD4 count and viral load. Participants who had a reading level below the 9th grade were one-third as likely as those with a reading level at or above the 9th grade to accurately define CD4 count and one-seventh as likely to accurately define viral load. These findings remained consistent, after taking into account race/ethnicity, self-reported education, and years in HIV care. These findings suggest that in addition to functional health literacy (i.e., TOFHLA), basic health literacy (i.e., REALM) is also an important indicator of HIV-related knowledge and health status.

Because racial and ethnic minority status tend to be predictors of HIV medication adherence among adults living with HIV, Osborn and colleagues (2007) sought to examine the mediating effect of health literacy on this relation. Participants were 204 adults living with HIV

with 45.1% Black and 79.9% male. The average age was 40.1 years and the majority (60%) reported some college education. Health literacy was measured using the REALM (Murphy et al., 1993) and medication adherence was measured by asking them to identify their medications and then report of how many doses they missed in the past 4 days for each medication. Participants were considered non-adherent if they missed one or more doses within the 4-day timeframe. Results indicated that African American participants were more likely to have marginal or low literacy skills and less likely to have self-reported adherence compared to their non-African American counterparts. Participants with low health literacy were more likely to be non-adherent than those with adequate health literacy and there was also a significant relationship between race and low literacy. However, when literacy was included as a predictor, low literacy remained a significant predictor of non-adherence and the effect of race diminished. These results suggest that health literacy is an important construct for understanding the health disparities across race and ethnicity and should be taken into account when determining predictors of non-adherence and when developing interventions to increase adherence.

The research on YLWH is much more scant. Murphy and colleagues (2010) sought to determine whether the factors associated with health literacy in adults living with HIV were the same for YLWH. One-hundred and eighty-six YLWH ages 16 to 24 years who met at least two of the following inclusion criteria participated in the study: currently prescribed ART and adhering <90% in the last month, advised they should be taking ART by a physician, had unprotected sexual intercourse within the previous 3 months, or screened at a problem level for alcohol and/or drugs. The average age was 20.5 years. Seventy-eight percent of the participants were African American, 11.3% were Hispanic, 3.2% were European American, and 7.5 were Mixed race/ethnicity. The sample was made up of an equal proportion of males (49.5%) and

females (47.3%), with 6 participants identifying as transgender/transsexual. Researchers administered the TOFHLA (Parker et al., 1995) to participants and found 11.8% had inadequate health literacy, 2.7% had marginal, and 85.5% had adequate functional health literacy. Self-reported 3-day adherence recall was used to measure rate of adherence and participants' CD4 count and viral load were abstracted from medical records. Participants were considered adherent if they reported taking ≥90% of doses, less than adherent if they reported taking >0% to <90% of doses, and totally nonadherent if they reported taking 0% of doses. Among participants with adequate health literacy approximately 36% were classified as adherent and 24% were classified as adherent among those with marginal/inadequate health literacy. Approximately 24% and 41%, were less than adherent and 40% and 35% were nonadherent for those with adequate and marginal/inadequate health literacy, respectively. Differences in adherence among levels of health literacy were not statistically significant. Additionally, health literacy was not associated with CD4 count or viral load. The Reading Comprehension subtest of the TOFHLA was associated with amount of medical care received by participants; there was an increased likelihood of receiving medical care with increasing health literacy. These results are contradictory to those found in the adult literature. YLWH in this study had to meet stringent inclusion criteria and thus results cannot be generalized to the larger population of YLWH. In addition, this study did not measure HIV-specific health literacy. Approximately 50% of the sample had an education less than a high school graduate, signifying that a large proportion of participants were still in school. As such, it is possible that the participants are currently performing at a level of literacy commiserate with their educational attainment. Longitudinal studies would need to be conducted to discern whether participant's health literacy continues to increase as they develop into adulthood. However, their level of HIV-related knowledge remains

unknown. Knowing their HIV-related health literacy could shed light on different aspects of the relationship between health literacy and health outcomes.

Another study conducted with 50 YLWH aged 13 to 24 years sought to further examine the relationship between health literacy and adherence to ART (Navarra, Neu, Toussi, Nelson, & Larson, 2014). Inclusion criteria were that participants have a fully disclosed HIV status, be English speaking, prescribed ART for 6 months or longer, and have an absence of neurocognitive deficits. The average age was 19.7 years, 56% were male, and 56% were African American. Participants were administered the TOFHLA (Parker et al., 1995) and REALM-teen (Davis et al., 2006) as measures of health literacy. An average missed dose calculation was computed from the reported number of missed doses per medication on a 3-day self-reported adherence estimate multiplied by the dosing schedule. This percentage was then subtracted from 100%. Eighty percent of the sample had adequate health literacy levels as measured by the TOFHLA and 72% had below-grade-level reading on the REALM-teen. There were no statistically significant associations between either measure of health literacy and adherence. However, the odds of 100% adherence were significantly lower among participants who demonstrated below-grade-level reading compared to those with 100% adherence and grade-level or above-grade-level reading. Despite this study having a wider age-range and less stringent inclusion criteria, making it more generalizable to the larger population of YLWH, there were still limitations. This study used self-reported adherence as the measure of medication adherence. These data were negatively skewed with a median 3-day adherence estimate of 100%, indicating these data may be an overestimate of actual adherence. Biological markers were not used to measure the relationship with health literacy, which could have strengthened the study. Similar

to the study conducted by Murphy and colleagues (2010), HIV-specific knowledge was not used as a measure of health literacy.

Taken together, there is a robust relationship between health literacy and health outcomes for adults living with HIV; however, the same relationship does not hold true for YLWH. As such, more research needs to be conducted that includes biological markers as an outcome variable as well as HIV-related health literacy measures. The current status of the literature suggests that in contrast to YLWH, health literacy may be a more important predictor of medication adherence and health outcomes for adults living with HIV. As YLWH grow older and transition to adult care, there is less support given from medical providers and they have to take more responsibility for their health. Additionally, material may become increasingly more difficult to read and comprehend which makes having adequate health literacy even more important. Because previous research has not found a relationship between health literacy and health outcomes for YLWH, it is important to determine whether different methods for measuring health literacy are more meaningful for this population.

Conclusions

Overall, the current body of literature points to several very important relationships. Biological markers such as CD4 counts and viral load are measures of the immune system's functioning. These markers are related to treatment adherence such that patients who adhere to their medication regimen have better immune functioning as indicated by higher CD4 counts and lower viral loads. Thus, the ultimate goal of HIV care is to decrease the patient's viral load and increase their CD4 count, making these health outcomes particularly important to research. Health literacy has been found to be associated with biological markers and health outcomes in the adult population. This relationship has not been found in YLWH; however, no study to date

has examined HIV-related knowledge and its relationship with health outcomes. Psychological disorders such as depression, anxiety, and PTSD have been found to be particularly high in YLWH and a few studies have explored their relationship with biological markers. As such, this study sought to expand the literature in a number of ways. Because of the literature's limitations with respect to YLWH, the first purpose of the current study was to identify the extent to which YLWH reported psychological symptoms of depression, anxiety, and PTSD. Because no studies with YLWH have used HIV-related health literacy as the measure of health literacy, this study also sought to identify the extent to which YLWH show this type of health literacy. The proposed study explored the extent to which HIV-specific health literacy was associated with health outcomes and the extent to which psychological symptoms predicted health outcomes. These purposes will provide further insight into the best way to measure health literacy with YLWH and how psychological issues impact this population.

CHAPTER THREE:

METHODS

The overarching purpose of this study was to gain insight into health literacy, depression, anxiety, and PTSD as predictors of biological markers of immune functioning (i.e., CD4 count and viral load) in a sample of youth living with HIV (YLWH) ages 13-25 years. This study examined the extent to which YLWH were health literate and the extent to which they reported psychological symptoms of depression, anxiety, and posttraumatic stress disorder (PTSD). The association between health literacy (i.e., health knowledge and health action) and health outcomes and the association between psychological symptoms (i.e., depression, anxiety, PTSD) and health outcomes were also examined. The following chapter provides an explanation of the methods that were used in this study including a description of participants, measures, and procedures.

Research Questions

1) To what extent do youth and young adults with HIV ages 13-25 years report psychological symptoms of depression, anxiety, and PTSD?
2) To what extent do youth and young adults with HIV ages 13-25 years demonstrate health literacy?
3) To what extent are health literacy and health outcomes (i.e., CD4 count and viral load) associated after controlling for demographic variables? It was hypothesized that increasing health literacy would be associated with better immune functioning.

4) To what extent are psychological symptoms and health outcomes (i.e., CD4 count and viral load) associated after controlling for demographic variables? It was hypothesized that more mental health symptoms would be associated with worse immune functioning.

Setting and Participants

Setting. This study utilized clinical data collected from the University of South Florida's Pediatric and Adolescent Infectious Disease Program (USF Peds ID). USF Peds ID provides services to individuals birth through 25 years infected with HIV as well as infants exposed to HIV and HIV negative family members (i.e., significant others of HIV positive partners). There are approximately 157 youth and young adults ages 18-24 years served at the clinic. The USF Peds ID clinic follows a Collaborative Care model (APA & APM, 2016) and includes professionals who provide specialty services such as nutrition counseling, social work, and psychological services in addition to medical treatment. These services are consistent with services provided at other pediatric HIV clinics in the United States (e.g., University of Miami Division of Pediatric Immunology and Infectious Diseases, Ann & Robert H. Lurie Children's Hospital of Chicago HIV/AIDS Prevention Program). USF Peds ID serves youth and young adults at three different locations: All Children's Hospital in St. Petersburg, Children's Medical Services in Tampa, and the Ybor Youth Clinic in Tampa. The providers are the same at each site and participants receive the same services. Participants are scheduled for physician and laboratory appointments every three months and have a minimum of four routine appointments throughout the year. If participants are experiencing medical concerns, or are newly diagnosed, they are seen at the clinic more frequently.

Participants. Data were obtained from YLWH between 13-25 years of age. YLWH included both those with perinatally and behaviorally acquired HIV who were fully aware of

their diagnosis. In order to complete the health literacy measure participants were being treated with antiretroviral therapy for ≥6 months. The time limit of 6 months allowed youth enough time to process their initial reaction toward their diagnosis and has been used with other studies on youth with chronic health conditions (Bradley-Klug et al., 2017). Additionally, by waiting 6 months youth would have received education regarding HIV during their medical visits. Those for whom English was not their primary language were not included in the study because all measures were given in English. Demographics for the total sample are provided in Table 1.

Research Design

This study was based on an analysis of a clinical database and utilized a non-experimental research design to examine relationships between health literacy, psychological symptoms, and health outcomes. The association between health literacy and health outcomes as well as psychological symptoms and health outcomes were of particular interest. A different regression equation was estimated for each psychological symptom and each health outcome for a total of eight equations.

Power Analysis

A power analysis was conducted to determine the number of participants needed to obtain adequate power for this study. G*Power 3.1 was used to calculate a range of needed sample sizes depending on the effect size. An alpha level at .05 and power of .80 were used for all calculations. For 7 predictors (i.e., age, race, sex, behavioral/perinatal, education, sexual orientation) assuming a small effect size of .05 would require 279 participants, a moderate effect size of .07 would require 202 participants, and a large effect size of .10 would require 143 participants. Based on these power analyses, data from 144 participants were obtained.

Table 1

Demographics of Participants for the Overall Sample

Variable	Frequency (%) (N = 145)
Age in years	
M (*SD*)	20.4 (*SD* = 2.86)
13	3 (2.1)
14	1 (.7)
15	3 (2.1)
16	7 (4.8)
17	12 (8.3)
18	13 (9.0)
19	10 (6.9)
20	14 (9.7)
21	15 (10.3)
22	27 (18.6)
23	19 (13.1)
24	17 (11.7)
25	4 (2.8)
Sexual Orientation	
Heterosexual	89 (61.4)
Homosexual	40 (27.6)
Other	16 (11.0)
Race	
African American	97 (66.9)
White	38 (26.2)
Other	10 (6.9)
Gender	
Male	81 (55.9)
Female	64 (44.1)
Mode of Transmission	
Behavioral	72 (49.7)
Perinatal	73 (50.3)
Educational Attainment	
Middle school	7 (4.8)
Some high school	50 (34.5)
High School	39 (26.9)
High School Equivalency	10 (6.9)
Some college, no degree	34 (23.4)
Bachelor's degree	4 (2.8)
Advanced degree	1 (.7)

Measures and Indicators

The following paragraphs provide a descriptive overview of each measure and variable that was used in this study. Measures not protected by copyright are included in the Appendices.

Demographics. Participants answered a series of demographic questions regarding sex, age, sexual orientation, race, educational attainment, and mode of transmission (i.e., behavioral, perinatal). This questionnaire was developed by the USF Peds ID behavioral health team (Appendix A). In addition, participant's level of education was obtained from record abstraction. Table 1 lists the specific categories for each of these variables.

Brief Estimate of Health Knowledge and Action- HIV Version (BEHKA-HIV). The BEHKA-HIV (Osborn, Davis, Bailey, & Wolf, 2010) is a 10-item measure made up of two factors: Knowledge and Action (Appendix A). This measure assesses both HIV-related knowledge and the ability to make decisions regarding medication adherence in everyday life, an important aspect of the definition of health literacy (Ratzan & Parker, 2010). The questions measuring knowledge ask about the definition of key medical terms associated with HIV treatment (i.e., CD4 count and viral load). Participants are then asked whether treatment is supposed to cause these to go up or down. Participants are given a score (correct = 1, incorrect = 0) regarding whether they give the correct definition and whether they answer the direction of treatment question correctly. Participants are also asked to name their medications. If the participant names all of their medications the item is scored as correct (i.e., 1). If the participant does not know or misses one or more of their medications, the item is scored as incorrect (i.e., 0). This yields a total score on the Knowledge subscale ranging from 0 to 5. Questions measuring Action ask about whether a participant takes medications under certain conditions: 1) when the medications make him or her feel bad, 2) because the medications taste bad, 4) when he or she is

too tired, 5) when feeling down or low, or 6) when feeling good. The response options are *agree, not sure,* or *disagree.* Responses of *disagree* are scored as 1 and *agree* or *not sure* are scored as 0. This yields a score ranging from 0-5 on the Action subscale. The BEHKA-HIV was validated with a sample of adults with a mean age of 40.1 years. The Cronbach's α for the Knowledge subscale was .73 and .79 for the Action subscale. Scores on the BEHKA-HIV were significantly associated with self-reported medication adherence. Participants who scored 4-5 (marginal) on the BEHKA-HIV were 2.6 times more likely to be nonadherent to treatment compared to those who scored 6-8 (adequate). Participants who scored 0-3 (low) were 11.4 times more likely to be nonadherent to treatment compared to those who scored in the adequate range. No studies have evaluated the validity of the BEHKA-HIV with youth and young adults. However, the questions on the BEHKA-HIV Knowledge subscale are questions that are addressed by the Peds ID nurses during each medical visit. Given the conceptual differences between Knowledge and Action scores, they were considered separately; a total health literacy score was not obtained. For the purposes of this study, Knowledge and Action scores were considered predictor variables.

Center for Epidemiologic Studies Depression Scale (CES-D). The CES-D (Radloff, 1977) is a 20-item measure of depressive symptoms in the general population. This measure is not included in the appendix due to being copyrighted. Participants are asked to rate how often they have felt certain ways during the past week. Examples include being happy, feeling lonely, being bothered by things they usually are not bothered by, and feeling disliked by other people. Response options range from *rarely or none of the time (less than 1 day), some or a little of the time (1-2 days), occasionally or a moderate amount of time (3-4 days),* and *most or all of the time (5-7 days).* Each item is scored on a scale from zero to three, which yields an overall possible range of scores from zero to 60. Lower scores are indicative of less depressive

symptoms. Although the CES-D is not to be used for clinical diagnosis of depression, a score of 16 of greater in the adult population (Radloff, 1977) and 24 or greater in the adolescent population (Rushton, Forcier, & Schechtman, 2002) is indicative of being at-risk for a depression diagnosis. The original validation of the CES-D found high internal reliability in a sample of the general population of adults (α =.85) and a sample of an adult psychiatric patient population (α = .90; Radloff, 1977). Test-retest correlations ranged from .51 for a two-week time interval to .67 for a four-week time interval. Additionally, participants who did not experience significant life events at either time point had higher test-retest correlations (r = .54) compared to those with either life events at both times (r = .31) or life events at one time and not the other (r = .48 and .47). Similarly high internal consistency (α = .88) and test-retest reliability (r = .61) was found in a sample of adolescents in grades 7-12 (Roberts et al., 1991). There was also a positive correlation between scores on the Beck Depression Inventory and the CES-D for the adolescent sample (r = .70; Roberts et al., 1991). The total score on the CES-D was a predictor variable in the current study.

Generalized Anxiety Disorder-7 (GAD-7). The GAD-7 (Spitzer, Kroenke, Williams, & Lowe, 2006) is a 7-item measure of generalized anxiety disorder in adults (Appendix A). Participants are asked how often during the last 2 weeks they were bothered by a number of symptoms. The symptoms include nervousness, not being able to control worrying, worrying too much, having trouble relaxing, restlessness, irritability, and being afraid. Responses range from *not at all* (scored 0), *several days* (scored 1) *more than half the days* (scored 2), and *nearly every day* (scored 3). The initial validation study of the GAD-7 included 2739 participants with a mean age of 47.4 years. Most participants were female (65%) and White (80%). Participants were administered the GAD which originally consisted of 13 items and structured interviews for

generalized anxiety disorder in addition to a number of mental health surveys (e.g., SF-20, Beck Anxiety Inventory). Items on the final GAD-7 were chosen based on having the highest correlations with the total 13 original items (r = .75-.85). Internal reliability of the scores on the GAD-7 was .92 and test-retest reliability was .83. The correlation between the GAD-7 scores and SF-20 subscales ranged from .30 with physical functioning and .75 with mental health. The GAD-7 correlated with the Beck Anxiety Inventory (r = .72) and the anxiety subscale of the Symptom Checklist (r = .74). Cut-off scores were decided based on sensitivity and specificity. Scores from 0-4 are categorized as *minimal,* 5-9 are *mild,* 10-14 are *moderate,* and 15-21 are *severe.* In a study conducted by Leventhal and colleagues (2015) the GAD-7 was used to measure anxiety in a sample of 2,467 rural adolescent girls in India with a mean age of 12.99 years. The reliability for the GAD-7 was .76. Lowe and colleagues (2008) sought to determine the validity and standardization of the GAD-7 in the general population. A sample of 634 youth and young adults ages 14 to 25 was used. The Cronbach's alpha was .89. Unidimensionality of the GAD-7 was assessed and the model had adequate fit. The GAD-7 has also been used in several additional studies with youth and young adults (e.g., Purcell et al., 2014; Wong, Kady, Mewton, Sunderland, Andrews, 2014). In the current study total GAD-7 scores were a predictor variable.

Primary Care- PTSD Screen (PC-PTSD). The PC-PTSD (Prins et al., 2003) is a brief four-item screening tool for PTSD used primarily in primary care settings (Appendix A). The items on the PC-PTSD reflect the four constructs of re-experiencing, numbing, avoidance, and hyperarousal, all of which have been found to be underlying factors of PTSD. Questions ask about nightmares or intruding thoughts, avoiding situations that remind the individual of the event, being on edge, and feeling cut off from individuals, activities, and surroundings.

Responses options are *Yes* and *No.* The readability for the PC-PTSD is at an eighth grade level. The PC-PTSD was administered to 188 individuals (66% female; 68.6% White; mean age = 52.1 years) who were part of the Department of Veterans Affairs Medical Center (VA). Participants were administered the PC-PTSD and one month later were again administered the PC-PTSD as well as the PTSD symptom checklist (PCL; Blanchard, Jones-Alexander, Buckley, & Forneris, 1996) and a diagnostic interview. Fifty-six percent completed the follow-up. Test-retest reliability was .83. The cut-off score of 3 yielded a sensitivity rate of .78 and a specificity rate of .87. The positive predictive value was .65 and negative predictive value was .92. The PC-PTSD outperformed the PCL on correlation with diagnosis (r = .83 vs. .18), sensitivity, specificity, and efficiency. In addition to the items on the PC-PTSD, an item regarding the nature of the trauma experienced by the participant was added. Pariticpants who answer "yes" to at least one item are asked to circle whether the experience was "illness/injury," "sexual trauma," "physical trauma," "emotional trauma," and "other." No studies have evaluated the validity of the PC-PTSD with youth and young adults. Thus, the reliability of this measure was included in preliminary analyses of this study. PC-PTSD scores were a predictor variable in the current study.

CD4 count and viral load. Health outcomes were obtained from blood samples collected during medical appointments. Viral load (VL) refers to the amount of HIV RNA in an individual's blood (HHS, 2014). An individual with less than 20-75 copies/mL of HIV RNA in a blood sample is said to have an undetectable viral load (HHS, 2014). This is desirable as it is evidence that the individual's immune system is not working as hard to fight HIV. CD4-cells and T-cells refer to the same type of white blood cell that protects an individual's body from infection and is another indicator of immune system functioning. The CDC (1992) created a classification system for HIV-infected adults and adolescents based on CD4 cell count.

Individuals with 500 or more cells/μL are classified as *asymptomatic or acute HIV* (i.e., a condition that develops within 2 to 4 weeks after exposure to the virus when HIV antibodies are not yet detected; New York State Department of Health AIDS Institute, 2015), those with a CD4 count between 200 and 499 cells/μL are in the *symptomatic* category, and those with less than 200 cells/μL are classified as having *AIDS-indicator conditions*. A higher VL is associated with a decline in CD4 cells as well as increased risk of transmission. Thus, the goal of any HIV treatment is to increase CD4 count and decrease VL. CD4 count and VL are used in this study as biologic markers of health outcomes and are the outcome variables used in the analyses.

Procedures

The principal investigator (PI) of the study was a member of the behavioral health team at the USF Peds ID clinic and was a member of this team since June 2015. The procedures for this study were implemented as part of the routine standard of care protocol at the USF Peds ID clinic. Data were collected from July 2016 to March 2017. Providers were trained in and given a manual outlining the administration procedures of the screeners (Appendix A).

Following the standard of care protocol established at the clinic, the PI, social worker, or case manager screened for depression, anxiety, posttraumatic stress, and health literacy during participants' regularly scheduled medical appointments. As described above, participants are scheduled for appointments at least every three months. During their first appointment of the year, participants receive a psychosocial update in which information about demographics, educational history, living situation, family life, and other psychosocial areas are obtained and updated in the electronic medical record. Screeners for mental health and health literacy also are administered during the psychosocial update. The screeners were administered without the psychosocial update during a medical appointment for participants who the psychosocial was

already completed. During these appointments, the provider approached participants and told them about the screening protocol being conducted at the clinic. Participants were given copies of each questionnaire to follow along as the provider read each question to the participant. In certain instances, if the clinic was busy and the participant was able to read, they completed all questionnaires except the BEHKA-HIV on their own. The BEHKA-HIV was always read aloud to the participant and they were not provided with any help when giving the definitions of HIV-related terms. Administration of questionnaires took between 8 to 10 minutes. Following administration of all questionnaires, if the participant met the cut-off score on any measure to indicate a positive screen for the various mental health disorders, a clinical interview was conducted to determine whether the participant met DSM-5 criteria for the specific mental health disorder. Clinical interviews were only conducted by social workers and psychology interns. If the case manager screened the participant, a referral was made to the social worker or psychology intern to conduct the clinical interview. If the participant met criteria or informed clinical opinion indicated a referral was necessary, a referral was made for counseling services. Data from the questionnaires were entered into a medical note in the participant's electronic medical record. The questionnaires were then given to the social worker or PI who were responsible for entering the data into a clinical database. The PI of the study went through and checked data entry with the original questionnaires. The clinical database was de-identified prior to data analysis.

Plan for Data Analysis

A series of statistical analyses were performed to answer the research questions for this study. In addition, several preliminary analyses also were conducted to include reliability of measures and descriptive statistics.

Variable construction. Items on each questionnaire were added to obtain a total score. Scores on the Knowledge and Action subscales of the BEHKA-HIV ranged from 0-5. Scores on the CES-D ranged from 0-60, the GAD-7 from 0-21, and the PC-PTSD from 0-4. For sexual orientation, a total of two participants identified as questioning and 14 identified as bisexual. As such, questioning and bisexual were combined to create an "other" category. The three categories for sexual orientation were heterosexual, homosexual, and other. For race, five participants identified as Asian and five participants identified as Bi-racial. These groups were combined to create an "other" category. The categories for race were African American, White, and Other. Educational attainment was categorized into middle school (1), some high school (2), high school degree (3), high school equivalency (4), some college (5), bachelor's degree (6), and advanced degree (7) and was treated as a continuous variable in all analyses.

Preliminary analyses. Preliminary analyses were conducted in order to determine the reliability of the measures used in this study. Cronbach's alphas were computed as a measure of internal consistency for each measure. In addition scores from each measure were analyzed using descriptive statistics such as mean, median, mode, and standard deviation. The dataset was screened for missing data. Participants with a missing measure were not included in analyses involving that measure. For example, if a participant completed the CES-D and GAD-7, but not the PC-PTSD, the participant's scores were not included in the model where PC-PTSD scores were associated with health outcomes. However, they were included in CES-D and GAD-7 analyses. If a participant was missing either the independent or dependent variable, the scores were not included in analyses. Characteristics of the sample were reported using descriptive analyses (i.e., mean, median, mode, standard deviation). In addition the demographics of the participants for each questionnaire were reported.

Prior to conducting the primary analyses, assumptions underlying regression techniques were conducted. Linearity, normality, homogeneity of error variance, and independence of errors were checked through visual analysis and follow-up statistical testing was conducted when necessary. Linearity of the relationship between the independent and dependent variables was examined using scatter plots. Normality was examined through visual analysis of residuals associated with CD4 count. Skewness and kurtosis also were calculated for these variables to assess normality. Visual examination of a plot of standardized residuals by standardized predicted values was used to test for homogeneity of error variance. To test independence of error, scatter plots of the residuals versus predicted values of the independent variables were created.

Primary analyses. A series of multiple regressions was conducted to examine the relationship between health literacy and health outcomes as well as psychological symptoms and health outcomes. Demographic variables (i.e., age, gender, race, mode of transmission, education, and sexual orientation) were entered into the model as control variables.

1) *To what extent do youth and young adults with HIV ages 13-25 years report psychological symptoms of depression, anxiety, and PTSD?*
2) *To what extent do youth and young adults with HIV ages 13-25 years demonstrate health literacy?*

In order to answer the first two research questions, scores from each measure were analyzed using descriptive statistics such as mean, median, mode, and standard deviation. Correlations between measures of depression, anxiety, and PTSD as well as health literacy were conducted. Multiple regression equations were calculated for the psychological and health literacy measures as outcomes with demographic variables as the predictors. Percentages of

participants who screened positive and negative for each measure of psychological symptoms as well as those who scored zero on measures of psychological symptoms were calculated. The percentages of participants who screened positive for zero, one, two, and three of the psychological screeners were also calculated. Percentages of participants who scored in the different severity levels on the GAD-7 were determined. In addition, percentages of participants who reported specific types of traumas were computed. Regarding health literacy, the percentage of participants who answered the Knowledge questions correctly on the BEHKA-HIV was determined. Lastly, the percentage of participants who indicated they take their medications under various conditions on the Action subtest of the BEHKA-HIV was calculated.

3) *To what extent is health literacy associated with health outcomes (i.e., CD4 count and viral load) after controlling for demographic variables?*
4) *To what extent are psychological symptoms associated with health outcomes (i.e., CD4 count and viral load) after controlling for demographic variables?*

In order to answer research questions 3 and 4, a series of multiple linear regressions and logistic regressions were conducted. A different multiple linear regression equation was estimated to determine the association between health literacy with CD4 count as well as each psychological symptom (i.e., depression, anxiety, and PTSD) with CD4 count. VL was treated as a dichotomous variable (1 = detectable, 0 = undetectable). A different logistic regression equation was estimated to determine the association between health literacy with VL as well as each psychological symptom (i.e., depression, anxiety, and PTSD) with VL category. Age, race, sex, mode of transmission, sexual orientation, and education were entered into the equation first in order to control for their effects. The interaction between mode of transmission and psychological symptoms as well as mode of transmission and health literacy was also explored.

Ethical Considerations

Several considerations were taken into account in order to protect the participants in this study. Because the data were used for clinical purposes as part of a clinical protocol and de-identified for research, the IRB determined the activities did not meet the definition of human subjects research (Appendix B). As such, approval was not required. In order to protect participants, all data were de-identified by clinical staff before access was granted. Participant confidentiality also was ensured by analyzing aggregate data so individual participants were not identified.

Attention was given to participants' reactions while completing the questionnaires and their scores on the measures. Follow-up action plans were utilized to link participants to mental health services when this was appropriate. The PI provided participants with motivational interviewing, psychoeducation, education regarding HIV, and referrals for outside services on a case-by-case basis.

CHAPTER FOUR:

RESULTS

This chapter describes the results from statistical analyses used to answer the research questions. The research questions analyzed in this study were as follows:

1) To what extent do youth and young adults with HIV ages 13-25 years report psychological symptoms of depression, anxiety, and PTSD?
2) To what extent do youth and young adults with HIV ages 13-25 years demonstrate health literacy?
3) To what extent are health literacy and health outcomes (i.e., CD4 count and viral load) associated after controlling for demographic variables?
4) To what extent are psychological symptoms and health outcomes (i.e., CD4 count and viral load) associated after controlling for demographic variables?

Preliminary Analyses

Data entry. The data collected, which involved a combination of clinical records and questionnaires, were entered into a password-protected Excel spreadsheet by the primary investigator and social worker. The PI completed data integrity checks for 20% of the participants' data. Every fifth participant's electronic data were checked with their original paper forms. Whenever an error occurred, one additional entry before and after the error was checked. During the data collection phase, providers administered the questionnaires and they were scanned for skipped items. Data were collected for clinical purposes, thus if an individual

skipped an item, the trained clinical provider worked with the participant to answer the item. As such, there were no missing data for items on individual questionnaires. If a participant did not have his or her biological markers of immune functioning measured during the past year, the participant was not included in the analyses. A total of three participants were missing CD4 count data and a total of five participants were missing viral load data.

Reliability of measures. Preliminary analyses were conducted in order to determine the reliability of the measures used in this study. Cronbach's alphas were computed as a measure of internal consistency for each measure (Table 2). The Cronbach's alphas for each measure were at or above .70 suggesting strong estimates of reliability.

Participants with a missing measure were not included in analyses involving that measure. For example, if a participant completed the CES-D, GAD-7, but not the PC-PTSD, the participant's scores were not included in the model where PC-PTSD scores were associated with health outcomes. However, they were included in CES-D and GAD-7 analyses. If a participant was missing either the independent or dependent variable, the scores were not included in analyses.

Table 2

Cronbach's Alphas for each Independent Variable Measure

Measure	*n*	Number of Items	Cronbach's Alpha
BEHKA-Action	102	5	.73
BEHKA-Knowledge	102	5	.74
CES-D	103	20	.92
PC-PTSD	131	4	.82
GAD-7	144	7	.86

Note. CES-D = Center for Epidemiologic Studies Depression Scale; GAD-7 = Generalized Anxiety Disorder 7-item Scale; PC-PTSD = Primary Care- PTSD Screener; BEHKA-Action = Brief Estimate of Health Knowledge and Action- HIV Version Action Subscale; BEHKA-Knowledge = Brief Estimate of Health Knowledge and Action- HIV Version Knowledge Subscale

Descriptive characteristics of the sample. Scores from each measure and continuous outcome variables were analyzed using descriptive statistics such as mean, median, mode, and standard deviation (Table 3). Table 4 includes the demographics of the participants for each questionnaire. The average age of the participants who completed the measures was slightly over 20 years. The percentage of males versus females was evenly distributed. The majority of participants across measures identified as heterosexual and African American. The percent of individuals infected with HIV through behavioral means was similar to those infected perinatally. The educational attainment category of *some high school* contained the largest percentage of participants across measures followed by *high school degree* and *some college*. The GAD-7 was the first screener implemented at the clinic followed by the PC-PTSD and the CES-D and BEHKA-HIV. Because the screeners were implemented at different time points, the sample size for each screener varies.

Table 3

Descriptive Statistics for Psychological Symptoms, Health Literacy Scales, and CD4 Count

	CES-D	GAD-7	PC-PTSD	BEHKA-HIV Knowledge	BEHKA-HIV Action	CD4 Count
n	103	144	131	102	102	142
Mean	14.98	6.03	1.06	3.34	4.57	610.25
SD	12.52	5.39	1.42	1.60	.98	320.25
Minimum	0	0	0	0	0	20.00
Maximum	51	19	4	5	5	1594.00
Skewness	0.90	0.66	0.98	-0.65	-2.90	.37
Kurtosis	0.35	-0.59	-0.54	-0.74	9.14	.06

Note. CES-D = Center for Epidemiologic Studies Depression Scale; GAD-7 = Generalized Anxiety Disorder 7-item Scale; PC-PTSD = Primary Care- PTSD Screener; BEHKA-HIV = Brief Estimate of Health Knowledge and Action-HIV Version; SD = standard deviation. Possible scores on the CES-D range from 0-60, GAD-7 from 0-21, PC-PTSD from 0-4, BEHKA-HIV Knowledge from 0-5, and BEHKA-HIV Action from 0-5. Higher scores on the measures of psychological symptoms indicate greater psychopathology and higher scores on the BEHKA-HIV indicate more health literacy. Higher values of CD4 Count indicate better immune functioning.

Table 4

Demographic Characteristics of Sample

Variable	CES-D (n = 103)	GAD-7 (n = 144)	PC-PTSD (n = 131)	BEHKA-HIV Knowledge and Action (n = 102)
Age in years				
M (*SD*)	20.31 (2.87)	20.41 (2.87)	20.34 (3.32)	20.50 (2.86)
Gender				
Male (%)	49 (47.6)	81 (56.3)	72 (55.0)	53 (52)
Female (%)	54 (52.4)	63 (43.8)	59 (45.0)	49 (48)
Sexual Orientation				
Heterosexual (%)	67 (65.1)	88 (61.1)	79 (60.3)	65 (63.7)
Homosexual (%)	27 (26.2)	40 (27.8)	37 (28.2)	27 (26.5)
Other (%)	9 (8.7)	16 (11.1)	15 (11.5)	10 (9.8)
Race/Ethnicity				
African American (%)	72 (69.9)	96 (66.7)	89 (67.9)	69 (67.6)
White (%)	25 (24.3)	38 (26.4)	35 (26.7)	28 (27.5)
Other (%)	6 (5.8)	10 (6.9)	7 (5.3)	5 (4.9)
Mode of Transmission				
Behavioral (%)	48 (46.6)	72 (50)	66 (50.4)	46 (45.1)
Perinatal (%)	55 (53.4)	72 (50)	65 (49.6)	56 (54.9)
Educational Attainment				
Middle school (%)	4 (3.9)	7 (4.9)	6 (4.6)	3 (2.9)
Some high school (%)	41 (39.8)	50 (34.7)	47 (35.9)	41 (40.2)
High school degree (%)	26 (25.2)	39 (27.1)	34 (26.0)	24 (23.5)
High school equivalency (%)	4 (3.9)	10 (6.9)	8 (6.1)	4 (3.9)
Some college (%)	25 (24.3)	33 (22.9)	31 (23.7)	26 (25.5)
Bachelor's degree (%)	3 (2.9)	4 (2.8)	4 (3.1)	4 (3.9)
Advanced degree (%)	0 (0.0)	1 (.7)	1 (.8)	0 (0.0)

Note. CES-D = Center for Epidemiologic Studies Depression Scale; GAD-7 = Generalized Anxiety Disorder 7-item Scale; PC-PTSD = Primary Care- PTSD Screener; BEHKA-HIV = Brief Estimate of Health Knowledge and Action-HIV Version; M = mean; SD = standard deviation. Sexual orientations of Bisexual, Questioning, and Other were grouped into Other. Races of American Indian/Native Alaskan, Asian, Hawaiian/Pacific Islander, and Other were grouped into Other.

Primary Analyses

Research questions one and two. The first and second research questions examined the extent to which YLWH ages 13-25 years reported psychological symptoms of depression, anxiety, and PTSD and the extent to which they demonstrated health literacy. To answer these questions, a series of descriptive analyses were conducted. Correlations between measures of

depression, anxiety, and PTSD as well as health literacy are presented in Table 5. According to Cohen's (1998) conventions for interpreting effect sizes, a correlation coefficient of .10 is considered a small effect, .30 a medium effect, and .50 a large effect. The three measures of psychological symptoms were positively and strongly correlated with each other such that greater symptoms of depression, anxiety, or PTSD were associated with greater symptoms on the other psychological measures. Health literacy action scores were negatively and moderately correlated with depression and anxiety. An increase in depression or anxiety was associated with a decrease in action scores. There was also a small but not significant correlation between action scores and PTSD.

Table 5

Correlations among Psychological Measures and Health Literacy Scales

	1	2	3	4
1. CESD				
2. GAD	.74** (n = 102)			
3. PCPTSD	.70** (n = 101)	.62** (n = 131)		
4. KNO	.02 (n = 91)	-.02 (n = 101)	-.01 (n = 100)	
5. ACT	-.34** (n = 91)	-.36** (n = 101)	-.19 (n = 100)	.07 (n = 102)

Note. CESD = Center for Epidemiologic Studies Depression Screener; GAD = Generalized Anxiety Disorder 7-Item Scale; PTSD = Primary Care PTSD Screener; KNO = Brief Estimate of Health Knowledge and Action- HIV Version Knowledge subscale; ACT = Brief Estimate of Health Knowledge and Action- HIV Version Action subscale.
*p<.05, **p<.01.

Multiple regression equations were calculated for the psychological and health literacy measures as outcomes with demographic variables as the predictors (Appendix C). The R^2 values for the PC-PTSD and BEHKA-Knowledge outcomes were significantly different from zero with the demographic variables explaining 12.2% of the variance in the PC-PTSD scores and 27.9% of the variance in the Knowledge scores. Overall, age was a consistent predictor for scores on all

measures except the PC-PTSD. Older participants reported more symptoms of depression and anxiety as well as HIV knowledge and reported lower scores on the Action subtest of the BEHKA-HIV. Educational attainment reached significance ($p < .05$) for the BEHKA-Action and PC-PTSD such that participants with more educational attainment reported fewer PTSD symptoms and reported taking more action when it came to medication adherence.

Percentages of participants who screened positive and negative for each measure of psychological symptoms as well as those who scored zero on measures of psychological symptoms are reported in Table 6. Over 20% of the participants screened positive for psychological disorders across measures. Over 50% of individuals reported an absence of symptoms of PTSD, whereas only 18.1% and 8.7% reported an absence of symptoms of anxiety and depression, respectively. The percentages of participants who screened positive for zero, one, two, and three of the psychological screeners are also presented in Table 6. Only participants who completed all three screeners for psychological disorders were included in this analysis. Over half of the participants screened negative on all three screeners for depression, anxiety, and PTSD. Nearly one third of participants screened positive on either two or three measures and approximately 14% screened positive on all three measures. The percentages of participants who scored in the different severity levels on the GAD-7 are presented in Table 7. The majority of participants scored in the Minimal or Mild anxiety categories and approximately 25% of participants scored in the Moderate or Severe categories.

Table 8 presents the percentages of participants who reported specific traumas on the PC-PTSD. Forty-three percent of the sample ($n = 57$) reported at least one symptom of PTSD and data regarding the nature of the trauma were obtained from 29 participants. Sexual assault and

emotional trauma were the most often reported followed by illness/injury, other traumas (e.g., loss of job), and emotional trauma.

Table 6

Frequency of Participants who Reported an Absence of Psychological Symptoms, Screened Positive and Negative on Psychological Measures, and Screened Positive on Multiple Psychological Measures

Variable	Frequency (%)
CES-D (*n* = 103)	
Score of Zero	9 (8.7)
Positive Screener: Score of ≥16 for participants ≥18 years and older and ≥24 for participants <18 years old)	36 (35.0)
Negative Screener	67 (65.0)
GAD-7 (*n* = 144)	
Score of Zero	26 (18.1)
Positive Screener: Score of ≥10	37 (25.7)
Negative Screener	107 (74.3)
PC-PTSD (*n* = 131)	
Score of Zero	74 (56.5)
Positive Screener: Score of ≥3	27 (20.6)
Negative Screener	104 (79.4)
Number of Positive Screeners (*n* = 101)	
0	57 (56.4)
1	15 (14.9)
2	15 (14.9)
3	14 (13.8)

Note. CES-D = Center for Epidemiologic Studies Depression Scale, GAD-7 = Generalized Anxiety Disorder 7-item Scale, PC-PTSD = Primary Care- PTSD Screener.

Table 7

Frequency of Participants who Scored in Different Severity Categories on the GAD-7

Severity Category	Frequency (%) (*n* = 144)
Minimal	69 (47.9)
Mild	38 (26.4)
Moderate	22 (15.3)
Severe	15 (10.4)

Note. GAD-7 = Generalized Anxiety Disorder 7-item Scale. Minimal = 0-4, Mild = 5-9, Moderate = 10-14, and Severe = 15-21.

Table 8

Types of Trauma Reported on the PC-PTSD

Type of Trauma	Frequency Endorsed (%)
	(*n* = 29)
Sexual assault	10 (34.4)
Emotional trauma	10 (34.4)
Illness/injury	8 (27.5)
Other traumas	8 (27.6)
Physical trauma	7 (24.1)

Note. PC-PTSD=Primary Care PTSD Screener. Items are in order of decreasing endorsement. Percentages do not add up to 100% because participants were able to endorse multiple traumas.

Table 9 includes the percentage of participants who answered the Knowledge questions correctly on the BEHKA-HIV. Table 10 includes the percentage of participants who indicated they take their medications under various conditions on the Action subtest of the BEHKA-HIV. Overall, 32.4% of participants (*n* = 33) answered all questions on the BEHKA-HIV Knowledge subtest correctly, 22.5% (*n* = 23) missed one question, 15.7% (*n* = 16) missed two questions, 12.7% (*n* = 13) missed three questions, 9.8% (*n* = 10) missed four questions, and 6.9% (*n* = 7) missed all of the questions. On the Action subtest, 76.5% (*n* = 78) of participants indicated they take their medications under all conditions, 13.7% (*n* = 14) indicated they do not take their medication under one condition, 3.9% (*n* = 4) indicated they do not take their medications under two conditions, 3.9% (*n* = 4) indicated they do not take their medications under three conditions, and 2.0% (*n* = 2) indicated they do not take their medications under any of the conditions. The most commonly missed item on the Knowledge subtest was "What is a CD4 count?" followed by "What is a viral load?" and "What medications are you currently taking to treat HIV?" Regarding the Action subtest, taking medications when they make the participant feel bad and because they taste bad were the top reasons participants reported as reasons for not taking their medications.

Table 9

Correct Responses on the BEHKA-HIV Knowledge Subtest

Item	Frequency Correct (%)	Frequency Incorrect (%)
	n = 102	
Should viral load go up or down as a result of treatment?	84 (82.4)	18 (17.6)
Should CD4 count go up or down as a result of treatment?	77 (75.5)	25 (24.5)
What mediations are you currently taking to treat HIV?	69 (67.6)	33 (32.4)
What is a viral load?	66 (64.7)	36 (35.3)
What is a CD4 count?	45 (44.1)	57 (55.9)

Note. BEHKA-HIV = Brief Estimate of Health Knowledge and Action- HIV Version. Items are in order of decreasing correctness. Correct responses for "What is a CD4 count?" included white blood cells, indicator of immune functioning, blood cells that fight off infections. Correct response for "Should CD4 count go up or down as a result of treatment?" was "up." Correct response for "What is a viral load?" included amount of virus in blood. Correct response for "Should viral load go up or down as a result of treatment?" was "down." Correct response for "What medications are you currently taking to treat HIV?" was being able to name all of the participants' medications.

Table 10

Responses on the BEHKA-HIV Action Subtest

Item	Frequency Disagree (%)	Frequency Agree or Sometimes (%)
I don't take my medicines...	*n* = 102	
When I feel good	98 (96.1)	4 (3.9)
When I am too tired	94 (92.2)	8 (7.8)
When I am feeling down or low	94 (92.2)	8 (7.8)
Because they taste bad	92 (90.2)	10 (9.8)
When they make me feel bad	88 (86.3)	14 (13.7)

Note. BEHKA-HIV = Brief Estimate of Health Knowledge and Action- HIV Version. Items are in order of decreasing correctness. A response of "disagree" is desired as that indicates the participant takes their medication under that condition.

Research questions three and four. The third and fourth research questions examined the extent to which health literacy and psychological symptoms were associated with health outcomes (i.e., CD4 count and viral load) while controlling for demographic variables (i.e., age, race, gender, mode of transmission, educational attainment, and sexual orientation). The outcome

of CD4 count was treated as a continuous variable and was analyzed using a series of multiple linear regressions. Viral load was treated as a dichotomous variable (0 = undetectable, 1 = detectable) and was analyzed using logistic regressions. Results for the multiple regressions are presented first followed by the results from the logistic regression.

Analysis of assumptions for the multiple linear regression model for CD4 count. Before conducting the multiple linear regression analyses, assumptions were analyzed. One of the assumptions of multiple linear regression analysis is that the residuals for the CD4 count are normally distributed. Visual analysis and measures of skewness and kurtosis (Table 11) revealed the residuals were normally distributed and, thus, this assumption was not violated. The next assumption is that the variance of the residuals is homogeneous across levels of the predicted values. Residuals versus predicted values were plotted and analyzed for heteroscedasicity. Visual analysis indicated this assumption was not violated. Multicollinearity was assessed by examining the correlations between the predictor variables (Table 12). Low correlations among variables indicated there was no multicollinearity. Scatter plots between the dependent variable and the predictor variable were analyzed for nonlinearity. Visual analysis revealed that all relationship were linear.

Table 11

Skewness and Kurtosis of Residuals for CD4 count

Predictor Variable for CD4 Count	*n*	Skewness	Kurtosis
CES-D	102	0.37	0.19
GAD-7	140	0.40	0.04
PC-PTSD	129	0.33	0.08
BEHKA-HIV Knowledge and Action	101	0.47	0.44

Note. CES-D = Center for Epidemiologic Studies Depression Scale, GAD-7 = Generalized Anxiety Disorder 7-item Scale, PC-PTSD = Primary Care- PTSD Screener, BEHKA-HIV = Brief Estimate of Health Knowledge and Action-HIV Version. Skewness and kurtosis of standardized residuals for CD4 count are reported separately for each equation that was calculated with demographic variables and either the CES-D, GAD-7, PC-PTSD, or BEHKA-HIV Knowledge and Action subtests as the predictors.

Table 12

Correlations among Predictor Variables

	1	2	3	4	5	6	7	8	9	10	11	12
1. AGE												
2. GEN (1 = male, 2 = female)	-.04											
3. TRAN (1 = perinatal, 2 = behavioral)	-.21*	-.17*										
4. EDU	.48**	-.17*	.13									
5. RACO[a]	.06	-.08	-.002	.11								
6. RACA[a]	-.09	.09	.09	-.16	-.39**							
7. SOHO[b]	.12	-.39**	.40**	.10	.14	-.09						
8. SOOT[b]	.09	-.18*	.22**	.09	-.01	.06	-.22*					
9. KNO	.35**	-.31**	.23*	.35**	-.02	-.19	.18	.16				
10. ACT	-.10	-.22*	.14	.16	.01	-.07	.04	.08	.07			
11. PTSD	.03	.08	.15	-.18*	.01	.17	.08	.09	-.01	-.19		
12. GAD	.16	.10	.08	-.07	.02	.12	-.01	-.04	-.02	-.36**	.62**	
13. CES	.17	.05	.14	-.08	.10	.12	-.03	.08	.02	-.34**	.70**	.74**

Note. AGE = age; GEN = Gender; TRAN = Mode of transmission; EDU = Educational attainment; RACO = Race Other; RACA = Race African American; SOHO = Sexual Orientation Homosexual; SOOT = Sexual Orientation Other; KNO = Brief Estimate of Health Knowledge and Action- HIV Version Knowledge subscale; ACT = Brief Estimate of Health Knowledge and Action- HIV Version Action subscale; PTSD = Primary Care PTSD Screener; GAD = Generalized Anxiety Disorder 7-Item Scale; CESD = Center for Epidemiologic Studies Depression Screener.

[a]Reference race group is White. [b]Reference sexual orientation group is Heterosexual.

*p<.05, **p<.01.

CD4 count as the dependent variable. To determine the extent to which health literacy and psychological symptoms were associated with CD4 count, multiple linear regressions were calculated. Age, race, sex, mode of transmission, sexual orientation, and education were entered into the equation first in order to control for their effects. Sexual orientation and race were dummy coded before entering into the regression analysis. Statistical significance was set at $p < .05$. Model 1 included age, race, sex, sexual orientation, mode of transmission, and education as the predictor variables and scores on psychological measures and health literacy were entered model 2. The interaction between mode of transmission and scores on psychological measures was entered in model 3. A different equation was calculated for each psychological measure due to differences in sample size. The BEHKA-HIV Knowledge and BEHKA-HIV Action scores were entered in model 2 together and the interactions between mode of transmission and Knowledge and Action scores were simultaneously entered in model 3. A summary of multiple regression of CD4 count with demographic variables, psychological symptoms, and the interaction between mode of transmission and scores on psychological measures as predictors are presented in Tables 13-15. A summary of multiple regression of CD4 count with demographic variables and health literacy as predictors are presented in Table 16.

CES-D as a predictor. The R^2 for model 1 using CD4 count as the outcome and the demographic variables as predictors was significantly different from zero, $F(8,93) = 2.06$, $p = .05$, $R^2 = .15$. Age ($b = -32.66$) and educational attainment ($b = 52.95$) were significant predictors of CD4 count in Model 1 ($t = -2.54$; $p = .01$ and $t = 2.04$; $p = .04$, respectively). Older participants had lower CD4 counts, whereas the more education participants had the higher their CD4 count. When CES-D score was added to the equation, the R^2 for model 2 was not significantly different from zero, $F(9,92) = 1.81$, $p = .08$, $R^2 = .15$, and CES-D Total score did

not contribute significantly to the prediction of CD4 count (t = .04, p = .97). Age (b = -32.77) and educational attainment (b = 53.14) remained significant predictors of CD4 count in Model 2 (t = -2.46; p = .02 and t = 1.99; p = .05, respectively) such that younger participants and those with more education had higher CD4 counts. When the interaction between mode of transmission and CES-D score was added to the equation, the R^2 for model 3 was significantly different from zero, $F(10,91) = 2.63$, p = .007, R^2 = .22. The interaction contributed significantly to the prediction of CD4 count (t = 2.93, p = .004). Gender (b = 154.34, t = 2.25, p = .03), educational attainment (b = 56.20, t = 2.19, p = .03), age (b = -27.84, t = -2.16, p = .03), and CES-D Total score (b = -10.62, t = -2.37, p = .02) were significant predictors of CD4 count in Model 3. Males, those with more education, younger participants, and those with lower CES-D scores had higher CD4 counts. When examining the significant interaction between mode of transmission and CES-D score, the slope of the line for those who acquired HIV behaviorally was not significant (simple slope/unstandardized regression coefficient [b] = 5.26, SE = 3.14, p = .10). The slope of the line for those who acquired HIV perinatally was significant (simple slope/unstandardized regression coefficient [b] = -10.62, SE = 4.49, p = .02), such that perinatally infected participants who reported more symptoms of depression had lower CD4 counts.

GAD-7 as a predictor. The R^2 for model 1 using CD4 count as the outcome and the demographic variables as predictors was not significantly different from zero, $F(8,132) = 1.67$, p = .11, R^2 = .09. Age (b = -27.85) was a significant predictor of CD4 count in Model 1 (t = -2.83; p = .005), older participants had lower CD4 counts. When GAD-7 score was added to the equation, the R^2 for model 2 was not significantly different from zero, $F(9,131) = 1.78$, p = .08, R^2 = .11, and GAD-7 Total score did not contribute significantly to the prediction of CD4 count

(t = -1.58, p = .12). Age (b = -26.00) remained a significant predictor in Model 2 (t = -2.37, p = .02), older participants had lower CD4 counts. When the interaction between mode of transmission and GAD-7 score was added to the equation, the R^2 for model 3 was significantly different from zero, $F(10,130) = 2.84$, $p = .003$, $R^2 = .12$. The interaction contributed significantly to the prediction of CD4 count ($t = 3.34$, $p = .001$). Educational attainment (b = 43.54, $t = 2.10$, $p = .04$), age (b = -25.55, t = -2.42, $p = .02$), and GAD-7 Total score (b = -27.98, t = -3.60, $p < .001$) were significant predictors of CD4 count in Model 3. Participants with more education, younger participants, and those with lower GAD-7 scores had higher CD4 counts. When examining the significant interaction between mode of transmission and GAD-7 score, the slope of the line for those who acquired HIV behaviorally was not significant (simple slope/unstandardized regression coefficient [b] = 5.74, SE = 6.59, $p = .39$). The slope of the line for those who acquired HIV perinatally was significant (simple slope/unstandardized regression coefficient [b] = -27.98, SE = 7.77, $p < .001$), such that perinatally infected participants who reported more symptoms of anxiety had lower CD4 counts.

PC-PTSD as a predictor. The R^2 for model 1 for PC-PTSD scores was not significantly different from zero, $F(8,120) = 1.04$, $p = .41$, $R^2 = .07$. No demographic variables were significant predictors of CD4 count in Model 1. When PC-PTSD score was added to the equation, the R^2 for model 2 remained not significantly different from zero, $F(9,119) = .92$, p = .51, $R^2 = .07$, and PC-PTSD Total score did not contribute significantly to the prediction of CD4 count ($t = .21$, $p = .84$). When the interaction between mode of transmission and PC-PTSD score was added to the equation, the R^2 for model 3 was not significantly different from zero, $F(10,118) = 1.40$, $p = .19$, $R^2 = .11$. The interaction contributed significantly to the prediction of CD4 count ($t = 2.33$, $p = .02$). When examining the significant interaction between mode of

transmission and PC-PTSD score, the slope of the line for those who acquired HIV behaviorally was not significant (simple slope/unstandardized regression coefficient [*b*] = 42.90, *SE* = 26.92, *p* = .11). The slope of the line for those who acquired HIV perinatally was not significant (simple slope/unstandardized regression coefficient [*b*] = -54.88, *SE* = 33.23, *p* = .10).

Health literacy scales as predictors. The R^2 for model 1 using CD4 count as the outcome and the demographic variables as predictors was not significantly different from zero, $F(8,92) = 1.93$, $p = .07$, $R^2 = .14$. Age ($b = -31.93$) and educational attainment ($b = 57.54$) were significant predictors of CD4 count in Model 1 ($t = -2.50$; $p = .01$ and $t = 2.32$; $p = .02$, respectively). Older participants had lower CD4 counts and those with a higher education had higher CD4 counts. When BEHKA-HIV Knowledge and Action scores were added to the equation, the R^2 for model 2 was significantly different from zero, $F(10,90) = 2.00$, $p = .04$, $R^2 = .18$. Adding the health literacy measures accounted for an additional 4% of variance in CD4 count. When the interactions between mode of transmission and knowledge and action scores were added to the equation, the R^2 for model 3 was significantly different from zero, $F(12,88) = 2.05$, $p = .03$, $R^2 = .22$. Neither the interaction between mode of transmission and knowledge scores ($t = -.49$, $p = .63$) nor the interaction between mode of transmission and action scores ($t = -1.63$, $p = .11$) contributed significantly to the prediction of CD4 count. As such, model 3 is not included in Table 16.

Table 13

Summary of Multiple Regression of CD4 Count with Demographic Variables, CES-D, and Interaction as Predictors

Variable	CES-D Added as a Predictor					
	Model 1		Model 2		Model 3	
	n = 102		*n* = 102		*n* = 102	
	B (SE)	*Beta*	*B (SE)*	*Beta*	*B (SE)*	*Beta*
Age	-32.66 (12.83)	-.29*	-32.77 (13.31)	-.29*	-27.84 (12.90)	-.25*
Race						
White[a]	46.14 (75.85)	.06	46.49 (76.89)	.06	15.68 (74.64)	.02
Other[a]	42.63 (137.37)	.03	42.04 (139.18)	.03	85.44 (134.58)	.06
Gender (1 = Male, 2 = Female)	130.02 (70.44)	.19^{+}	129.96 (70.84)	.19^{+}	154.36 (68.59)	.24*
Mode of Transmission (0 = Perinatal, 1 = Behavioral)	112.30 (76.76)	.17	112.20 (77.24)	.17	-138.41 (113.19)	-.21
Education	52.95 (25.91)	.23*	53.14 (26.65)	.23*	56.20 (25.63)	.25*
Sexual Orientation						
Homosexual[b]	-109.92 (89.22)	-.15	-109.80 (89.76)	-.15	-74.84 (87.09)	-.10
Other[b]	42.63 (137.37)	.08	42.04 (139.18)	.06	85.51 (120.90)	.07
CES-D	-	-	.09 (2.71)	.004	-10.62 (4.49)	-.40*
Mode of Transmission x CES-D	-	-	-	-	15.88 (5.41)	.63*
R^2	.15		.15		.22	
F for change in R^2	2.06*		.001		8.60*	

Note. CES-D = Center for Epidemiologic Studies Depression Scale; SE = Standard Error

[a]Reference race group is African American. [b]Reference sexual orientation group is Heterosexual.

***p<.001, *p<.05, $^{+}$p<.10.*

Table 14

Summary of Multiple Regression of CD4 Count with Demographic Variables, GAD-7, and Interaction as Predictors

Variable	GAD-7 Added as a Predictor					
	Model 1		Model 2		Model 3	
	n = 140		*n* = 140		*n* = 140	
	B (SE)	*Beta*	*B (SE)*	*Beta*	*B (SE)*	*Beta*
Age	-30.27 (10.69)	-.27*	-26.00 (10.97)	-.24*	-25.55 (10.57)	-.23*
Race						
White[a]	61.92 (61.25)	.09	49.47 (61.41)	.07	43.54 (59.19)	.06
Other[a]	75.64 (111.68)	.06	66.65 (111.20)	.05	77.96 (107.18)	.06
Gender (1 = Male, 2 = Female)	62.93 (61.49)	.10	65.87 (61.17)	.10	95.99 (59.61)	.15
Mode of Transmission (0 = Perinatal, 1 = Behavioral)	76.07 (63.32)	.12	81.02 (63.04)	.13	-118.87 (85.26)	-.19
Education	52.70 (25.93)	.23*	53.10 (26.67)	.23^{+}	43.54 (20.78)	.20*
Sexual Orientation						
Homosexual[b]	-65.86 (77.19)	-.09	-67.37 (76.76)	-.10	-50.62 (74.11)	-.07
Other[b]	81.28 (96.28)	.08	73.76 (95.85)	.07	70.85 92.35	.07
GAD-7	-	-	-8.34 (5.26)	-.14	-27.98 (7.77)	-.46**
Mode of Transmission x GAD-7	-	-	-	-	33.72 (10.10)	.54*
R^2	.09		.11		.18	
F for change in R^2	1.67		2.51		11.15*	

Note. GAD-7 = Generalized Anxiety Disorder 7-item Scale; SE = Standard Error

[a]Reference race group is African American. [b]Reference sexual orientation group is Heterosexual.

***p*<.001, **p*<.05, $^{+}$*p*<.10.

Table 15

Summary of Multiple Regression of CD4 Count with Demographic Variables, PC-PTSD, and Interaction as Predictors

Variable	PC-PTSD Added as a Predictor					
	Model 1		Model 2		Model 3	
	n = 129		*n* = 129		*n* = 129	
	B (SE)	*Beta*	*B (SE)*	*Beta*	*B (SE)*	*Beta*
Age	-15.16 (9.98)	-.16	-15.47 (10.13)	-.16	-14.70 (9.95)	-.15
Race						
White[a]	38.67 (65.04)	.05	40.70 (66.03)	.06	34.91 (64.88)	.05
Other[a]	72.83 (127.83)	.05	72.21 (128.38)	.05	107.26 (126.95)	.08
Gender (1 = Male, 2 = Female)	73.43 (65.98)	.16	71.96 (66.62)	.12	91.57 (65.95)	.14
Mode of Transmission (0 = Perinatal, 1 = Behavioral)	48.66 (70.94)	.08	48.36 (71.24)	.08	-67.37 (85.80)	-.11
Education	29.25 (22.60)	.14	30.44 (23.39)	.14	24.83 (23.09)	.12
Sexual Orientation						
Homosexual[b]	-64.77 (84.49)	-.09	-67.28 (85.67)	-.10	-28.97 (85.72)	-.04
Other[b]	113.14 (105.53)	.11	110.02 (107.00)	.11	144.96 (106.13)	.15
PC-PTSD	-	-	4.54 (21.69)	.02	-54.88 (33.23)	-.24
Mode of Transmission x PC-PTSD	-	-	-	-	97.78 (41.97)	.37*
R^2	.07		.07		.11	
F for change in R^2	1.04		.04		5.43*	

Note. PC-PTSD = Primary Care- PTSD Screener; SE = Standard Error

[a]Reference race group is African American. [b]Reference sexual orientation group is Heterosexual.

***p<.001, *p<.05, +p<.10.*

Table 16

Summary of Multiple Regression of CD4 Count with Demographic Variables and Health Literacy Scores as Predictors

Variable	Model 1			Model 2		
	n = 101			*n* = 101		
	B (SE)	*Beta*	*p*	*B (SE)*	*Beta*	*p*
Age	-31.93 (12.77)	-.29	.01*	-24.01 (13.26)	-.22	.07
Race						
White[a]	35.39 (72.29)	.05	.63	35.44 (73.31)	.05	.63
Other[a]	5.50 (146.96)	.004	.97	5.08 (145.42)	.003	.97
Gender (1 = Male, 2 = Female)	102.14 (69.23)	.16	.14	113.41 (72.04)	.18	.12
Mode of Transmission (1 = Perinatal, 2 = Behavioral)	88.35 (79.32)	.14	.27	68.00 (80.31)	.11	.40
Education	57.54 (24.81)	.27	.02*	50.39 (25.39)	.23	.05*
Sexual Orientation						
Homosexual[b]	-90.85 (89.62)	-.13	.31	-74.50 (89.04)	-.10	.41
Other[b]	164.38 (118.09)	.16	.17	172.72 (116.78)	.16	.14
BEHKA-Knowledge				-15.99 (23.03)	-.08	.49
BEHKA-Action				64.07 (33.21)	.20	.06
R^2	.14			.18		
F for change in R^2	1.93			2.13*		

Note. BEHKA-Knowledge = Brief Estimate of Health Knowledge and Action- HIV Version Knowledge Subscale; BEHKA-Action = Brief Estimate of Health Knowledge and Action- HIV Version Action Subscale; OR = Odds ratio; B = Logit form.
*$^{*}p<.05$, $^{+}p<.10$.

Preliminary analyses. The first assumption for logistic regression is that the dependent variable is measured on a dichotomous scale. Viral load is categorized as either "detectable" or "undetectable" and thus does not violate this assumption. The second assumption is that there be one or more independent variables that are either continuous or categorical. None of the predictor variables violate this assumption, as all variables are continuous or categorical in nature.

Viral load as the dependent variable. A series of logistic regression analyses was conducted to determine the extent to which psychological symptoms as well as health literacy predicted viral load category (i.e., 0=undetectable, 1=detectable). Age, race, sex, mode of transmission, sexual orientation, and education were entered into the equation first in order to

control for their effects. Statistical significance was set at $p < .05$. Model 1 included age, race, sex, sexual orientation, mode of transmission, and education as the predictor variables and scores on psychological measures or health literacy were entered model 2. The interaction between mode of transmission and scores on psychological measures was entered in model 3. A different equation was calculated for each psychological measure due to differences in sample size. The BEHKA-HIV Knowledge and BEHKA-HIV Action scores were entered in model 2 together and the interactions between mode of transmission and Knowledge and Action scores were simultaneously entered in model 3. A summary of logistic regression of viral load with demographic variables and health literacy as predictors are presented in Table 17. A summary of logistic regression of viral load with demographic variables and psychological symptoms as predictors are presented in Table 18.

CES-D as a predictor. A logistic regression was performed to determine the effects of demographic variables and CES-D scores on the likelihood that participants had a detectable viral load (i.e., 0=undetectable, 1=detectable). The predictors added to model 1 did not produce a significant improvement in the model that only contained the intercept, $\chi^2(8) = 8.17$, $p = .42$. Increasing age was associated with an increased likelihood of having a detectable viral load. Adding the CES-D Total Score to model 2 did not produce a significant improvement in the model that only contained the demographic variables, $\chi^2(9) = 8.84$, $p = .45$. None of the variables were significant predictors in model 2. Adding the interaction between mode of transmission and CES-D Total Score to model 3 did not produce a significant improvement in the model that contained the demographic variables and CES-D Total Score, $\chi^2(10) = 10.60$, $p = .39$. None of the variables were significant predictors in model 3. Because the interaction was not significant, it is not included in Table 17.

GAD-7 as a predictor. Another logistic regression was performed to establish the effects of demographic variables and GAD-7 scores on the likelihood that participants have a detectable viral load (i.e., 0=undetectable, 1=detectable). The predictors added to model 1 did not produce a significant improvement in the model that only contained the intercept, $\chi^2(8) = 9.21$, $p = .33$. Increasing age was associated with an increased likelihood of having a detectable viral load. Adding the GAD-7 Total Score to model 2 did not produce a significant improvement in the model that only contained the demographic variables, $\chi^2(9) = 10.04$, $p = .35$. None of the variables were significant predictors in model 2. Adding the interaction between mode of transmission and GAD-7 Total Score to model 3 did not produce a significant improvement in the model that contained the demographic variables and GAD-7 Total Score, $\chi^2(10) = 11.40$, $p = .33$. None of the variables were significant predictors in model 3. Because the interaction was not significant, it is not included in Table 17.

PC-PTSD as a predictor. The effects of demographic variables and PC-PTSD scores on the likelihood that participants have a detectable viral load (i.e., 0=undetectable, 1=detectable) was determined through a logistic regression. The predictors added to model 1 did not produce a significant improvement in the model that only contained the intercept, $\chi^2(8) = 8.43$, $p = .39$. Increasing age was associated with an increased likelihood of having a detectable viral load. Adding the PC-PTSD Total Score to model 2 did not produce a significant improvement in the model that only contained the demographic variables, $\chi^2(9) = 8.70$, $p = .47$. In model 2, increasing age was associated with an increased likelihood of having a detectable viral load. Adding the interaction between mode of transmission and PC-PTSD Total Score to model 3 did not produce a significant improvement in the model that contained the demographic variables and PC-PTSD Total Score, $\chi^2(10) = 8.70$, $p = .56$. Age remained a significant predictor in model

3 with increasing age being associated with an increased likelihood of having a detectable viral load. Because the interaction was not significant, it is not included in Table 17.

Health literacy as predictors. A final logistic regression was performed to ascertain the effects of demographic variables and health literacy scores on the likelihood that participants have a detectable viral load (i.e., 0=undetectable, 1=detectable). The predictors added to model 1 did not produce a significant improvement in the model that only contained the intercept, $\chi^2(8) = 7.02$, $p = .54$. No variables were significant predictors. Adding the BEHKA-HIV Knowledge and Action Total Scores to model 2 produced a significant improvement in the model that only contained the demographic variables, $\chi^2(10) = 20.37$, $p = .03$. BEHKA-Action scores were statistically significant such that decreasing action was associated with an increased likelihood of having a detectable viral load ($p = .004$). Adding the interaction between mode of transmission and BEHKA-HIV Knowledge and Action scores to model 3 produced a significant improvement in the model that contained the demographic variables and BEHKA-HIV Knowledge and Action Total Scores, $\chi^2(12) = 22.36$, $p = .03$. BEHKA-Action scores remained statistically significant such that decreasing action was associated with an increased likelihood of having a detectable viral load ($p = .02$). Because the interactions were not significant predictors, they are not included in Table 18.

Summary of Significant Findings

Several findings were gleaned from the variables of interest. Overall, the sample reported high levels of symptoms of depression, anxiety, and PTSD. Participants had a moderate amount of HIV knowledge and the majority reported taking their medications under most conditions. Age was a significant predictor of CD4 count and viral load across models such that increasing age was associated with worse immune system functioning. Educational attainment was a

significant predictor of CD4 count and to a lesser extent viral load indicating that greater education was associated with better immune system functioning. There was a significant interaction between mode of transmission and depression, anxiety, and PTSD symptoms such that for perinatally infected youth and young adults, increasing mental health symptoms was associated with a decrease in CD4 count. Health literacy (knowledge and action) added significantly to the explanation of the variance in viral load. Decreasing action scores were statistically associated with an increased likelihood of having a detectable viral load.

Table 17

Summary of Logistic Regression of Viral Load with Demographic Variables and Psychological Measures as Predictors

Variable	CES-D added as a Predictor				GAD-7 added as a Predictor				PC-PTSD added as a Predictor			
	Model 1		Model 2		Model 1		Model 2		Model 1		Model 2	
	n = 100		*n* = 100		*n* = 139		*n* = 139		*n* = 126		*n* = 126	
	OR (SE)	*B*	*OR (SE)*	*B*	*OR (SE)*	*B*	*OR (SE)*	*B*	*OR (SE)*	*B*	*OR (SE)*	*B*
Age	1.20 (.09)	.18*	1.17 (.10)	.16^{+}	1.18 (.07)	.16*	1.16 (.08)	.15^{+}	1.18 (.08)	.17*	1.18 (.08)	.16*
Race												
White[a]	1.33 (.53)	.29	1.27 (.54)	.24 -.48	1.09 (.41)	.09 -.75	1.04 (.41)	.04 -.74	.85 (.43)	-.43 -.85	.83 (.43)	-.19 -.81
Other[a]	.56 (.95)	-.59	.62 (.97)		.47 (.72)		.48 (.73)		.44 (.85)		.45 (.85)	
Gender (1 = Male, 2 = Female)	.57 (.50)	-.57	.56 (.50)	-.57	.62 (.42)	-.47	.64 (.42)	-.45	.57 (.45)	-.55	.59 (.45)	-.53
Mode of Transmission (1 = Perinatal, 2 = Behavioral)	1.73 (.54)	.55	1.73 (.54)	.55	1.26 (.43)	.23	1.28 (.43)	.24	1.22 (.47)	.20	1.22 (.47)	.20
Education	.92 (.17)	-.08	.95 (.18)	-.05	.91 (.14)	-.09	.93 (.14)	-.07	.89 (.15)	-.12	.90 (.15)	-.10
Sexual Orientation												
Homosexual[b]	2.15 (.82)	.76	2.00 (.82)	.69 1.22	1.63 (.63)	.49 .79	1.69 (.63)	.53 .83	1.36 (.65)	.31 .71	1.35 (.66)	.30 .66
Heterosexual[b]	3.60 (.85)	1.28	3.38 (.85)		2.21 (.66)		2.30 (.66)		2.04 (.71)		1.93 (.72)	
Psychological Measure	-	-	1.02 (.02)	.02	-	-	1.03 (.04)	.03			1.08 (.14)	.07

Note. Dichotomous dependent variable was coded as 1=detectable viral load and 0=undetectable viral load. An undetectable viral load is desired. CES-D = Center for Epidemiologic Studies Depression Scale; GAD-7 = Generalized Anxiety Disorder 7-item Scale; PC-PTSD = Primary Care- PTSD Screener; BEHKA-HIV = Brief Estimate of Health Knowledge and Action- HIV Version.

[a]Reference race group is African American. [b]Reference sexual orientation group is Other.

**p<.05, $^{+}$p<.10.*

Table 18

Summary of Logistic Regression of Viral Load with Demographic Variables and Health Literacy Scores as Predictors

Variable	Model 1		Model 2	
	n = 101		*n* = 101	
	OR (SE)	*B*	*OR (SE)*	*B*
Age	1.16(.10)	.15	1.07 (.11)	.07
Race				
White[a]	1.74(.53)	.55	1.54 (.59)	.43
Other[a]	1.06(1.03)	.05	1.19 (1.12)	.18
Gender (1 = Male, 2 = Female)	.61 (.50)	-.50	.77 (.57)	-.26
Mode of Transmission (1 = Perinatal, 2 = Behavioral)	2.49 (.57)	.91	1.90 (.62)	.18
Education	1.04 (.17)	.04	1.19 (.19)	.18
Sexual Orientation				
Homosexual[b]	1.61 (.80)	.48	1.97 (.83)	.68
Heterosexual[b]	2.23 (.82)	.80	2.15 (.86)	.77
BEHKA-Knowledge	-	-	1.07 (.18)	.07
BEHKA-Action	-	-	.35 (.36)	-1.05*

Note. Dichotomous dependent variable was coded as 1=detectable viral load and 0=undetectable viral load. An undetectable viral load is desired. BEHKA-Knowledge = Brief Estimate of Health Knowledge and Action- HIV Version Knowledge Subscale; BEHKA-Action = Brief Estimate of Health Knowledge and Action- HIV Version Action Subscale.

[a]Reference race group is African American. [b]Reference sexual orientation group is Other.

**p<.05, [+]p<.10.*

CHAPTER FIVE:

DISCUSSION

The goal of this study was to explore the health literacy and mental health symptoms of youth living with HIV (YLWH) and how these factors relate to immune functioning. This study was guided by four research questions. The first and second research questions examined the extent to which YLWH reported symptoms of depression, anxiety, and posttraumatic stress disorder (PTSD) as well as their health literacy. Then, the association between these variables and biological markers of immune functioning, while controlling for several demographic variables, was calculated.

This chapter begins with an overview of the study followed by a discussion of the results. The limitations of the study, recommendations for future research, and implications and considerations for future practice are then presented. The chapter concludes with an overall summary of the research findings.

Overview of the Study

Human immunodeficiency virus (HIV) destroys the body's immune system and subsequently its ability to fight infections and cancers (NIH, 2012). In 2015, 22% percent of new HIV diagnoses were youth and young adults (CDC, 2017). However, youth and young adults are disproportionately affected by HIV given they only represent 17% of the United States population (CDC, 2017). YLWH face increased risk of depression, anxiety, and PTSD. In addition to mental health symptoms, health literacy has appeared as a factor that influences

individuals with HIV. As such, youth ages 13 to 25 years have been identified as a population needing support for HIV prevention and engagement in care (White House Office of National AIDS Policy, 2015**)**.

Discussion of the Results

Research question one. To what extent do youth and young adults with HIV ages 13-25 years report psychological symptoms of depression, anxiety, and PTSD?

Findings obtained from descriptive analyses indicated 35% of the sample screened positive for depression, 26% screened positive for anxiety, and 20% screened positive for PTSD. These percentages are much higher than those found in the general population. Merikangas and colleagues (2010) examined the lifetime prevalence rates of mental health disorders in the National Comorbidity Survey-Adolescent Supplement. Researchers found a lifetime prevalence rate of 11.7% for major depressive disorder or dysthymia, 8.3% for any anxiety disorder, and 1.5% for posttraumatic stress disorder (Merikangas et al., 2010).

Although the percentages in this study are elevated compared to those in the general population, they are similar to those found in other studies of YLWH. In a study of 2,032 YLWH, 18% of participants endorsed mental health symptoms on the Brief Symptom Inventory that were clinically significant (Brown et al., 2015). When looking at specific subscales, approximately 21% of the sample scored above the clinical threshold for depression, 13.5% for anxiety, and 19% for paranoid symptoms (Brown et al., 2015). In the Reaching Excellence in Adolescent Care and Health (REACH) large, multi-site project of youth who acquired HIV behaviorally, 17% of participants ($N = 230$) scored one standard deviation above the mean for depression on the CES-D and 18% reported at least moderately elevated anxiety scores (Rogers et al., 1998). In another study with 161 behaviorally infected youth, 37% met the criteria for

depression (Murphy et al., 2001) and yet another found 15% (N = 174) met criteria for major depressive disorder (Martinez, Hosek, & Carleton, 2009). Data obtained from the same clinic in which this study took place found 23.5% of YLWH had a positive depression screen using the Patient Health Questionnaire (Walsh et al., 2017). Regarding anxiety, Martinez and colleagues (2009) found 17% of their sample met criteria for generalized anxiety disorder. In a study of trauma and YLWH, 57% of participants reported symptoms of posttraumatic stress (Radcliffe et al., 2007). Of those who experienced receiving a diagnosis of HIV as traumatic (n = 30), 20% experienced posttraumatic stress symptoms and 13% met the DSM-IV criteria for PTSD. Regarding other traumatic events, 23% reported posttraumatic stress symptoms and another 23% met criteria for PTSD (Radcliffe et al., 2007). Overall, the percentages of reported symptoms of depression, anxiety, and PTSD found in this study are consistent with those in other studies of YLHW. Additionally, the percentages found in this current study as well as those in other studies are considerably higher than the average rates of depression, anxiety, and PTSD in the general population. Thus, these findings contribute to the literature suggesting the need for mental health prevention and intervention services for YLWH.

Participants in this study reported a similar number of traumatic experiences as those reported by Martinez and colleagues (2009). In the current study, only participants who reported symptoms of PTSD were asked to indicate the nature of the trauma. Forty-three percent of the sample (n = 57) reported at least one symptom of PTSD and there were missing data for nearly 50% of participants who endorsed symptoms. Of those who indicated the nature of their trauma (n = 29), 24.1% reported illness/injury (i.e., being diagnosed with HIV) as a traumatic event, 34.4% reported sexual assault, 24.1% physical trauma, 31% emotional trauma, and 27.6% other traumas. In a study of 174 inner-city YLWH ages 14-24 years, 18.8% reported physical abuse by

a sexual partner, 16.7% physical abuse as an adult, 24.3% physical abuse as a child, 14.5% sexual abuse as an adult, 27.8% sexual abuse as a child, 44.4% witnessed family violence while growing up, and nearly 30% witnessed someone get seriously injured or violently killed (Martinez et al., 2009). However, the number of traumatic events in the current study is less than that reported by Radcliffe and colleagues (2007). Out of 30 participants in this earlier study, 100% reported experiencing at least one traumatic event and 93% of participants reported that receiving a diagnosis of HIV was traumatic (Radcliffe et al., 2007). Furthermore, of those who experienced sexual abuse 100% reported it as traumatic, 100% of those who experienced being separated from a caregiver reported it as traumatic, 100% who reported emotional abuse experienced it as traumatic, and 94% who reported physical attack experienced it as traumatic (Radcliffe et al., 2007). There are several possible reasons for this discrepancy between studies. Unlike Radcliffe and colleagues (2007), in the current study only participants who reported symptoms of PTSD were asked to indicate the nature of the trauma. It is possible to have experienced a traumatic event without related posttraumatic stress symptoms. Radcliffe and colleagues (2007) as well as Martinez and colleagues (2009) gave participants a list of traumatic events and asked them to indicate whether they have experienced that event. Participants were then asked whether they perceived that event as traumatic (Radcliffe et al., 2007). As such, the way in which traumatic events were assessed was different in the current study. In addition the demographics of the samples were different. The current study utilized participants who were both behaviorally and perinatally infected with HIV. Behaviorally infected youth reported on average 1.27 symptoms of PTSD, whereas perinatally infected youth reported .85. This difference reached significance at the .10 alpha level. Other studies included participants who

were infected with HIV through unsafe sex (Radcliffe et al., 2007), thus they may be at higher risk for experiencing violence and trauma.

Age was a significant predictor for all psychological measures except PTSD -- being older was associated with an increase in anxiety and depressive symptoms. As YLWH grow older, they are required to manage more of their medical care as well as handle the typical developmental challenges associated with adolescence and young adulthood. Additionally, HIV disproportionately affects racial/ethnic and sexual minorities as well as the poor. As YLWH age, they may start to become more aware of the hardships they face. Another hypothesis for this finding is that individuals who are older could have a better understanding of HIV and thus experience more anxiety and depression surrounding their health status. Educational attainment also was a significant predictor of psychological measures. Findings regarding mental health and educational attainment are unclear. Sledjeski, Delahanty, and Bogart (2005) found that PTSD symptoms were not related to educational attainment in a sample of 69 adults living with HIV. In a longitudinal study of the general population (N = 5,001, age = 15-54 years), depression/ anxiety/PTSD were associated with a lower likelihood of graduating high school and also a lower likelihood of going to college (Mojtabai et al., 2015). Furthermore, evidence from the U.S. National Longitudinal Survey of Youth found that cumulative violence exposure was associated with a decreased likelihood of graduating high school (Boynton-Jarrett, Hair, & Zuckerman, 2013). A symptom of many mental health disorders is feeling detached from others and situations or losing interest in activities that were once pleasurable. One such activity that youth often lose interest in is school. The Youth Resilience Framework (Rew & Horner, 2003) identified aspects of the community that influence health outcomes in adolescence. School environment and school connectedness was one of the community influences. Resnick and

colleagues (1997) found that school connectedness was related to lower levels of maladaptive coping strategies (e.g., drinking alcohol) and high daily attendance at school was associated with positive behaviors such as engaging in sexual intercourse at a later age. As such, being connected to school and attending school has the possibility of decreasing one's likelihood of contracting HIV, by engaging in healthy behaviors.

Research question two. To what extent do youth and young adults with HIV ages 13-25 years demonstrate health literacy?

In the current study approximately 56% were unable to define CD4 count and 36% were unable to define viral load. A smaller proportion of 25% were unable to indicate whether CD4 count should go up or down as a result of treatment and 18% were unable to indicate whether viral load should go up or down as a result of treatment. Nearly one-third of participants were unable to name the medications they were currently taking to treat HIV. These percentages are significantly higher than those reported in other studies of adults living with HIV. Kalichman and colleagues (2000) reported 15.6% of participants (N = 294) did not know their CD4 count and 29% did not know their viral load, indicating the majority of participants knew their biological markers of immune functioning. To our knowledge this is the first study to report HIV-related knowledge of YLWH. These percentages point to the need for better patient education. One of the primary duties for nurses is to provide health promotion, counseling and education (American Nurses Association, 2017); however, the consistency of nurse education practices is unclear. The CDC (1995) set forth activities that should be included in effective Health Education and Risk Reduction programs. These activities included stating realistic, specific, measurable, and attainable goals and assuring that educational materials and messages are relevant, culturally competent, and language- and age-appropriate. In a study of 295

perinatally infected YLWH (Garvie et al., 2015), full scale IQ was calculated using the Wechsler Intelligence Scale for Children, 4th Edition (Wechsler, 2003). Average full scale IQ was 86.7 (Garvie et al., 2015) suggesting that YLWH may need additional supports and strategies to be able to learn information about their health condition.

Regarding Action scores, YLWH reported rates of adherence similar to the average adherence rates found in other studies (e.g., Simoni et al., 2007). Approximately 77% of participants reported taking their medications under all conditions. Although studies have found adherence rates to vary by assessment method (e.g., 82.6% for caregiver report, 60.9% for pharmacy refill report, and 76.1% for appointment maintenance data; Burack, Guar, Marone, & Petrova, 2010), there is consensus that overall adherence rates in the pediatric population are suboptimal (Simoni et al., 2007; Steele & Grauer, 2003; Vreeman, Wiehe, Pearce, Nyandiko, 2008). Kahana and colleagues (2013) conducted a meta-analysis of 37 studies measuring ART adherence and clinical outcomes in youth and young adults. The aggregate sample included 5,344 individuals who ranged in age from newborn to 25 years. The majority of studies involved individuals who were perinatally infected (78.38%), 16.22% of the studies were with individuals who were behaviorally infected, and 5.41% of the studies had a mixed sample. Overall 67.58% of the sample was treatment adherent and all of the studies used at least an 85% cut-off point to define adequate adherence. The rates found in this study are similar to those in other studies and suggest the need for future research to address the issue of nonadherence with YLWH.

Research question three. To what extent are health literacy and health outcomes (i.e., CD4 count and viral load) associated after controlling for demographic variables? For research question three, it was hypothesized that an increase in health literacy would be associated with an increase in CD4 count and an undetectable viral load.

Analyses supported the hypotheses: health literacy scores predicted CD4 count and whether participants had a detectable viral load, however the interaction was not significant. Although these findings are inconsistent with previous studies on health literacy and medication adherence in YLWH, this is likely due to the differences between the ways in which health literacy was measured. In a study of 186 YLWH ages 16 to 24 years who engaged in at least one at-risk behavior (e.g., unprotected sexual intercourse, problem level alcohol and/or drug use, nonadherence to medications), participants' health literacy was measured by the TOFHLA (Murphy et al., 2010). Findings indicated that health literacy was associated with neither CD4 count nor viral load. In another study with YLWH ages 13 to 24 years ($N = 50$), results indicated that scores on the TOFHLA and REALM-teen were not associated with self-reported adherence (Navarra et al., 2014). These two studies measured health literacy by an individual's ability to read health-related words. The current study used a measure of health literacy that assessed HIV-related knowledge as well as specific health-related behaviors. The Action subscale on the health literacy measure is similar to a measure of treatment adherence. Thus is would follow conceptually that those who report taking their medications under more conditions have better immune functioning than those who report taking their medications under fewer conditions.

The Action subscale was a significant predictor for health outcomes. The questions on the Action subtest are related to treatment adherence and whether the participant takes their medication under a variety of conditions. Conceptually, measures of treatment adherence should relate to biological markers of immune functioning. There are several different methods for assessing treatment adherence in YLWH including self-reported adherence, medication event monitoring systems, prescription refills, and biological markers (e.g., VL and CD4). A task force of Division 54 of the American Psychological Association (Quittner et al., 2008) developed

several recommendations for evidence-based assessment of adherence in a pediatric population. Recommendations included using at least two different assessment methods of adherence, assessing barriers to adherence, using treatment plans, and determining whether the patient has the knowledge and skills to carry out the treatment plan, among others (Quittner et al., 2008). One common measure of treatment adherence, and the one used at the clinic in which this study was conducted, is self-report. Patients are asked to estimate how many missed doses they have had in the past month and the nurses calculate a percentage for adherence. In addition to this method, the questions on the Action subtest can be used as another measure of treatment adherence in order to provide more than one assessment method. An added advantage of the Action subtest is that the questions also assess barriers to treatment adherence. If patients report not taking their medications because they are too tired or the medication makes them feel sick, the doctors and psychologists can work with the patient to overcome these barriers by changing their medication regimen when possible. Future research should determine the extent to which the questions on the Action subscale relate to other measures of treatment adherence for YLWH and determine its feasibility and reliability for use in a clinical setting.

The Knowledge subscale was not a significant predictor of health outcomes. Previous studies of youth with a variety of health conditions have found similar results. For example, researchers found no association between asthma knowledge and treatment adherence (Ho et al., 2003). Additionally, in Nutbeam's (2002) health promotion model, factors such as motivation, personal skills, and self-efficacy also were important for contributing to behavior change. Quittner and colleagues (2008) suggested that knowledge of the disease is not the important variable, but rather knowledge of the treatment regimen. The current study asked participants to answer questions about HIV in particular. Questions about when and how they are supposed to

perform treatments in addition to whether they have the appropriate skills to perform the actions may be better predictors of treatment adherence and immune functioning (Quittner et al., 2008). In a study of children and parents with cystic fibrosis, misconceptions about treatment regimen affected adherence (Modi & Quittner, 2006). Additionally, knowing how to use equipment such as an inhaler is an essential component to treatment adherence (Burkhart, Rayens, & Bowman, 2005). The Health Literacy and Resiliency Scale-Youth Version (Bradley-Klug et al., 2017) takes an approach to measuring health literacy by determining whether youth are able to make decisions based on their knowledge, an important aspect of the definition of health literacy (Ratzan & Parker, 2008). For example, questions include such items as "I get extra rest or 'take it easy' when needed for my health condition" and "I limit or modify my daily activities based on my body's symptoms." These questions require the individual to first understand their condition and their symptoms in order to make informed decisions for their health. Overall, disease-specific knowledge may not be sufficient to affect behavior change; however, assessing one's self-efficacy and how they make decisions based on their knowledge may be better indicators.

Research question four. To what extent are psychological symptoms and health outcomes (i.e., CD4 count and viral load) associated after controlling for demographic variables? For research question four, it was hypothesized that an increase in mental health symptoms would be associated with a decrease in CD4 count as well as a detectable viral load.

Results from multiple linear regression and logistic regression analyses did not support the hypothesis that an increase in mental health symptoms was associated with a decrease in CD4 count as well as a detectable viral load. There was, however, a significant interaction between mode of transmission and mental health symptoms such that participants who were perinatally infected with HIV experienced a decline in CD4 count as their mental health

symptoms increased. The same decline was not seen for participants with behaviorally acquired HIV. There are several possible explanations for these findings. In a review of the role of mental health symptoms (i.e., depression, stress, and trauma) in HIV disease progression, Leserman (2008) found consistent evidence that chronic depression, cumulative stress, and traumatic events were associated with increased disease progression. These findings are especially true in studies that are performed for a longer period of time (Leserman, 2008). In a longitudinal study of 618 YLWH between the ages of 12 months and 21 years (M = 6.4), having experienced at least one stressful life event was associated with an increased likelihood of immune suppression at week 52 (Howland et al., 2000). Leserman (2003) suggested a cascade of hormonal changes (e.g., increase in corticosteroids) in response to mental health symptoms that have the ability to impact HIV-disease progression. In addition to neuroimmunological changes, mental health symptoms may lead to a decrease in medication adherence, which in turn affects immune functioning (Howland et al., 2000). Due to the overall young age of the participants in this study, those who were behaviorally infected have been diagnosed with HIV for a shorter period of time than those who were perinatally infected. As such, it is possible that the participants who were behaviorally infected have not had the virus significantly long enough in order to begin to experience detrimental immune functioning as a result of mental health symptoms. However, for the participants who were perinatally infected, they have had the virus their entire life and thus there has been more time for mental health symptoms to impact immune functioning.

Another possible explanation is that the behaviorally infected participants have more chances for social support and receive more opportunities for mental health interventions. Male-to-male sexual contact was the number one transmission category in 2015 with 26,365 new diagnoses (CDC, 2017). There also were 1,202 new diagnoses in the transmission category of

male-to-male sexual contact *and* injection drug use (CDC, 2017). Heterosexual contact was the second leading transmission category with 9,339 new diagnoses in 2015 (CDC, 2017). Because of the high prevalence of HIV in the Lesbian, Gay, Bisexual, Transgender, and Questioning (LGBTQ) community, interventions to increase HIV awareness and support are often aimed at men who have sex with men and transgender persons (Rhodes et al., 2016) in order to reduce the public health impact of HIV. Thus, these interventions offer men, specifically men who have sex with men, an opportunity to receive support from each other to curtail the effects of mental health symptoms. In a study of social support for YLWH, behaviorally infected youth reported having more friends who knew their HIV status compared to perinatally infected youth (Abramowitz et al., 2009). Another possible explanation as to why those with behaviorally acquired HIV did not experience the same decline in CD4 count is that those with behaviorally acquired HIV may feel more of a personal responsibility for having HIV and will take the necessary measures manage their health. In a qualitative study regarding the disclosure process of HIV status to youth with perinatally acquired HIV, participants emphasized they let their child know it was not their fault, allowing the child to relinquish the need for taking personal responsibility for contracting HIV (Madiba, 2016). Furthermore, perinatally infected youth were more likely to have another person available to bring them to their medial appointments and were more likely to have someone else who would coordinate their care compared to behaviorally infected youth (Abramowitz et al., 2009), again suggesting that those who acquired HIV behaviorally have to take more responsibility for their health.

Models of Health Literacy

Nutbeam (2000) created an outcome model that suggested that health promotion actions can lead to outcomes such as increased health literacy and subsequently better health outcomes.

Manganello (2008) proposed a model for studying adolescent health literacy specifically, in which individual traits influence health literacy, which then influence health outcomes. At the systemic level are the influences of peers and media, as well as the educational and health care systems among others. However, the model does not include the influence of mental health symptoms, which researchers have found to be present at high rates in YLWH. Results from this study found that health literacy was associated with health outcomes as suggested by Nutbeam (2000) and Manganello (2008). Furthermore, this study contributed to models of health outcomes by suggesting that mental health is an important factor that needs to be considered in addition to health literacy.

Limitations of Study

This study is not without limitations. A main limitation of this study was that the data used for analyses were collected for clinical purposes and the research utility of the information collected was not of primary concern. Although several precautions were included in the clinical protocol to ensure fidelity of administration (i.e., training on administration), the screeners' primary purpose was that of clinical utility. In many cases participants had a long-standing relationship with the administrator of the screeners and certain biases could have been present. Participants may have not wanted to report significant symptoms as to not concern the administrator with the state of their mental health. Participants also are aware of the services available at the clinic and may have not disclosed mental health symptoms in order to avoid being referred to see a mental health professional. On the other hand, because of the rapport established with the patients, some of them may have been more willing to disclose information and thus increase the accuracy of the data.

When choosing measures to administer to an entire clinical population, issues such as ease of administration, number of questions, and time for administration are weighed against the reliability of the measures. As such, a limitation of this study is that the measures used for data collection were part of a clinical protocol and were chosen on that basis only. Some of the measures were originally created for adults and this study used them with youth and young adults. Although these specific measures have not been used with this population, the questions on these measures are typical of those asked of youth in a clinical setting and analyses indicated acceptable reliability for use with this sample.

The PI administered a portion of the questionnaires, which creates another limitation. In addition, although providers were trained on administering the questionnaires, the fidelity of administration remains unknown. The purpose of data collection was that of clinical utility. As such the rapid pace of the clinic and workload of the providers prohibited the ability of all providers to complete fidelity checklists after administration.

The sample used in this study consisted of YLWH from one geographic location. As such, the results of this study may not be representative of the larger YLWH population. The screeners in this study were self-report measures and participants may have given socially desirable responses. Although this is a limitation, self-report is the most common method for assessing mental health symptoms. Additionally, family members, significant others, or friends may have been present during administration due to the fact that these occurred during regular medical visits. In order to minimize the possibility of socially desirable responses, part of the clinical protocol was to ask the participant if they would like the individuals to leave the room during administration of measures due to their sensitive nature.

The sample size obtained in this study is another limitation. Despite the statistical implications (e.g., lack of power to detect significant differences), small sample sizes are common in studies with youth with chronic health conditions, especially in studies of YLWH. For example, the sample sizes for this population in studies of health literacy (i.e., Murphy et al., 2010; Navarra et al., 2014) were 50 and 186. Studies of the mental health of YLWH ranged from 30 (O'Cleirigh et al., 2008) to 230 (Rogers et al., 1998). However, it is important to note that studies with well over 100 participants were multi-site, grant-funded projects. Thus, the current study did not have the resources available to obtain such a large sample size. Additionally, there were structural changes to the clinic in which data were being collected that limited the collection of data beyond a total of 144 participants. Researchers have also been urged to use effect size as an important indicator of how much a treatment affects an individual instead of relying solely on *p* value (Sullivan & Feinn, 2012). Despite the limitation of having a small sample size, the overall sample size of 145 participants was considered adequate for this study and effect sizes were calculated to determine the magnitude of effect when results were not statistically significant.

Recommendations for Future Research

Given the rates of positive screeners for depression (35%), anxiety (26%), and PTSD (20%) reported in the current study as well as other studies examining YLWH, research needs to be conducted to determine the most optimal prevention and intervention strategies to use with YLWH. The demographics of the population, risk-factors associated with obtaining the virus, and importance of treatment adherence to long-term health are additional factors that need to be taken into consideration when developing interventions for this population.

One of the major limitations to this study that needs to be addressed by future research concerns the measures used. Although specifically recommended for primary care by the Substance Abuse and Mental Health Services Administration (SAMHSA, n.d.), the PC-PTSD was four questions in length and may not have provided enough variability in symptoms. Other studies on YLWH and PTSD have used checklists of traumatic events and more in-depth measures of posttraumatic stress symptoms such as the PTSD Checklist-Civilian version (Lang & Stein, 2005). Future research should consider using similar measures and methods as have been used in previous studies (e.g., Radcliffe et al., 2007) in order to determine the relationship between PTSD and health outcomes. In addition to PTSD, anxiety and depression were also measured in this study. Given the limited power of the current study coupled with small effect sizes, future research should continue to explore the relationship between mental health symptoms and health outcomes with larger samples. Additionally, future research needs to determine the directionality of the relationship between immune functioning and depression, anxiety, and PTSD. The current study was cross-sectional in nature and longitudinal studies need to be conducted to determine whether compromised immune functioning leads to depression and anxiety over time.

Measuring health literacy continues to be an area of research in its infancy. Future research should assess health literacy beyond that of disease-specific knowledge by asking whether individuals are able to make healthy decisions using their knowledge. The Health Literacy and Resiliency Scale- Youth Version (Bradley-Klug, et al., 2017) is a measure that holds potential for future research. In addition to measuring health literacy, future research needs to explore effective strategies for teaching YLWH HIV-related information as well as effective interventions to promote treatment adherence.

Additionally, future research should aim for larger sample sizes with more geographic diversity to better represent the population of YLWH. A larger, more diverse sample will also allow for more power to detect significant differences and will increase the external validity of the results.

Implications and Considerations for Practice

Causal relationships are beyond the scope of this study and all analyses should be considered exploratory. However, given the limited research in the area of YLWH the findings of the current study point to several considerations for behavioral health providers and school psychologists to take into account when working with YLWH.

In general there are several unique challenges for YLWH of which behavioral health providers and school psychologists should be aware and take into consideration when working with this population. The stigma associated with HIV serves as a barrier to HIV education, testing, treatment, and retention in care (Katz et al., 2013), is associated with poor medication adherence and an increase in risk-taking behavior (Mahajan, 2008), isolates families (Ji, Li, Lin, & Sun, 2007), and can lead to people scrutinizing, blaming, and expressing fear of contracting HIV (Stinnett, Cruce, & Choate, 2004). Clinicians need to be prepared to assess their own beliefs and be aware of their own biases and stigma when working with these youth. HIV disproportionately impacts racial/ethnic and sexual minority youth as well as the poor and school psychologists need to take these cultural factors into play when assessing and developing interventions for YLWH. Clinicians also need to be aware of laws and ethics in order to protect the confidentiality of YLWH. In the schools, the Family Educational Rights and Privacy Act (FERPA, 1974) protects the confidentiality of student records by requiring permission to release student records and only allowing individuals with a legitimate reason to know to view such

records. The Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104-191 (United States, 2004) protects patients' medical records and health information and requires an individual's HIV status be kept confidential.

The findings from the current study pointed to high rates of mental health symptoms in YLWH. As such, YLWH should be screened for mental health disorders, specifically depression, anxiety, and PTSD. It is recommended that youth over the age of 12 years be screened for mental health problems at patients' medical appointments, which occur every three months (Siu, 2016). By following an integrated care model in which psychologists and other behavioral health providers are present during medical visits, screening for mental health disorders can be part of the standard protocol of care. School psychologists can follow a similar protocol and screen for depression, anxiety, and PTSD in the school. Many schools provide regular screenings for their students (Doll, Cummings, & Chapla, 2014). Given the research suggesting high rates of mental health symptoms in this population, YLWH should receive more frequent screening for mental health disorders and high-risk behaviors and be given early intervention tailored to meet their individual needs (Chenneville, 2014). Choosing Life: Empowerment! Action! Results! (CLEAR) is a modularized intervention targeting YLWH ages 15 years and older who use substances (Lightfoot & Rotheram-Borus, 2007). Additionally, Healthy Choices (Naar-King et al., 2010) is a brief motivational interviewing protocol delivered to YLWH ages 15-24 years. Youth receiving the intervention had decreases in depression and growth in willingness to change (Naar-King et al., 2010). Health and Wellness Cognitive Behavior Therapy (Kennard et al., 2014) is a manualized intervention that focuses on reducing depression, increasing adherence, and promoting mental health in youth ages 16-24 years with comorbid HIV and depression.

Clinicians also should regularly monitor health literacy. Findings from the current study support the importance of health literacy in determining one's health outcomes. The Health Literacy and Resiliency Scale- Youth Version (Bradley-Klug et al., 2017) is a measure of health literacy that can be used to determine specific areas in which youth and young adults need additional intervention. The scale assesses one's ability to use information about their chronic health condition to make every day decisions. For example, the measure asks whether the patient understands the different ways his or her health impacts relationships with family and whether the patient knows what medications to take to manage his or her health condition. Depending on answers to items on this measure, education can be provided and interventions can be put in place to impact the patient's health literacy. This measure is diverse in that it can be implemented in a variety of settings including schools and specialty clinics. Additionally, the overall low rates of medication adherence point to the need for interventions to improve this aspect of treatment. In the educational research, the use of scoring scales and tracking student progress toward a goal is one of the most effective instructional strategies (Haystead & Marzano, 2009). Self-monitoring also is another intervention used throughout the applied behavioral analysis literature for changing behavior (Cooper, Heron, Heward, 2007). Clinicians can take a similar approach by having patients graph their medication use as well as their CD4 count and viral load. This will provide them with the visual feedback that when they take their medication their viral load goes down while their CD4 count goes up. Similarly, when they skip doses of their medication they will be able to see that their viral load went up and their CD4 count went down.

In collaboration with school nurses and other health providers, clinicians should provide HIV-related education and prevention to individuals with HIV in addition to the Tier I

comprehensive sexuality education provided to all students by schools (Chenneville, 2014). Comprehensive sexuality education programs should aim to promote health protective behaviors (e.g., condom use) and reduce sexual risk behaviors (e.g., number of sex partners) both of which can prevent the spread of HIV (Chin et al., 2012). In-the-Mix (Kalichman et al., 2011) is a seven-session intervention for health literacy in which participants learn about HIV. In addition, the intervention is based on the Conflict Theory of Decision Making (Janis & Mann, 1977) and participants learn to use a decisional balance and weigh the pros and cons of various scenarios (e.g., HIV disclosure, relationships, medication adherence). This program has been implemented at the USF Peds ID clinic and is also suitable for a school format.

Clinicians should aim to promote communication and collaboration between home, school, and medical providers (Grier & Bradley-Klug, 2011). The training school psychologists have received in consultation, problem-solving, intervention development, and evaluation of response to intervention place them in an ideal position to be the liaison between such systems. By bridging services across settings providers can better identify strengths and problems, analyze the problem and provide services, implement interventions, and evaluate interventions (Sheridan et al., 2009).

Although there are interventions tailored to meet the diverse needs of YLWH, youth and families are not required to disclose their own or their child's HIV status to the school. Largely due to the stigma associated with HIV, many families opt to keep the information private. As such, many YLWH are not provided the school services from which they might benefit. The push for integrated health care provides an ideal opportunity to provide services to youth in a non-stigmatizing setting. Universal screenings for mental health disorders help to identify individuals who are in need of more intensive and more frequent support than what is provided

to everyone (Doll, Cummings, & Chapla, 2014). Given the high rates of mental health disorders in YLWH, it is likely they would screen positive on a mental health screener given in the school setting. Interventions should focus on the needs the youth bring to the table and not only their HIV diagnosis (Chenneville, 2014). As such, even if the school interventions are not tailored specifically to YLWH, youth are still likely to benefit. Schools should also provide universal, school-based HIV stigma-reduction programs in order to decrease stigma and discrimination but also provide a safe place for YLWH to seek out help.

Conclusions

Although psychological measures were not significant predictors of health outcomes, there was an interaction between mode of transmission and scores on psychological measures. For perinatally infected youth, there was a significant decline in CD4 count as mental health symptoms increased. Age and educational attainment were consistently associated with viral load. Health literacy scores predicted whether participants had a detectable or undetectable viral load as well as their CD4 count. Participants' Action score was a significant predictor of CD4 count and viral load, whereas participants' Knowledge score was not.

In conclusion, this study is one of the first to explore how psychological symptoms and health literacy relate to biological markers of immune functioning. Furthermore, to our knowledge it is one of the first studies to explore HIV-related health literacy in YLWH. Overall findings suggest an overall high rate of mental health symptoms and the need for prevention and intervention in this area. Perinatally infected youth may be at greater risk for experiencing detrimental effects to their immune system as a result of mental health problems. Additionally, the low rates of health literacy found in this study can potentially inform educational efforts to promote accurate understanding and knowledge of HIV in youth and young adults.

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APPENDIX A:

SCREENING MANUAL

USF Pediatric Infectious Diseases Behavioral Health Assessment Guide

Table of Contents

How to Administer Mental Health Screeners

General Guidelines

1. Following the standard of care protocol established at the clinic, a trained behavioral health provider will screen for depression, anxiety, posttraumatic stress, substance use, and health literacy during patients' regularly scheduled medical appointments. This will occur at least once a year either as part of or independent of the psychosocial update.
2. The clinician will approach patients and tell them about the screening protocol being conducted at the clinic.
3. Patients will be given copies of each questionnaire (except the BEKHA-HIV) to follow along as the clinician reads each question to the patient or the patient can sit next to the clinician so they have clear view of the questionnaire.
4. The clinician will read the directions for each screener verbatim.
5. After administration, clinician will check for missing responses and obtain missing information to ensure all screeners are complete.
6. If the patient is confused about a particular item, clinician will provide clarification.
7. If, and only if, the clinician is 100% certain the patient can read and has adequate comprehension skills and the clinician is pressed for time, behavioral health screeners (except the BEHKA-HIV) can be completed by the patient.
    a. *Note: Often times patients may say they can read when they really cannot because they are too embarrassed to admit it. Even if a patient can read, they may have questions about what certain items mean. As such, it is best to administer the screeners verbally.*

Special Instructions for Completing the PC-PTSD

1. If the patient answers "Yes" to any of the items on the PC-PTSD, the experience to which the patient was referring should be documented
2. Often times the patient will not want to discuss the experience. If this is the case, the clinician will read off the list of traumatic experiences and ask the patient to choose one or more items.

Special Instructions for Completing the BEHKA-HIV

1. The BEHKA-HIV is the only screener that cannot be self-administered by the patient
2. The clinician will make a list of medications patient is taking prior to administering the questionnaire
3. The clinician will read all of the items verbally
4. The clinician will allow the patient to respond without assistance or prompting
5. The clinician will write down patient's responses verbatim

Special Instructions for Completing the CRAFFT

1. If patient answers "yes" to any questions in Part A, ask all 6 CRAFFT questions.
2. If patient answers "no" to all questions in Part A, only ask CAR question then stop.

How to Score Mental Health Screeners

Patient Health Questionnaire-9 and Patient Health Questionnaire- Adolescent (PHQ-9 or PHQ-A)

1. Add the total points for each of the columns 2-4 separately (Column 1 = Several days; Column 2 = More than half the days; Column 3 = Nearly every day) .
2. Add the totals for each of the three columns together. This is the Total Score.
3. Scores can range from 0-27 and should be entered next to the Total Score box.
4. At the bottom of the screener, clinician should circle *Positive* or *Negative* to indicate whether the patient scored positive or negative on the screener for depression (scoring guidelines on positive and negative screeners are found later in this document [page 7]).
5. Clinician should circle *Yes* or *No* under the CI category to indicate whether a Clinical Interview for depression was conducted.
6. If a clinical interview was conducted, the date, diagnosis, and follow-up action plan option should be entered at the bottom of the form (more detailed instructions on clinical interviewing can be found later in this document [page 7]).

Center for Epidemiological Studies-Depression (CES-D)

1. Each item is given a number (0-3).
2. Add the total points for each item. ***Note***: Some items are reversed scored (i.e., Rarely = 3, Some or a little of the time = 2, Occasionally or a moderate amount of time = 1, All of the time = 0). Retain the reverse scoring when adding up the totals.
3. Scores can range from 0-60 and should be entered in the Total Score box at the bottom of the screener.
4. At the bottom of the screener, clinician should circle *Positive* or *Negative* to indicate whether the patient scored positive or negative on the screener for depression (scoring guidelines on positive and negative screeners are found later in this document [page 7]).
5. Clinician should circle *Yes* or *No* under the CI category to indicate whether a Clinical Interview for depression was conducted.
6. If a clinical interview was conducted, the date, diagnosis, and follow-up action plan option should be entered at the bottom of the form (more detailed instructions on clinical interviewing can be found later in this document [page 7]).

Generalized Anxiety Disorder- 7 item Scale (GAD-7)

1. Add the total points for each of the columns 2-4 separately (Column 1 = Several days; Column 2 = More than half the days; Column 3 = Nearly every day).
2. Add the totals for each of the three columns together. This is the Total Score.
3. Scores can range from 0-21 and should be entered next to *Total Score*.
4. At the bottom of the screener, clinician should circle *Positive* or *Negative* to indicate whether the patient scored positive or negative on the screener for anxiety (scoring guidelines on positive and negative screeners are found later in this document [page 7]).
5. Clinician should circle *Yes* or *No* under the CI category to indicate whether a Clinical Interview for anxiety was conducted.
6. If a clinical interview was conducted, the date, diagnosis, and follow-up action plan option should be entered at the bottom of the form (more detailed instructions on clinical interviewing can be found later in this document [page 7]).

Primary Care PTSD Screen (PC-PTSD)

1. Add up the number of items scored as "Yes" (1 point) and write it next to *Total Yes.*
2. Add up the number of items scored as "No" and write it next to *Total No.*
3. The total score is the number of "Yes" responses.
4. Scores can range from 0-4.
5. At the bottom of the screener, clinician should circle *Positive* or *Negative* to indicate whether the patient scored positive or negative on the screener for PTSD (scoring guidelines on positive and negative screeners are found later in this document [page 7]).
6. Clinician should circle "Yes" or "No" under the CI category to indicate whether a Clinical Interview for PTSD was conducted.
7. If a clinical interview was conducted, the date, diagnosis, and follow-up action plan option should be entered at the bottom of the form (more detailed instructions on clinical interviewing can be found later in this document [page 7]).

Brief Estimate of Health Knowledge and Action- HIV Version (BEHKA-HIV)

1. Add up the total number of correct items for the Knowledge subtest and write it next to *Knowledge Score.*
2. Add up the total number of "Disagree" items for the Action subtest and write it next to *Action Score.*
3. Add the Knowledge and Action scores to obtain the Total Score and write it next to *Total Score.*
4. Scores can range from 0-10 and should entered next to *Total Score* at the bottom of the screener.

CRAFFT

1. Add up the number of items scored as "Yes" (1 point) in Part B and write it next to *Total.*
2. Scores can range from 0-6.
3. At the bottom of the screener, clinician should circle *Positive* or *Negative* to indicate whether the patient scored positive or negative on the screener for substance use (scoring guidelines on positive and negative screeners are found later in this document [page 7]).
4. Clinician should circle "Yes" or "No" under the Referral category to indicate whether a referral to a substance abuse counselor or program was made.

Documentation of Mental Health Screeners

- **Text of EPIC note**: For ease of creating an EPIC note, a screener SmartNote can be found under the name *.amwscreener*. If only screeners were conducted and a referral for a clinical interview was made, the note can be found under *.amwscreenerreferal*. A clinical interview SmartNote can be found under *.amwdepression, .amwanxiety,* and *.amwptsd* for depression, anxiety, and PTSD, respectively. Any information the clinician finds relevant can also be entered into the body of the note. Notes documenting screeners and clinical interviews should ***always*** be routed to Audra Walsh. When screeners are positive and/or a diagnosis is made, providers should also be routed the note.
- **Doc Flow Sheet**: Raw scores entered into doc flowsheet of epic so that symptom endorsement can be monitored over time.
- **CAREware Data Entry**:
  - If you are licensed SW or Psych (or supervised by a licensed provider) **AND** the patient meets DSM-5 criteria then this should be documented on the 1) Annual MH screen and on the 2) services tab under Mental Health Assessment/Services (any future MH services for this patient should be documented under tabs labeled with 'Dx').
  - If you are licensed SW or Psych (or supervised by a licensed provider) **AND** the patient **DOES NOT** meet DSM-5 criteria then this should be documented on the 1) Annual MH screen and on the 2) services tab under Psychosocial Services.
  - If you are not licensed, then this should be documented on the 1) Annual MH screen and on the 2) services tab under Psychosocial Services.
- **Problem List in EPIC:**
  - Go to patient's chart and click "Snapshot" on the left-hand side.
  - Click "Problem List" on the left-hand side.
  - Type in diagnosis under "Add a new problem," then click "Add."
  - Answer questions about specifiers if needed.
  - Click "Accept."

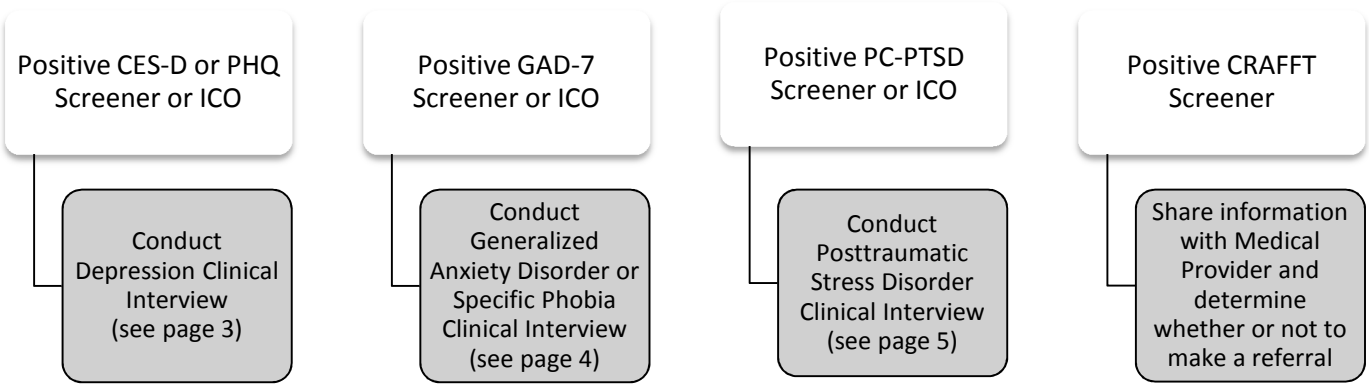
Hard copy protocols will be given to Alex Cario (by the last day of each month), team member designated to enter data into Bx Health clinical database

Pediatric Infectious Diseases Behavioral Health Clinical Interview

When to Conduct a Clinical Interview:

If a patient screens positive on a screener then a clinical interview is to be conducted to determine whether the patient meets DSM-5 diagnostic criteria for that disorder. For example, if a patient screens positive on the GAD-7 but negative on all other screeners then *only* a clinical interview for Generalized Anxiety Disorder needs to be conducted. However, if a patient screens negative on a screener but clinical symptoms are reported or observed by clinician, informed clinical opinion can be used to decide whether to conduct a clinical interview. Clinical interviews must be conducted by licensed mental health professionals (LCSW or Licensed Psychologist), a trained medical provider, or a clinician working under a licensed provider's direct supervision. All positive screens must be reported to the medical provider AND the mental health professional conducting the clinical interview on the day the positive screen is obtained before the client is discharged from clinic. The scores for a positive screen for each measure are below.

Screener	Positive Screen Score
PC-PTSD	≥3
GAD-7	≥10
CES-D	Adult ≥ 16, Adolescent ≥ 24
PHQ-9 and PHQ-A	≥10
CRAFFT	≥2



How to Conduct a Clinical Interview:

The purpose of a conducting clinical interview is to gather information enabling the clinician to determine a mental health diagnosis. The diagnosis sets up a treatment plan, which is expressed by treatment interventions. The results of the interventions are continually assessed as to whether or not client symptoms are reduced or relieved.

Clinician should ask the patient the questions in italics on the following pages. When people present for the first time, they usually have a story to tell. The clinician may have to redirect the client, in order to stay focused and complete the assessment. Of course, managing the client in this way is best done with respect and cultural sensitivity. Transitional sentences can be used. For example:

"I understand (clinician paraphrases what client had just said), and I wanted to get back to a few questions I have to ask you."

"I can see that is important to you. As soon as I'm finished with a few more of my regular questions, I'd like to return to what you just mentioned."

Clinical Interview for Depressive Disorders *(Positive screen on PHQ or CES-D or ICO)*

Screening questions: *Have you been feeling sad, blue, down, depressed, or irritable? Have you lost interest in, or do you get less pleasure from, the things you used to enjoy?*

If yes, ask: *Did these times ever last at least 2 weeks? Did these periods ever cause you significant trouble with your friends or family, at work, or in another setting?*

- If yes, proceed to major depressive disorder criteria.

1. Major Depressive Disorder, Single and Recurrent Episodes
    a. Inclusion: Requires the presence of at least five of the following symptoms, which must include either depressed mood or lost of interest or pleasure, during the same 2-week episode.
        i. Depressed mood most of the day (already assessed)
        ii. Markedly diminished interest in activities or pleasures (already assessed)
        iii. Significant weight loss or gain: *During that period, did you notice any change in your appetite? Did you notice any change in your weight?*
        iv. Insomnia or hypersomnia: *During that period, how much and how well were you sleeping?*
        v. Psychomotor agitation or retardation: *During that period, did anyone tell you that you seemed to move faster or slower than usual?*
        vi. Fatigue or loss of energy: *During that period, what was your energy level like? Did anyone tell you that you seemed worn down or less energetic than usual?*
        vii. Feelings of worthlessness or excessive guilt: *During that period, did you feel tremendous regret or guilt about current or past events or relationships?*
        viii. Diminished concentration: *During that period, were you unable to make decisions or concentrate like you usually do?*
        ix. Recurrent thoughts or death or suicide: *During that period, did you think about death more than you usually do? Have you thought about hurting yourself or taking your own life?*
    b. Exclusion: If there has ever been a manic episode or a hypomanic episode, or the major depressive episode is attributable to the physiological effects of a substance or to another medical condition, the diagnosis is not given.
    c. Exclusion: If the major depressive episode is better explained by schizoaffective disorder, schizophrenia, schizophreniform disorder, delusional disorder, or other specified or unspecified schizophrenia spectrum and other psychotic disorder, the diagnosis is not given.

ICD-10 Diagnostic codes

Major Depressive Disorder, Single episode, Mild (F32.0)
Major Depressive Disorder, Single episode, Moderate (F32.1)
Major Depressive Disorder, Single episode, Severe (F32.2)
Major Depressive Disorder, Single episode, With psychotic features (F32.3)
Major Depressive Disorder, Single episode, In partial remission (F32.4)
Major Depressive Disorder, Single episode, In full remission (F32.5)
Major Depressive Disorder, Single episode, Unspecified (F32.9)
Major Depressive Disorder, Recurrent episode, Mild (F33.0)
Major Depressive Disorder, Recurrent episode, Moderate (F33.1)
Major Depressive Disorder, Recurrent episode, Severe (F33.2)
Major Depressive Disorder, Recurrent episode, With psychotic features (F33.3)
Major Depressive Disorder, Recurrent episode, In partial remission (F33.41)
Major Depressive Disorder, Recurrent episode, In full remission (F33.42)
Major Depressive Disorder, Recurrent episode, Unspecified (F33.9)

Clinical Interview for Anxiety Disorders *(Positive screen on GAD-7 or ICO)*

Screening question: *During the past several months, have you frequently been worried about a number of things in your life? Is it hard for you to control or stop your worrying? A panic attack is a sudden rush of intense fear or anxiety that comes on from out of the blue for no apparent reason, or in situations where you did not expect it to occur. Have you experienced recurrent panic attacks? Do these experiences ever cause you significant trouble with your friends or family, at work, or in another setting?*

If yes, ask: *Can you identify specific objects, places, or social situations that make you feel very anxious or tearful?*

- If a specific phobia is elicited, proceed to specific phobia disorder criteria.
- If no, first proceed to panic disorder criteria. Then proceed to generalized anxiety disorder criteria.

1. Specific Phobia
    a. Inclusion: Requires that for at least 6 months, a person has experienced marked fear, anxiety, or avoidance as characterized by the following three symptoms.
        i. Specific fear: *Do you fear a specific object or situation such as flying, heights, animals, or something else so much that being exp*
        ii. Fear or anxiety provoked by exposure: *When you encounter this, do you experience an immediate sense of fear or anxiety?* For children, ask, *When you encounter this, do you cry, experience tantrums, or hold on to a parent?*
        iii. Avoidance: *Do you find yourself taking osed to it makes you feel immediately afraid or anxious? What is it?steps to avoid this? What are they? When do you have to encounter this, do you experience intense fear or anxiety?*
    b. Exclusion: The fear, anxiety, and avoidance are not restricted to objects or situations related to obsessions, reminders of traumatic events, separation from home or attachment figures, or social situations.
2. Generalized Anxiety Disorder
    a. Inclusion: Requires excessive anxiety and worry that is difficult to control, occurring more days than not for at least 6 months, about a number of events or activities, associated with at least three of the following symptoms.
        i. Restlessness: *When you think about events or activities that make you anxious or worried, do you often feel restless, on edge, or keyed up?*
        ii. Easily fatigued: *Do you find that you often tire or fatigue easily?*
        iii. Difficulty concentrating: *When you are anxious or worried, do you often find it hard to concentrate or find that your mind goes blank?*
        iv. Irritability: *When you are anxious or worried, do you often feel irritable or easily annoyed?*
        v. Muscle tension: *When you are anxious or worried, do you often experience muscle tightness or tension?*
        vi. Sleep disturbance: *Do you find it difficult to fall asleep or stay asleep, or experience restless and unsatisfying sleep?*
    b. Exclusion: If the anxiety and worry are better explained by another mental disorder or are attributable to the physiological effect of a substance/medication or another medical condition, do not make the diagnosis. *****If patient also meets criteria for PTSD, diagnosis of PTSD is used instead of Generalized Anxiety Disorder*****

ICD-10 Diagnostic codes
Generalized Anxiety Disorder (F41.1)
Specific Phobia: Animal (F40.218), Natural Environment (F40.228), Fear of blood (F40.230), Fear of injections and transfusions (F40.231), Fear of other medical care (F40.232), Fear of injury (F40.233), Situational (F40.248), Other (F40.298)

Clinical Interview for Trauma and Stressor-Related Disorders *(Positive screen on PC-PTSD or ICO)*

Screening questions: *What is the worst thing that has ever happened to you? Have you ever experienced or witnessed an event in which you were seriously injured or your life was in danger, or you thought you were going to be seriously injured or endangered?*

If yes, ask: *Do you think about or reexperience these events? Does thinking about these experiences ever cause you significant trouble with your friends or family, at work, or in another setting?*

- If yes, proceed to posttraumatic stress disorder criteria.
- If a child says no but his family or caregivers report disturbances in his primary attachments, proceed to reactive attachment disorder criteria.

1. Posttraumatic Stress Disorder
    a. Inclusion: Requires exposure to actual or threatened death, serious injury, or sexual violation. The exposure can be firsthand or witnessed. In addition, a person must experience at least one of the following intrusion symptoms for at least 1 month after the traumatic experience.
        i. Memories: *After that experience, did you ever experience intrusive memories of the experience when you did not want to think about it?* For children, repetitive reenactment through play qualifies. *Do you repeatedly reenact that experience with your toys or dolls or when playing?*
        ii. Dreams: *Did you have recurrent, distressing dreams related to the experience?* For children, frightening dreams without recognizable content qualifies. *Do you frequently have very frightening dreams that you cannot recall or describe?*
        iii. Flashbacks: *After that experience, did you ever feel like it was happening to you again, like in a flashback where the event is happening again?* For children, this may be observed in their play.
        iv. Exposure distress: *When you are around people, places, and objects that remind you of that experience, do you feel intense or prolonged distress?*
        v. Physiological reactions: *When you think about or are around people, places, and objects that remind you of that experience, do you have distressing physical responses?*

    b. Inclusion: In addition, a person must experience at least one of the following avoidance symptoms for at least 1 month after the traumatic experience.
        i. Internal reminders: *Do you work hard to avoid thoughts, feelings, or physical sensations that bring up memories of this experience?*
        ii. External reminders: *Do you work hard to avoid people, places, and objects that bring up memories of this experience?*

    c. Inclusion: In addition, a person must experience at least two of the following negative symptoms for at least 1 month.
        i. Impaired memory: *Do you have trouble remembering important parts of the experience?*
        ii. Negative self-image: *Do you frequently think negative thoughts about yourself, other people, or the world?*
        iii. Blame: *Do you frequently blame yourself or others for your experience, even when you know that you or they were not responsible?*
        iv. Negative emotional state: *Do you stay down, angry, ashamed, or fearful most of the time?*
        v. Decreased participation: *Are you much less interested in activities in which you used to participate?*
        vi. Detachment: *Do you feel detached or estranged from the people in your life because of this experience?*
        vii. Inability to experience positive emotions: *Do you find that you cannot feel happy, loved, or satisfied? Do you feel numb, or like you cannot love?*

Trauma and Stressor-Related Disorders (continued)

    d. Inclusion: In addition, a person must experience at least two of the following arousal behaviors.

i. Irritable or aggressive: *Do you often act very grumpy or get aggressive?*
ii. Reckless: *Do you often act reckless or self-destructive?*
iii. Hypervigilance: *Are you always on edge or keyed up?*
iv. Exaggerated startle: *Do you startle easily?*
v. Impaired concentration: *Do you often have trouble concentrating on a task or problem?*
vi. Sleep disturbance: *Do you often have difficulty falling asleep or staying asleep, or do you often wake up without feeling rested?*

e. Exclusion: The episode is not directly caused by a substance or by another medical condition

f. Modifiers
   i. Subtypes
      - With dissociative symptoms, either depersonalization or derealization
      - Posttraumatic stress disorder for children 6 years and younger: Reserved for children under age 6 years who experienced trauma themselves, witnessed trauma, or learned of trauma experienced by a parent or other caregiver
   ii. Specifiers
      - With delayed expression: Use if a person does not exhibit all the diagnostic criteria until at least 6 months after the traumatic experience.

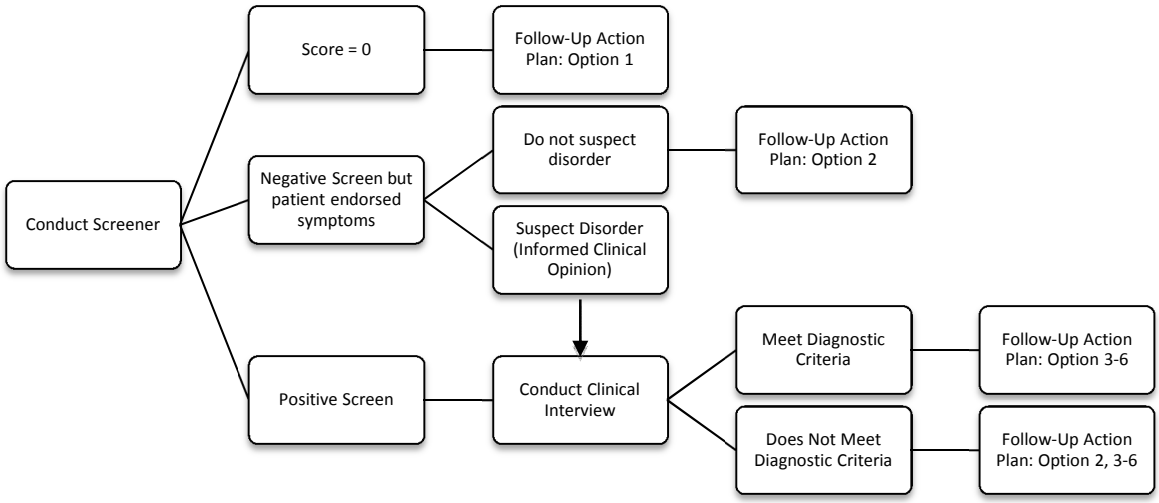
ICD-10 Diagnostic codes
Posttraumatic Stress Disorder (F43.10)

Follow-Up Procedures

Regardless of whether the patient meets diagnostic criteria, the scope of psychological services available through USF Peds ID should be described to the patient. If the patient meets diagnostic criteria, if your clinical judgment deems it useful, or if the patient is interested, try to schedule an initial intake assessment with the patient for therapy. Use your clinical judgment to determine the appropriate follow-up action below. The follow-up action plan option should be entered at the bottom of each screener.

Follow-up Action Options (Therapy):

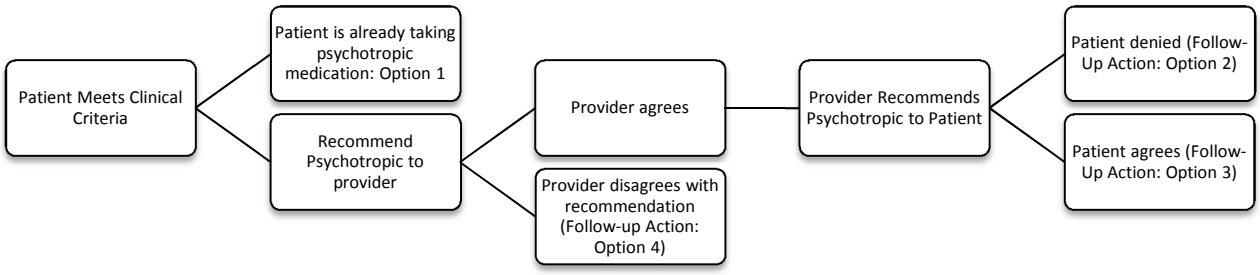
1. None
2. Watchful waiting; repeat screener at follow-up
3. Recommended behavioral health treatment (counseling, therapy) but client denied need for services.
4. Recommended behavioral health treatment and set up an initial counseling appointment
5. Currently in treatment for mental/behavioral health through USF Peds ID clinic
6. Currently in treatment for mental/behavioral health through an outside agency



If the patient meets diagnostic criteria, a referral for psychotropic medication consideration should be given to the Medical Provider for them to decide whether initiation of psychotropic medication is necessary. Follow-up actions are described below. The follow-up action plan option must be entered at the bottom of each screener.

Follow-up Action Options (Psychotropic Treatment):

1. Patient already being treated with psychotropic medication
2. Behavioral Health Clinician recommended psychotropic treatment to Medical Provider, Medical Provider recommended to patient, and patient denied
3. Behavioral Health Clinician recommended psychotropic treatment to Medical Provider, Medical Provider recommended to patient, and patient initiated treatment
4. Behavioral Health Clinician recommended psychotropic treatment to Medical Provider and Medical Provider did not recommend treatment to patient



Completing Demographic Form

In addition to the screeners, a Demographics Form needs to be completed once a year as part of the patient's annual psychosocial update. The information obtained on the demographics form can be gleaned from the annual psychosocial update and/or additional follow-up questioning if necessary. On the demographics form, answers should be clearly circled. Where indicated, additional data should be entered into the blank space (e.g., age). If follow-up is provided at the patient's subsequent medical appointment due to mental health concerns, another Demographics Form ***does not*** need to be completed.

Patient: _____ Clinician: _____
MRN: _____
Date: _____

Patient Health Questionnaire-Adolescent Version (PHQ-A)

How often have you been bothered by each of the following symptoms during the past **7 days**? For each symptom circle the number under the answer that best describes how you have been feeling.	Not at all	Several Days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, irritable, or hopeless	0	1	2	3
3. Trouble falling, staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite, weight loss, or overeating	0	1	2	3
6. Feeling bad about yourself-or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things like school work, reading, or watching TV	0	1	2	3
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	0	1	2	3
9. Thoughts that you would be better off dead or hurting yourself in some way	0	1	2	3
Add the score for each column	0 +	+	+	
Total Score (*add your column scores)* =				

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

Not difficult at all _____
Somewhat difficult _____
Very difficult _____
Extremely difficult _____

For clinician use only: Positive screen ≥10, or endorsing item 9

Screen: POSITIVE NEGATIVE

CI: YES NO Date of CI: _____

Dx: _____ Follow-up Action Therapy (1-6): _____

Follow-Up Action Psychotropic Treatment (1-4):_____

Patient: _____ Clinician: _____
MRN: _____
Date: _____

Patient Health Questionnaire-9 (PHQ-9)

Over the last 2 weeks, how often have you been bothered by the following problems?	Not at all	Several Days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself-or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
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	0	1	2	3
9. Thoughts that you would be better off dead or hurting yourself in some way	0	1	2	3
Add the score for each column	0 +	+	+	
Total Score (*add your column scores)* =				

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

Not difficult at all _____
Somewhat difficult _____
Very difficult _____
Extremely difficult _____

For clinician use only: Positive screen ≥10, or endorsing item 9

Screen: POSITIVE NEGATIVE

CI: YES NO Date of CI: _____

Dx: _____ Follow-up Action Therapy (1-6): _____

Follow-Up Action Psychotropic Treatment (1-4):_____

Patient: _____ Clinician: _____
MRN: _____
Date: _____

The Generalized Anxiety Disorder 7-Item Scale

Over the last 2 weeks, how often have you been bothered by the following problems?	Not at all	Several Days	Over half the days	Nearly every day
1. Feeling nervous, anxious, or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it's hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3
Add the score for each column		+	+	+
Total Score (*add your column scores)* =				

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

Not difficult at all _____
Somewhat difficult _____
Very difficult _____
Extremely difficult _____

For clinician use only: Positive screen = ≥10

Screen: POSITIVE NEGATIVE

CI: YES NO Date of CI: _____

Dx: _____ Follow-up Action Therapy (1-6): _____

Follow-Up Action Psychotropic Treatment (1-4):_____

Patient: _____ Clinician: _____
MRN: _____
Date: _____

Primary Care PTSD Screen (PC-PTSD)

Instructions:
Read the sentence below and answer the following questions by circling either YES or NO.

In your life, have you ever had any experience that was so frightening, horrible, or upsetting that, in the past month, you:

1. Have had nightmares about it or thought about it when you did not want to?
YES **NO**

2. Tried hard not to think about it or went out of your way to avoid situations that reminded you of it?
YES **NO**

3. Were constantly on guard, watchful, or easily startled?
YES **NO**

4. Felt numb or detached from others, activities, or your surroundings?
YES **NO**

Total Yes: _____ *Total No*: _____

If you answered YES to any of the above questions please circle the experience you were referring to:

1. Illness/injury (HIV diagnosis, hospitalization)
2. Sexual trauma (sexual assault/abuse)
3. Physical trauma (victim or witness to physical abuse)
4. Emotional trauma (victim or witness to emotional violence)
5. Other (please describe): _____

For clinician use only: Positive screen = ≥3

Screen: POSITIVE NEGATIVE

CI: YES NO Date of CI: _____

Dx: _____ Follow-up Action Therapy (1-6): _____

Follow-Up Action Psychotropic Treatment (1-4):_____

Patient: _____ Clinician: _____
MRN: _____
Date: _____

The Brief Estimate of Health Knowledge and Action – HIV (BEHKA-HIV)

Part 1: *Knowledge* – "We would like to know if patients are familiar with two HIV terms: a CD4 count and viral load. Would you mind if I ask you a few questions about that?"

1a. What is a CD4 count or T-cells? (write verbatim response)
CORRECT (1) INCORRECT (0)

1b. Is the goal of treatment (taking your medication and coming to appointments) to make the CD4 count or T-cells go up or down?
UP (1) DOWN (0)

2a. What is a viral load? (write verbatim response)
CORRECT (1) INCORRECT (0)

2b. Is the goal of treatment to make the viral load go up or down?
UP (0) DOWN (1)

3. What medicines are you currently taking to treat HIV? (write response)
Respondent must identify all medications in HAART regimen to be correct
CORRECT (1) INCORRECT (0) DON'T KNOW (0)

Knowledge Score:_____*(total possible 5)*

Part 2: *Action* – "Please tell me if you agree, are not sure, or disagree with these 5 statements."

1. I don't take my medicines when they make me feel bad
AGREE (0) NOT SURE (0) DISAGREE (1)

2. I don't take my medicines when I am too tired
AGREE (0) NOT SURE (0) DISAGREE (1)

3. I don't take my medicines when I am feeling down or low
AGREE (0) NOT SURE (0) DISAGREE (1)

4. I don't take my medicines because they taste bad
AGREE (0) NOT SURE (0) DISAGREE (1)

5. I don't take my medicines when I feel good
AGREE (0) NOT SURE (0) DISAGREE (1)

Action Score:_____ *(total possible 5)* **Total Score:** _____

Patient: _____ Clinician: _____
MRN: _____
Date: _____

The CRAFFT Screening Tool for Adolescent Substance Abuse

The following questions concern information about your potential involvement with alcohol and other drugs during the past 12 months. Carefully read each question and decide if your answer is "YES" or "NO". Then mark in the appropriate box beside the question. Please answer every question. If you cannot decide, then choose the response that is mostly right.

When the word "drug" is used, it refers to the use of prescribed or over-the-counter drugs that are used in excess of the directions and any non-medical use of drugs. The various classes of drugs may include but are not limited to: cannabis (e.g., marijuana, hash), solvents (e.g., gas, paints etc…), tranquilizers (e.g., Valium), barbiturates, cocaine, and stimulants (e.g., speed), hallucinogens (e.g., LSD) or narcotics (e.g., Heroin, Oxycontin).

Part A

During the PAST 12 MONTHS, did you:	**No**	**Yes**
1. Drink any alcohol (more than a few sips)? (Do not count a few sips of alcohol taken during family or religious events)	☐	☐
2. Smoke any marijuana or hashish?	☐	☐
3. Use anything else to get high? ("anything else" includes illegal drugs, synthetic marijuana, over-the-counter and prescription drugs, or things that people sniff or "huff")	☐	☐

Part B: CRAFFT	**No**	**Yes**
1. Have you ever ridden in a **CAR** driven by someone (including yourself) who was "high" or had been using alcohol or drugs?	☐	☐
2. Do you ever use alcohol or drugs to **RELAX**, feel better about yourself, or fit in?	☐	☐
3. Do you ever use alcohol or drugs while you are by yourself, or **ALONE**?	☐	☐
4. Do you ever **FORGET** things you did while using alcohol or drugs?	☐	☐
5. Do your **FAMILY** or **FRIENDS** ever tell you that you should cut down on your drinking or drug use?	☐	☐
6. Have you ever gotten into **TROUBLE** while you were using alcohol or drugs?	☐	☐

Total: _____

For clinician use only: Positive screen = ≥2
Screen: POSITIVE NEGATIVE Referral Made: YES NO

Name:_____ MR#_____

Date_____

Assigned SW/CM (circle one): TSWTCM SPSW

Type:
(1) Annual
(2) Follow-up

Location:
(1) ACH
(2) CMS
(3) YYC
(4) Satellite

Gender:
(0) Male
(1) Female
(2) Other

Age: _____

Race:
(1) African American/black
(2) White
(3) American Indian/native Alaskan
(4) Asian
(5) Hawaiian/pacific islander
(6) Other

Ethnicity:
(0) Hispanic
(1) Non-Hispanic

Transmission:
(0) Perinatal
Age of disclosure:_____
(1) Behavioral
Age of diagnosis:_____
Date of diagnosis (if known):_____

Sexual Orientation:
(1) Heterosexual
(2) Homosexual
(3) Bisexual
(4) Questioning
(5) Other

Substance Use Reported:
(0) No
(1) Yes

Main Source of Transportation:
(0) Personal vehicle
(1) Public Transit

Ever Kicked out of Family Home
(0) No
(1) Yes

Ever Paid for Sex
(0) No
(1) Yes

Educational Attainment:
(1) Elementary School
(2) Middle School
(3) Some High School
(4) High School degree
(5) High School Equivalency
(6) Some College, no degree
(7) Associate's Degree
(8) Bachelor's Degree
(9) Advanced Degree

Current Employment Status:
(0) Unemployed, not looking
(1) Unemployed, looking
(2) Employed part-time
(3) Employed full-time
(4) Student

Living Situation:
(0) Alone
(1) Spouse
(2) Parent(s)
(3) Sibling(s)
(4) Child/Children
(5) Other relatives
(6) Roommate(s) or Friend(s)
(7) Significant Other
(8) Other residents (group living situation)
(9) Correctional Facility
(10) Homeless

Number of Partners in the Past Month: _____

Condomless Sex in the Past Month
(0) No
(1) Yes

History of Positive STI Tests
(0) No
(1) Yes
Names of
STIs:_____

Received Mental Health Counseling
(0) Never
(1) In the past
(2) Currently

Taken Psychotropic Medications
(0) Never
(1) In the past
Names:_____
(2) Currently
Names:_____

APPENDIX B:

INSTITUTIONAL REVIEW BOARD LETTER OF RESEARCH DETERMINATION

USF
UNIVERSITY OF
SOUTH FLORIDA

RESEARCH INTEGRITY AND COMPLIANCE
Institutional Review Boards, FWA No. 00001669
12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799
(813) 974-5638 • FAX(813)974-7091

11/8/2016

Audra Walsh, PhD.
Educational and Psychological Studies
1039 Park St N
St. Petersburg , FL 33710

RE: **Not Human Subjects Research Determination**
IRB#: Pro00028131
Title: Evaluating Effectiveness of a Universal Psychological Screening Program among Youth with HIV

Dear Dr. Walsh:

The Institutional Review Board (IRB) has reviewed your application and determined the activities do not meet the definition of human subjects research. Therefore, this project is not under the purview of the USF IRB and approval is not required. If the scope of your project changes in the future, please contact the IRB for further guidance.

All research activities, regardless of the level of IRB oversight, must be conducted in a manner that is consistent with the ethical principles of your profession. Please note that there may be requirements under the HIPAA Privacy Rule that apply to the information/data you will utilize. For further information, please contact a HIPAA Program administrator at 813-974-5638.

We appreciate your dedication to the ethical conduct of research at the University of South Florida. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

V Jorgensen MD

E. Verena Jorgensen, M.D., Chairperson
USF Institutional Review Board

APPENDIX C:

MULTIPLE REGRESSION ANALYSES

Summary of Multiple Regressions of Psychological Measures and Health Literacy with Demographic Variables as Predictors

Variable	CES-D		GAD-7		PC-PTSD		BEHKA-Knowledge		BEHKA-Action	
	n = 102		*n* = 144		*n* = 131		*n* = 101		*n* = 101	
	B (SE)	*Beta*	*B (SE)*	*Beta*	*B (SE)*	*Beta*	*B (SE)*	*Beta*	*B (SE)*	*Beta*
Age	1.10 (.50)	.25*	.48 (.18)	.26*	.06 (.04)	.14	.13 (.06)	.23*	-.09 (.04)	-.28*
Race										
White[a]	-3.87 (2.95)	-.13	-1.62 (1.04)	-.13	-.47 (.28)	-.15^{+}	.70 (.33)	.20*	.17 (.22)	.08
Other[a]	5.98 (5.35)	.11^{+}	.18 (1.80)	.01	.11 (.55)	.02	-.30 (.68)	-.04	-.08 (.45)	-.02
Gender (1 = Male, 2 = Female)	.91 (2.74)	.04	.59 (1.03)	.06	.39 (.28)	.14	-.70 (.32)	-.22*	-.37 (.21)	-.19^{+}
Mode of Transmission (1 = Perinatal, 2 = Behavioral)	2.05 (2.95)	.08	.92 (1.05)	.09	.15 (.30)	.05	.27 (.36)	.09	.42 (.24)	.21^{+}
Education	-1.83 (1.00)	-.21^{+}	-.61 (.36)	-.16^{+}	-.24 (.10)	-.25*	.17 (.11)	.16	.16 (.08)	.23*
Sexual Orientation										
Homosexual[b]	-1.86 (3.46)	-.07	-.66 (1.29)	-.06	.51 (.36)	.16	.11 (.41)	.03	-.27 (.27)	-.12
Other[b]	1.62 (4.83)	.04	-1.33 (1.61)	-.08	.63 (.45)	.14	.33 (.54)	.06	-.09 (.36)	-.03
R^2	.11		.09		.12		.28		.14	
F for change in R^2	1.52		1.66		2.12*		4.49**		1.81^{+}	

Note. CES-D = Center for Epidemiologic Studies Depression Scale, GAD-7 = Generalized Anxiety Disorder 7-item Scale, PC-PTSD = Primary Care- PTSD Screener, BEHKA-Knowledge = Brief Estimate of Health Knowledge and Action- HIV Version Knowledge Subscale, BEHKA-Action = Brief Estimate of Health Knowledge and Action- HIV Version Action Subscale

[a]Reference race group is African American. [b]Reference sexual orientation group is Heterosexual.

**p<.05, $^{+}$p<.10.*