

September 2015

# Health-Related Quality of Life and Positive Mental Health Indicators in Youth with Human Immunodeficiency Virus

Sim Yin Tan

*University of South Florida, simyintan@mail.usf.edu*

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Health-Related Quality of Life and Positive Mental Health Indicators in Youth with Human  
Immunodeficiency Virus

by

Sim Yin Tan

A dissertation submitted in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy in School Psychology  
Department of Educational and Psychological Studies  
College of Education  
University of South Florida

Major Professor: Kathy Bradley-Klug, Ph.D.  
Shannon Suldo, Ph.D.  
Tiffany Chenneville, Ph.D.  
Jeffrey Kromrey, Ph.D.

Date of Approval:  
June 4, 2015

Keywords: physical health, subjective well-being, social-emotional strengths, adolescents, HIV

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## **DEDICATION**

To my parents, for giving me the opportunity to travel more than ten thousand miles away from home to pursue my academic dream. I am forever grateful for your unconditional love and unwavering support throughout these years. I owe my academic success to the both of you.

To Jamie, for standing by me through the ups and downs of graduate school and life. Thank you for believing in me and constantly reminding me that I can do this. I am glad I proved you right.

## **ACKNOWLEDGMENTS**

I would like to express my gratitude to everyone who has assisted and supported me throughout the process of this dissertation project. Firstly, I would like to acknowledge my major professor, Dr. Kathy Bradley-Klug. She played an important role in shaping my research and clinical interests in youth with chronic health conditions. She provided me with valuable advice when I encountered roadblocks and constructive feedback on the many drafted versions of this document. I am grateful for her mentorship, not only for this project, but also throughout my doctoral training. I would also like to thank Dr. Shannon Suldo, for inspiring me to view youth's mental health from the positive lenses. Her enthusiasm for improving youth's subjective well-being is commendable and I am grateful for the opportunity to work with her. Additionally, I would like to thank Dr. Tiffany Chenneville for sharing her expertise in the youth population with HIV and providing me with knowledge to work effectively with this population. Furthermore, I would like to thank Dr. Jeffery Kromrey, for his statistical guidance and patience with my numerous questions regarding data analyses. He did a great job translating statistics into a language that I could understand. The completion of this project would have not been possible without the help of the staff at the recruitment sites. I am thankful for the staff of USF Pediatric and Adolescent Infectious Disease clinic, USF Upward Bound program, and the Dream Center of Tampa Bay, for the support they have given me throughout the recruitment and data collection process. Finally, I am grateful for my internship supervisor, Dr. Heather Agazzi, for giving me the flexibility in my clinical schedule so that I could work on my data collection, analyses, and the writing of this document. I thank you all.

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## **ABSTRACT**

Human Immunodeficiency Virus (HIV) is a chronic health condition that is increasingly affecting both children and adolescents (Center for Disease Control and Prevention, 2011). Although many studies have investigated the impact of HIV on cognitive, physical, academic, and psychosocial functioning, little is known about the self-perception of health-related quality of life, subjective well-being, social-emotional well-being, and psychopathology risks of youth who are infected with HIV. This study is one of first to examine the presence of these positive and negative health indicators and the relationship among these factors in youth with HIV and a community-based sample.

A total of 84 youth ( $n=42$  in each group) between 13-18 years old participated in this study. All participants completed a packet of self-report measures, which included the Pediatric Quality of Life Scale (PedsQL™ 4.0; Varni, Burwinkle, Seid, & Skarr, 2003), Student Life Satisfaction Scale (SLSS; Huebner, 1991), Positive Affect and Negative Affect Scale-Children (PANAS-C; Laurent et al., 1999), Social Emotional Assets and Resiliency Scale-Adolescent Form (SEARS-A; Merrell, 2011), and Behavioral and Emotional Screening System (BASC-2 BESS; Kamphaus & Reynolds, 2007). The data were analyzed for significant correlations, group differences, and social-emotional predictors of physical functioning and subjective well-being.

Specifically for youth with HIV, several health-related quality of life indicators were found to be positively correlated with life satisfaction and social-emotional strengths indicators,

but negatively correlated with negative affect and psychopathology symptoms. Stronger, but non-significant correlation coefficients were noted for participants in the HIV group than youth in the community-based sample. In particular, stronger associations between the positive mental health indicators (i.e., subjective well-being and social emotional strengths) were observed for youth with HIV than youth in the community-based sample. Youth with HIV also reported a greater association between their subjective well-being and psychopathology when compared to youth in the community-based sample.

Additionally, there was a significant main effect of family structure on participants' perceptions of their social functioning and psychopathology symptoms. When the differences in family structure were controlled for, the overall mean ratings of participants' health-related quality of life, subjective well-being, social-emotional well-being, and psychopathology risks did not significantly differ between groups. Furthermore, family structure and self-rated empathy skills significantly predicted physical functioning of youth with HIV, but no significant or meaningful variables were found to predict their subjective well-being. Finally, no significant variables were found to predict the physical functioning or subjective well-being of youth in the community-based sample. The limitations of the current study, implications of findings, and directions for future research are discussed.

## **CHAPTER ONE:**

### **INTRODUCTION**

#### **Statement of the Problem**

Human immunodeficiency virus (HIV) is a serious health and psychosocial condition that affects children and adolescents at an alarming rate (Centers for Disease Control and Prevention, 2011). As a result of medical improvements (e.g., highly active antiretroviral therapy), the survival trajectory of youth with HIV has been extended. HIV has transitioned from being a devastating terminal health condition to a more manageable chronic health condition, potentially resulting in more youth with HIV being included in the schools. Furthermore, changes in the healthcare system such as the provision of outpatient services and increased availability of medical support outside of the clinical setting have resulted in less in-hospital care for youth so that they can lead normal and meaningful lives (Clay, 2004). With the increased rate of school-age youth with significant health needs, school personnel are challenged to provide a comprehensive system of support services to meet the unique educational and social-emotional needs of their students.

Management of HIV during the adolescent developmental period represents a significant challenge. Youth with HIV are confronted with similar developmental tasks (e.g., strive for autonomy, initiating and maintaining peer relationships) as their healthy counterparts along with the unique stressors associated with their health condition, such as treatment management and psychosocial issues related to social stigma and disclosure (Brown, Lourie, & Pao, 2000).

Furthermore, youth with chronic health conditions such as HIV are more likely to experience frequent disruptions to their academic and social functioning due to absenteeism related to their health conditions (Gortmaker, Walker, Weitzman, & Sobol, 1999). These unique stressors and disruptions can adversely impact youth's educational progress, quality of life, and social-emotional well-being.

Given the transition in the course of HIV from a terminal to a chronic health condition, quality of life issues become more prominent and may play a crucial role in health behaviors. Because of the complex issues related to HIV, some would argue that quality of life issues must take precedence over the focus on academic performance and cognitive growth for individuals with this condition (Wodrich, Swerdlik, Chenneville, & Landau, 1999). Therefore, the educational goals of youth with HIV need to be reframed, to prioritize not only academic but also social-emotional well-being and overall quality of life. In order to ensure appropriate educational and health planning within the school system, school personnel must be familiar with the youth's overall functioning by looking beyond the assessment of pathology and taking into consideration youth's quality of life and individual strengths.

### **Conceptual Framework**

**Traditional assessments of health.** The majority of previous research on youth's physical and mental health focused exclusively on psychopathology (e.g., Bennett, 1994), providing limited information on aspects of functioning that are promotive, such as quality of life and social-emotional strengths. In recent years, there has been a shift in focus from the identification and reduction of symptoms to a greater emphasis on the assessment of health-related quality of life and positive indicators of well-being in youth. This shift was prompted by the argument that assessments of health outcomes based exclusively on medical and

symptomatic markers provide only a limited picture of the impact of a chronic health condition in youth (Starfield & Riley, 1999).

**Health-related quality of life.** Recognition of the limitations of traditional health assessments for youth with health concerns has led to an interest in the assessment of health-related quality of life (HRQOL). HRQOL measures assess the subjective perception of the impact of one's chronic health condition on a wide range of daily life domains such as physical functioning, social roles, and family activities (Matza, Swensen, Flood, Secnik, & Leidy, 2004).

Although HRQOL is widely studied in youth with chronic health conditions (e.g., Barrera et al., 2003; Dale, Cochran, Roy, Jernigan, & Buchanan, 2011; Kalyva, Malakonaki, Eiser, & Mamoulakis, 2011; Riazi, Shakoor, Dundas, Eiser, & McKenzie, 2010; Sawyer et al., 2004), indicators of HRQOL in youth with HIV are less well known. In fact, there is only one study that examined HRQOL indicators in youth with HIV using self-reported measures (Jeifez-Zagigi, 2004). Studies using parent-report measures suggest that other stressful life events may have greater impact on youth with HIV's HRQOL than the health condition itself (Lee, Gortmaker, McIntosh, Hughes, & Oleske, 2006).

Although the assessment of HRQOL provides important information by taking into consideration an individual's subjective perception of the impact of their chronic health condition, it does not assess the presence of well-being indicators such as life satisfaction, positive emotions, and strengths. The presence of well-being indicators may be promotive and could potentially increase our understanding of the differential impact of chronic health conditions in youth.

**Subjective well-being.** Health is considered a state of complete wellness that is not exclusively based the absence of illness or symptoms (Eiser & Morse, 2001). For example, the

dual-factor model of mental health suggests that psychopathology symptoms and positive well-being are not opposite poles on the same continuum. A presence of one does not equal the absence of another. In fact, an individual can exhibit high or low levels of both psychopathology and well-being (Greenspoon & Saklofske, 2001; Suldo & Shaffer, 2008). Assessments that focus solely on psychopathology symptoms fail to take into consideration individuals who present no psychopathology but are low in positive subjective well-being indicators (e.g., life satisfaction, positive affect). Thus, the traditional deficit-based assessment may lead to the under-identification of individuals who are in need of intervention. Hence, the incorporation of both positive and negative indicators of well-being into assessment is necessary to ensure a more comprehensive evaluation of an individual's overall functioning.

Studies that have incorporated the assessment of positive well-being indicators (e.g., Suldo & Shaffer, 2008; Zullig, Valois, Huebner, & Drane, 2005) have consistently reported that positive indicators such as high life satisfaction and high frequency of positive affect are linked to better physical health outcomes in general samples of healthy adolescents. However, this relationship is unclear within samples of adolescents with chronic health conditions.

Hexdall and Huebner (2007) were the first, and thus far the only, researchers to explore the subjective well-being indicators of youth with chronic health conditions. Using a sample of pediatric oncology patients, these researchers found that youth with cancer did not differ significantly from the community-based sample on self-report measures of life satisfaction, hope, positive affect, or negative affect. Due to several limitations of this study (e.g., small sample size, homogenous group) and a paucity of research in this topic area, further investigation is necessary to expand the current knowledge of well-being indicators within the population of youth with chronic health conditions so that more conclusive statements can be drawn.

**Social-emotional strengths.** Consistent with the movement away from traditional deficit-based approaches to assessment, strength-based assessment has gained popularity (Jimerson, Sharkey, Nyborg, & Furlong, 2004). Strength-based assessment highlights social-emotional skills that have proven to play a promotive role in youth's functioning. Such skills may include, but are not limited to: self-awareness, self-management, social-awareness, relationship skills, and problem-solving skills (Collaborative to Advance Social and Emotional Learning, 2008). Knowledge of the relationship between one's social-emotional strengths and overall well-being is emerging. Findings from a study conducted by Frank and colleagues (2013) suggest a relationship between the presence of social-emotional strengths (i.e., self-regulation, social competence, empathy, and responsibility) and high subjective well-being in a community sample of adolescents. This relationship, while new and yet to be replicated in samples of youth with chronic health condition, provides the impetus for further investigation. More research is necessary to elucidate our current understanding of the importance of strength-based assessment in the promotion of well-being in youth, specifically those with a chronic health condition such as HIV. Furthermore, this extended knowledge may eventually be translated into policies and practices that will ultimately benefit the needs of youth with chronic health conditions within the educational environment.

### **Purpose of the Study**

Currently, there is a dearth of research on the quality of life of youth with HIV. Empirical studies to date have relied solely on parent report of youth's quality of life (e.g., Butler et al., 2009; Lee, Gortmaker, McIntosh, Hughes, & Oleske, 2006). Given that this construct is internal and subjective in nature, it is important to consider youth's perception of their quality of life to better understand the impact of their health condition.



Hence, this study aimed to extend the research conducted by Hexdall and Huebner (2007) and further explore the nature of the relationship between positive mental health indicators (e.g., subjective well-being and social-emotional strengths), psychopathology, and health-related quality of life in a sample of adolescents with HIV, in comparison to a community-based sample. Specifically, the following research questions were investigated:

**Research questions.**

1. What is the strength and direction of the relationships among the scores on self-reported measures of health-related quality of life, subjective well-being, psychopathology, and social-emotional strengths for adolescents with HIV and a community-based sample?
2. Do the correlation coefficients among the self-reported measures of health-related quality of life, subjective well-being, psychopathology, and social-emotional strengths differ between adolescents with HIV and a community-based sample?
3. Do the mean scores on self-reported measures of health-related quality of life, subjective well-being, psychopathology, and social-emotional strengths differ between adolescents with HIV and a community-based sample?
4. Which social-emotional strengths are most strongly predictive of the physical functioning (as rated on a subscale of the health-related quality of life measure) and subjective well-being of adolescents with HIV and a community-based sample?

**Hypotheses.** For research question one, it was hypothesized that self-report of health-related quality of life would be positively correlated with life satisfaction and positive affect and negatively correlated with negative affect (factors of the subjective well-being). Life satisfaction and positive affect were also expected to be negatively related to psychopathology outcomes and positively related to social emotional strengths. These hypotheses were based on the literature

reviews summarized in the next chapter, which suggest that high subjective well-being is associated with positive physical and mental health functioning of adolescents.

Currently, there is a lack of literature to guide the hypotheses for research questions two, three, and four. Available research suggests either preliminary or inconsistent findings. Therefore, these research questions were considered exploratory and no hypotheses were generated.

### **Significance of the Study**

**Importance of proposed study to school psychology.** The role and function of school psychologists have evolved from being a traditional gatekeeper of special education to a more indirect and comprehensive service provider. Nastasi (2000) asserts that, “school psychologists have a key role as health care providers” (p. 541). School psychological services can provide a continuum of services ranging from prevention to intervention to address the unique academic and social-emotional challenges faced by youth with HIV.

Rather than working with youth with HIV from merely a traditional deficit model approach that emphasizes the identification and treatment of symptoms, it is equally important to consider youth’s positive psychological attributes, such as subjective well-being (i.e., life satisfaction, positive affect) and social-emotional strengths. Additional information from a strengths-based perspective will allow school personnel to gain a comprehensive picture of the overall well-being of youth with HIV and help inform prevention and intervention efforts to promote school success.

**Contributions to the literature.** This study will contribute to the existing knowledge base in the areas of positive psychology and pediatric psychology, considering that there is only one published study that examined subjective well-being in youth with chronic health conditions

(Hexdall & Huebner, 2007). Although many studies have demonstrated a strong relationship between positive indicators of well-being and physical health among healthy youth, it is unclear whether these findings generalize to youth with chronic health conditions. Therefore, it was important to extend the investigation of this relationship to youth with chronic health conditions to determine if findings from the healthy youth sample are consistent with those from youth with chronic health conditions. Understanding the positive characteristics possessed by chronically ill youth could potentially promote adaptation and foster resilient outcomes.

Furthermore, this study contributes to the current literature by expanding the study by Hexdall and Huebner (2007) to youth with HIV so that comparisons between findings can be drawn. Additionally, this study introduced an additional positive indicator of well-being, which is social-emotional strengths, in relation to health-related quality of life and subjective well-being. Understanding the roles social-emotional strengths play in the relationship between physical health and subjective well-being can potentially inform intervention research and efforts across systems (i.e., home, school, and community) to promote resiliency and improve the overall well-being of youth with HIV.

### **Constitutive Definition of Key Terms**

**Chronic health conditions.** A health condition that has lasted or is expected to last more than three months, which causes functional impairment (e.g., physical, social-emotional, and adaptive functioning) and requires medical attention (Perrin et al., 1993).

**Community-based sample.** A sample of youth between 13-18 years old, who have no known chronic health conditions based on information obtained from self- and/or parent reports.

**Health-related quality of life.** Health-related quality of life is defined as one's subjective perception of the impact of health status, including illness and treatment, on physical, psychological, and social functioning (Leidy, Rich, & Geneste, 1999).

**Subjective well-being.** Subjective well-being, a scientific term for happiness, is comprised of three factors: frequent positive affect, infrequent negative affect, and high life satisfaction (Diener, 2000). Affect comprises emotions and mood states such as joy and anger. Life satisfaction involves one's cognitive judgment of the overall quality of life and is considered a stable construct of subjective well-being.

**Social-emotional strengths.** This term will be used to refer to one's ability to a) regulate and express emotions, b) develop and express empathy, c) develop and maintain relationships with others, and d) use effective problem-solving skills.

## **CHAPTER TWO: REVIEW OF THE LITERATURE**

This chapter begins with an overview of HIV and the current knowledge base on the impact of this health condition on youth's cognitive and psychosocial development. Specific issues related to HIV in the context of adolescent development also are presented. Subsequently, the construct of health-related quality of life in children and adolescents with chronic health conditions is explored. There is extensive literature in this area, with most studies focusing on one specific chronic health condition. Hence, selected studies that investigated several chronic health conditions concurrently are included to provide a broader picture of health-related quality of life across different conditions. This overview is then followed by a discussion of health-related quality of life issues specific to youth with HIV. Next, this chapter provides a discussion of subjective well-being and its relationship to adolescents' physical health. Finally, social-emotional strengths will be presented within a resiliency framework to promote subjective well-being and buffer the psychosocial risks related to chronic health conditions. Studies on subjective well-being and social-emotional strengths in the context of adolescents' physical health are limited, therefore available literature associated with the topic are presented in detail to provide a rationale and methodological basis for this study.

### **Overview of HIV in Youth**

**Definition.** HIV is the acronym for Human Immunodeficiency Virus. HIV affects the human body by destroying specific blood cells, known as CD4 white blood cells, which play a

major function in helping the body fight infections (Centers for Disease Control and Prevention [CDC], 2012). An individual infected with HIV may develop flu-like symptoms such as fatigue or fever that lasts for at least a week, or have no symptoms at all. Although an infected individual may appear externally physically healthy and asymptomatic, HIV is still affecting the body internally and regular medical treatment is crucial to maintain immune functioning, limit the likelihood of transmission, and improve overall health and well-being. Unmanaged and untreated HIV can lead to the development of Acquired Immunodeficiency Syndrome (AIDS), a terminal condition whereby an individual's immune system is critically damaged and unable to fight diseases and certain cancer-related health conditions. AIDS is defined as the presence of HIV and a CD4 cell count of 200 or lower and/or the diagnosis of an opportunistic infection such as pneumonia.

**Prevalence.** There are more than 1.1 million individuals living with HIV infection in the United States (CDC, 2011). An estimated number of 2,485 new infections were diagnosed in 2011 within the youth population age 19 and under. Youth are among the fastest growing groups of individuals infected with HIV. One in every four new infections occurs in youth ages 13-24 (CDC, 2012). Between 2010 and 2012, a total of 637 new HIV infections were reported among adolescents between 13-19 years old in Florida alone (Florida Department of Health, 2011). In fact, Florida ranks second ( $N=1,571$ ), behind New York ( $N=2,457$ ), in the number of pediatric HIV cases diagnosed through 2011 (Florida Department of Health, 2012). Through 2011, Florida had reported a cumulative total of 2,509 cases of individuals who were HIV-infected prior to the age of 13. These statistics should be of specific concern for school personnel because they have important implications for educational programming, as youth with HIV are very likely to be included in general education settings.

**Routes of transmission.** The modes of HIV transmission are well understood. Among adolescents, behaviorally acquired HIV infection (e.g., through unprotected sexual contact or injection of drugs) continues to account for the majority of new cases (Brown, Lourie, & Pao, 2000). Children under the age of 12 living with HIV typically suffer from perinatally acquired infection, which refers to maternal transmission that can occur before, during, or after childbirth (Pumariega, Shugart, & Pumariega, 2006). Transmission via blood transfusion is also likely, but less common due to rigorous screening practices. HIV is not transmitted through air or water, insects, saliva, tears, or sweat or through casual contact (e.g., shaking hands) as HIV cannot reproduce outside of the human body (CDC, 2012).

### **Impact of HIV Infection on Youth Development**

**Neuropsychological and cognitive implications.** HIV has a direct effect on the central nervous system (CNS). Youth with HIV may exhibit at least three different forms of cognitive impairments: 1) encephalopathy, 2) neuropsychological deficits, and 3) apparently normal functioning (Wolters, Brouwers, & Moss, 1995). These impairments are discussed further in the paragraphs below.

**Encephalopathy.** HIV-associated encephalopathy is characterized by severe and pervasive CNS dysfunction. The clinical manifestation of HIV-associated encephalopathy depends on the age of infection, mode of transmission, strain of HIV, and genetic vulnerabilities (Brown et al., 2000; Donenberg & Pao, 2005). Among youth with HIV, encephalopathy has an estimated prevalence rate of 13 to 23% (Lobato, Caldwell, Ng & Oxtoby, 1995). Earlier HIV infection through perinatal transmission seems to be related to higher risk of CNS dysfunction and more severe symptom manifestation while adolescents who acquire HIV through risky behaviors tend to have less CNS symptoms (Mitchell, 2001). Youth with HIV-associated

encephalopathy display deficits in cognitive, language, motor, and social-emotional skills that negatively impact their academic and adaptive functioning (Allison, Wolters, & Brouwers, 2009). Specifically, in the area of language development, expressive language appears to be more severely impaired or may decline quicker than receptive language (Pumariiega et al., 2006). The implementation of antiretroviral treatment may be preventative and/or therapeutic for HIV-associated encephalopathy (Allison et al., 2009).

***Neuropsychological deficits.*** HIV-related neuropsychological deficits, also known as the compromise of CNS functioning, are characterized by overall cognitive functioning that is within average ranges, but with selective deficits in neurodevelopmental functioning such as memory, attention, and perceptual-motor abilities (Wolters et al., 1995). Considering the availability of antiretroviral therapy, youth with HIV who display CNS dysfunction are more likely to display this subtle form of deficit instead of encephalopathy (Allison et al., 2009).

***Apparently normal functioning.*** Youth with HIV are considered to have apparently normal functioning when their cognitive functioning is at least within the average range, with no indication of HIV-associated CNS dysfunction, regression in functioning or neurological abnormalities (Allison et al., 2009). These youth might seem “normal” because their pre-infection level of functioning may have been in the high average or superior range or because they have yet to exhibit any evidence of cognitive decline (Wolters et al., 1995).

***Psychosocial implications.*** Although HIV is a chronic health condition, there are significant distinctions that separate it from other chronic health conditions such as asthma and diabetes. The social stigma associated with HIV, potential regression in cognitive development, and the intergenerational nature of the condition can have an overwhelming effect on youth’s psychological functioning and social emotional development. Youth may experience direct



psychosocial effects that are associated with HIV-related encephalopathy or indirect effects through HIV-associated environmental factors such as paternal/maternal HIV, pre- and postnatal drug exposure, and poverty (Wiener, Moss, Davidson, & Fair, 1992). Therefore, it is crucial for school personnel to be aware of the unique psychosocial issues experienced by youth with HIV.

***Internalizing behaviors.*** Symptoms related to depression and anxiety are not uncommon in youth with HIV (Mellins et al., 2009; Pao et al., 2000). As mentioned earlier, internalizing behaviors may be the result of direct effects of HIV. The direct effects of HIV related to depression are typically associated with more severe abnormality on brain imaging and clinically elevated scores on behavior rating scales (Brouwers et al., 1995). Increased levels of anxiety symptoms, on the other hand, have been found to be correlated with lower CD4 counts (Nichols et al., 2000). Depression may also be the result of indirect effects of HIV. Murrain and Barker (1999) found that depression symptoms in youth with HIV were related to parental drug use, parental illness or death. Furthermore, the social stigma associated with HIV may contribute to peer rejection, loneliness, social phobia, and in severe cases, suicidal ideation (Prinstein, Boergers, Spirito, Little, & Grapentine, 2000). Other related factors, such as pain, secrecy with HIV diagnosis, and fear of becoming ill or dying, can potentially influence the development of anxiety symptoms as well. For example, Yaster and Schechter (1996) found that almost 60% of youth with HIV experience pain, which negatively impacts their quality of life and sleep hygiene. In a more recent study, high levels of self-reported pain in HIV youth were associated with higher symptom severity for generalized anxiety, major depression, and dysthymia (Serchuck et al., 2010)

***Externalizing behaviors.*** The literature suggests higher prevalence of externalizing behaviors (e.g., hyperactivity, conduct problems) in youth with HIV, compared to healthy youth.

For example, Nozyce et al. (2006) found that 20% of youth with HIV in their study were identified as having symptoms related to Attention-Deficit/Hyperactive Disorder (ADHD), and this prevalence rate was higher when compared to the general non-HIV infected population, as well as samples of youth with other chronic health conditions. However, these findings are inconsistent and inconclusive. Although caregivers in another study also reported ADHD as the most common behavioral problem among youth with HIV, the scores on rating scales were also higher than normal for the control group of uninfected siblings, suggesting that genetics and environmental factors may have a more significant impact on the development of externalizing behaviors in these youth than the direct effects of HIV (Mellins et al., 2003). Externalizing problems in youth with HIV can have serious health and social implications when associated with high-risk behaviors such as medical nonadherence, intravenous drug use, and risky sexual behaviors. Youth with HIV may be susceptible to high-risk behaviors as a coping mechanism to stressors related to their health status. Engagement in high-risk behaviors may also be an attempt to “be normal” in order to gain acceptance from their peers. Involvement in risky behaviors carries an additional threat because these behaviors can exacerbate their existing health symptoms.

***Disclosure.*** Disclosure of HIV status can be a struggle for infected youth and their families. Because of the fear of stigmatization, families may be reluctant to disclose to their young child his or her own HIV status, leading the child to believe that he or she has some other health conditions (Chenneville, 2008). Barriers to disclosure often reflect parental concerns such as maternal guilt related to perinatal transmission, emotional unpreparedness, limited knowledge and skills, and lack of comfort discussing HIV related issues (Kouyoumdjian, Meyers, & Mtshizana, 2005). The research on chronic health conditions suggests that disclosure of

developmentally appropriate facts about the health condition improves the youth's psychological adaptation and health literacy. Disclosure can promote trust, engage youth in their own medical care, promote adherence to treatment regimens, and enhance long-term health and emotional well being (Lipson, 1994). Mellins et al. (2002) found that HIV status disclosure to infected youth did not result in increased mental health problems. On the contrary, youth who knew their HIV status tended to be less depressed than youth who did not know. Youth's self-disclosure of HIV status to a friend has also been associated with positive outcomes, such as improved immune functioning (Sherman, Bonanno, Wiener, & Battles, 2000).

**Treatment issues.** The development of new drugs and use of combination therapies have contributed to significant progress in medical treatment of youth with HIV. The goals of treatment have evolved from extending survival to promoting normal growth, preventing infections, and improving quality of life (Smith, Martin, & Wolters, 2004). Highly active antiretroviral therapy (HAART) can effectively inhibit the progression of HIV through the reduction of CD4 cells and thus minimize the replication of virus, if it is taken as prescribed. A missed dose of medication will allow the virus to mutate, making it resistant to certain classes of drugs. Medical adherence is poor among youth and adherence barriers include forgetfulness, too many pills, side effects (e.g., nausea, diarrhea), special diet requirements, fear of disclosure and stigma (Koenig & Bachanas, 2006). Additionally, social stressors such as poverty, unstable living situation, and mental health issues may make treatment adherence less of a priority among youth. The treatment regimen is a challenging course for youth with HIV and school personnel need to be knowledgeable and sensitive toward these issues.

## **HIV in the Context of Adolescent Development**

Adolescence is a period of significant and rapid changes in the biological, psychological, cognitive, social, and sexual domains of development. The major goals for an adolescent include the achievement of autonomy, expression of self-identity, development of peer relationships, and transition into adulthood. It is also a time of heightened focus on issues such as body image, sexuality, and social acceptance. Having a chronic health condition such as HIV can impact all of these important areas of development (Boice, 1998). As fears about HIV transmission emerge, youth's normal process of exploring sexuality will be challenged and they must face decisions regarding disclosure of their status to a potential partner. Anxiety about disclosure and anticipation of possible rejection increase the stress associated with sexuality development (Smith et al., 2004). The stress of living with and managing HIV, in addition to dealing with the normative challenges of adolescent development, can contribute to higher levels of psychological distress.

**Academic and social functioning.** Having HIV can be potentially detrimental to an individual's academic and social functioning. Youth with HIV are at risk for developing academic challenges associated with the neurocognitive effects of HIV. Secondary effects, such as high rates of school absenteeism and fatigue may also disrupt learning. These secondary effects increase the likelihood of youth falling behind in their schoolwork, resulting in recommendations for special education services or grade retention. Frequently missed school days not only affect youth's academic progression but also limit the opportunity for social interaction with peers. Peer acceptance may also be difficult for youth with HIV because of physical abnormalities. Youth with perinatally acquired HIV are usually smaller in height, weight, and head circumference (Moye et al., 1996), and may exhibit other physical conditions

(e.g., skin rash, joint pains, hypersensitive reactions) due to the side effects of medications. The development of peer relationships can also be impacted if youth with HIV are uncertain about disclosing their health status.

**Summary.** The management of HIV during the adolescent developmental period represents a serious challenge for youth, their family, healthcare teams, and school personnel. A multidisciplinary team approach to intervention is an ideal means to help youth cope with the physical and psychosocial impact of this chronic health condition. School-based mental health professionals, such as school psychologists, can play an integral role in the psychosocial assessment and provision of prevention and intervention services. It is important to acknowledge that school personnel are not always aware of youth's HIV status, which complicates the ability for schools to intervene. When HIV status is known, comprehensive assessment is extremely important, considering the neuropsychological and psychosocial implications associated with this health condition. An ecological evaluation approach is recommended to include both traditional measures such as behavioral rating scales and non-traditional measures such as quality of life and strength-based assessments. Assessments should be conducted periodically so that health functioning can be compared across time to monitor signs of disease progression (Chenneville, 2008).

A thorough assessment of youth's health status that includes the identification of positive and negative indicators of adjustment will help school personnel to approach HIV within the tiered framework of prevention and intervention. Within this framework, youth with HIV who are not symptomatic and are traditionally under-identified will have access to preventative services while youth who present with symptoms will be able to receive targeted interventions

tailored to their needs to prevent the development of future problems and improve their quality of life.

### **Health-Related Quality of Life (HRQOL)**

Traditionally, health outcome measures for youth with HIV focused mainly on medical laboratory tests such as CD4 cell counts. However, these outcome measures fail to take into consideration the impact of the health condition on the individual's day-to-day functioning (e.g., limitations in physical and social activities, changes in social roles). Starfield and Riley (1998) argue that health outcomes defined solely on biological and medical markers do not adequately explain the broad implications of chronic health conditions in children and adolescents.

The growing recognition of the association between chronic health conditions and the challenges inherent in adolescent development has led to increased assessment of health-related quality of life for this population. Health-related quality of life (HRQOL) is defined as one's subjective perception of the impact of health status, including illness and treatment, on physical, psychological, and social functioning (Leidy, Rich, & Geneste, 1999).

HRQOL measures are designed to assess a wide range of domains in youth's daily functioning. Empirical findings suggest that HRQOL measures provide a broader understanding of the psychosocial outcomes related to the health condition. HRQOL measures allow for the evaluation of individual's subjective perception of the impact of a chronic health condition, thus providing useful information that are beyond clinical measures of health symptoms (Matza, Swensen, Flood, Secnik, & Leidy, 2004). Assessing HRQOL is considered an important outcome indicator in the evaluation of health-care interventions, in understanding the impact of chronic health conditions, in identifying health disparities, and in allocating health resources (Solans et al., 2008). HRQOL instruments can be beneficial in identifying and prioritizing health

problems for youth, facilitating communication between families and health-care professionals, and in monitoring changes in health status. Both generic and condition-specific measures have been developed to assess HRQOL in youth. Some examples of these measures are summarized in Table 1.

Table 1

*Examples of Generic and Condition-Specific HRQOL Measures*

Measures	Respondent (Age group)	Number of Items	Scales
*Child Health Questionnaire (CHQ; Landgraf, Abetz, & Ware, 1999)	Self (10–19) Parent (4–19)	87 28, 50, 98	Physical Functioning, Role/Social Emotional, Role/Social Behavioral, Role/Social Physical, Bodily Pain, General Behavior, Mental Health, Self-Esteem, General Health Perceptions, Change in Health, Parental Impact-Emotional, Parental Impact-Time, Family Activities, Family Cohesion
*Pediatric Quality of Life Inventory (PedsQL™ 4.0; Varni, Burwinkle, Seid, & Skarr, 2003).	Self (5-18) Parent (2-18)	23	Physical Functioning, Emotional Functioning, Social Functioning, School Functioning
Pediatric Asthma Quality of Life Questionnaire (PAQLQ; Juniper et al., 1996)	Self (7–17)	23	Activity Limitations, Symptoms, Function
Pediatric Cancer Quality of Life Inventory (PCQL; Varni et al., 1998)	Self and Parent (8–18)	32	Disease- and Treatment-Related Symptoms, Physical Functioning, Psychological Functioning, Social Functioning, Cognitive Functioning

*Note.* Generic measures are marked with an asterisk (\*)

Studies that have examined HRQOL in children and adolescents within and outside of the United States have consistently documented lower HRQOL in children and adolescents with chronic health conditions (e.g., sickle cell, diabetes, and obesity) when compared to a healthy comparison sample (Dale, Cochran, Roy, Jernigan, & Buchanan, 2011; Kalyva, Malakonaki, Eiser, & Mamoulakis, 2011; Riazi, Shakoor, Dundas, Eiser, & McKenzie, 2010).

For example, Sawyer et al. (2004) investigated the differences in self-reported HRQOL of youth with diabetes, asthma, or cystic fibrosis as compared to a healthy community sample. Youth aged 10-16 years with the chronic health conditions ( $N=123$ ), rated their HRQOL using the Child Health Questionnaire (CHQ; Landgraf, Abetz, & Ware, 1999) and one of the three disease-specific measures. When compared to a representative healthy community sample, youth with chronic health conditions reported significantly lower HRQOL in several areas. They reported that their health conditions frequently affected their participation in physical activities, family activities, schoolwork and peer activities.

Although children and adolescents with chronic health conditions typically reported poorer HRQOL outcomes as compared to the community-based sample, HRQOL may be influenced by factors such as age differences and time since diagnosis. Using standardized measures (e.g., Child Behavioral Checklists [CBCL], Achenbach & Rescorla, 2001; Play Performance Scale [PPS], Lansky, List, Lansky, Ritter-Sterr, & Miller, 1987), completed by mothers of 69 preschool, school-aged, and adolescent patients of cancer, Barrera et al. (2003) found a significant age group difference in the patients' psychological adjustment and HRQOL. Specifically, preschoolers were reported to exhibit more externalizing behaviors than adolescents. It is possible that preschoolers lack the ability to express their feelings as a means of coping, resulting in the manifestation of behavioral problems. Although adolescents were at



higher risk for poor HRQOL compared to younger children, their HRQOL improves as more time has passed since the diagnosis.

**Parent vs. youth self-report.** The question of who should be reporting HRQOL for the chronically ill youth remains debatable. In general, there is a higher level of agreement between parent and youth self-report on the objective aspects of chronic health conditions (e.g., self-care and physical functioning) than the subjective impact (e.g., emotions and pain). The subjective impact of one's chronic illness is considered a crucial outcome of health interventions; therefore it warrants a thorough assessment and progress monitoring (Wiklund, Erling, & Albertsson-Wikland, 1998). Wiklund et al. (1998) concluded that parents tend to view the HRQOL of their child more negatively, and that their perceptions of their child may reflect their own psychological adjustment. Similarly, Vance et al. (2001) also reported discrepancies between parent and child report and suggested that parents tend to put more emphasis on the future impact (e.g., school performance) of their child's chronic health condition while the child tends to focus more on the immediate impact (e.g., physical appearance, social relationships). Therefore, it is essential to obtain HRQOL information directly from the child as they provide useful information on their self-perceptions of health status beyond parental reports.

### **Health-Related Quality of Life in Youth with HIV**

Although there are compelling reasons to measure the HRQOL of youth with chronic health conditions, the knowledge on HRQOL of youth with HIV is somewhat limited. Research focusing on the adult population with HIV suggested that high HRQOL, as measured by the General Health Assessment Scale, is associated with previous participation in antiretroviral therapy (Lenderking, Testa, Katzenstein, & Hammer, 1997), absence of a mental health condition, high levels of social support, and low engagement in risky behaviors (Ruiz Perez et

al., 2004). Lenderking et al. (1997) also found a significant main effect of gender and ethnicity on HRQOL. Female adults tend to report lower HRQOL than males. While Caucasians were more likely to have lower general health perceptions (e.g., overall health, physical health, emotional health, personal life, and job-related roles) than African Americans, they reported higher physical and social functioning than other ethnic groups. No ethnic group differences were found within the psychological functioning domain of HRQOL.

Some studies have investigated the nature and correlates of HRQOL within the population of youth with HIV, but most of these studies relied on parent or caregiver reports of HRQOL. For example, Lee, Gortmaker, McIntosh, Hughes, and Oleske (2006) studied 1847 youth who were infected perinatally and compared their findings to 712 uninfected youth. Based on parent report of youth's HRQOL on the General Health Assessment for Children scale, children (5-11 years old) and adolescents (12-21 years old) who were not receiving antiretroviral therapy were reported to have significantly worse health perceptions and outcomes than the control group. Young children with HIV who were below 4 years of age were reported to have the worse functional status while children between 5-11 years old were reported to have lower physical functioning, physical resiliency, and social role functioning than the control group. Interestingly, the study found that uninfected children between 5-11 years old were reported to have lower psychological functioning than infected children of the same age group. These uninfected children, however, had higher negative life events scores and reported more occurrence of significant life events such as loss of housing, loss of family member, parental separation, and change in financial status. These findings may suggest that other stressful family life events have a greater impact on psychological functioning than HIV infection itself. It is also

hypothesized that the constant social support and services that infected children received from their health care providers served as a buffer against psychosocial risks.

HRQOL in youth with HIV has also been investigated in the context of disclosure. A longitudinal study on the impact on HIV status disclosure on youth HRQOL, as reported by caregivers, found no significant differences between pre- and post-disclosure on all domains of HRQOL as measured by the General Health Assessment for Children scale (Butler et al., 2009). The domains that were examined included general health perceptions, symptom distress, psychological status, physical functioning, social role functioning, and health care utilization. Based on the findings, the authors suggested that disclosure of HIV status should not be delayed because of fear of negative impact on youth's quality of life.

Thus far, there is only one study that examined the HRQOL in youth with HIV using self-reported measures. Jeifez-Zagigi (2004) investigated the association between family system, demographic variables, and illness knowledge factors on HRQOL of 6-16 year olds in the domains of physical functioning, psychological functioning, and general health perceptions, as measured by the Child Health Questionnaire. Results showed that these variables did not predict youth self-report of HRQOL. Only parents' mental health status contributed significantly to the youth's general health perceptions. Specifically, positive mental health functioning in parents was associated with favorable self-ratings in youth's health perceptions. Additionally, the study found that youth who were living with their biological parents were more likely to report lower levels of self-esteem and more behavioral problems than those living with another relative. It may be that their biological parents were also infected with HIV, hence contributing additional stressors to their daily functioning. Although the sample included in this study was small ( $N=29$ ), which might have contributed to the non-significant results, findings also suggest areas for

further exploration that variables intrinsic to the youth may be stronger predictors of youth HRQOL than those external to youth. While changes in the environment can have a significant influence on one's quality of life, Edgerton (1996) argued that this influence is temporary and that quality of life is a stable trait related to one's personal character and temperament. His argument implies that quality of life involves a strong affective component.

Although the assessment of HRQOL can provide an understanding of the effects of HIV on physical and psychosocial outcomes, it does not measure the presence of well-being indicators as potential promotive factors. As such, an understanding of youth's overall health status based solely on the measures of HRQOL is incomplete. Further investigation of the relationship between HRQOL and positive mental health indicators, such as life satisfaction, positive emotions, and social-emotional assets may further contribute to our current understanding of youth's ability to adapt to their chronic health condition.

### **Subjective Well-Being**

The World Health Organization defined health as the state of complete physical, psychological, and social well-being and not merely the absence of disease (Eiser & Morse, 2001). This definition provides a strong justification for the emergence of the positive psychology movement, in which researchers attempt to shift the predominant focus on psychological distress and the reduction of pathology symptoms to the promotion of subjective well-being to support overall physical and mental health. Researchers who provide support for this shift emphasize that an absence of symptoms is not adequate to assume that youth are doing well. For example, one study demonstrated that youth may report low subjective well-being even though they also reported low levels of psychopathology (Greenspoon & Saklofske, 2001). The researchers argue that psychopathology and subjective well-being are not opposite extremes at

the ends of a bipolar continuum. On the contrary, they are separate dimensions of functioning that can co-exist at the same levels (e.g., high psychopathology, high subjective well being). Regardless of the levels of reported psychopathology, youth who had low subjective well-being scores demonstrated poor academic self-concept and social communication skills. Their findings support the dual-factor model of mental health, suggesting that the assessment of positive indicators is a valuable complement to the traditional assessment approach. Park (2004) asserts that the inclusion of positive indicators such as subjective well-being is necessary to fully understand the meaning of psychological well-being in youth.

Subjective well-being (SWB), a scientific term for happiness, is comprised of three factors: positive affect, negative affect, and life satisfaction (Diener, 2000). Affect comprises emotions and mood states associated with various life events. Positive affect reflects how often a person feels pleasurable emotions such as joy, excitement, and affection. Negative affect reflects how often a person experience unpleasant emotions such as sadness, guilt, anger and fear. A person can experience positive and negative affect simultaneously. Higher frequency of positive affect in comparison to lower frequency of negative affect is an indicator of high SWB. Fredrickson's (1998) broaden-and-build model of positive emotions proposed that the promotion of health and well-being can be achieved through an increased emphasis on positive affect. Positive emotions (e.g., excitement) broaden an individual's momentary thoughts (e.g., curiosity) and actions (e.g., exploring and seeking out new experiences), which in turn build and strengthen physical, cognitive, and social resources. Positive emotions are both factors and outcomes of successful coping.

Life satisfaction, the third factor of subjective well-being, involves one's cognitive judgment of the overall quality of life and is considered the most stable construct of SWB. Life

satisfaction can be assessed globally or within specific domains such as family, friends, and living environment. Traditionally, SWB research has been limited mostly to studies of adults (Keyes, 2005; Pilcher, 1998). Such studies have revealed strong associations between life satisfaction and a variety of physical and mental health outcomes. In a cross-national study, adults who reported higher subjective well-being are more likely to have better coping and social skills and lower risk of developing psychopathology as compared to those who reported lower subjective well-being (Diener & Diener, 1996).

**Subjective well-being in adolescents.** In recent years, researchers have started to investigate the development, correlates, and consequences of SWB factors in adolescents. Studies have found that high levels of life satisfaction in adolescents are associated with stronger self-esteem, better parent-child relationships, reduced depressive and anxiety symptoms, better attitudes toward school (Gilman & Huebner, 2006), and reduced risk for suicidal ideation (Valois, Zullig, Huebner, & Drane, 2004). Additionally, adolescents with high levels of life satisfaction are also more likely to demonstrate higher academic, emotional, and social functioning and fewer behavioral problems as compared to peers with low or moderate levels of life satisfaction (Suldo & Huebner, 2006).

In a thorough review of existing literature on life satisfaction in youth, Proctor, Linley, and Maltby (2009) examined 141 empirical studies that were conducted around the world (e.g., United States, Australia, Norway, Netherlands, China, South Korea, Israel, and Africa). The authors found that demographic variables such as age, gender, race, and socioeconomic status have a weak to modest relationship in predicting life satisfaction in youth. Some of the variables that were observed to be strongly linked to high levels of life satisfaction include: extraversion, social efficacy, emotional stability, optimism, social support, low levels of substance use, and

low levels of stressful life events. The authors concluded that life satisfaction is a strength, and learning to build that strength can buffer against the development of psychopathological problems. Additionally, they also pointed out that there is a dearth of knowledge on life satisfaction pertaining to specific populations such as youth with disabilities and youth experiencing physical or mental health conditions.

**Subjective well-being and physical health.** Zullig, Valois, Huebner and Drane (2005) were the first to document the relationship between physical health and perceived life satisfaction in adolescents. In their study, a random sample of 4,914 adolescents, ages 13-18 years, were asked to report their perceived life satisfaction in six domains (self, family, friends, living environment, school, and overall) using the Brief Multidimensional Student Life Satisfaction Scale (BMSLSS; Selgison, Huebner, & Valois, 2003) as well as their perceived HRQOL on a 4-item scale (overall health, number of poor physical days, number of poor mental health days, and activity limitation days during the past month). Continuous data obtained from the study were collapsed into categorical levels and analyzed using logistic regression. Results showed that poor health-related outcomes (e.g., frequency of sick days) were significantly related to low life satisfaction, regardless of race and gender. Although the study demonstrated good external validity, the relationships observed in this study may be underestimated due to the use of categorical levels in the analyses. Despite this limitation, results of this study suggest that assessment of life satisfaction may be a viable tool to complement HRQOL measures, as it provides important information to aid the understanding of the development and subsequent outcomes of youth's physical and mental health.

In their study examining the existence and function of the dual-factor model of mental health (i.e., the assessment of SWB in addition to symptoms of psychopathology) in early

adolescence, Suldo and Shaffer (2008) included physical health as one of the outcome variables. This study was the first to examine all of the components of SWB (i.e., positive affect, negative affect, and life satisfaction) in relation to adolescents' health status. Three hundred and forty nine middle school students completed self-reported measures of SWB, psychopathology and physical health using the Students' Life Satisfaction Scale (SLSS; Huebner, 1991), Positive Affect and Negative Affect Scale-Children (PANAS-C; Laurent et al., 1999), Achenbach's Youth Self-Report (YSR; Achenbach & Rescorla, 2001), and physical health scales on the Child Health Questionnaire-Child Form 87 (CHQ-CF87; Landgraf et al., 1999), respectively. Their teachers also completed the Achenbach's Teachers' Report Form (TRF). An aggregated SWB index was obtained by adding the standardized scores for life satisfaction and positive affect scales, and then subtracting the standardized scores for negative affect scale, based on recommended guidelines from previous research (Kasser & Sheldon, 2002). Data analyzed using multivariate analysis of covariance indicated that students who fell within the complete mental health group (i.e., high SWB, low psychopathology) reported significantly better general health, fewer sick days, and fewer limitations in family activities than students in the vulnerable (i.e., low SWB, high psychopathology), symptomatic but content (i.e., high SWB, high psychopathology), and troubled (i.e., low SWB, low psychopathology) groups. Additionally, students who fell within the symptomatic but content group reported better physical health outcomes in all areas when compared to students in the troubled group.

The relationship between SWB and physical health was further investigated by Shaffer-Hudkins, Suldo, Loker, and March (2010), using the dataset from Suldo and Shaffer (2008). Significant relationships were found between indicators of SWB, psychopathology and physical health. Specifically, perceived physical health was positively correlated with life satisfaction and



positive affect, while inversely correlated with negative affect, internalizing and externalizing psychopathology. Using simultaneous regression analysis, results showed that all of the positive indicators of SWB, as well as levels of internalizing behaviors significantly predicted adolescents' perception of physical health. One key finding is that positive affect, an indicator of SWB, accounted for the most variance in physical health perceptions. This finding lends support to Fredrickson's (1998) argument that an increased emphasis on positive affect can help promote general well-being, in terms of physical health.

Overall, findings from both studies suggest that positive indicators of mental health are indeed separate from negative indicators of mental health. The inclusion of SWB factors in assessment can provide a crucial piece of additional information in predicting adolescents' physical health. Findings highlight the importance of attending to the positive indicators of well-being in establishing the association with physical health among youth. However, studies on this relationship thus far are mostly focused on the general population of healthy adolescents. Limited research has investigated SWB in youth with chronic health conditions. Increasing the current knowledge of the relationship between SWB and youth's health status has the potential to explain the differential impact of a chronic health condition. As such, assessing the SWB of youth with HIV can potentially lead to valuable insights about their overall development and facilitate collaborative efforts among healthcare and school professionals in order to promote healthy functioning within this population.

**Subjective well-being and chronic health conditions.** To date, there is only one published study that examined the positive indicators of SWB in youth with chronic health conditions. Hexdall and Huebner (2007) explored the extent to which SWB differed between 29 pediatric oncology patients and an equal number within a community-based sample, matched in

race and gender. The age of the youth ranged between 11 to 21 years of age. The researchers examined the conceptualization of SWB that included the dimensions of life satisfaction, positive affect, negative affect, and hope. These dimensions were assessed using the Multidimensional Students' Life Satisfaction Scale (MSLSS; Huebner, 1994), Positive Affect and Negative Affect Scale-Children (PANAS-C; Laurent et al., 1999) and Children's Hope Scale (CHS; Snyder et al., 1997). Applying multivariate analysis of variances, data indicated that youth with cancer did not differ significantly from healthy controls on self-report measures of life satisfaction, positive affect, negative affect or hope. Despite the lack of significant differences, youth with cancer reported higher means for life satisfaction, positive affect, and hope and lower negative affect than healthy controls. Additionally, hope was the only indicator related to the time since diagnosis. Youth reported higher levels of hope as time since diagnosis increased.

There are several hypotheses that might explain the non-significant group differences in the Hexdall and Huebner (2007) study. First, the sample size was relatively small, making it challenging to obtain meaningful differences. Second, oncology patients who willingly consent to participate in this study may be more likely to have higher functioning than those who chose not to consent. Lastly, based on set point theory (Headey & Wearing, 1989), it can be speculated that SWB varies accordingly to life events, but returns to a pre-established level because of stability in personal trait characteristics. It is plausible that youth's SWB decreases upon the news of a diagnosis and eventually returns to a set point as they learn to adapt and adjust to this condition and the necessary treatments.

Although this study provided some knowledge of the positive indicators of mental health in youth with cancer, further investigation with a more diverse group of youth with chronic health conditions is necessary to allow for comparison of findings so that stronger conclusions

can be drawn about the well-being needs of this population. To date, there are no published studies investigating the positive indicators of mental health in youth with HIV. Considering the multifaceted psychosocial issues that are experienced by youth with HIV, it will be beneficial to explore these factors in the sample of youth with HIV to better understand the potential facilitators and pathways that will enhance positive physical and mental health outcomes as well as overall quality of life.

In addition to subjective well-being, another positive mental health indicator that has sparked research interest in recent years is social-emotional strengths. The following paragraphs will explore what is currently known about social-emotional strengths and how those factors may contribute to the stability of subjective well-being and physical health outcomes of youth with HIV and other chronic health conditions.

### **Social-Emotional Strengths as a Resiliency Factor**

Despite the adverse impact of chronic health conditions, such as HIV, youth have the ability to overcome these health challenges and lead a successful life. The extent to which chronic health conditions impact psychosocial functioning of youth depends on the interaction of numerous factors. Wallander and Varni (1998) conceptualized the possible contributing factors in a framework based on risk and resilience. The major tenets of this framework are that modifiable risk and resilience factors can be identified and provide guidance to improve the development trajectory of youth with chronic health conditions. Risk factors such as family stress and social rejection make it more difficult for youth to adjust to their chronic health conditions. On the other hand, resilience factors such as social competence, problem-solving ability, and social support, serve to protect youth's psychosocial functioning and can decrease the impact of chronic health conditions. Specifically, Wallander and Varni (1998) argued that the

development of intrapersonal factors can help build and facilitate positive social experiences for youth, resulting in greater perceived support from interpersonal resources. This perceived support then serves as a buffer against the risks associated with their health conditions.

The school setting is one environmental setting outside of a youth's home that is most conducive to the implementation of educational activities to promote personal growth and prosocial behaviors that can directly contribute to academic and social success. The most effective school-based health promotion programs typically focus on the development of social-emotional competencies to prevent health-disparaging behaviors such as substance abuse, violence, and risky sexual behaviors (Wallander, Eggbert, & Gilbert, 2004).

The Collaborative to Advance Social and Emotional Learning (CASEL) identified a framework of core social-emotional competencies that are critical contributions to youth's cognitive and academic success as well as their physical and mental health functioning (CASEL, 2008). The five core competencies include: self-awareness (ability to evaluate one's emotions, interests, values, and strength and maintain a healthy self-esteem), self-management (ability to regulate and express one's emotions appropriately, to overcome adversities, and engage in goal-directed behaviors), social awareness (ability to empathize with others, to recognize and accept individual and group differences, and to seek out social resources), relationship skills (ability to develop and maintain relationships, to resist social pressure, and to manage interpersonal conflict), and responsible decision-making (ability to make sound decisions based on consideration of ethical standards, social norms, safety and respect for others).

The benefit of social-emotional skills is well documented. According to a meta-analysis of 213 school-based social and emotional learning programs involving kindergarteners through high school students found that in comparison to control groups, students who received explicit

social-emotional learning instruction demonstrated significantly improved social-emotional skills (e.g., emotion identification, perspective taking, goal setting, conflict resolution), attitudes toward self and others (e.g., self-concept, self-esteem, school perceptions, social justice), positive social behavior (e.g., peer and adult relationships), academic performance (e.g., grades, standardized test scores) and lower levels of conduct problems and emotional distress (Durlak et al., 2011).

As shown by research evidence, social-emotional competence is an important risk-prevention and well-being promotion tool. The core social-emotional competencies may be important considerations when studying the cross-cutting issues related to chronic health conditions in youth. Based on the positive outcomes of social-emotional learning within the general youth population as reported by Durlak et al. (2011), it is postulated that strong social-emotional skills may benefit youth with chronic health conditions. Specifically, social-emotional strengths may increase their ability to understand the implications of their health-related choices, seek social support, be assertive in resisting peer pressure, advocate for their health needs and treatment decisions, adapt to changes in daily routine, and adhere to their treatment regimens.

In addition to the potential of promoting positive health outcomes in youth with chronic health conditions, social-emotional strengths can also help prevent the development of externalizing and internalizing behaviors. For example, Bromley et al. (2006) found in their longitudinal study that adolescents at the mean age of 16 years, who were rated by their mothers as displaying a higher frequency of resiliency traits, such as empathy, self-confidence, and coping skills, demonstrated lower levels of behavioral problems when they reached the mean age of 22 years. Additionally, Gillham et al. (2011) found that adolescents who rated themselves high on strengths directed to others, such as social responsibility and teamwork, demonstrated

fewer symptoms related to depression as compared to those with low self-ratings of other-directed strengths. The social-emotional strengths that adolescents possess may contribute to positive social experiences that can lead to positive SWB and protect against maladaptive functioning.

However, studies on the social-emotional functioning of 4 to 15-year-old children with various chronic health conditions in comparison to healthy controls have shown mixed results (Martinez, Carter, & Legato, 2011). A meta-analytic review of 57 studies found overall medium effect sizes (Cohen's  $d = -0.44$ ) on decreased social competence in children with chronic health conditions compared to those without chronic health conditions. The effects were not associated with age, gender, and ethnicity, but varied depending on the type of health condition. Specifically, children with neurological disorders and obesity had the poorest outcomes, followed by children with blood disorders. Other health condition groups either had small effect sizes or demonstrated no differences when compared to healthy controls on measure of social competence.

Among the majority of the studies reviewed, social competence was measured through parent report on the Child Behavioral Checklist. Although parent reports may be more appropriate for younger children whose social interactions are still under close parental supervision, it may be more practical to use self-reports for the adolescent population. Adolescents tend to spend more time alone and with their peers, hence their social competence may not be accurately observed by their parents. Furthermore, social-emotional measures such as the Child Behavior Checklist tend to emphasize a deficit-based approach (i.e., identification of symptoms) to assessment, failing to fully capture the positive indicators of youth's social-emotional functioning. Hence, an inclusion of a strength-based assessment may prove to be

beneficial.

Strength-based assessment focuses on youth’s social-emotional assets and is highly compatible with the assessment of SWB. There is a small but increasing number of strength-based assessment tools that have been suggested to be potentially advantageous in identifying areas for intervention, empowering youth and families, enhancing professional collaboration, and promoting hope among professionals, youth, and families (Jimerson, Sharkey, Nyborg, & Furlong, 2004). Examples of strength-based assessment tools are presented in the Table 2.

Table 2

*Strength-Based Assessment Tools for Adolescents*

Measures	Respondent (Age group)	Number of Items	Scales
Behavioral and Emotional Rating Scales-Second Edition (BERS-2; Epstein, 2004)	Self Parent Teacher (5-18)	57	Intrapersonal Strength, Interpersonal Strength, Involvement with Family, School Functioning, Affective Strength, Career Strength
Devereux Student Strengths Assessment (DESSA; LeBuffe, Shapiro, & Naglieri, 2009)	Parent Teacher (K-8th grade)	72	Personal Responsibility, Optimistic Thinking, Goal-directed Behavior, Social awareness, Decision-making Skills, Relationship Skills, Self-awareness, Self-management
Social Emotional Assets and Resilience Scales (SEARS; Merrell, 2011)	Self (Child; 8–12)	35	Self-regulation, Social Competence, Empathy, Responsibility
	(Adolescent, 13-18)		
	Parent (5–18)	39	
	Teacher (5-18)	41	

Research on the relationship between social-emotional strengths and subjective well-being is in its infancy. In an unpublished study, Frank et al. (2013) investigated the extent to which self-rated and teacher-rated social strengths predicts youth's academic achievement and mental health (both subjective well-being and psychopathology) in a sample of 425 high school students. Although weak correlations were found between self-rated and teacher-rated strengths, all of the social-emotional strength factors (as measured by SEARS-A and SEARS-T; Merrell 2011) predicted positive outcomes in youth. The increased presence of social-emotional strengths (i.e., self-regulation, social competence, empathy, and responsibility) is linked to high subjective well-being, strong academic self-perceptions, and low levels of internalizing problems. These findings suggest that evaluation of youth' social-emotional strengths may be worthwhile to broaden our current understanding of resiliency factors that promote positive functioning in youth, especially those with chronic health conditions.

The inclusion of strength-based assessment for social-emotional skills can potentially inform prevention and intervention efforts to stabilize and improve SWB and HRQOL in youth infected with HIV. As discussed previously, both SWB and HRQOL involve a strong affective component that fluctuates depending on environmental forces such as major life events and a cognitive component (e.g., life satisfaction) that is relatively stable. Possessing social emotional skills may help youth with HIV to regulate the wide range of emotions that may be associated with their medical condition and to establish positive relationship with others as means of coping. Therefore, social-emotional strengths can potentially create some stability in positive emotions and consequently increase and maintain the well-being of youth with HIV.



## **Conclusion**

The overall health-related quality of life and mental health functioning of youth with HIV are less than satisfactory when compared to their healthy counterparts (Lee et al., 2006). Because of the unique psychosocial issues associated with HIV, youth may experience a wide range of emotions (e.g., guilt, fear, and anxiety) that may affect their academic and behavioral functioning. The current understanding of the pathway to enhancing the overall well-being of youth with HIV is inadequate as most studies in the literature tend to focus on the assessment of psychopathological symptoms. Specifically, there is a dearth of studies exploring the health-related quality of life and subjective well-being factors in youth with HIV. Little is known about the life satisfaction, affective state, and social-emotional profile of youth with HIV. Therefore, it is important to understand the processes that can be put in place to buffer any risks that are related to their health condition.

As such, this study addressed the gaps in knowledge by further exploring the psychosocial outcomes of youth with HIV from a strength-based perspective using measures of positive indicators of mental health. This study explored the relationship between health-related quality of life, subjective well-being, and social-emotional strengths to develop a more comprehensive understanding of the physical and psychological well being of youth with HIV. The increased knowledge of the psychosocial consequences shared by a sample of youth with HIV can potentially provide a solid theoretical and practical framework in the design, implementation, and evaluation of comprehensive health services for this population.

## **CHAPTER THREE:**

### **METHOD**

This chapter provides a detailed explanation of the methods for this study, including a description of participant selection, the demographics of study participants, measures, data collection procedures, and ethical considerations. Finally, an overview of the plan for data analyses to examine each research question is specified.

#### **Participants**

This section begins with a description of the inclusion and exclusion criteria for the participant selection and the power analyses conducted to determine the intended sample size. Next, a description of the settings where participants were recruited is provided, followed by a discussion on the demographics of the study participants.

**Inclusionary and exclusionary criteria for youth with HIV.** Adolescents between 13-18 years of age, who were diagnosed with HIV and were aware of their HIV diagnosis for at least 6 months, were included in the study. The HIV awareness time limit criterion was established to ensure that adolescents had time to process their diagnosis and to minimize the potential effect of their initial reactions toward their diagnosis (e.g., anger, depression) on their survey responses. Those for whom English was not their primary language were excluded from the study because all the self-report measures included in the study were written in English. Eligibility for participation was determined by the healthcare team (i.e., physician, nurse, and social worker) based upon review of patient records.

**Inclusionary and exclusionary criteria for the community-based sample.** A sample of adolescents between 13-18 years of age, who reported no known chronic physical health conditions were recruited from a local community center and a local university's Upward Bound Program. Those for whom English was not their primary language were excluded from the study because all the self-report measures included in the study were written in English. Eligibility for participation was determined by child and parental reports during screening. The community-based sample was not systematically matched on demographic variables with the sample of participants with HIV, as previous research suggests a weak to modest relationship between demographic variables and well-being indicators in youth (e.g., Proctor, Linley & Maltby, 2009). However, the community-based sample was recruited from sites that serve youth in areas with similar demographics to those in the HIV group.

**Intended sample size.** To determine the number of participants necessary for this study, the G\*Power 3.1 (Faul, Erdfelder, Buchner, & Lang, 2009) program was used to assess a priori power calculations for correlation analyses, analyses of differences in correlations coefficients, multivariate analyses of variance and multiple regression.

Because of the exploratory nature of this study and focus on a specific sample of participants (adolescents with HIV), a more liberal alpha value of .10 was used. Applying medium population effect sizes based on Cohen's conventions, Table 3 presents the total number of participants required for power to be .80 for each analysis. The power of .80 is often recommended because anything smaller would result in higher risk of a Type II error (i.e., failure to reject a false null hypothesis; Cohen, 1992).

Table 3

*Total Number of Required Participants Based on A Priori Power Analyses*

Analyses	<i>N</i>
Correlations ( <i>r</i> )	98
Differences in correlations coefficients ( <i>z</i> )	282
Multivariate analyses of variances ( <i>f</i> <sup>2</sup> )	110
Multiple regression ( <i>R</i> <sup>2</sup> )	86

*Note.* Based on alpha value of .10 and medium population effect sizes.

Considering the results of the a priori power analyses, a sample size of 100 participants (50 adolescents with HIV and 50 community-based sample) met the power requirements for two out of the four analyses. Although a larger sample size was preferred, recruitment of adolescents with HIV was constrained by the fact that study recruitment was limited to a small geographic region. Table 4 presents the estimated power for small, medium, and large population effect sizes, given the intended sample size of 100 participants.

Table 4

*Estimated Power Given N=100*

Tests/Effect Sizes	Small	Medium	Large
Correlations ( <i>r</i> )	.28	.81	.99
Differences in correlations coefficients ( <i>z</i> )	.13	.43	.78
Multivariate analyses of variances ( <i>f</i> <sup>2</sup> )	.18	.76	.99
Multiple regression ( <i>R</i> <sup>2</sup> )	.26	.85	.99

*Note.* Based on an alpha value of .10.

Despite the statistical implications (e.g., under-power for the statistical analyses), small samples sizes are not uncommon in studies conducted with youth who have chronic health conditions. For example, the sample sizes for this population in studies of health-related quality of life (Jeifez-Zagigi, 2004), psychological adjustment (Bachanas et al., 2001, Bose, Moss, Brouwers, Pizzo, & Lorion, 1994; Moss, Bose, Wolters, & Brouwers, 1998), and subjective well-being (Hexdall & Huebner, 2007) ranged between 24-36 participants.

## **Setting**

**Youth with HIV.** Youth participants with HIV were recruited from University of South Florida's Pediatric and Adolescent Infectious Disease Program. The program provides comprehensive medical care to children and adolescents infected with HIV and to infants exposed to HIV and their families. Approximately 325 infected youth are currently receiving primary (e.g., comprehensive health care services and treatment management) and specialty HIV services (e.g., nutrition, social work services, and psychological services) under the program, which has several clinic locations within west central and southwest Florida. However, data for this study were collected primarily from two main clinic sites: All Children's Hospital in St. Petersburg and Children's Medical Services in Tampa, as well as two other satellite clinic sites: All Children's Hospital in Lakeland and in Sarasota. Psychosocial services are offered to all patients and may include psychological evaluation, consultation, and therapy, but the percentages of patients who took advantage of these services were unknown at the time of data collection. Assessment of the youth with HIV recruited for the study occurred at the clinics during regular scheduled clinic appointments.

**Community-based sample.** Participants from the community-based sample were recruited from two community sites. The first site, the Dream Center of Tampa Bay, is an after-school center for children and adolescents between 5-18 years of age. The center offers mentoring opportunities, computer access, homework assistance, and athletic programs to help low-income youth develop resiliency and build life skills. The second site, the University of South Florida's Upward Bound Program, is a federally funded program that provides support and academic mentoring opportunities to high school students from low-income families in their preparation for college entrance. Both sites were included in this study for two reasons: a) the

demographics of the youth they serve are similar to the demographics of participants from the HIV group and b) site directors' willingness to participate in the recruitment process.

### **Study Participants**

A total of 84 participants ( $n=42$  in each group) were recruited for the study. This final sample was less than the intended sample size ( $n=50$  in each group). During the 7-month recruitment phase (February, 2014 to September, 2014), several challenges were encountered that restricted the intended sample size. First, during this time frame there were a limited number of youth patients between 13-18 years of age served at the clinic recruitment sites. The exact number of patients within this age range was difficult to determine because of the inconsistencies in patients' engagement in their medical care. However, approximately 55 patients were included in the potential participants list, as reported by staff at the clinic sites. Second, not all of the patients had regularly scheduled clinic appointments, thus limiting the opportunity for recruitment. Third, there were high no-show and cancellation rates for scheduled appointments, mainly due to the lack of insurance and transportation problems. Lastly, four patients on the potential participants lists were not approached for the study due to ineligibility. Two of them were ineligible per IRB protocol because of their involvement with the juvenile justice system at time of recruitment and two others were siblings of participants who had already been included in the study (to prevent the violation of independent observations). Overall, 46 eligible patients were approached for the study. Four of the patients who were approached declined participation.

A revised power analysis was conducted based on the sample size of 84 participants and the power consequences of the smaller than intended sample size was found to be relatively minor. Therefore, a decision was made to conclude the recruitment process with 84 participants as justified by: a) the progress made despite the challenges, b) minor power consequences, and c)

knowledge that a small sample size is a common issue when studying a low incidence population such as youth with HIV.

**Demographics of participants.** Descriptive statistics of the demographics of all study participants are provided in Table 5. The mean age of all 84 participants included in the study was 16.07 years ( $SD=1.65$ ). The majority of the participants in both groups were females, African-Americans, and from low-income families (as reported by their free or reduced lunch status). All of the participants in the HIV group were perinatally infected. There was a significant between group difference in their biological parents' marital status. More participants in the community-based sample (33.7%) reported that their biological parents were married than participants in the HIV group (16.7%). Almost half of the participants in the HIV group (42.9%) reported that their biological parents were never married. Additionally, about 10% of the participants in the HIV group reported no knowledge of their biological parents' marital status because they were adopted at a young age. Participants in both groups most frequently endorsed that they were either living with both of their parents (who could be either biological or adoptive parents) or with their mothers only. Specifically, 23.8% of participants from the HIV group and 35.7% of participants in the community-based sample reported that they were living with both of their parents. Approximately 28.6% of participants from the HIV group and 35.7% of participants in the community-based sample indicated that they are living with their mothers only.

Table 5

*Demographics of Participants*

	Youth with HIV ( <i>n</i> = 42)		Community-based sample ( <i>n</i> = 42)		Effect sizes
	Total	Percent	Total	Percent	
<u>Age</u>					<i>d</i> =0.20
13	3	7.1	4	9.5	
14	5	11.9	7	16.7	
15	5	11.9	6	14.3	
16	7	16.7	6	14.3	
17	10	23.8	10	23.8	
18	12	28.6	9	21.4	
<u>Gender</u>					<i>w</i> =0.08
Male	13	31.0	16	38.1	
Female	29	69.0	26	61.9	
<u>Race/Ethnicity</u>					<i>w</i> =0.17
African-American	27	64.3	29	69.1	
Asian	1	2.4	2	4.8	
Caucasian	6	14.5	2	4.8	
Hispanic	5	11.9	5	11.9	
Bi-racial	3	7.1	4	9.52	
<u>Parent's Marital Status</u>					<i>w</i> =0.42
Married	7	16.7	14	33.3	
Divorced	5	11.9	9	21.4	
Separated	4	9.5	7	16.7	
Never married	18	42.9	8	19.1	
Never married, living together	0	0	2	4.8	
Widowed	4	9.5	2	4.8	
Not known	4	9.5	0	0	
<u>Living With</u>					<i>w</i> =0.40
Both parents	10	23.8	15	35.7	
Mother only	12	28.6	15	35.7	
Father only	3	7.1	1	2.4	
Mother and stepfather	3	7.1	8	19.1	
Father and stepmother	0	0	0	0	
Legal guardian	5	11.9	0	0	
Group home/Foster home	1	2.4	1	2.4	
Relatives	5	11.9	2	4.8	
Other	3	7.1	0	0	
<u>Free/Reduced Lunch Status</u>					<i>w</i> =0.12
Yes	31	73.8	34	81.0	
No	10	23.8	8	19.0	
Don't know	1	2.4	0	0	



## Measures

Five measures were used in this study. The following paragraphs provide a descriptive overview of each measure and its psychometric properties. Measures that are not copyrighted are included in the Appendices.

**Brief Demographic Questionnaire.** The Brief Demographic Questionnaire, created by the primary investigator, contained six questions regarding each adolescent's age, gender, race/ethnicity, parent's marital status, living condition, and family socioeconomic status, using free-or-reduced school lunch status as a proxy (see Appendix A). This questionnaire was completed by the youth.

**Pediatric Quality of Life Inventory (PedsQL™ 4.0).** The PedsQL™ 4.0 (Varni, Burwinkle, Seid, & Skarr, 2003) Generic Core Scales and Multidimensional Fatigue Scale were included in the study. The Generic Core Scales consist of 23-items that measure health-related quality of life (HRQOL) in children and adolescents. The adolescent self-report form is appropriate for youth between 13-18 years of age. The Generic Core Scales contain four scales: 1) Physical Functioning, 2) Emotional Functioning, 3) Social Functioning, and 4) School Functioning. All four scales were analyzed in this study. On a 5-point frequency scale ranging from 0 (*Never a problem*) to 4 (*Almost always a problem*), youth were asked how much of a problem each item has been during the past month. All items were reverse scored and transformed to a 0-100 scale (0=100, 1=75, 2=50, 3=25, and 4=0). Higher scores indicate better HRQOL. The adolescent self-report version of the Generic Core Scales has demonstrated strong internal consistency with coefficient alphas ranging from .79 (School Functioning) to .82 (Physical Functioning). This measure has been shown to significantly discriminate HRQOL of

healthy children from children with chronic health conditions, with effect sizes ranging from .52 (Social Functioning) to .81 (School Functioning) (Varni et al., 2003).

The Multidimensional Fatigue Scale consists of 18 items that measure general fatigue, sleep/rest fatigue, and cognitive fatigue in children and adolescents. The adolescent self-report form is appropriate for youth between 13-18 years of age. The scale format and scoring instructions are the same as the Generic Core Scales. The Total Fatigue score was included in the analysis of this study. Internal consistency for the Total Fatigue score was reported to be .92 (Varni, Burwinkle, Katz, Meeske, & Dickinson, 2002).

**Students' Life Satisfaction Scale (SLSS).** The SLSS (Huebner, 1991) is a 7-item self-assessment scale that measures global life satisfaction of children and adolescents between 8-18 years old (see Appendix B). On a 6-point intensity scale ranging from 1 (*Strongly Disagree*) to 6 (*Strongly Agree*), students respond to statements such as, "My life is going well" and "I have a good life." Higher mean scores represent higher levels of life satisfaction. To obtain a total score for the measure, two items were reverse-scored and the mean score was calculated across all seven items. The SLSS has strong internal consistency (Cronbach's alpha = .82) and moderate test-retest reliability at one and two weeks ( $r = .74$  and  $.68$ ). The measure was found to yield a small and non-signification correlation ( $r = .05$ ) with a social desirability measure (Huebner, 1991).

**Positive and Negative Affect Scale for Children (PANAS-C).** The PANAS-C (Laurent et al., 1999) is a 27-item self-report rating scale that consists of two subscales, with 12 items measuring positive affect (e.g., excited, proud) and 15 items measuring negative affect (e.g., sad, guilty) (see Appendix C). Both subscales were included in the study. Each item was scored on a 5-point intensity scale ranging from 1 (*Not at all*) to 5 (*Extremely*). Scores were summed for

each scale to generate an overall score for positive and negative affect. Internal consistency is reported to be .92 for both the positive and negative scales. The correlation between the positive and negative scales is -.16. This measure is appropriate for children in fourth grade and above.

It should be noted that an aggregated subjective well-being (SWB) index was obtained using scores from the SLSS and PANAS-C. In accordance with previous research (e.g., Kasser & Sheldon, 2002; Suldo & Shaffer, 2008), the SWB index was determined by adding the standardized scores for life satisfaction and positive affect scales, and then subtracting the standardized scores for the negative affect scale.

**Behavioral and Emotional Screening System-Student Form (BASC-2 BESS).** The BASC-2 BESS (Kamphaus & Reynolds, 2007) is a brief self-report measure that assesses internalizing and externalizing problems in children and adolescents. The Student Form, which is appropriate for youth between grades 3-12, contains 30 items that are rated on a 4-point frequency scale ranging from 0 (*Never*) to 3 (*Always*). Some of the items were reverse scored and the total raw scores were summed and transformed to a Total Problem *T*-Score. *T*-scores were used in the analyses. *T*-scores can range between 26 to 106, with higher scores indicating higher risk of internalizing and externalizing problems. The BASC-2 BESS Student Form is found to have high internal consistency ( $r=.92$ ) and strong validity (Kamphaus & Reynolds, 2007). Specifically, the Total Problem Score is strongly correlated with all the composite scales on the BASC-2 Self-Report Form and the ASEBA Youth Self-Report (YSR). Correlations range from .70 to .84 (Kamphaus & Reynolds, 2007).

**Social-Emotional Assets and Resiliency Scales-Adolescents (SEARS-A).** The SEARS-A (Merrell, 2011) is a 35-item self-report measure that assesses the social-emotional assets for adolescents between 13 to 18 years of age. Statements such as “I make friends easily” and “I stay

in control when I am angry” are rated on a 4-point frequency scale ranging from 0 (*Never*) to 3 (*Always*). The SEARS-A has four subscales: 1) Self-Regulation, 2) Social Competence, 3) Empathy, and 4) Responsibility. All four subscale raw scores were transformed into *T*-scores which were then used for analysis in this study. The SEARS-A has demonstrated high internal consistency with coefficient alphas ranging from .80 (Empathy) to .85 (Social Competence). Test-retest reliability at six weeks ranged from .68 (Empathy) to .81 (Self Regulation).

## **Procedures**

**Pilot study.** A brief initial pilot test was conducted to make sure the readability of all measures was appropriate for the sample of adolescents aged 13-18 years who were included in the study. A convenience sample of four adolescents (two with no known chronic health conditions and two diagnosed with a chronic health condition) were included in the pilot study. The estimated length of time to complete all of the measures was 15-20 minutes. Based on findings from the pilot study, no procedural and/or content changes were warranted.

**Recruitment of participants and ethical considerations.** Prior to recruitment and data collection, written approval was obtained from All Children’s Hospital’s Institutional Review Board (IRB) to conduct the study (see Appendix D). Convenience and purposive sampling methods were used in this study.

**Youth with HIV.** The sample of adolescents with HIV were recruited from two main clinics: All Children’s Hospital in Saint Petersburg and Children’s Medical Services in Tampa and two satellite clinics: All Children’s Hospital in Lakeland and Sarasota. It should be noted that, for this sample, a waiver for parental consent was requested from, and approved by, IRB. The rationale for this waiver is based on a number of issues. First, youth ages 13 and older in the state of Florida can consent for testing and receive treatment for HIV (Perlmutter, 2005). Second,

youth with HIV are entitled to healthcare access without parental consent and thus should be able to provide their own consent to participate in a minimal risk research study. Furthermore, some youth may not have disclosed their HIV status to their parents, limiting eligible participants to those who have informed their parents about their status. Lastly, parents who are aware of their youth's HIV status may not always participate in the youth's clinic appointments, making it difficult to reach parents for signed consent. Without the waiver of parental consent, many youth with HIV would have been prohibited from participating in this minimal risk study.

Prior to the recruitment of youth participants with HIV, a document explaining the purpose of the study and study procedures, including specific inclusion and exclusion criteria, was shared with the healthcare team at the clinic (Appendix E). The healthcare team identified potential participants who met the inclusion criteria and approached the eligible participants during their regularly scheduled clinic appointments. The healthcare team also noted if the eligible participants were perinatally or behaviorally infected. If eligible participants indicated interest in the study, they were directed to the primary investigator who met them in the clinic room.

Youth participants in the HIV group were approached directly for recruitment and participant assent (for 13-17 year olds) or consent (for 18 year olds). A detailed explanation of the study was provided to the youth at this time, both in writing and in person. If they agreed to participate, they were then asked to sign the assent form (see Appendix F) or consent form (see Appendix G). Once participant assent or consent was obtained, the demographic questionnaire and the self-report measures were administered.

*Community-based sample.* The recruitment of the community-based sample occurred in two phases. In the first phase, an indirect recruitment method was implemented. Recruitment

flyers explaining the purpose of study and participant eligibility were posted at the community center (see Appendix H). Parents who were interested in having their child participate in the study were asked to contact the primary investigator directly via the phone number or email address provided.

When contacted, the primary investigator asked the following screening questions to ensure that the inclusion criteria were met: a) Is your child between 13-17 years old?, b) Is your child's primary language English? and c) Is your child physically healthy (i.e., with no known chronic physical health conditions)? If eligibility for participation was not met, parents were thanked for their time. If eligibility for participation was met, parents were given the opportunity to discuss their concerns about their child's participation and ask questions about the study.

The first phase of recruitment lasted for a month. During this first phase, the response rate was unexpectedly low ( $n=5$ ). Therefore, a second phase of direct and active recruitment was implemented. In the second phase, information about the study was provided in writing and/or in person to youth and their parents in both of the recruitment sites. Eligibility for participation was determined based on child and parent reports. Detailed information about the study was then provided to parents to ensure their understanding of the potential risks, which were regarded to be minimal, and the benefits of participation. Parents were informed that their child's participation, or the lack thereof, would not affect their current services at the recruitment sites. Parents were then asked to sign the consent form (see Appendix I), if their child was between 13-17 years old. A detailed explanation of the study was provided to the youth at this time and they were asked to sign the assent form (see Appendix J) or consent form, if they were 18 years old (See Appendix K). Once parent consent and participant assent or consent were obtained, the

demographic questionnaire and the self-report measures were administered to the youth at the recruitment sites, where a quiet space was available.

**Data collection.** Participants were given a packet of the self-report measures previously described. The measures were counterbalanced for both groups in an effort to control for order effects. Confidentiality of responses was assured. No personal identifying information was included on the self-report measures. Each packet of measures had a unique identification number that matched the number on the participants' demographic questionnaire.

The primary investigator was present throughout the data collection phase to assist participants with questions. Participants also had the option to have the items read to them if they requested assistance. However, none of the participants requested for reading assistance. Data collection for the sample of adolescents with HIV was conducted individually at the clinic during their regularly scheduled appointments. Administration of the measures for the community-based sample was conducted individually or in small groups within the recruitment sites. A system of support was in place for follow-up and debriefing if participants experienced emotional discomfort during the completion of the questionnaires. At both the clinic and community sites, the primary investigator provided the opportunity for participants to discuss their experiences upon completion of the measures. Participants were also told that they could speak to the social worker (at the clinic sites) or site director (at the community sites) if they had further questions. None of the participants reported any experiences of discomfort during or upon completion of the study.

After each participant completed the questionnaires, the primary investigator visually scanned the measures for skipped items, and participants were asked to complete the items as needed. All participants took approximately 15-20 minutes to complete the self-report measures.

Lastly, all participants who completed the survey packet received a \$10 Walmart gift card to compensate for their time and participation.

### **Plan for Data Analyses**

The data obtained were scored by the primary investigator and entered into a password-protected Excel spreadsheet. Data accuracy checks were completed by two graduate-level research assistants. Every fifth entry in the dataset was checked and when an error was found, the entry prior to and after the error was checked as well. The data were then imported into SAS® software, Version 9.4, for data analyses.

**Preliminary analyses.** Mean, standard deviation, skewness, and kurtosis information were used to examine the distribution of the data. Additionally, the psychometric properties (e.g., internal consistency) of all the self-reported measures in the study were assessed to determine the quality of data collected. Relationships among demographic variables, group status, and the outcome variables (scores on all the self-reported measures) were examined.

**Research question one.** What is the strength and direction of the relationships among the scores on self-reported measures of health-related quality of life, subjective well-being, psychopathology, and social-emotional strengths for adolescents with HIV and a community-based sample? The data used to identify health-related quality of life included participants' scores on The PedsQL™ 4.0 Generic Core Scales (i.e., Physical Functioning, Social Functioning, Emotional Functioning, and School Functioning) and Multidimensional Fatigue Scale (i.e., Total Fatigue). Participants' scores on the SLSS and subscales scores on the PANAS-C were used to define subjective well-being. The BASC-2 BESS Total Problem Score was used to determine psychopathology. Lastly, social-emotional strengths were determined based on



participants' scores on the four subscales of the SEARS-A (i.e., Empathy, Self-Regulation, Responsibility, and Social Competence).

To answer the first research question, a correlational analysis using Pearson product-moment correlation coefficients was used to examine the relationships between all the subscales defined above. Correlational analyses were conducted separately for participants in the HIV and the community-based sample.

**Research question two.** Do the correlation coefficients among the self-reported measures of health-related quality of life, subjective well-being, psychopathology, and social-emotional strengths differ between adolescents with HIV and community-based sample? The data used to identify health-related quality of life, subjective well-being, psychopathology, and social-emotional strengths included all the subscales as described in the analyses for research question one.

The second research question was examined using a z-test. First, the Pearson's correlation coefficients for each pair of variables were transformed to Fisher's Z using the table provided by Glass and Hopkins (1996). The observed z-ratio was then obtained by dividing the group differences in z-scores with the standard error of group differences. The *p* values for each observed z-ratio were computed and then compared to the adjusted alpha value using modified Bonferroni procedure.

**Research question three.** Do the mean scores on self-reported measures of health-related quality of life, subjective well-being, psychopathology, and social-emotional strengths differ between adolescents with HIV and the community-based sample? The data used to identify health-related quality of life, subjective well-being, and social-emotional strengths are as described in the analyses for research question one. All subscale scores, except for subjective

well-being subscales, were included in the analyses.

The third research question was tested using factorial multivariate analysis of variances (MANOVA). Factorial MANOVA was considered an appropriate test because it takes into account the correlations between the multiple dependent variables of interest and provides statistical control for the demographic covariate. The independent variables included adolescents' health status and family structure (a variable constructed from parents' marital status). Data were assessed to ensure that the following statistical assumptions were met:

***Independence of observation vectors.*** This assumption was assessed by examining the nature of interaction between participants and sampling methods. Each participant completed the self-report measures independently and interactions with other participants were minimized. Participants who were closely related to one another (e.g., siblings, best friends) were excluded from the study.

***Multivariate normality of population.*** First, univariate normality was examined graphically using box plots and statistically using the Shapiro-Wilk test. Non-normality in univariate distributions would indicate non-normality in multivariate distributions. However, if all univariate distributions are normal, it is possible that the multivariate distribution is not normal (Stevens, 2009). Therefore, multivariate normality was determined by examining multivariate skewness and kurtosis. Mahalanobis distance test was conducted to assess the presence of a potential outlier. Potential outliers were found, and the data were checked again for possible data entry error. Because scores on all the variables fell within permissible range, further analyses of the outliers were conducted. Even though the assumption of multivariate normality of population was violated, MANOVA is expected to be robust to this violation (Stevens, 2009).

***Equal covariance matrices in population.*** This assumption was examined using the Box M test. A non-significant Box M test would indicate no evidence of heterogeneity of covariance matrices. Because the sample size was equal between groups, MANOVA is expected to be robust to this violation (Stevens, 2009).

Once the statistical assumptions were assessed, significant group differences in the means of the set of variables was examined by evaluating the value of Wilk's  $\lambda$ . Post-hoc analyses using modified Bonferroni adjustment were conducted to further examine the significant differences that were found.

**Research question four.** Which social-emotional strengths are most strongly predictive of the physical functioning and subjective well-being of adolescents with HIV and a community-based sample? The data used included the four social-emotional strengths (i.e., Empathy, Self-Regulation, Responsibility, and Social Competence subscales on SEARS-A), physical functioning (as measured by one of the Generic Core Scales of the PedsQL™ 4.0) and subjective well-being. An aggregated subjective well-being index was obtained by adding the standardized scores for life satisfaction and positive affect scales, and then subtracting the standardized scores for negative affect scale, based on recommended guidelines from previous research (Kasser & Sheldon, 2002).

The fourth research question was examined using multiple regression analyses. Specifically the four following statistical assumptions were assessed:

***Variables are normally distributed.*** First, the data were examined graphically using boxplots. Skewness and kurtosis values as determined and the Shapiro-Wilk test were used to provide inferential statistics on normality.

***Linear relationship between independent and dependent variables.*** To assess this assumption, an examination of residual plots (standardized residuals by the standardized predicted values) was conducted.

***No measurement error.*** To ensure that the variables were measured reliably in the study, the psychometric properties (e.g., Cronbach alphas) of all the self-reported measures were assessed.

***Homoscedasticity.*** To ensure that the variance of errors was the same across all levels of the independent variables, the data were visually examined using the residual plots (standardized residuals by the regression standardized predicted values).

Once the statistical assumptions were tested, the four social-emotional strengths were entered into the regression equation simultaneously as these variables were found to be correlated with each other. Family structure was dummy coded and entered in the equation as well. Separate analyses were conducted for each group of participants.  $R^2$  value was reported to indicate the amount of variance in self-reported physical functioning and subjective well-being that were explained by social-emotional strengths and family structure. Squared semi-partial correlation coefficients were used to determine which variables were most strongly predictive of the physical functioning and subjective well-being of adolescents with HIV and a community-based sample.

## **CHAPTER FOUR:**

### **RESULTS**

This chapter includes the results of analyses conducted to answer the research questions. First, the results from preliminary analyses and descriptive statistics are discussed. Next, the correlation analyses among the variables of interest are reported to address research questions one and two. Finally, results from the multivariate analyses of variances and regression analyses are provided to address the last two research questions.

#### **Preliminary Analyses**

**Data entry.** All the data collected were entered into a password-protected Excel spreadsheet by the primary investigator. Two research assistants then completed data integrity checks for 20% of the participants' data. Whenever an error in data entry was identified, two additional data entries before and after the error were checked. A total of 33% of the participant data were checked until no additional errors were found. During the data collection phase, all completed questionnaires were scanned for skipped items. Therefore, missing data were not an issue. All 84 cases were included in the analyses detailed in the following sections.

**Variable construction.** An aggregated subjective well-being (SWB) index was obtained using scores from the SLSS and PANAS-C. The SWB index was determined by adding the standardized scores for life satisfaction and positive affect scales, and then subtracting the standardized scores for the negative affect scale (Kasser & Sheldon, 2002; Suldo & Shaffer, 2008). The aggregated SWB variable was included in all subsequent analyses.

Table 6

*Descriptive Statistics of Scores on Self-Reported Measures for Adolescents with HIV (Top Number) and Community-Based Sample (In Parentheses)*

	$\alpha$	Mean	<i>SD</i>	<i>d</i>	Skewness	Kurtosis	CI (90%)	
							Lower	Upper
<u>Health-Related Quality of Life</u>								
Physical	.83	87.87 (87.57)	15.51 (13.78)	0.02	-1.26 (-1.30)	0.74 (1.41)	-5.03	5.63
Emotional	.82	74.76 (72.02)	21.55 (20.75)	0.13	-0.63 (-0.58)	-0.29 (-0.04)	-4.94	10.42
Social	.79	83.33 (86.19)	17.06 (17.87)	-0.16	-0.65 (-1.86)	-0.86 (4.02)	-9.20	3.48
School	.62	69.40 (72.02)	19.45 (13.88)	-0.16	0.09 (-0.51)	-1.39 (1.32)	-8.75	3.51
Total Fatigue	.92	213.59 (226.09)	57.02 (44.31)	-0.24	-0.50 (-0.37)	-0.53 (-0.57)	-31.04	6.04
<u>Subjective Well-Being</u>								
		1.90 (2.18)	1.06 (0.73)	-0.31	-0.39 (-0.97)	-0.64 (0.57)	-0.61	0.05
Life Satisfaction	.89	4.07 (4.35)	1.34 (0.82)	-0.25	-0.37 (-0.03)	-1.09 (-0.48)	-0.68	0.12
Positive Affect	.93	3.47 (3.73)	1.06 (0.75)	-0.28	-0.52 (-0.57)	-1.00 (-0.06)	-0.59	0.07
Negative Affect	.86	1.53 (1.59)	0.42 (0.48)	-0.13	1.54 (1.08)	2.05 (1.11)	-0.22	0.10
<u>Psychopathology</u>								
Problem Score	.89	38.43 (37.29)	7.91 (6.50)	0.16	0.54 (0.66)	-0.19 (-0.56)	-1.49	3.77
<u>Social-emotional Strengths</u>								
Empathy	.89	49.86 (49.83)	11.37 (11.29)	0.002	-0.24 (-0.20)	-0.98 (-0.90)	-4.08	4.14
Self-Regulation	.86	48.05 (50.81)	10.84 (10.16)	-0.26	0.66 (0.30)	0.12 (-0.67)	-6.57	1.05
Responsibility	.84	49.86 (51.19)	11.10 (10.67)	0.08	-0.03 (-0.40)	-0.78 (-0.89)	-5.25	2.65
Social Competence	.87	50.26 (50.88)	11.24 (11.06)	-0.06	0.05 (-0.23)	-0.89 (-0.97)	-4.44	3.65

**Demographic confounding variable.** Chi-square and *F*-tests were conducted to determine if any of the participants' demographic variables differed significantly between group status and the outcome variables. Biological parents' marital status was found to be significant, and therefore the variable (collapsed into four categories and renamed as family structure) was statistically controlled in subsequent multivariate tests of group differences and regression analyses.

**Distribution of data.** Descriptive statistics for the data set are presented in Table 6. The skewness and kurtosis for each of the variables were calculated to examine univariate normality. All obtained values for skewness fell between the acceptable ranges of -2.0 and 2.0, which suggest approximate normal distribution of scores on each of the variables. All the obtained values for kurtosis, except for social functioning (for community-based sample only), fell within the conventional ranges. The positive kurtosis value of >3.0 suggest that the score distribution for Social Functioning is leptokurtic. Because of a relatively small sample size in this study, the skewness and kurtosis values of each of the variables should be interpreted with caution as outliers can greatly impact the average distribution of the dataset. Further analyses of multivariate normality and multivariate outliers were conducted and results are reported in the following paragraphs, outlined under the section of multivariate analyses.

**Reliability of measures.** Prior to conducting further analyses to address the research questions, all the measures were assessed to determine internal consistency. Cronbach's alphas for each of the measures of interest are presented in Table 6. The Cronbach's alphas for each of the measures in the current study (except for School Functioning,  $\alpha=.62$ ) were at or above .79, indicating strong estimates of reliability of the measures in the given sample. Internal

consistencies of all the measures in the current study were comparable to values reported by the scale developers.

### **Correlational Analyses**

**Research question one.** The first research question examined the strength and direction of the relationships among the scores on self-reported measures of health-related quality of life, subjective well-being, psychopathology, and social-emotional strengths for adolescents with HIV and a community-based sample. To answer this research question, a correlational analysis using Pearson product-moment correlation coefficients was used to examine the relationships between all the variables of interest, separately for adolescents with HIV and the community-based sample.

The modified Bonferroni (i.e., Holm's test) was used to adjust the  $p$ -values in order to control Type I error rates as the result of multiple comparisons. The pairwise correlations were arranged in ascending positions by their lowest to highest  $p$ -values. Using alpha of 0.10, the adjusted alpha values were calculated for each position (0.10 divided by the number of tests - position in the sequence + 1). The adjusted alpha values were then compared to the obtained  $p$ -values to determine significant correlations.

Based on the obtained  $p$ -values, 71 pairs of correlations within the HIV group and 63 pairs of correlations within the community-based sample were found to be statistically significant. However, when the adjusted alpha values were applied, only 49 relationships within the HIV group (adjusted  $\alpha < .002$ ) and 23 relationships within the community-based sample (adjusted  $\alpha < .0015$ ) were found to be statistically significant. The correlations among all the variables included in the analyses are presented in Table 7. Significant correlations using the modified Bonferroni procedure are indicated by asterisks in the same table.



Table 7

*Correlations among Variables for Adolescents with HIV (Top Number) and Community-Based Sample (In Parentheses)*

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
1. PHY	-													
2. EMO	.65* (.34)	-												
3. SOC	.47* (.37)	.49* (.58)*	-											
4. SCH	.51* (.24)	.56* (.30)	.42 (.61)*	-										
5. TF	.66* (.50)*	.80* (.33)	.48* (.29)	.71* (.44)	-									
6. SWB	-.05 (-.05)	.20 (-.15)	.11 (.04)	.15 (-.09)	.18 (.13)	-								
7. LS	.18 (.05)	.52* (.36)	.24 (.33)	.34 (.06)	.44 (.22)	.89* (.76)*	-							
8. PA	.14 (.42)	.41 (.25)	.18 (.41)	.28 (.13)	.40 (.31)	.62* (.23)	.69 (.41)	-						
9. NA	-.50* (-.10)	-.72* (-.71)*	-.32 (-.39)	-.43 (-.20)	-.59* (-.10)	.07 (.37)	-.38 (-.30)	-.15 (-.15)	-					
10. TPS	-.48* (-.47)	-.66* (-.40)	-.43 (-.53)*	-.57* (-.41)*	-.72* (-.48)*	-.48* (-.16)	-.70* (-.39)	-.65* (-.59)*	.52* (.27)	-				
11. EMP	-.06 (.25)	.13 (.11)	.33 (.41)	.04 (.34)	.16 (.35)	.36 (.07)	.39 (.20)	.53* (.60)*	-.07 (-.12)	-.41* (-.59)*	-			
12. SREG	.19 (.22)	.32 (.07)	.18 (.43)	.25 (.36)	.39 (.29)	.46* (.28)	.55* (.41)	.50* (.43)	-.25 (-.14)	-.50* (-.53)*	.61* (.48)*	-		
13. RESP	.35 (.42)	.50* (.30)	.50* (.45)	.40 (.38)	.53* (.44)	.50* (.10)	.66* (.35)	.48* (.53)*	-.43 (-.31)	-.76* (-.84)*	.58* (.64)*	.58* (.62)*	-	
14. SCOM	.31 (.33)	.50* (.30)	.58* (.66)*	.40 (.35)	.48* (.35)	.49* (.06)	.61* (.28)	.57* (.69)*	-.31 (-.24)	-.66* (-.62)*	.66* (.76)*	.63* (.53)*	.71* (.59)*	-

*Note.* PHY=Physical Functioning, EMO=Emotional Functioning, SOC=Social Functioning, SCH=School Functioning, TF=Total Fatigue, SWB=Subjective Well-Being, LS=Life Satisfaction, PA=Positive Affect, NA=Negative Affect, TPS=Total Problem Score, EMP=Empathy, SREG=Self-Regulation, RESP=Responsibility, SCOM=Social Competence. \*significant correlations after modified Bonferroni adjustments, using  $\alpha=.10$ .

**Research question two.** The second research question examined the differences in the correlation coefficients among the self-reported measures of health-related quality of life, subjective well-being, psychopathology, and social-emotional strengths between adolescents with HIV and community-based sample. To answer this research question, a z-test was conducted. First, the Pearson’s correlation coefficients for each pair of variables were transformed to Fisher’s Z using the table provided by Glass and Hopkins (1996). The observed z-ratio was then obtained by dividing the group differences in z-scores with the standard error of group differences. Standard error of group differences was calculated using the following

formula:  $\sqrt{\frac{1}{n_1-3} + \frac{1}{n_2-3}}$ , which equaled to 0.226.

The *p* values for each of the observed z-ratios were computed and compared with alpha values obtained using modified Bonferroni adjustments. Based on an unadjusted alpha value of 0.10, a total of 13 pairs of correlation coefficients were found to be significantly different between the two groups. The correlation coefficient variables are presented in Table 8.

Table 8

*Significant Group Differences in Correlation Coefficients*

Variable 1	Variable 2	Observed z-ratios
Physical Functioning	Emotional Functioning	1.80
Physical Functioning	Negative Affect	-1.99
Emotional Functioning	Self-Regulation	1.94
School Functioning	Total Fatigue	1.81
Total Fatigue	Total Problem Score	-1.70
Total Fatigue	Negative Affect	-2.56
Life Satisfaction	Positive Affect	1.79
Life Satisfaction	Responsibility	1.97
Positive Affect	Subjective Well-Being	2.25
Subjective Well-Being	Total Problem Score	-2.15
Subjective Well-Being	Empathy	2.11
Subjective Well-Being	Social Competence	2.11
Subjective Well-Being	Responsibility	2.03

*p* < 0.10

The correlations of physical functioning with emotional functioning and negative affect in the HIV group were higher than the correlations in the community-based sample. Participants in the HIV group also indicated a stronger association between emotional functioning and self-regulation when compared to participants in the community-based sample. Additionally, the relationships of overall energy level (i.e., total fatigue) with school functioning, negative affect, and psychopathology (i.e., total problem score) were greater for participants in the HIV group than those in the community-based sample.

Furthermore, stronger correlations between the positive mental health indicators (i.e., subjective well-being and social-emotional strengths factors) were noted for participants in the HIV group than participants in the community-based sample. Participants in the HIV group also reported a greater negative relationship between subjective well-being and psychopathology than participants in the community-based sample. However, when modified Bonferroni adjusted alpha values were applied to the analyses to control for Type I error, significant group differences in correlation coefficients were no longer evident.

### **Multivariate Analyses of Variances**

**Research question three.** The third research question examined the differences in the mean scores on self-reported measures of health-related quality of life, subjective well-being, psychopathology, and social-emotional strengths differ between adolescents with HIV and a community-based sample. To answer this research question, a factorial multivariate analysis of variances (MANOVA) was used to control for the significant group and outcome differences in family structure. The independent variables included: a) adolescents' health status that had two levels (HIV group and community-based sample), and b) family structure (parents' marital status collapsed into four levels): 1) married, 2) divorced/separated, 3) never married/never married,

but living together, and 4) widowed/unknown. This was done in order to prevent the problem of empty cells in the factorial MANOVA analyses. Factorial MANOVA was considered an appropriate test because it takes into account the correlations between the multiple dependent variables of interest and provides statistical control. Data were assessed to ensure that the following statistical assumptions were met:

***Independence of observation vectors.*** The observations were assumed to be independent because all participants completed the questionnaires by themselves under the supervision of the primary investigator. Potential participants that were closely related to each other (e.g., close friends, siblings) were excluded from the study.

***Multivariate normality of population.*** The examination of box plots, descriptive statistics, and test of multivariate normality assumption [ $B_{1P}=26.82$ ,  $\chi^2(286, N=84)=391.25$ ,  $p<.05$ ,  $B_{2P}=150.71$ ,  $Z_{upper}=2.09$ ,  $Z_{lower}=-3.43$ ] suggest the violation of multivariate normality. Potential multivariate outliers were noted [Mahalanobis distance=30.09,  $F(11,72)=3.79$   $p<.05$ ]. Consequently, the observation with the highest distance value was removed and the values for the remaining observations were recalculated. This procedure was repeated until no potential multivariate outliers were noted, as evidenced by a non-significant  $F$ -test. The multivariate analyses were then conducted with and without the multivariate outliers. Results showed that the inclusion and exclusion of the multivariate outliers did not change the significance of the findings in this study. Therefore, all the multivariate outliers were included in the following analyses. Even though the assumption of multivariate normality of population was violated, the factorial MANOVA procedure was expected to be robust to this violation (Stevens, 2009).

***Equal covariance matrices in population.*** This assumption was examined using the Box's M test. A non-significant Box's M test [ $\chi^2(462, N=84)=126.20$ ;  $p>.05$ ] indicated a lack of

evidence that the homogeneity of variance-covariance matrix assumption was violated.

**Results of factorial MANOVA.** A 2 (Group) × 4 (Family structure) factorial MANOVA was conducted to determine if the mean scores on self-reported measures of health-related quality of life, subjective well-being, psychopathology, and social-emotional strengths differ between adolescents with HIV and the community-based sample, while taking into consideration the differences in family structure. The factorial MANOVA results are presented in Table 9.

Table 9

*Factorial MANOVA: Group Differences in the Dependent Variables (Controlled for Family Structure)*

	$\lambda$	$F$	$p$	Effect size ( $\eta^2$ )
Group	.79	1.56	.13	.21
Family Structure	.43	1.97	.002	.57
Group × Family Structure	.63	1.02	.45	.37

There was no statistical evidence for an interaction between group and family structure on the dependent variables, Wilk's  $\lambda=.63$ ,  $F(33,195.15)=1.02$ ,  $p>.10$ . The multivariate effect size and degree of association was quantified by calculating  $\eta^2$ . The obtained value of .37 indicated that approximately 37% of generalized variance in the sample set of dependent variables was accounted for by group differences and family structure.

The main effect of group differences on the dependent variables was also not significant, Wilk's  $\lambda=0.79$ ,  $F(11,66)=1.56$ ,  $p>.10$ . The obtained value of  $\eta^2=.21$  indicated that approximately 21% of generalized variance in the sample set of dependent variables was accounted for by group differences. Lastly, as expected, a significant main effect of family structure on the dependent variables was found, Wilk's  $\lambda=.43$ ,  $F(33,195.15)=1.97$ ,  $p<.10$ . The obtained value of  $\eta^2=.57$  indicated that approximately 57% of generalized variance in the sample set of dependent variables was accounted for by family structure. Univariate post-hoc analyses using modified Bonferroni adjustment (to control for Type I error rate) revealed statistically

significant family structure differences in two of the variables, social functioning and psychopathology (i.e., total problem score). Specifically, youth participants who had widowed parents or indicated no knowledge of their parents' marital status were found to report lower social functioning ( $M=58.75$ ) than participants whose parents were married ( $M=90.54$ ), divorced/separated ( $M=87.64$ ), or never married ( $M=86.42$ ). Youth participants who had widowed parents or did not have any background on their parents also reported higher risk of psychopathology symptoms ( $M=44.75$ ) when compared to participants whose parents are divorced or separated ( $M=34.49$ ).

Multivariate analyses were further conducted without the controlled variable (family structure) to explore the effect of group differences only. One-way MANOVA findings also indicated no significant group differences in youth's self-perception of health-related quality of life and mental health outcomes. Results from this supplemental analysis are included in Appendix L.

### **Multiple Regression Analyses**

**Research question four.** The last research question examined which social-emotional strengths are most strongly predictive of the physical functioning and subjective well-being of adolescents with HIV and a community-based sample. To answer this research question, multiple regression analyses were conducted. The four following statistical assumptions were assessed:

***Variables are normally distributed.*** The dataset was first examined graphically using boxplots. Skewness and kurtosis values and Shapiro-Wilk test were used to provide inferential statistics on normality. Data suggested some violations of normality and further analyses on the outliers were conducted. The outliers were found to fall within the permissible ranges of scores. Further analyses indicated that the inclusion and exclusion of the outliers did not change the

significance of the findings in the regression procedures. Therefore, all the outliers were included in the following analyses:

***Linear relationship between independent and dependent variables.*** To assess this assumption, an examination of residual plots (standardized residuals by the standardized predicted values) was conducted. Visual inspection of the residual plots did not appear to suggest a violation of this assumption.

***No measurement error.*** To ensure that the variables were measured reliably in the study, the psychometric properties (e.g., Cronbach alphas) of all the self-reported measures were assessed. The alpha values of all the self-reported measures fell within moderate to strong reliability ranges.

***Homoscedasticity.*** To ensure that the variance of errors was the same across all levels of the independent variables, the data were visually examined using the residual plots (standardized residuals by the regression standardized predicted values). Visual inspection of the residual plots did not appear to suggest a violation of this assumption.

**Results of multiple regression analyses.** The four social-emotional strengths (e.g., Empathy, Self-Regulation, Responsibility, and Social Competence) were entered into the regression equation simultaneously as these variables were found to be correlated with each other. Similar to previous analyses, the four collapsed variables for parents' marital status (family structure) were included. Family structure was dummy coded into three dichotomous variables with "never married/never married living together" as a reference group because it had the largest sample size with both group of participants combined. The dichotomous variables were then entered into the regression equation simultaneously with variables associated with social-emotional strengths. Multiple regression analyses were conducted for each dependent

variable: a) physical functioning and b) subjective well-being, separately for each group of participants.

***Social-emotional strengths as predictors of physical functioning.*** The linear combination of social-emotional strengths factors and family structure accounted for 37% of the variance in the physical functioning [ $F(7,34)=2.84, p<.05$ ] of youth with HIV. As presented in Table 10, results indicated that only one of the social-emotional strengths factors was a unique predictor of physical functioning in youth with HIV. The empathy factor ( $t=-2.88, p<.01$ ) explained the most unique variance in physical functioning (15%). The tolerance indicator (0.48) is higher than the recommended minimum level of .10 (Tabachnick & Fidell, 2007), which suggests minimal concerns with multicollinearity. It is interesting to note that the physical functioning scores for youth with HIV decreased by 0.79 point for every 1-point increase in self-perception of empathy skills, when other variables were held constant.

Table 10

*Social-Emotional Strengths Predictors of Physical Functioning in Youth with HIV (Top Number) and Community-Based Sample (In Parentheses), Controlled for Family Structure*

Variable	B	SE B	$\beta$	sr <sup>2</sup>	Tolerance
1. Empathy	-0.79 (-0.29)	0.28 (0.30)	-0.58** (-0.24)	0.15 (0.02)	0.48 (0.36)
2. Self-Regulation	0.25 (-0.12)	0.29 (0.27)	0.17 (-0.09)	0.01 (0.004)	0.47 (0.53)
3. Responsibility	0.39 (0.47)	0.30 (0.29)	0.27 (0.37)	0.03 (0.06)	0.40 (0.42)
4. Social Competence	0.39 (0.33)	0.32 (0.30)	0.28 (0.26)	0.03 (0.04)	0.36 (0.35)
5. Married	0.74 (5.82)	6.27 (5.56)	0.02 (0.20)	0.00 (0.02)	0.80 (0.59)
6. Divorced/Separated	-0.34 (7.81)	5.72 (5.70)	-0.01 (0.28)	0.00 (0.04)	0.79 (0.52)
7. Widowed/Unknown	-11.23 (-5.68)	6.15 (10.75)	-0.28* (-0.09)	0.06 (0.01)	0.57 (0.76)

\* $p<.10$  and \*\* $p<.01$



Additionally, one of the family structure categories was found to be a significant predictor of physical functioning in youth with HIV. Relative to those with parents who were never married, youth with HIV who had widowed parents or no knowledge of their parents' marital status ( $t=-1.83, p<.10$ ) were predicted to have 11.23 points lower in their physical functioning score, when other variables were held constant.

As for the group of community-based sample, the linear combination of social-emotional strengths factors and family structure, accounted for 27% of the variances in their physical functioning. However, this regression model was found non-significant [ $F(7,34)=1.80, p>.10$ ].

Multiple regression analyses were further conducted without the controlled variable (family structure) to explore the variances in youth's physical functioning explained by social-emotional strengths only. Findings indicated that empathy continues to explain the most unique variances in the physical functioning of youth with HIV, even without the controlled variable. Additionally, another social-emotional strength (responsibility) was found to be a significant predictor of physical functioning for both groups of youth. Results from this supplemental analysis are included in Appendix L.

***Social-emotional strengths as predictors of subjective well-being.*** The linear combination of social-emotional strengths factors and family structure accounted for 39% of the variance in the subjective well-being [ $F(7,34)=3.06, p<.05$ ] of youth with HIV. However, as shown in Table 11, none of the social-emotional strengths factors were found to be a significant predictor of subjective well-being in participants of the HIV group. Family structure also was not found to be a significant predictor of subjective well-being in youth with HIV.

Table 11

*Social-Emotional Strengths Predictors of Subjective Well-Being in Youth with HIV (Top Number) and Community-Based Sample (In Parentheses), Controlled for Family structure*

Variable	B	SE B	$\beta$	sr <sup>2</sup>	Tolerance
1. Empathy	0.004 (0.0004)	0.02 (0.02)	0.04 (0.007)	0.001 (0.00)	0.45 (0.36)
2. Self-Regulation	0.02 (0.03)	0.02 (0.02)	0.16 (0.46)*	0.01 (0.11)	0.47 (0.52)
3. Responsibility	0.02 (-0.01)	0.02 (0.02)	0.20 (-0.18)	0.02 (0.01)	0.40 (0.42)
4. Social Competence	0.02 (-0.001)	0.02 (0.02)	0.21 (-0.01)	0.02 (0.00)	0.36 (0.35)
5. Married	-0.58 (0.14)	0.42 (0.32)	-0.20 (0.10)	0.03 (0.005)	0.80 (0.58)
6. Divorced/Separated	0.38 (0.26)	0.38 (0.32)	0.15 (0.17)	0.02 (0.02)	0.79 (0.52)
7. Widowed/Unknown	-0.17 (0.99)	0.41 (0.61)	-0.07 (0.29)	0.003 (0.06)	0.75 (0.76)

\*p<.05

As for the group of community-based sample, the linear combination of social-emotional strengths factors and family structure accounted for 16% of the variance in their subjective well-being. However, this regression model does not significantly predict the subjective well-being of participants in the community-based sample [ $F(7,34)=0.94$ ,  $p>.10$ ]. Despite a non-significant linear combination, self-regulation was found to be a significant predictor of their subjective well-being ( $t=2.13$ ,  $p<.05$ ) and explained the most unique variance in their subjective well-being (11%). However, self-regulation is unlikely to be a meaningful predictor due to the non-significant regression model.

Multiple regression analyses were further conducted without the controlled variable (family structure) to explore the variances in youth's subjective well-being explained by social-emotional strengths only. Findings were consistent with previous analyses conducted with the controlled variable. Results from this supplemental analysis are included in Appendix L.

## **Summary of Significant Findings**

Several significant pairs of correlations were found between the variables of interest, even though some of these relationships were inconsistent between participants in the HIV and community-based sample. Specifically, a few relationships were noteworthy. For participants in the HIV group, several health-related quality of life indicators were positively correlated with life satisfaction and social-emotional strengths indicators, but negatively correlated with negative affect and psychopathology symptoms. Furthermore, stronger, but non-significant associations were found between several of the variables of interest for participants in the HIV group, when compared to participants in the community-based sample.

Additionally, results revealed a significant main effect of family structure on participants' self-ratings of their social functioning and risk for psychopathology.

When the differences in family structure were accounted for, the overall mean ratings of all the variables of interest did not significantly differ between participants in the HIV group and participants in the community-based sample.

Lastly, social-emotional factors and family structure significantly predicted physical functioning in HIV youth, but no significant or meaningful variables were found to predict their subjective-well being. For participants in the community-based sample, no significant predictors were found to predict their physical functioning or subjective well-being. Detailed discussion about these significant findings is presented in the next chapter.

## **CHAPTER FIVE:**

### **DISCUSSION**

The overarching goal of this study was to examine the health related quality of life and positive mental health indicators in youth with HIV as compared to a community-based sample. This study has four research questions. First, the study examined the correlations among the variables of health-related quality life, subjective well-being, psychopathology, and social-emotional strengths for both groups of youth. Then, the group differences in the correlation coefficients among all the variables were examined. Third, the means differences of all variables between the two groups were analyzed. Lastly, the study investigated if social-emotional strengths factors predict overall physical functioning and subjective well-being of youth with and without HIV.

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

#### **Overview of the Study**

Human Immunodeficiency Virus (HIV) is a chronic health condition that is increasingly affecting both children and adolescents. Although many studies have investigated the impact of HIV on youth's cognitive, physical, academic, and psychosocial functioning, little is known about their self-perception of health-related quality of life, psychopathology symptoms,

subjective well-being, and social-emotional well-being. Therefore, the purpose of this study was to examine the relationship between these factors in youth with HIV, in comparison to a community-based sample. The increased understanding of psychosocial consequences shared by a sample of youth with HIV can potentially inform initiatives to promote comprehensive health services for this population.

## **Discussion of Results**

**Research question one.** What is the strength and direction of the relationships among the scores on self-reported measures of health-related quality of life, subjective well-being, psychopathology, and social-emotional strengths for adolescents with HIV and a community-based sample?

For research question one, it was hypothesized that self-reports of health-related quality of life would be positively correlated with life satisfaction and positive affect while negatively correlated with negative affect. It was also hypothesized that life satisfaction and positive affect would be negatively correlated with psychopathology outcomes while positively correlated with social emotional strengths.

Findings obtained from the correlational analyses indicated that although health-related quality of life factors were positively correlated with life satisfaction and positive affect for both groups of youth, almost all of the correlations (except for emotional functioning in youth with HIV) were non-significant. These results were inconsistent with findings of previous studies indicating that positive health-related outcomes were associated with high life satisfaction and positive affect (Shaffer-Hudkins et al., 2008; Suldo & Shaffer, 2008; Zullig et al., 2005). The discrepancy in findings may be attributed to the small sample size in this study and the differences observed in the demographics of the participants compared to prior studies. The

majority of the participants in the current study (>60%) were identified as African-Americans and low socio-economic status (SES) compared to participants in previous studies, who were mostly identified as White/Caucasian with middle to high SES (Shaffer-Hudkins et al., 2008; Suldo & Shaffer, 2008; Zullig et al., 2005).

Consistent with the proposed hypothesis, negative relationships were found between health-related quality of life factors and negative affect. Specifically, physical functioning, emotional functioning, and total fatigue scales were negatively correlated with negative affect for youth with HIV. This finding indicated that lower frequency of negative emotions is associated with better physical and emotional health, as well as overall vitality. Additionally, psychopathology symptoms were found to be positively linked to negative affect and negatively correlated with life satisfaction and positive affect in youth with HIV. These findings are in accordance with results observed in the study by Shaffer-Hudkins et al. (2008). Results of the current study also indicated a positive association between life satisfaction and social-emotional strengths (for HIV group only) as well as positive affect and social-emotional strengths (for both groups). Not surprisingly, all of these variables are considered positive mental health indicators. Furthermore, as expected, higher risk of psychopathology is linked to lower health-related quality of life outcomes and lower self-perception of social-emotional functioning for both groups of participants.

These findings revealed several significant relationships that would have not otherwise been discovered if the assessment of health outcomes of youth focused merely on negative indicators such as symptoms of psychopathology. It is important to note that the absence of symptomology is not equivalent to complete health (Eiser & Morse, 1991). Therefore, these findings highlight the critical importance of addressing health outcomes holistically (i.e., positive

and negative indicators of physical and mental health) in efforts to understand and promote comprehensive wellness in youth with or without HIV.

**Research question two.** Do the correlation coefficients among the self-reported measures of health-related quality of life, subjective well-being, psychopathology, and social-emotional strengths differ between adolescents with HIV and a community-based sample?

Findings from the current study revealed several bivariate correlation pairs that presented stronger associations within the group of youth with HIV than the community-based sample. Given the modest sample size, the power to detect differences in correlation coefficients is relatively weak. The outcomes of this examination depend not only on the size of absolute differences between the coefficients but also on the sample size and the individual coefficient size of each association. In this case, relatively large differences between correlation coefficients would be necessary in order to detect statistical significance. Even though the group differences in correlations coefficients were not statistically significant based on modified Bonferroni adjustments, the differences may be meaningful for further discussion.

In comparison to youth in the community-based sample, youth with HIV reported stronger associations between their physical functioning and other health-related variables such as their emotional functioning and negative affect. Youth with HIV also reported stronger correlations between their emotional functioning and self-regulation when compared to participants in the community-based sample. Furthermore, the relationships between fatigue levels and other health-related variables such as school functioning, negative affect, and psychopathology were greater in youth with HIV when compared to youth in the community-based sample. It is particularly noteworthy that stronger correlations between the positive mental health indicators (i.e., subjective well-being and social-emotional strengths factors) were

observed for participants in the HIV group than the community-based sample. Participants in the HIV group also reported a greater negative relationship between subjective well-being and psychopathology than participants in the community-based sample. This specific finding poses the question as to whether psychopathology and subjective well-being present as opposite extremes of a bipolar continuum for youth with HIV, as opposed to being separate dimensions of functioning that can co-exist at the same levels, a notion that was supported by the dual-factor model of mental health in studies with the general youth population (Greenspoon & Saklofske, 2001; Suldo & Shaffer, 2008). Because of the small sample size, these data should be considered preliminary. However, these results are worthy of further investigation.

**Research question three.** Do the mean scores on self-reported measures of health-related quality of life, subjective well-being, psychopathology, and social-emotional strengths differ between adolescents with HIV and a community-based sample?

Two important findings emerged from this research question. As indicated in the Results section, analyses using factorial MANOVA failed to yield a statistically significant main effect of group differences on the dependent variables. The first major finding is that self-perceptions of health-related quality of life, subjective well-being, psychopathology, and social-emotional strengths of youth with HIV did not differ from the self-perceptions of the community-based sample. This result is similar to the study by Hexdall and Huebner (2007), whereby they found no significant group differences in the subjective well-being of youth with or without cancer.

There are several plausible explanations for this lack of significant differences between groups. The simplest explanation as indicated in Hexdall and Huebner's (2007) study is that the two groups of youth simply do not differ in their self-perceptions of physical and mental health outcomes at the time of this study. However, it also possible that the groups do differ in their



self-perceptions, but statistically significant differences were undetectable because of a small sample size in this current study.

As speculated by Heady and Wearing (1989), youth's self-perceptions of their health outcomes fluctuate depending on life events and return to a set-point. It is possible that the participants in the HIV group may have experienced poor health-related quality of life and mental health status upon the diagnosis or disclosure of their HIV status. It also is likely that youth with HIV become accustomed to their stressful health experiences, such that the emotional impact of the experience weakens over time. This is a psychological process known as the hedonic adaption (Lyubomirsky, 2011).

Furthermore, other studies have reported that youth who were told about their HIV status were found to have lower risk of internalizing problems compared to youth who were unaware of their HIV status (Mellins et al., 2002). Given that all of the youth included in the HIV group in the current study were aware of their diagnoses for more than six months, they may have had the opportunity to process their emotions, engage in medical care, and adapt to their health condition. As such, their self-perceptions of their current physical and mental health status might have returned to a pre-established set point at the time of comparison. Previous studies also have found that health-related quality of life and level of hope in youth with chronic health conditions tend to improve as time since their diagnosis increased (Barrera et al., 2003; Hexdall & Huebner, 2007).

It also is important to note that all participants in the HIV group were receiving medical care and prescribed specific anti-retroviral therapy at the time of this study. As discussed in Chapter Two, the lack of engagement in anti-retroviral therapy was associated with worse health outcomes in youth with HIV, when compared to their healthy counterparts (Lee et al., 2006).

Although the medical adherence rates of the participants in the study were unknown, it is possible that for those who were engaged in their prescribed anti-retroviral therapy to some degree, their health outcomes are well-managed and maintained at a level similar to those without HIV.

Additionally, the sample of youth with HIV in this study consisted only of those who were perinatally infected. The majority of youth who are perinatally infected with HIV began receiving medical care at the clinic since they were infants. Therefore, it is hypothesized that the enduring support and services that the youth received from their healthcare team (which consisted of doctors, nurses, nutritionist, and social worker) most likely contributed to the development of therapeutic relationships that not only help buffer any psychosocial risks associated with their health conditions, but also promote resiliency outcomes (Wallander & Varni, 1998).

Finally, it is plausible that the HIV condition itself has no direct effect on the youth's health-related quality of life and mental health outcomes. As suggested by Mellins et al. (2003) and Lee et al. (2006), other genetic (e.g., predisposition to psychopathology) and environmental factors (e.g., stressors related to low socio-economic status) may have a greater effect on youth's psychological functioning than the HIV infection itself.

The second major finding, which revealed a significant main effect of family structure on the set of variables, lends some support to the notion of environmental influences on youth's functioning. Specifically, statistically significant marital status differences were identified on the variables of youth's social functioning and psychopathology. Participants who had widowed parents or indicated no knowledge of their parents' marital status were found to have lower levels of social functioning when compared to participants whose parents were married, never

married, or divorced/separated. Additionally, participants who had widowed parents or indicated no knowledge of their parents' marital status reported higher risk of psychopathology when compared to participants whose parents were divorced/separated. Thus, the role of the environment, particularly family structure in this case, may have a significant bearing on youth's overall psychosocial functioning, regardless of their physical health condition.

**Research question four.** Which social-emotional strengths are most strongly predictive of the physical functioning and subjective well-being of adolescents with HIV and a community-based sample?

As previously reported in Chapter Four, family structure and empathy skills significantly predicted physical functioning in HIV youth, but no significant or meaningful variables were found to predict their subjective well-being. Specifically, findings indicated that the decrease in physical functioning scores of youth with HIV was associated with an increase in self-perception of empathy skills, when other variables were held constant.

One possible explanation for this finding is that youth with significant physical conditions may have developed strong empathy skills as a result of frequent exposure to others with similar health problems (e.g., during clinic visits, support groups) and have experienced their own emotional ups and downs throughout the course of their medical conditions (Sterling & Friedman, 1996). With the increased opportunities to empathize, youth with HIV may be internalizing the feelings of others around them, which in turn induced a sense of compassion fatigue that negatively impacts their own health. It is also likely that youth with HIV who endorsed high levels of empathy skills are more aware and sensitive to the affective changes related to their physical functioning. Therefore, they may be less susceptible to positive bias in their self-perceptions of physical health-related quality of life. Lastly, it is possible that the

relationship between empathy and physical functioning represents merely a statistical artifact associated with the multicollinearity and shared variance among the social-emotional strengths factors, rather than a meaningful prediction.

Additionally, results indicated that relative to those whose parents were never married, youth with HIV who had widowed parents or no knowledge of their parents' marital status were most likely to report lower physical functioning. This finding is important as it potentially suggests the significance of the family structure as a contributing factor to physical health outcomes in youth with HIV. Specifically within the perinatally infected youth population, family disclosure can be particularly challenging and stressful due to barriers such as maternal guilt. Additional unique stressors, such as losing a biological parent to HIV/AIDS complications, and being removed from their biological parents (e.g., due to medical neglect) and consequently placed for adoption or foster care, may affect the youth's engagement in their medical care. Therefore, addressing these family-related issues, among others, might help improve dynamics within the family that promote adequate medical and psychosocial management of the HIV condition.

Within the community-based sample, no significant social-emotional factors were found to predict their physical functioning or subjective well-being. These findings are inconsistent with a previous investigation by Frank et al. (2013), which revealed that the increase in the presence of social-emotional strengths (i.e., self-regulation, social competence, empathy, and responsibility) was associated with improved levels of subjective well-being in a community sample of high school students. This discrepancy in findings may be attributable to the comparatively smaller sample size in this current study and the differences in participants' demographics across studies. Specifically, significantly more participants in the current study

were identified as African-Americans with low socio-economic status when compared to participants in the study by Frank et al. (2013).

### **Limitations of Study**

The interpretation of the results from this study should take into consideration the presence of several limitations. First, the nature of the study called for a research design that employed correlational and non-experimental analyses. This type of research design restricts the control of extraneous variables, which impacts internal validity. The significant relationships found among the health-related quality of life, subjective well-being, psychopathology, and social-emotional variables merely suggest bivariate associations rather than causal inferences. Furthermore, extraneous variables that are not accounted for through statistical controls (i.e., factorial MANOVA) can potentially threaten the internal validity of the study.

Second, the use of self-report measures also is a potential limitation to the design of the study. Self-report rating scales rely heavily on participants' individual judgments at the time of data collection and are subject to personal bias and social desirability. However, considering that the variables of interest in this study are internal and subjective constructs, self-report measures appeared to be the most appropriate method of assessment. Besides, self-reports may be the only source of information available when working with the HIV population, as many youth may have not disclosed their health status to their family members or school personnel.

Third, population validity, which refers to the generalizability of findings outside of the sample in the study, is restricted. The participants sampled in this study have unique characteristics that could limit the application of the study findings to other population. Specifically, only participants whose primary language is English were included in the study as the self-report measures were written in English. Additionally, all of the participants in the HIV

group were perinatally infected. Therefore, it is unknown if the physical and mental health self-perceptions of the perinatally infected group would reflect the self-perceptions of youth who were behaviorally infected with HIV. It may be that youth who were behaviorally infected with HIV present worse health outcomes than those who were perinatally infected because of the recency of their diagnoses, as well as the social stigma associated with the behavioral infection.

Furthermore, the recruitment of the participants was limited to a small geographic region in the United States and a majority of the participants in this study reported low socio-economic status. These characteristics, among others that were not accounted for (e.g., symptom severity, medical adherence, other life stressors), could potentially limit the applicability of findings from this study to a larger population of youth with HIV.

Finally, the small sample size and its statistical implications represent issues for consideration as well. Although the rate of HIV is increasing within the youth population (Centers for Disease Control and Prevention, 2011), HIV is considered a low-incidence condition in youth when compared to other chronic pediatric health conditions such as cancer or diabetes. The low-incidence rate as well as other recruitment challenges discussed earlier that were unique to the pool of potential participants in the HIV population resulted in a smaller than intended sample size. The modest sample size significantly affects the power of the statistical analyses conducted in this study. Underpowered studies tend to result in greater variance of parameter estimates and increase the risk of Type II error. Considering that the alpha levels were adjusted to .10 because of the exploratory nature of the study, the risk of Type I error is also evident. These statistical implications are important to consider when interpreting the results, as findings can potentially be misleading with small sample sizes.

## **Recommendations for Future Research**

There is a significant need for additional research on the presence of, and relationship between, positive and negative mental health indicators in youth with HIV. Considering that the current study is one of the first to study subjective well-being and social-emotional functioning in youth with HIV, further replications of this study would be necessary to establish more conclusive findings on the comprehensive wellness of this specific population.

First, it would be necessary to reexamine this study with a larger sample size to increase the power of the statistical analyses and to improve the ability to detect any small significant relationships or group differences. It may also be beneficial to replicate the study with a wider range of participant demographics represented to increase generalizability of the results. It would also be important to conduct a similar study to include youth who were behaviorally infected with HIV to determine if mode of transmission has a differential effect on self-perceptions of health-related quality of life and mental health indicators.

Additionally, it would be ideal to obtain information from other sources (e.g., parents/caregivers and teachers) to complement the youth's self-reports in future studies. Although this task may be challenging in certain clinical settings because of issues related disclosure, the ability to triangulate data from multiple sources can help address the personal biases associated with self-ratings, allow for a closer examination of the physical and mental health status of youth with HIV, and improve validity of study findings.

Because the current study is considered as exploratory and the results presented are considered preliminary, a more thorough examination of health-related quality of life and mental health indicators in youth in HIV is warranted. For example, it would be interesting to investigate the factors that may be contributing to youth's perceptions of their health status and

the development of positive mental health indicators. Additionally, future studies might consider investigating whether youth's self-perceptions of their health-related and mental health status are related to the biological markers of their health status (e.g., viral loads, T-cell counts). Further examination of the possible contributing factors and relationships between these health-related variables can help inform prevention and intervention efforts to promote complete wellness in the youth population infected with HIV.

Lastly, the impact of health-related quality of life and positive mental health indicators on youth outcomes is also worth further investigation. Although there is increasing knowledge about the contributions of subjective well-being factors in the academic and behavioral outcomes of the general youth population, little is known about these relationships for the youth population with HIV. Since the trajectory of lifespan is improving for youth with HIV, and more of them are being included in general education settings, the understanding of the association between the youth's physical and mental health outcomes and their overall school functioning is essential to ensure appropriate educational and health-related planning within their learning environment.

### **Implications and Considerations for Practice**

Given the exploratory nature of the current study, results obtained from this investigation should be considered as preliminary and interpreted with caution because of the statistical implications related to small sample sizes. Even though the data are inconclusive at this point to significantly inform school psychology practices, the preliminary data underscore several valuable considerations for school psychologists when working with youth who are infected with HIV.

Based on the findings, the self-reports on the measures of subjective well-being and social-emotional strengths suggest the presence of positive mental health indicators and



resiliency factors in youth despite their medical condition. These positive indicators are aspects of functioning that are promotive and may be overlooked, if the assessments of youth are based merely on the traditional deficit model of symptom identification. Therefore, it is important for practitioners (both school-based and clinical) to consider complementing their evaluations with a strength-based component so that intervention planning can be based on capitalizing the skills that the youth already possess as a way to buffer the risk of maladaptive outcomes. Furthermore, assessments should be conducted periodically because of the variable nature of HIV progression (Chenneville, 2008). Recurring assessments allow for the youth's progress to be monitored across time and for the potential risks to their functioning to be identified early.

In addition to assessing the presence and absence of individual promotive and risk factors in youth with HIV, it is equally important to assess the environmental context that may be contributing to the overall functioning of youth. Preliminary data from this study suggest that family composition and relationship dynamics could possibly play a vital role in youth's self-perception of their physical and mental health functioning. Gaining more information about the environmental context in which the behavior occurs can help school psychologists to be more efficient in their problem-solving process to ensure that appropriate interventions are in place to address the challenges that youth with HIV are facing within the school settings.

In order to successfully obtain more information about the youth's environmental context, consultation and collaboration with the youth's family and community healthcare providers is essential. The active exchange of information between different settings has been reported by healthcare professionals to be beneficial in improving youth's functioning, promoting cross-disciplinary problem-solving, assessing youth's progress across settings, sharing resources and expertise, and in preventing duplication of services (Bradley-Klug et al., 2010).

Given the training and background that school psychologists possess in the area of communication and collaboration, they are likely in the best position to facilitate these relationships and act as a liaison between the key stakeholders who are involved in the youth's healthcare. Establishing a respectful relationship with family of the youth with HIV is particularly important because gaining their trust and confidence will help facilitate the consent procedure that will allow for the communication and collaboration process to take place.

Lastly, and most importantly, when working with youth with HIV it is important to consider the legal and ethical issues that are specific to the medical condition. Specifically, the issues of disclosure can be particularly complex within the school settings because of the social stigma associated with the condition. By law, individuals who are HIV positive do not have to disclose their status to school personnel. However, considering the unique expertise of school psychologists as educational and healthcare consultants, it is possible that the school psychologist would be the first and only school personnel to learn about a student's HIV diagnosis. Considering the increased prevalence of youth with HIV (CDC, 2011), it is essential for school psychologists as well other educators to be well informed about the legal and ethical issues to assist them in program planning and implementing the evidence-based interventions to support youth with HIV within the school settings. School psychologists can play a critical role in the professional development of school personnel regarding the best-practices in HIV prevention and intervention efforts and in working collaboratively with others to address the stigma and discrimination associated with HIV (Walsh & Chenneville, 2013).

## **Conclusion**

The current study examined the relationship among health-related quality of life, subjective well-being, psychopathology symptoms, and social-emotional strengths in youth with

HIV, in comparison to a community-based sample. Findings suggest several significant pairs of correlations between the variables of interest, even though some of these relationships were discrepant between groups. Consistent with the literature, the current study revealed several health-related quality of life indicators that were positively correlated with life satisfaction and social-emotional strengths indicators, but negatively correlated with negative affect and psychopathology symptoms, specifically for youth with HIV. Furthermore, stronger, but non-significant associations were noted between several of the variables of interest for participants in the HIV group than the community-based sample.

Additionally, results indicated a significant main effect of family structure on participants' self-ratings of their social functioning and psychopathology symptoms. Controlling for differences in family structure, the overall mean ratings on all the variables of interest did not significantly differ between groups. Finally, social-emotional factors and family structure significantly predicted physical functioning in HIV youth, but no significant or meaningful variables were found to predict their subjective well-being. No significant variables were found to predict the physical functioning or subjective well-being of youth in the community-based sample.

In summary, this study is one of the first to explore both positive and negative mental health indicators in youth with HIV. Overall findings suggest possible benefits of considering a comprehensive assessment framework to gain a better understanding of the overall well-being of youth with HIV. Increased knowledge in this area can potentially inform prevention and intervention efforts to promote resiliency in physical health, psychological functioning, and academic outcomes of this specific population.

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## **APPENDICES**

## Appendix A: Brief Demographic Questionnaire

### Brief Demographic Questionnaire

1. Your Age: \_\_\_\_\_
2. Gender:
  - Male
  - Female
3. Race/Ethnicity:
  - African American/Black
  - Asian/Pacific Islander
  - Caucasian/White
  - Hispanic
  - Native American/Alaska Native
  - Bi-racial/Multi-racial
  - Other, please specify \_\_\_\_\_
4. Your biological parents are:
  - Married
  - Divorced
  - Separated
  - Never married
  - Never married but living together
  - Widowed
5. You are living with:
  - Both parents
  - Mother only
  - Father only
  - Mother and stepfather
  - Father and stepmother
  - Legal guardian
  - Group home/foster care
  - Relatives
  - Other, please specify \_\_\_\_\_
6. Do you receive school lunch for free or at a reduced price?
  - Yes
  - No
  - Don't know

## Appendix B: Students' Life Satisfaction Scale (SLSS)

### SLSS

Directions: We would like to know what thoughts about life you have had during the past several weeks. Think about how you spend each day and night and then think about how your life has been during most of this time. Here are some questions that ask you to indicate your satisfaction with your overall life. Please circle the response that indicates the extent to which you agree or disagree with each statement. For example, if you Strongly Agree with a statement, you would circle number 6.

It is important to know what you REALLY think, so please answer the questions the way you really think, not how you should think. This is NOT a test. There are NO right or wrong answers.

	Strongly Disagree	Moderately Disagree	Mildly Disagree	Mildly Agree	Moderately Agree	Strongly Agree
1. My life is going well.	1	2	3	4	5	6
2. My life is just right.	1	2	3	4	5	6
3. I would like to change many things in my life.	1	2	3	4	5	6
4. I wish I had a different kind of life.	1	2	3	4	5	6
5. I have a good life.	1	2	3	4	5	6
6. I have what I want in life.	1	2	3	4	5	6
7. My life is better than most kids.	1	2	3	4	5	6

## Appendix C: Positive and Negative Affect Scale for Children (PANAS-C)

### PANAS-C

Directions: This scale consists of a number of words that describe different feelings and emotions. Read each item and then circle the appropriate response next to that word. Indicate to what extent you have felt this way during the past few weeks.

Feeling/Emotion	Very slightly or not at all	A little	Moderately	Quite a bit	Extremely
1. Interested	1	2	3	4	5
2. Sad	1	2	3	4	5
3. Frightened	1	2	3	4	5
4. Excited	1	2	3	4	5
5. Ashamed	1	2	3	4	5
6. Upset	1	2	3	4	5
7. Happy	1	2	3	4	5
8. Strong	1	2	3	4	5
9. Nervous	1	2	3	4	5
10. Guilty	1	2	3	4	5
11. Energetic	1	2	3	4	5
12. Scared	1	2	3	4	5
13. Calm	1	2	3	4	5
14. Miserable	1	2	3	4	5
15. Jittery	1	2	3	4	5
16. Cheerful	1	2	3	4	5
17. Active	1	2	3	4	5
18. Proud	1	2	3	4	5
19. Afraid	1	2	3	4	5
20. Joyful	1	2	3	4	5
21. Lonely	1	2	3	4	5
22. Mad	1	2	3	4	5
23. Disgusted	1	2	3	4	5
24. Delighted	1	2	3	4	5
25. Blue	1	2	3	4	5
26. Gloomy	1	2	3	4	5
27. Lively	1	2	3	4	5

## Appendix D: Institutional Review Board Approval

JHM ACH IRB  
ACH Box #9496  
FWA# 00000977  
IRB# 00001642  
727.767.4275



January 06, 2014

Tiffany Chenneville, PhD  
140 7th Ave. South, DAV 258  
St. Petersburg FL 33701

Dear Dr. Chenneville,

Your new protocol entitled, "Health-Related Quality of Life and Positive Mental Health Indicators in Youth with Human Immunodeficiency Virus (HIV)" IRB# 13-0668, Ref# 108921 was approved under the expedited review process pending administrative changes. Those changes have been received, reviewed and found to be appropriate. This will be reported at the 02/12/2014 meeting of the JHM ACH Institutional Review Board. This protocol meets the criteria 45 CFR 46.404, research not involving greater than minimal risk. This protocol meets the criteria for expedited review under research category 45 CFR 46.110 (b) (1) Category #7.

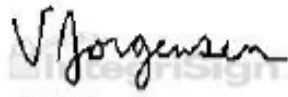
The initial approval period is for a maximum of one year. The IRB approval for this protocol will expire on 1/5/2015. Please submit your continuation request by 12/5/2014 in order to avoid lapses in approval of your research and possible suspension of subject enrollment. If during the course of the study, there are any changes or amendments, or you decide to terminate the study, please notify the JHM ACH Institutional Review Board.

As Principal Investigator of this protocol, it is your responsibility to keep the necessary documentation, and not add further responsibility to the role of nurses, pharmacists or other healthcare providers not directly involved with this study.

Per Hospital Administrative Policy No. 014-0024-9581-000-A *Research Administrative Review Process*, your protocol must receive administrative approval prior to commencing the study. For administrative review questions, please contact the Department of Research Administration at (727) 767-4813.

Thank you for your participation in the JHM ACH Institutional Review Board process. If you have any questions, please contact the office of the JHM ACH Institutional Review Board at (727) 767-4275.

Sincerely,

A handwritten signature in black ink that reads "V Jorgensen". The signature is written in a cursive style. Below the signature, there is a faint, semi-transparent watermark that says "eScribeSign".

Signature applied by Verena Jorgensen on 01/06/2014 03:06:59 PM EST

E. Verena Jorgensen, M.D.  
Chair, JHM ACH IRB

EVJ:se

JHM ACH IRB  
ACH Box #9496  
FWA# 00000977  
IRB# 00001642  
727.767.4275



January 29, 2014

Tiffany Chenneville, PhD  
140 7th Ave. South, DAV 258  
St. Petersburg FL 33701

Dear Dr. Chenneville,

Your change in procedure for the protocol entitled "Health-Related Quality of Life and Positive Mental Health Indicators in Youth with Human Immunodeficiency Virus (HIV)" IRB# 13-0668, Ref# 109123 was approved under expedited review. This will be reported at JHM ACH Institutional Review Board meeting on 03/12/2014. This change in procedure includes the request to increase the participants' age range from 13-17 years old to 13-18 years old. A revised recruitment flyer has also been submitted. This change in procedure also includes the addition of the ACH satellite clinic in Lakeland as one of the recruitment sites. This action fits the criteria for expedited review under research category 45 CFR 46.110 (b)(2).

As Principal Investigator of this protocol, it is your responsibility to keep the necessary documentation, and not add further responsibility to the role of nurses, pharmacists, or other health care providers not directly involved with this study.

Thank you for your participation in research at All Children's Hospital. If you have any questions, please contact the JHM ACH IRB office at (727) 767-4275.

Sincerely,

A handwritten signature in black ink that reads "Dawn A. Bruton". The signature is written in a cursive style. Below the signature is a faint, light blue watermark that says "IntegrSign".

File: Apr 30 10:17:24 2007

Signature applied by Dawn A. Bruton on 01/30/2014 08:16:03 AM EST





April 16, 2014

Tiffany Chenneville, PhD  
140 7th Ave. South, DAV 258  
St. Petersburg FL 33701

Dear Dr. Chenneville,

Your change in procedure for the protocol entitled "Health-Related Quality of Life and Positive Mental Health Indicators in Youth with Human Immunodeficiency Virus (HIV)" IRB# 13-0668, Ref# 109339 was approved under expedited review. This will be reported at JHM ACH Institutional Review Board meeting on 05/14/2014. This change in procedure includes the addition of another study site. Participants will also be recruited from the All Children's Hospital's satellite clinic in Sarasota. This action fits the criteria for expedited review under research category 45 CFR 46.110 (b)(2).

As Principal Investigator of this protocol, it is your responsibility to keep the necessary documentation, and not add further responsibility to the role of nurses, pharmacists, or other health care providers not directly involved with this study.

Thank you for your participation in research at All Children's Hospital. If you have any questions, please contact the JHM ACH IRB office at (727) 767-4275.

Sincerely,

A handwritten signature in black ink that reads "Rhonda Cofield". Below the signature is a small, faint digital timestamp.

Signature applied by Rhonda Cofield on 04/16/2014 10:52:03 AM EDT

Rhonda Cofield, LCSW  
Member, JHM ACH IRB

RC:se



June 11, 2014

Tiffany Chenneville, PhD  
140 7th Ave. South, DAV 258  
St. Petersburg FL 33701

Dear Dr. Chenneville,

Your change in procedure for the protocol entitled "Health-Related Quality of Life and Positive Mental Health Indicators in Youth with Human Immunodeficiency Virus (HIV)" IRB# 13-0668, Ref# 109417 was approved under expedited review. This will be reported at JHM ACH Institutional Review Board meeting on 07/09/2014. This change in procedure includes the addition of The Dream Center of Tampa Bay as a recruitment site for the healthy comparison sample. This action fits the criteria for expedited review under research category 45 CFR 46.110 (b)(2).

As Principal Investigator of this protocol, it is your responsibility to keep the necessary documentation, and not add further responsibility to the role of nurses, pharmacists, or other health care providers not directly involved with this study.

Thank you for your participation in research at All Children's Hospital. If you have any questions, please contact the JHM ACH IRB office at (727) 767-4275.

Sincerely,

A handwritten signature in black ink that reads "V. Jorgensen". The signature is written over a faint, light-colored watermark that says "iSign".

Signature applied by Verena Jorgensen on 06/11/2014 02:44:02 PM EDT

E. Verena Jorgensen, M.D.  
Chair, JHM ACH IRB

EVJ:se



August 27, 2014

Tiffany Chenneville, PhD  
140 7th Ave. South, DAV 258  
St. Petersburg FL 33701

Dear Dr. Chenneville,

Your change in procedure for the protocol entitled "Health-Related Quality of Life and Positive Mental Health Indicators in Youth with Human Immunodeficiency Virus (HIV)" IRB# 13-0668, Ref# 109627 was approved under expedited review. This will be reported at JHM ACH Institutional Review Board meeting on 09/10/2014. This change in procedure includes an additional site being added to recruit participants for the healthy comparison group. The Upward Bound Program at USF has agreed to participate as a recruitment site. Per current protocol, youth who expressed interest in the survey research will need parent consent in order to participate. This action fits the criteria for expedited review under research category 45 CFR 46.110 (b)(2).

As Principal Investigator of this protocol, it is your responsibility to keep the necessary documentation, and not add further responsibility to the role of nurses, pharmacists, or other health care providers not directly involved with this study.

Thank you for your participation in research at All Children's Hospital. If you have any questions, please contact the JHM ACH IRB office at (727) 767-4275.

Sincerely,

A handwritten signature in black ink that reads "V. Jorgensen". Below the signature is a small, faint watermark logo for "All Children's Hospital".

Signature applied by Verena Jorgensen on 08/27/2014 01:35:06 PM EDT

E. Verena Jorgensen, M.D.  
Chair, JHM ACH IRB

EVJ:se



November 19, 2014

Tiffany Chenneville, PhD  
140 7th Ave. South, DAV 258  
St. Petersburg FL 33701

Dear Dr. Chenneville,

Your renewal for the protocol entitled "Health-Related Quality of Life and Positive Mental Health Indicators in Youth with Human Immunodeficiency Virus (HIV)" IRB# 13-0668, Re# 109763 was approved and will be reported at the JHM ACH Institutional Review Board at its 12/10/2014 meeting. This protocol was determined to meet the criteria 45 CFR 46.404, research not involving greater than minimal risk. This action fits the criteria for expedited review under research category 45 CFR 46.110 (b)(1).

The IRB approval for this protocol will expire on 11/18/2015. Please submit your continuation request by 10/19/2015 in order to avoid lapses in approval of your research and possible suspension of subject enrollment. If during the course of the study, there are any changes or amendments, or you decide to terminate the study, please notify the JHM ACH Institutional Review Board.

As Principal Investigator of this protocol, it is your responsibility to keep the necessary documentation, and not add further responsibility to the role of nurses, pharmacists, or other health care providers not directly involved with this study.

If you have any questions, please contact JHM ACH IRB office (727) 767-4275.

Sincerely,

Signature applied by Verena Jorgensen on 11/19/2014 03:44:20 PM EST

E. Verena Jorgensen, M.D.  
Chair, JHM ACH IRB

EVJ:se

## **Appendix E: Study Information for Healthcare Team**

Dear Dr. \_\_\_\_\_,

This letter provides information about a study that will be conducted at the pediatric HIV clinics at All Children's Hospital and USF Children's Medical Services. This research study intends to examine the health-related quality of life and positive mental health indicators (e.g., life satisfaction, positive emotions, and social-emotional strengths) in youth diagnosed with Human Immunodeficiency Virus (HIV) in comparison with healthy youth.

The Principal Investigator of this study is Dr. Tiffany Chenneville and the Co-Investigator is Sim Yin Tan, a doctoral candidate at USF School Psychology Program. The study is Sim Yin Tan's dissertation project. Other graduate students of the program will also be assisting in this research study.

We hope to include approximately 100 youth between 13-18 years of age (50 who are diagnosed with HIV and 50 who are healthy comparisons). Youth will be asked to complete a brief demographic questionnaire and a packet of self-report measures. The completion of the self-report measures should take anywhere between 30-45 minutes. Youth who complete the study will receive a \$10 gift card.

As part of the recruitment process, we would like for you to help us identify potential participants who meet the inclusion criteria and approach the eligible participants during their regularly scheduled clinic appointments. The inclusionary and exclusionary criteria for youth with HIV are as follows:

- Adolescents between 13-18 years old, who have been diagnosed with HIV and have been aware of their HIV diagnosis for at least 6 months
- Those whom English is not their primary language will be excluded from the study because all the self-report measures included in the proposed study are written in English

If eligible participants indicate interest in the study, they will be directed to the Co-Investigator or a graduate research assistant, who will be waiting at the clinic. A detailed explanation of the study will be provided to the youth, both in writing and in person. They will be asked to sign the assent form, complete the demographic questionnaire, and self-report measures.

Further information about the study and recruitment process will be shared and discussed with the healthcare team during one of the weekly departmental meetings. In the meantime, if you have questions about this research study, please contact Dr. Tiffany Chenneville at 727-873-4585.

Thank you for your support in this study and we look forward to working with you.

## Appendix F: Letter to Participants and Participant Assent (HIV Sample)



Date: January 6, 2014  
Principal Investigator: Tiffany Chenneville, Ph.D.  
Application No.: 13-0668

### RESEARCH ASSENT FORM

**Protocol Title :** Health-Related Quality of Life and Positive Mental Health Indicators in Youth with Human Immunodeficiency Virus (HIV)

**Application No. :** 13-0668

**Principal Investigator:** Tiffany Chenneville, Ph.D.

**Date:** \_\_\_\_\_

We want to tell you about a research study we are doing. A research study is a way to learn information about something. We would like to find out more about the thoughts and feelings of teenagers infected with HIV related to their health and life in general. We also want to see if the thoughts and feelings of teenagers infected with HIV are the same or different from the thoughts and feelings of teenagers without HIV. You are being asked to join the study because you are a teenager between the ages of 13-17 years old who has been diagnosed with HIV and has been aware of your diagnosis for at least 6 months.

If you agree to join this study, you will be asked to complete a set of paper-and-pencil questionnaire. The questionnaires will ask you about your thoughts and feelings. It will take no more than 45 minutes to complete the questionnaire. Your responses will be kept private. To the best of our knowledge, your participation in this study will not hurt you. However, if some of the questions cause you to feel uneasy about yourself, please talk to us so we can find ways to help you feel better.

We do not know if you will be helped by being in this study. Your responses will help increase our knowledge of difficulties frequently encountered by teenagers with HIV and help us understand the strengths that you have to cope with these difficulties. We need to learn more about the thoughts and feelings of teenagers infected with HIV so we can help them to be successful in school and in life. We may learn something that will help others teenagers with HIV some day. As part of your participation, you will receive a \$10 gift card for completing all the questionnaires.

You do not have to join this study. It is up to you. You can say okay now, and you can change your mind later. All you have to do is tell us. No one will be mad at you if you change your mind.

Before you say yes to being in this study, we will answer any questions you have.

If you want to be in this study, please sign your name. You will get a copy of this form to keep for yourself.

\_\_\_\_\_  
(Sign your name here)

\_\_\_\_\_  
(Date)

## Appendix G: Letter to Participants and Participant Consent (HIV Sample)



Date: January 29, 2014  
Principal Investigator: Tiffany Chenneville, Ph.D.  
Application No.: 13-0668



### **RESEARCH PARTICIPANT INFORMED CONSENT AND PRIVACY AUTHORIZATION FORM**

**Protocol Title :** Health-Related Quality of Life and Positive Mental Health Indicators in Youth with Human Immunodeficiency Virus (HIV)  
**Healthy Participants**

**Application No. :** 13-0668

**Principal Investigator:** Tiffany Chenneville, Ph.D.  
Department of Psychology, University of South Florida St. Petersburg  
140 Seventh Avenue South, Davis Hall 117  
St. Petersburg, Florida 33701  
Phone: 727-873-4585 Fax: 727-873-4526

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#### **1. What you should know about this study:**

- You are being asked to join a research study.
- This consent form explains the research study and your part in the study.
- Please read it carefully and take as much time as you need.
- Please ask questions at any time about anything you do not understand.
- Ask your study doctor or the study team to explain any words or information in this informed consent that you do not understand.
- You are a volunteer. If you join the study, you can change your mind later. You can decide not to take part or you can quit at any time. There will be no penalty or loss of benefits if you decide to quit the study.
- During the study, we will tell you if we learn any new information that might affect whether you wish to continue to be in the study.
- When Johns Hopkins is used in this consent form, it includes The Johns Hopkins University, The Johns Hopkins Hospital, Johns Hopkins Bayview Medical Center, Howard County General Hospital, Johns Hopkins Community Physicians, Suburban Hospital, Sibley Memorial Hospital and All Children's Hospital.
- The Johns Hopkins School of Medicine Institutional Review Board (IRB) sometimes reviews studies that are conducted at other institutions. These other institutions are solely responsible for conducting the study safely and according to the protocol that the Johns Hopkins IRB has approved. Information about how to contact the investigator at the institution that is responsible for the study is included in this form. When another institution is conducting the study, the word "we" in this consent form may include both Johns Hopkins and the participating institution.

**2. Why is this research being done?**

This research is being done to examine the health-related quality of life and positive mental health indicators (e.g., life satisfaction, positive emotions, and social-emotional strengths) in youth with chronic health conditions in comparison with healthy teenagers.

People with no known chronic health conditions between the ages of 13-18 years old may join.

**How many people will be in this study?**

Approximately 100 youth between 13-18 years of age (50 who are diagnosed with a chronic health condition and 50 who are healthy comparisons) will participate in this study.

**3. What will happen if you join this study?**

If you agree to be in this study, we will ask you to do the following things:

You will be asked to complete a set of paper-and-pencil questionnaires. The questionnaires will ask about your perception of your physical health functioning and your feelings about yourselves.

**How long will you be in the study?**

You will be in this study for no longer than 45 minutes.

**4. What are the risks or discomforts of the study?**

There are minimal risks to you for participating in this research. You may get tired or bored when we are asking you questions. You may find it tiring or boring if you are asked to complete questionnaires. You do not have to answer any question you do not want to answer. If you experience discomfort when completing the questionnaires, participation may be terminated and a system will be in place if follow-up or a debriefing session is needed.

**5. Are there benefits to being in the study?**

There is no direct benefit to you from being in this study. If you take part in this study, you may help others in the future.

**6. What are your options if you do not want to be in the study?**

You do not have to join this study. If you do not join, your care and services at the community center or clinic will not be affected.

**7. Will it cost you anything to be in this study?**

No.

**8. Will you be paid if you join this study?**

You will be receiving a \$10 gift card for completing the study. Only those who complete the study will receive the \$10 gift card.

**9. Can you leave the study early?**

- Yes. You can leave the study at any time.
- Leaving this study early will not stop you from getting regular care and services at the community center of clinic.





Approved: January 29, 2014

Date: January 29, 2014  
Principal Investigator: Tiffany Chenneville, Ph.D.  
Application No.: 13-0668

- If you leave the study early, All Children's Hospital Johns Hopkins Medicine or the University of South Florida may use or give out your health information that it already has, if the information is needed for this study or any follow-up activities.

#### 10. Why might we take you out of the study early?

We might take you out of the study if:

- Staying in the study would be harmful.
- You need treatment not allowed in the study.
- You fail to follow instructions.
- There may be other reasons to take you out of the study that we do not know at this time.
- If you are taken out of the study early, All Children's Hospital Johns Hopkins or the University of South Florida may use or give out your health information that it already has if the information is needed for this study or any follow-up activities.

#### 11. How will your privacy be protected?

We have rules to protect information about you. Federal and state laws and the federal medical Privacy Rule also protect your privacy. By signing this form you provide your permission, called your "authorization," for the use and disclosure of information protected by the Privacy Rule.

The research team working on the study will collect information about you. This includes things learned from the procedures described in this consent form. They may also collect other information including your name, address, date of birth, and information from your medical records. This could include information about HIV and genetic testing, or treatment for drug or alcohol abuse or mental health problems.

The research team will know your identity and that you are in the research study. Other people at Johns Hopkins, particularly your doctors, may also see or give out your information. We make this information available to your doctors for your safety. If you think this study might affect your clinical care, please inform your doctor.

People outside of Johns Hopkins may need to see or receive your information for this study. Examples include government agencies (such as the Food and Drug Administration), safety monitors, other sites in the study and companies that sponsor the study.

We cannot do this study without your authorization to use and give out your information. You do not have to give us this authorization. If you do not, then you may not join this study.

We will use and disclose your information only as described in this form and in our Notice of Privacy Practices; however, people outside Johns Hopkins who receive your information may not be covered by this promise or by the federal Privacy Rule. We try to make sure that everyone who needs to see your information keeps it confidential – but we cannot guarantee that your information will not be re-disclosed.

The use and disclosure of your information has no time limit. You may revoke (cancel) your permission to use and disclose your information at any time by notifying the Principal Investigator of this study by phone or in writing. If you contact the Principal Investigator by phone, you must follow-up with a written request that includes the study number and your contact information. The Principal Investigator's name, address, phone and fax information are on page one of this consent form.

If you do cancel your authorization to use and disclose your information, your part in this study will end and no further information about you will be collected. Your revocation (cancellation) would not affect information already collected in the study, or information we disclosed before you wrote to the Principal Investigator to cancel your authorization.

Your privacy and research records will be kept confidential to the extent of the law. Authorized research personnel from University of South Florida and the Johns Hopkins All Children's Hospital Institutional Review Board may inspect records from this research study but your responses will not be shared with anyone else. Your specific responses will be assigned a code number to protect the confidentiality of his or her responses. Only the Primary Investigator, and authorized research personnel will have access to all records linking code numbers to participants' names and all information gathered during this study. All records and information will be secured in a locked file cabinet and will be destroyed in five years.

## 12. What other things should you know about this research study?

### a. What is the Institutional Review Board (IRB) and how does it protect you?

The Johns Hopkins Medicine IRB is made up of:

- Doctors
- Nurses
- Ethicists
- Non-scientists
- and people from the local community.

The IRB reviews human research studies. It protects the rights and welfare of the people taking part in those studies. You may contact the IRB if you have questions about your rights as a participant or if you think you have not been treated fairly. The IRB office number is 727-767-4275. You may also call this number for other questions, concerns or complaints about the research.

### b. What do you do if you have questions about the study?

Call the principal investigator, *Dr. Tiffany Chenneville* at 727-873-4585. If you wish, you may contact the principal investigator by letter or fax. The address and fax are on page one of this consent form. If you cannot reach the principal investigator or wish to talk to someone else, call the IRB office at 727-767-4275.

### c. What happens to Data that are collected in the study?

Johns Hopkins and our research partners work to understand and cure diseases. The data you provide are important to this effort.

If you decide to join this study, you should understand that you will not own your data, and should researchers use them to create a new product or idea, you will not benefit financially.

The information from this study will be used to increase our understanding of how perceptions of quality of life and social-emotional well-being are similar or different between youth who have HIV and those who are healthy. The aggregated group results of this study will be reported and shared through presentations and publications. The reported results will not include information that will identify you or your individual responses.



Date: January 29, 2014  
Principal Investigator: Tiffany Chenneville, Ph.D.  
Application No.: 13-0668

**13. What does your signature on this consent form mean?**

Your signature on this form means that:

- you understand the information given to you in this form
- you accept the provisions in the form
- you agree to join the study

You will not give up any legal rights by signing this consent form.

**WE WILL GIVE YOU A COPY OF THIS SIGNED AND DATED CONSENT FORM**

---

Signature of Participant (Print Name) Date/Time

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Signature of Person Obtaining Consent (Print Name) Date/Time

**NOTE: A COPY OF THE SIGNED, DATED CONSENT FORM MUST BE KEPT BY THE PRINCIPAL INVESTIGATOR; A COPY MUST BE GIVEN TO THE PARTICIPANT; AND A COPY MUST BE PLACED IN THE PARTICIPANT'S MEDICAL RECORD.**

**ONLY CONSENT FORMS THAT INCLUDE THE JOHNS HOPKINS MEDICINE LOGO CAN BE USED TO OBTAIN THE CONSENT OF RESEARCH PARTICIPANTS. IF THIS CONSENT FORM DOES NOT HAVE A JOHNS HOPKINS MEDICINE LOGO, DO NOT USE IT TO OBTAIN THE CONSENT OF RESEARCH PARTICIPANTS.**

Appendix H: Recruitment Flyer (Community-Based Sample)

## YOUTH PARTICIPANTS NEEDED FOR A RESEARCH SURVEY!

The goal of this research is to understand how youth think and feel about their health and life in general.

You may be able to participate in this research if you:

- Are between 13-18 years old
- Have no known chronic health conditions

You will be asked to complete paper-and-pencil questionnaires that will take no longer than 45 minutes. You will receive a \$10 gift card for your participation. Parent consent is required, if you are below 18 years old.

For more information, please contact:

**Sim Yin Tan**  
Co-Investigator,  
University of South  
Florida

**Phone:**  
(715) 529-5802

**Email:**  
simyintan@mail.usf.edu

Approved: January 29, 2014  
IRB # 13-0668

Youth Survey Research  
715-529-5802

Youth Survey Research  
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## Appendix I: Parent Consent Letter (Community-Based Sample)



Date: January 29, 2014  
Principal Investigator: Tiffany Chenneville, Ph.D.  
Application No.: 13-0668



### **PARENT INFORMED CONSENT AND PRIVACY AUTHORIZATION FORM**

**Protocol Title:** Health-Related Quality of Life and Positive Mental Health Indicators in Youth with Human Immunodeficiency Virus (HIV)

**Application No.:** 13-0668

**Principal Investigator:** Tiffany Chenneville, Ph.D.  
Department of Psychology, University of South Florida St. Petersburg  
140 Seventh Avenue South, Davis Hall 117  
St. Petersburg, Florida 33701  
Phone: 727-873-4585 Fax: 727-873-4526

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#### **1. What you should know about this study:**

- You are being asked to allow your child to join a research study.
- This consent form explains the research study and your child's part in the study.
- Please read it carefully and take as much time as you need.
- Please ask questions at any time about anything you do not understand.
- Ask your study doctor or the study team to explain any words or information in this informed consent that you do not understand.
- Joining this study is voluntary. If you allow your child to join the study, you can change your mind later. You can decide not to allow your child to take part at any time. There will be no penalty or loss of benefits if you decide not to allow your child to continue the study.
- When Johns Hopkins is used in this consent form, it includes The Johns Hopkins University, The Johns Hopkins Hospital, Johns Hopkins Bayview Medical Center, Howard County General Hospital, Johns Hopkins Community Physicians, Suburban Hospital, Sibley Memorial Hospital and All Children's Hospital.
- The Johns Hopkins School of Medicine All Children's Hospital Institutional Review Board (IRB) sometimes reviews studies that are conducted at other institutions. These other institutions are solely responsible for conducting the study safely and according to the protocol that the Johns Hopkins IRB has approved. Information about how to contact the investigator at the institution that is responsible for the study is included in this form. When another institution is conducting the study, the word "we" in this consent form may include both Johns Hopkins and the participating institution.

#### **2. Why is this research being done?**

This consent form provides information about a study that will be conducted at a community center or a clinic where your child receives care. The study intends to examine the health-related quality of life and



Approved: January 29, 2014

Date: January 29, 2014  
Principal Investigator: Tiffany Chenneville, Ph.D.  
Application No.: 13-0668

positive mental health indicators (e.g., life satisfaction, positive emotions, and social-emotional strengths) in youth with chronic health conditions in comparison with healthy teenagers.

Your child is being asked to participate because he or she is a physically healthy individual.

**How many children will be in this study?**

Approximately 100 youth between 13-18 years of age (50 who are diagnosed with a chronic health condition and 50 who are healthy comparisons) will participate in this study.

**3. What will happen if you allow your child to join this study?**

If you agree to allow your child to be in this study, we will ask you to allow your child to do the following things:

Your child will be asked to complete a set of paper-and-pencil questionnaires. The questionnaires will ask about your child's perception of their physical health functioning and their feelings about themselves.

**How long will your child be in the study?**

It is estimated that the participation in this study will take no longer than 45 minutes. We will personally administer the questionnaires individually or in small groups at a time that is most convenient for you and your child.

**4. What are the risks or discomforts of the study?**

There are minimal risks to your child for participating in this research. Your child may get tired or bored when we are asking her/him questions. Your child may find it tiring or boring if s/he is asked to complete questionnaires. Your child does not have to answer any question s/he does not want to answer. If your child experiences discomfort when completing the questionnaires, participation may be terminated and a system will be in place if follow-up or a debriefing session is needed.

**5. Are there benefits to your child from being in the study?**

There is no direct benefit to your child from being in this study. If your child takes part in this study, your child may help others in the future.

**6. What are your options if you do not want your child to be in the study?**

Your decision to allow your child to participate in this research study is completely voluntary. You are free to allow your child to participate in this research study or to withdraw him or her at any time. You do not have to allow your child to join this study. If your child does not take part in the study, your child's care at the community center or clinic will not be affected.

**7. Will it cost you anything to allow your child to be in this study?**

No.

**8. Will you or your child be paid if you allow your child to join this study?**

Your child will be receiving a \$10 gift card for completing the study. Only those who complete the study will receive the \$10 gift card.



Approved: January 29, 2014

Date: January 29, 2014  
Principal Investigator: Tiffany Chenneville, Ph.D.  
Application No.: 13-0668

**9. Can your child leave the study early?**

- Yes. Your child can leave the study at any time.
- Leaving this study early will not stop your child from getting regular medical care.
- If your child leaves the study early, All Children's Hospital Johns Hopkins Medicine or the University of South Florida may use or give out your child's health information that it already has, if the information is needed for this study or any follow-up activities.

**10. Why might we take your child out of the study early?**

Your child may be taken out of the study if:

- Staying in the study would be harmful.
- Your child needs treatment not allowed in the study.
- You or your child fails to follow instructions.
- There may be other reasons to take your child out of the study that we do not know at this time.
- If your child is taken out of the study early, All Children's Hospital Johns Hopkins or the University of South Florida may use or give out your child's health information that it already has if the information is needed for this study or any follow-up activities.

**11. How will your child's privacy be protected?**

We have rules to protect information about your child. Federal and state laws and the federal medical Privacy Rule also protect your child's privacy. By signing this form you provide your permission, called your "authorization," for the use and disclosure of information protected by the Privacy Rule.

The research team working on the study will collect information about your child. This includes things learned from the procedures described in this consent form. They may also collect other information including your child's name, address, date of birth, and information from your child's medical records. This could include information about HIV and genetic testing, or treatment for drug or alcohol abuse or mental health problems.

The research team will know your child's identity and that your child is in the research study. Other people at Johns Hopkins, particularly your doctors, may also see or give out your child's information. We make this information available to your child's doctors for your child's safety. If you think this study might affect your child's clinical care, please inform your child's doctor.

People outside of Johns Hopkins may need to see or receive your child's information for this study. Examples include government agencies (such as the Food and Drug Administration), safety monitors, other sites in the study and companies that sponsor the study.

We cannot do this study without your authorization to use and give out your child's information. You do not have to give us this authorization. If you do not, then you may not join this study.

We will use and disclose your child's information only as described in this form and in our Notice of Privacy Practices; however, people outside Johns Hopkins who receive your child's information may not be covered by this promise or by the federal Privacy Rule. We try to make sure that everyone who needs to see your child's information keeps it confidential – but we cannot guarantee that your information will not be re-disclosed.



Approved: January 29, 2014

Date: January 29, 2014  
Principal Investigator: Tiffany Chenneville, Ph.D.  
Application No.: 13-0668

The use and disclosure of your child's information has no time limit. You may revoke (cancel) your permission to use and disclose your child's information at any time by notifying the Principal Investigator of this study by phone or in writing. If you contact the Principal Investigator by phone, you must follow-up with a written request that includes the study number and your contact information. The Principal Investigator's name, address, phone and fax information are on page one of this consent form.

If you do cancel your authorization to use and disclose your child's information, your child's part in this study will end and no further information about your child will be collected. Your revocation (cancellation) would not affect information already collected in the study, or information we disclosed before you wrote to the Principal Investigator to cancel your authorization.

Your child's privacy and research records will be kept confidential to the extent of the law. Authorized research personnel from University of South Florida and the Johns Hopkins All Children's Hospital Institutional Review Board may inspect records from this research study but your child's responses will not be shared with anyone else. Your child's specific responses will be assigned a code number to protect the confidentiality of his or her responses. Only the Primary Investigator, and authorized research personnel will have access to all records linking code numbers to participants' names and all information gathered during this study. All records and information will be secured in a locked file cabinet and will be destroyed in five years.

## 12. What other things should you know about this research study?

### a. What is the Institutional Review Board (IRB) and how does it protect you?

The Johns Hopkins Medicine All Children's Hospital IRB is made up of:

- Doctors
- Nurses
- Ethicists
- Non-scientists
- and people from the local community.

The IRB reviews human research studies. It protects the rights and welfare of the people taking part in those studies. You may contact the IRB if you have questions about your child's rights as a participant or if you think you or your child have not been treated fairly. The IRB office number is 727-767-4275. You may also call this number for other questions, concerns or complaints about the research.

### b. What do you do if you have questions about the study?

Call the principal investigator, *Dr. Tiffany Chenneville* at 727-873-4585. If you wish, you may contact the principal investigator by letter or fax. The address and fax are on page one of this consent form. If you cannot reach the principal investigator or wish to talk to someone else, call the IRB office at 727-767-4275.

### c. What happens to Data that are collected in the study?

Johns Hopkins and our research partners work to understand and cure diseases. The data you provide are important to this effort.

If you allow your child to join this study, you should understand that you/your child will not own your child's data, and should researchers use them to create a new product or idea, you/your child will not benefit financially.





Approved: January 29, 2014

Date: January 29, 2014  
Principal Investigator: Tiffany Chenneville, Ph.D.  
Application No.: 13-0668

The information from this study will be used to increase our understanding of how perceptions of quality of life and social-emotional well-being are similar or different between youth who are healthy and those who are not healthy. The aggregated group results of this study will be reported and shared through presentations and publications. The reported results will not include information that will identify your child or your child's individual responses.

**13. Assent Statement**

This research study has been explained to my child in my presence in language my child can understand. He/she has been encouraged to ask questions about the study now and at any time in the future.

**14. What does your signature on this consent form mean?**

Your signature on this form means that:

- you understand the information given to you in this form
- you accept the provisions in the form
- you agree to allow your child to join the study

You and your child will not give up any legal rights by signing this consent form.

**WE WILL GIVE YOU A COPY OF THIS SIGNED AND DATED CONSENT FORM**

\_\_\_\_\_  
Signature of Parent (Print Name) Date/Time

\_\_\_\_\_  
Signature of Person Obtaining Consent (Print Name) Date/Time

**NOTE: A COPY OF THE SIGNED, DATED CONSENT FORM MUST BE KEPT BY THE PRINCIPAL INVESTIGATOR; A COPY MUST BE GIVEN TO THE PARTICIPANT; AND A COPY MUST BE PLACED IN THE PARTICIPANT'S MEDICAL RECORD.**

**ONLY CONSENT FORMS THAT INCLUDE THE JOHNS HOPKINS MEDICINE LOGO CAN BE USED TO OBTAIN THE CONSENT OF RESEARCH PARTICIPANTS. IF THIS CONSENT FORM DOES NOT HAVE A JOHNS HOPKINS MEDICINE LOGO, DO NOT USE IT TO OBTAIN THE CONSENT OF RESEARCH PARTICIPANTS.**

## Appendix J: Letter to Participants and Participant Assent (Community-Based Sample)



Date: January 6, 2014  
Principal Investigator: Tiffany Chenneville, Ph.D.  
Application No.: 13-0668

### RESEARCH ASSENT FORM

**Protocol Title:** Health-Related Quality of Life and Positive Mental Health Indicators in Youth with Human Immunodeficiency Virus (HIV)  
**Healthy Teenager**

**Application No.:** 13-0668

**Principal Investigator:** Tiffany Chenneville, Ph.D.

**Date:** \_\_\_\_\_

We want to tell you about a research study we are doing. A research study is a way to learn information about something. We would like to find out more about teenagers' thoughts and feelings related to their health and life in general. We also want to see if the thoughts and feelings of teenagers who are healthy are the same or different from the thoughts and feelings of teenagers who have a health condition. You are being asked to join the research study because you are healthy teenager between the ages of 13-17 years old.

If you agree to join this study, you will be asked to complete a set of paper-and-pencil questionnaires. The questionnaires will ask you about your thoughts and feelings. It will take no more than 45 minutes to complete the questionnaires. Your responses will be kept private. You will receive a \$10 gift card for completing all the questionnaires.

To the best of our knowledge, your participation in this study will not hurt you. However, if some of the questions cause you to feel uneasy about yourself, please talk to us so we can find ways to help you feel better.

We do not know if you will be helped by being in this study. Your responses will help increase our knowledge of difficulties frequently encountered by teenagers (with or without a chronic health condition) and help us understand the strengths that teenagers have to cope with the difficulties. We need to learn more about the thoughts and feelings of teenagers so we can help them to be successful in school and in life. We may learn something that will help other teenagers with chronic health conditions some day.

You do not have to join this study. It is up to you. You can say okay now, and you can change your mind later. All you have to do is tell us. No one will be mad at you if you change your mind.

Before you say yes to being in this study, we will answer any questions you have.

If you want to be in this study, please sign your name. You will get a copy of this form to keep for yourself.

\_\_\_\_\_  
(Sign your name here)

\_\_\_\_\_  
(Date)

## Appendix K: Letter to Participants and Participant Consent (Community-Based Sample)



Date: January 29, 2014  
Principal Investigator: Tiffany Chenneville, Ph.D.  
Application No.: 13-0668



### **RESEARCH PARTICIPANT INFORMED CONSENT AND PRIVACY AUTHORIZATION FORM**

**Protocol Title :** Health-Related Quality of Life and Positive Mental Health Indicators in Youth with Human Immunodeficiency Virus (HIV)

#### **Healthy Participants**

**Application No . :** 13-0668

**Principal Investigator:** Tiffany Chenneville, Ph.D.  
Department of Psychology, University of South Florida St. Petersburg  
140 Seventh Avenue South, Davis Hall 117  
St. Petersburg, Florida 33701  
Phone: 727-873-4585 Fax: 727-873-4526

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#### **1. What you should know about this study:**

- You are being asked to join a research study.
- This consent form explains the research study and your part in the study.
- Please read it carefully and take as much time as you need.
- Please ask questions at any time about anything you do not understand.
- Ask your study doctor or the study team to explain any words or information in this informed consent that you do not understand.
- You are a volunteer. If you join the study, you can change your mind later. You can decide not to take part or you can quit at any time. There will be no penalty or loss of benefits if you decide to quit the study.
- During the study, we will tell you if we learn any new information that might affect whether you wish to continue to be in the study.
- When Johns Hopkins is used in this consent form, it includes The Johns Hopkins University, The Johns Hopkins Hospital, Johns Hopkins Bayview Medical Center, Howard County General Hospital, Johns Hopkins Community Physicians, Suburban Hospital, Sibley Memorial Hospital and All Children's Hospital.
- The Johns Hopkins School of Medicine Institutional Review Board (IRB) sometimes reviews studies that are conducted at other institutions. These other institutions are solely responsible for conducting the study safely and according to the protocol that the Johns Hopkins IRB has approved. Information about how to contact the investigator at the institution that is responsible for the study is included in this form. When another institution is conducting the study, the word "we" in this consent form may include both Johns Hopkins and the participating institution.

**2. Why is this research being done?**

This research is being done to examine the health-related quality of life and positive mental health indicators (e.g., life satisfaction, positive emotions, and social-emotional strengths) in youth with chronic health conditions in comparison with healthy teenagers.

People with no known chronic health conditions between the ages of 13-18 years old may join.

**How many people will be in this study?**

Approximately 100 youth between 13-18 years of age (50 who are diagnosed with a chronic health condition and 50 who are healthy comparisons) will participate in this study.

**3. What will happen if you join this study?**

If you agree to be in this study, we will ask you to do the following things:

You will be asked to complete a set of paper-and-pencil questionnaires. The questionnaires will ask about your perception of your physical health functioning and your feelings about yourselves.

**How long will you be in the study?**

You will be in this study for no longer than 45 minutes.

**4. What are the risks or discomforts of the study?**

There are minimal risks to you for participating in this research. You may get tired or bored when we are asking you questions. You may find it tiring or boring if you are asked to complete questionnaires. You do not have to answer any question you do not want to answer. If you experiences discomfort when completing the questionnaires, participation may be terminated and a system will be in place if follow-up or a debriefing session is needed.

**5. Are there benefits to being in the study?**

There is no direct benefit to you from being in this study. If you take part in this study, you may help others in the future.

**6. What are your options if you do not want to be in the study?**

You do not have to join this study. If you do not join, your care and services at the community center or clinic will not be affected.

**7. Will it cost you anything to be in this study?**

No.

**8. Will you be paid if you join this study?**

You will be receiving a \$10 gift card for completing the study. Only those who complete the study will receive the \$10 gift card.

**9. Can you leave the study early?**

- Yes. You can leave the study at any time.
- Leaving this study early will not stop you from getting regular care and services at the community center of clinic.

- If you leave the study early, All Children's Hospital Johns Hopkins Medicine or the University of South Florida may use or give out your health information that it already has, if the information is needed for this study or any follow-up activities.

#### 10. Why might we take you out of the study early?

We might take you out of the study if:

- Staying in the study would be harmful.
- You need treatment not allowed in the study.
- You fail to follow instructions.
- There may be other reasons to take you out of the study that we do not know at this time.
- If you are taken out of the study early, All Children's Hospital Johns Hopkins or the University of South Florida may use or give out your health information that it already has if the information is needed for this study or any follow-up activities.

#### 11. How will your privacy be protected?

We have rules to protect information about you. Federal and state laws and the federal medical Privacy Rule also protect your privacy. By signing this form you provide your permission, called your "authorization," for the use and disclosure of information protected by the Privacy Rule.

The research team working on the study will collect information about you. This includes things learned from the procedures described in this consent form. They may also collect other information including your name, address, date of birth, and information from your medical records. This could include information about HIV and genetic testing, or treatment for drug or alcohol abuse or mental health problems.

The research team will know your identity and that you are in the research study. Other people at Johns Hopkins, particularly your doctors, may also see or give out your information. We make this information available to your doctors for your safety. If you think this study might affect your clinical care, please inform your doctor.

People outside of Johns Hopkins may need to see or receive your information for this study. Examples include government agencies (such as the Food and Drug Administration), safety monitors, other sites in the study and companies that sponsor the study.

We cannot do this study without your authorization to use and give out your information. You do not have to give us this authorization. If you do not, then you may not join this study.

We will use and disclose your information only as described in this form and in our Notice of Privacy Practices; however, people outside Johns Hopkins who receive your information may not be covered by this promise or by the federal Privacy Rule. We try to make sure that everyone who needs to see your information keeps it confidential – but we cannot guarantee that your information will not be re-disclosed.

The use and disclosure of your information has no time limit. You may revoke (cancel) your permission to use and disclose your information at any time by notifying the Principal Investigator of this study by phone or in writing. If you contact the Principal Investigator by phone, you must follow-up with a written request that includes the study number and your contact information. The Principal Investigator's name, address, phone and fax information are on page one of this consent form.

If you do cancel your authorization to use and disclose your information, your part in this study will end and no further information about you will be collected. Your revocation (cancellation) would not affect information already collected in the study, or information we disclosed before you wrote to the Principal Investigator to cancel your authorization.

Your privacy and research records will be kept confidential to the extent of the law. Authorized research personnel from University of South Florida and the Johns Hopkins All Children's Hospital Institutional Review Board may inspect records from this research study but your responses will not be shared with anyone else. Your specific responses will be assigned a code number to protect the confidentiality of his or her responses. Only the Primary Investigator, and authorized research personnel will have access to all records linking code numbers to participants' names and all information gathered during this study. All records and information will be secured in a locked file cabinet and will be destroyed in five years.

**12. What other things should you know about this research study?**

**a. What is the Institutional Review Board (IRB) and how does it protect you?**

The Johns Hopkins Medicine IRB is made up of:

- Doctors
- Nurses
- Ethicists
- Non-scientists
- and people from the local community.

The IRB reviews human research studies. It protects the rights and welfare of the people taking part in those studies. You may contact the IRB if you have questions about your rights as a participant or if you think you have not been treated fairly. The IRB office number is 727-767-4275. You may also call this number for other questions, concerns or complaints about the research.

**b. What do you do if you have questions about the study?**

Call the principal investigator, *Dr. Tiffany Chenneville* at 727-873-4585. If you wish, you may contact the principal investigator by letter or fax. The address and fax are on page one of this consent form. If you cannot reach the principal investigator or wish to talk to someone else, call the IRB office at 727-767-4275.

**c. What happens to Data that are collected in the study?**

Johns Hopkins and our research partners work to understand and cure diseases. The data you provide are important to this effort.

If you decide to join this study, you should understand that you will not own your data, and should researchers use them to create a new product or idea, you will not benefit financially.

The information from this study will be used to increase our understanding of how perceptions of quality of life and social-emotional well-being are similar or different between youth who have HIV and those who are healthy. The aggregated group results of this study will be reported and shared through presentations and publications. The reported results will not include information that will identify you or your individual responses.



Date: January 29, 2014  
Principal Investigator: Tiffany Chenneville, Ph.D.  
Application No.: 13-0668

**13. What does your signature on this consent form mean?**

Your signature on this form means that:

- you understand the information given to you in this form
- you accept the provisions in the form
- you agree to join the study

You will not give up any legal rights by signing this consent form.

**WE WILL GIVE YOU A COPY OF THIS SIGNED AND DATED CONSENT FORM**

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Signature of Participant (Print Name) Date/Time

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Signature of Person Obtaining Consent (Print Name) Date/Time

**NOTE: A COPY OF THE SIGNED, DATED CONSENT FORM MUST BE KEPT BY THE PRINCIPAL INVESTIGATOR; A COPY MUST BE GIVEN TO THE PARTICIPANT; AND A COPY MUST BE PLACED IN THE PARTICIPANT'S MEDICAL RECORD.**

**ONLY CONSENT FORMS THAT INCLUDE THE JOHNS HOPKINS MEDICINE LOGO CAN BE USED TO OBTAIN THE CONSENT OF RESEARCH PARTICIPANTS. IF THIS CONSENT FORM DOES NOT HAVE A JOHNS HOPKINS MEDICINE LOGO, DO NOT USE IT TO OBTAIN THE CONSENT OF RESEARCH PARTICIPANTS.**

## Appendix L: Supplemental Analyses

### Multivariate Analyses of Variances (MANOVA)

Multivariate analyses were further conducted without the controlled variable (family structure) to explore the effect of group differences only using one-way MANOVA. As indicated in Table 12, there were no significant group differences in youth's self-perception of health-related quality of life and mental health outcomes, Wilk's  $\lambda=0.90$ ,  $F(11,72)=0.72$ ,  $p>.10$ . The obtained value of  $\eta^2=.09$  indicated that approximately 9% of generalized variance in the sample set of dependent variables was accounted for by group differences.

Table 12

*MANOVA: Group Differences in the Dependent Variables*

	$\lambda$	$F$	$p$	Effect size ( $\eta^2$ )
Group	.90	0.72	.72	.09

### Multiple Regression Analyses

**Social-emotional predictors of physical functioning.** Multiple regression analyses were further conducted without the controlled variable (family structure) to explore the variances in youth's physical functioning explained by social-emotional strengths only. The linear combination of social-emotional strengths accounted for 30% of the variance in the physical functioning [ $F(4,37)=3.98$ ,  $p<.05$ ] of youth with HIV and 20% of the variance in the physical functioning [ $F(4,37)=2.32$ ,  $p<.10$ ] of youth in the community-based sample. As indicated in Table 13, empathy continues to explain the most unique variances (17%) in the physical functioning of youth with HIV, even without the controlled variable. Similar to results reported in Chapter Four, physical functioning scores for youth with HIV decreased by 0.79 point for every 1-point increase in self-perception of empathy skills, when other variables were held



constant.

Additionally, findings also revealed another significant social-emotional strengths predictor (responsibility) of physical functioning for youth with HIV ( $t=1.81, p<.10$ ) and community-based sample ( $t=2.04, p<.05$ ), when family structure was not controlled for. It is interesting to note that the physical functioning scores for both group of youth increased by 0.52 point (youth with HIV) or 0.57 point (community-based sample) for every 1-point increase in self-perception of responsibility skills, when other variables were held constant.

Table 13

*Social-Emotional Strengths Predictors of Physical Functioning in Youth with HIV (Top Number) and Community-Based Sample (In Parentheses)*

Variable	B	SE B	$\beta$	sr <sup>2</sup>	Tolerance
1. Empathy	-0.79 (-0.20)	0.27 (0.29)	-0.58** (-0.17)	0.17 (0.01)	0.49 (0.37)
2. Self-Regulation	0.13 (-0.14)	0.28 (0.26)	0.09 (-0.10)	0.004 (0.006)	0.51 (0.57)
3. Responsibility	0.52 (0.57)	0.29 (0.28)	0.37* (0.44)	0.06 (0.09)	0.45 (0.46)
4. Social Competence	0.52 (0.31)	0.31 (0.30)	0.37 (0.26)	0.05 (0.02)	0.37 (0.38)

\* $p<.10$  and \*\* $p<.01$

**Social-emotional predictors of subjective well-being.** Multiple regression analyses were further conducted without the controlled variable (family structure) to explore the variances in youth's subjective well-being explained by social-emotional strengths only. The linear combination of social-emotional strengths accounted for 31% of the variance in the subjective well-being [ $F(4,37)=4.18, p<.05$ ] of youth with HIV. However, as shown in Table 14, none of the social-emotional strengths factors were found to be a significant predictor of subjective well-being in participants of the HIV group.

As for the group of community-based sample, the linear combination of social-emotional

strengths factors accounted for 9% of the variance in their subjective well-being. However, this regression model does not significantly predict the subjective well-being of participants in the community-based sample [ $F(4,37)=0.96, p>.10$ ]. Despite a non-significant linear combination, self-regulation was found to be a significant predictor of their subjective well-being ( $t=1.85, p<.10$ ) and explained the most unique variance in their subjective well-being (8%). However, self-regulation is unlikely to be a meaningful predictor due to the non-significant regression model.

Table 14

*Social-Emotional Strengths Predictors of Subjective Well-Being in Youth with HIV (Top Number) and Community-Based Sample (In Parentheses)*

Variable	B	SE B	$\beta$	sr <sup>2</sup>	Tolerance
1. Empathy	-0.005 (0.002)	0.02 (0.01)	-0.06 (0.03)	0.001 (0.0002)	0.48 (0.37)
2. Self-Regulation	0.02 (0.02)	0.02 (0.01)	0.22* (0.38)	0.02 (0.08)	0.51 (0.57)
3. Responsibility	0.03 (-0.006)	0.02 (0.01)	0.27 (-0.09)	0.03 (0.004)	0.45 (0.46)
4. Social Competence	0.02 (-0.007)	0.02 (0.02)	0.20 (-0.11)	0.01 (-0.004)	0.37 (0.38)

\* $p<.10$