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Living with HIV: A Potential Source of Trauma in Children and Adolescents

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LIVING WITH HIV:

A POTENTIAL SOURCE OF TRAUMA IN CHILDREN AND ADOLESCENTS

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Living with HIV: A Potential Source of Trauma in Children and Adolescents

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Due to advances in medical treatment for HIV/AIDS, individuals infected with HIV are living longer. HIV is now considered a chronic illness, and there has been limited research into the mental health problems that can arise from living with HIV, particularly among children and adolescents. Past research has demonstrated that posttraumatic stress disorder (PTSD) can result from experiences related to chronic illness. Importantly, HIV could affect children and adolescents in a distinct way when compared to any other incurable, chronic illness. The present study examined the mental health issues faced by children and adolescents who are infected with HIV as well as those who are affected by HIV (i.e., have an infected family member), specifically the extent to which they experience traumatic events. The study measured how children and adolescents who are infected with and affected by HIV experience HIV-related traumatic events, such as: receiving an HIV diagnosis and witnessing HIV-related death. The study explored how children and adolescents living with HIV experience posttraumatic stress symptoms (PTSS) from these HIV-related events, as well as non-HIV-related events, and if participants meet criteria for PTSD as a result. The prevalence of additional mental health problems, such as depression and anxiety, were assessed as well. Participants were children and adolescents ages 8 to 19, and participants living with HIV were compared to clinical and community pediatric samples. Contrary to the hypotheses, children and adolescents living with HIV did not differ significantly in their levels of PTSS, anxiety and depressive symptoms, or level of psychological adjustment from clinical pediatric samples. Further, children and adolescents did not experience a greater number of non-HIV-related traumatic events when compared to those with medical problems or disabilities. While children and adolescents did not differ significantly from a pediatric sample, they still experienced elevated levels of PTSS and PTSD in relation to prevalence rates reported in the community samples, including in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5; American Psychiatric Association, 2013; Trent et al., 2013). Importantly, exploratory analyses revealed that camp experiences might be protective and beneficial for children and adolescents living with HIV, which highlights the importance of providing support for this highly vulnerable population.

Introduction

Posttraumatic stress disorder (PTSD) is a serious mental health condition that is characterized by an individual experiencing a traumatic event that involves exposure to actual or threatened death and/or serious injury (American Psychiatric Association [APA], 2013). Exposure to combat, criminal or sexual assaults, natural disasters, or manmade accidents are some of the most common traumatic events associated with PTSD, particularly in adults (Tedstone & Tarrier, 2003). However, research has also suggested that living with a chronic illness often involves exposure to actual or threatened death and/or serious injury, which satisfies Criterion A1 for PTSD (APA, 2013).

A variety of illnesses have been identified in the PTSD literature as related to the development of the disorder and its symptoms. For instance, researchers have hypothesized that the experience of cancer should be considered a traumatic stressor because it is a potentially chronic and debilitating illness that is often accompanied by a range of adverse events (Kangas et al., 2002). In cancer patients of a variety of ages, prevalence rates for both anxiety (including PTSD) and affective disorders have been reported to fall between 1% and 58% (Kangas et al., 2002). This wide range appears to be related to the variability in associated factors such as the sites of cancer, cancer status and prognosis, associated medical complications (including pain, limited physical functioning, and hospitalization status), and social support (Kangas et al., 2002). Relatively high incidence rates of both intrusive and avoidance symptoms associated with posttraumatic stress symptoms (PTSS) in male (10%) and female (20%) cancer patients as well as in advanced stage patients (21%) have been found (Kangas et al., 2002). In adolescent cancer patients, 35% of the patients met full diagnostic criteria for PTSD (Pao & Bosk, 2011).

In addition to cancer, research with cardiac surgery patients reported PTSD prevalence rates ranging from 10.8% to 18% (Tedstone & Tarrier, 2003). A study by Pao and Bosk (2011) showed that 30% of organ transplant patients exhibited posttraumatic stress symptoms. Similar to surgery patients, myocardial infarction patients have reported prevalence rates for PTSD up to 16% (Tedstone & Tarrier, 2003). Finally, Tedstone and Tarrier (2003) identified the prevalence of individuals experiencing intensive care unit (ICU) treatment who fulfill PTSD criteria to range from 14% to 49%. In adolescents in particular, 21% of ICU patients met PTSD criteria (Pao & Bosk, 2011). As the twelve-month prevalence among adults in the United States is estimated at about 3.5%, the majority of chronic illnesses result in a higher prevalence of PTSD than is experienced in the general population (APA, 2013). In addition, children living with chronic illness have been found to have significantly more mental health problems than children who are healthy, including learning problems and attentional disorders, behavioral problems, and cognitive deficits (New, Lee, & Elliott, 2007).

Although PTSD symptoms and other mental health outcomes have been studied in children and adolescents with chronic illness, a limited number of empirical studies have specifically examined the prevalence of mental health problems in HIV (human immunodeficiency virus) positive children and adolescents. The extent of new HIV infections among this age group and the difficult challenge HIV-positive children and adolescents face in managing their needs underscores the need for mental health research in this population (Radcliffe et al., 2007). Between 2002 and 2007, approximately 100,000 adolescents and young adults between the ages of 13 and 24 were infected with HIV (Radcliffe et al., 2007). According to the Center for Infectious Disease, 68,600 young people (ages 13 to 24) in the United States were living with HIV in 2008 (Center for Disease Control and Prevention, 2011). By the end of

2009, an estimated 1,148,200 persons aged 13 or older in the United States were living with an HIV infection (Center for Disease Control and Prevention, 2012). Ultimately, HIV and AIDS (acquired immunodeficiency syndrome) are a pressing concern in children and adolescents in the United States, particularly with the rise of cases in this population ("HIV Infections," 2008).

There have been dramatic improvements in the health outcomes for children born with HIV due to significant HIV treatment advances (New et al., 2007). The development of highly active antiretroviral therapy (HAART) has greatly reduced HIV mortality (Radcliffe et al., 2007). Due to the increased rate of survival among individuals infected with HIV, HIV has become a chronic disease that can be stabilized with therapy for many years (Tsasis, 2000). However, given the complex physiology of HIV, the challenges of its treatment, and its potential to affect multiple family members, children living with HIV are at an increased risk for many medical, neurological, and psychosocial issues (New et al., 2007). Because HIV is a virus that significantly weakens an individual's immune system, individuals are extremely susceptible to opportunistic infections and cancers (Gillard, Witt, & Watts, 2011). When children and adolescents are infected with HIV there are medical and neurodevelopmental consequences as a result of HIV infection, particularly of the central nervous system (CNS) (Havens, Mellins, & Pilowski, 1996). Neurological abnormalities, pneumonia, prolonged fever, diarrhea, fatigue, and mouth and skin disorders have all been recorded as potential physical symptoms of HIV/AIDS (Gillard et al., 2011). Neuroimaging studies have shown a high incidence of structural brain abnormalities in children infected with HIV, such as cortical atrophy, white matter abnormalities, and calcifications (Coscia et al., 2001). Furthermore, progressive encephalopathy has been found to occur in children infected with HIV, which is characterized by the loss of developmental milestones as well as declining IQ scores (Havens et al., 1996). In older children,

difficulties with language, concentration, attention, and memory have been noted (Havens et al., 1996). These cognitive changes resemble AIDS Dementia Complex (ADC), which often occurs in adults, and is a type of dementia that occurs in late stages of AIDS.

Treatment adherence is an extremely important component to ensure that immune function is not completely reduced. In order to prevent the development of resistant viruses and to reach stable viral suppression, 95% adherence to HAART is recommended (Davey et al., 2009). Davey and colleagues (2009) reported that poor treatment adherence is the second strongest predictor of progression from HIV to AIDS and death. In a number of studies, investigators have found that treatment adherence is often suboptimal for children and adolescents (Gillard et al., 2011). Rates of adherence have been documented as ranging between 27% and 47% in youth (ages 16 to 25) infected with HIV (Davey et al., 2009). Lack of family support, HIV stigma and disclosure-related issues, confusion, treatment skepticism, being reminded that they are HIV-infected, and medication side effects are some of the reasons listed as to why children and adolescents do not always strictly adhere to their medication regimens (Davey et al., 2009; Gillard et al., 2011).

In high numbers of children and adolescents infected with HIV, these physical effects can be amplified in home environments with prenatal drug exposure, poverty, violence, and abuse (Gillard et al., 2011). Stoff, Mitnick, and Kalichman (2004) emphasize that the HIV epidemic has shifted to more socially vulnerable populations, such as racial and ethnic minorities, the impoverished, and individuals living with HIV in addition to co-occurring mental and substance use disorders. HIV is frequently prevalent in families that already struggle with substance abuse, psychiatric disorders, and multigenerational histories of victimization and trauma (Havens et al., 1996). Furthermore, HIV/AIDS has evolved into a disease of families with children, as women

of childbearing age have become one of the groups with the fastest rising rate of HIV infection (Havens et al., 1996). Children and adolescents with HIV-infected parents may witness the deaths of their parent(s), sibling(s), or other family member(s) (Domek, 2009). This can cause HIV-positive children and adolescents to prematurely become the head of household or become institutionalized in group homes or foster care (Domek, 2009). Furthermore, children who are orphaned or institutionalized may be subjected to instability in the home environment as they are shuffled between extended family, foster homes, institutions, and/or adoptive families (Domek, 2009). In addition, if children were not infected perinatally, they are at an increased risk for their own HIV infection because they are exposed to many of the same risk factors as their HIV-infected parents (Havens et al., 1996). For instance, early exposure to substance abuse and sexual behavior, limited supervision, family history of psychiatric disorders, and learning disabilities are associated with risky sexual and drug use behaviors in adolescents (Havens et al., 1996).

Importantly, HIV may affect children in unique ways when compared to any other chronic or incurable childhood illness (Domek, 2009). Research has suggested that HIV-positive children experience stigmatization and discrimination that is distinct to this particular disease (Domek, 2009). Stigmatized children and adolescents may be socially ostracized and bullied, which is known to have detrimental mental health risks (Domek, 2009). Overall, HIV-positive children and adolescents may face emotional pain and complex feelings of loneliness, guilt, anger, confusion, depression, and anxiety (Domek, 2009). These many challenges may result in comorbid mental health conditions that can compromise the ability of HIV-infected children to manage their disease, specifically through treatment adherence, and may lead to risky or unhealthy behaviors (Radcliffe et al., 2007).

Despite what has been assumed or extrapolated from research on other chronic illnesses, there has been limited research on children and adolescents living with HIV and the mental health issues that can arise from living with a chronic, highly stigmatized illness. More mental health research has been conducted with adults living with HIV and AIDS, although this research is also sparse. Reported rates of depression in adults living with HIV are elevated compared to those in the general population and range from 5% to 42% (Boarts et al., 2006). In addition, researchers have found that depression in adults leads to changes in viral load and a faster disease progression from HIV to AIDS (Boarts et al., 2006). Israelski and colleagues (2007) also examined the prevalence rates of depression, as well as acute stress disorder and PTSD, in a sample of HIV-positive adults. Fifty-six percent of participants met symptom criteria for at least one psychiatric disorder; 43% met symptom criteria for acute stress disorder, 38% for depression, and 34% for PTSD (Israelski et al., 2007). Furthermore, 38.1% of participants met criteria for two or more psychiatric disorders. In addition, results from a recent meta-analysis conducted by Machtinger and colleagues (2012) estimated that 30% of HIV-infected women met diagnostic criteria for PTSD. Studies within the meta-analysis revealed rates as high as 74% and as low as 9.7% (Machtinger et al., 2012). Ultimately, the prevalence of posttraumatic stress disorder is elevated when compared with the prevalence rates of the general population (3.5%) (APA, 2013).

Given the criteria for PTSD, New and colleagues (2007) posited that because HIV is a chronic and life-threatening illness, multiple experiences may recur over the course of the illness during which HIV poses a threat to physical integrity or causes physical harm (PTSD criterion A1; APA, 2000). Some experiences such as the diagnosis and prognosis, noxious treatment, and disease and treatment side effects may lead to compromised physical, social, and occupational

functioning that threaten body integrity and life, which are additional symptoms of PTSD (New et al., 2007; Theuninck et al., 2010). Also, the re-experiencing of HIV-related symptoms can cause distress that interferes with daily function, and hyperarousal can interfere with both sleep and having healthy relationships (Radcliffe et al., 2007).

Along these lines, Theuninck and colleagues (2010) investigated whether a broad range of HIV-related events met criterion A1 (trauma exposure; APA, 2000) for PTSD in adults. The distressing HIV-related events studied and the percentage of participants who experienced these events as traumatic were: receiving the HIV diagnosis (55%), receiving treatment (19%), experiencing side effects (29%), experiencing HIV-related physical symptoms (40)%, self-disclosing HIV status (15%), and witnessing HIV/AIDS-related death (30%) (Theuninck et al., 2010). Theuninck and colleagues (2010) found correlations that showed that posttraumatic stress symptoms for all of these distressing HIV-related events were positively associated with the extent to which the event was perceived as a threat to physical integrity (Criterion A1) as well as with the extent to which it caused fear, helplessness, or horror (Criterion A2). Researchers found that a total of 65% of participants experienced at least one HIV-related event as traumatic and 33% met criteria for PTSD. A key finding from this study was that a wide range of events could 'threaten physical integrity' and inspire traumatic fear beyond the disease itself. Three events in this study stood out as the main predictors of experiencing posttraumatic stress symptoms: receiving treatment, experiencing physical symptoms, and witnessing HIV-related death. Theuninck and colleagues (2010) noted that each of these events capture a different aspect of living with HIV, including direct threat, social reminders, and treatment challenges.

In a related study, Nightingale and colleagues (2011) examined whether an adult population of HIV-infected individuals experienced their HIV diagnosis as a traumatic stressor

and how ongoing, HIV-related traumatic symptoms negatively impact health related quality of life (HRQL). The researchers found that 31% of the participants reported experiencing their HIV diagnosis as a traumatic stressor, as measured by the Impact of Event Scale (IES). The perception of one's HIV diagnosis as a traumatic stressor was significantly related to greater levels of HIV-related trauma symptoms, coronary artery diseases (CAD), and diminished mental HRQL. In addition, individuals with histories of prior severe traumatic stressors were found to be more likely to experience their HIV diagnosis as a traumatic stressor.

Bogart and colleagues (2011) examined PTSD and depression in people living with HIV, specifically in relation to discrimination. Based on past research that indicated that people living with HIV significantly associated PTSD and depression with internalized HIV stigma, Bogart and colleagues (2011) focused on HIV-positive participants who identified as ethnic and sexual minorities. Forty-nine percent of participants screened positive for depression, 40% screened positive for PTSD, and 27% screened positive for both depression and PTSD (Bogart et al., 2011). Of the participants who reported a traumatic event in addition to their HIV diagnosis, the most frequently identified "worst" traumatic event was being diagnosed with HIV (Bogart et al., 2011). The researchers explored the relationship between discrimination due to race/ethnicity, HIV serostatus (the presence of HIV antibodies in the bloodstream), and sexual orientation and found that all three types of discrimination were associated with high levels of depression and PTSD symptoms (arousal, avoidance, re-experiencing) (Bogart et al., 2011). However, when other types of discrimination were held constant, the only significant predictor of PTSD symptoms was HIV serostatus (Bogart et al., 2011). Forty-five percent of study participants experienced prevalent discrimination within the past year due to their HIV serostatus (29% rejected by potential sexual/romantic partners; 18% being insulted or made fun of; 17% being

ignored, excluded, or avoided by close others) (Bogart et al., 2011). Bogart and colleagues

(2011) concluded that because HIV is a trauma that can lead to PTSD, the experience of HIV-

related discrimination events may serve as a reminder of past trauma as well as aggravate PTSD

symptoms through revictimization in extreme cases (e.g., hate crimes).

Given the deleterious impact of HIV/AIDS diagnoses in adults and the correlation with

PTSD, research with children and adolescents who may be even more vulnerable is imperative.

As HIV-positive children and adolescents live longer due to HAART, both predicting and

preventing the long-term consequences of the psychological and psychosocial distress these

children face is critically significant (Domek, 2009). Preliminary research with children and

adolescents living with HIV has found that they are at an elevated risk of psychiatric

hospitalizations when compared with the general pediatric population (New et al., 2007). In a

study by Radcliffe and colleagues (2007), the researchers explored the extent to which

adolescents and young adults aged 18 to 24 years experienced potentially traumatic events,

including HIV diagnosis. There were high levels of potentially traumatic events experienced in

this population in addition to receiving a diagnosis of HIV, and the number of total traumatic

events experienced by participants was elevated relative to community samples (Radcliffe et al.,

2007). Radcliffe and colleagues (2007) found that reactions to receiving an HIV diagnosis were

as intense as reactions to other life stressors and that 93% of participants indicated that receiving

their HIV diagnosis was 'traumatic,' as measured by the Traumatic Events Screening Inventory

(TESI). The TESI was modified by Radcliffe and colleagues (2007) to include one additional

item, 'receiving an HIV diagnosis,' to the survey of potentially traumatic events. Among the 15

potentially traumatic events surveyed, the majority of participants (57%) reported traumatic

stress symptoms in response to at least one traumatic stressor. Thirty-three percent of

participants reported moderately severe levels of posttraumatic stress in response to their HIV diagnosis, and 59% of participants reported their HIV diagnosis as the "worst" traumatic event they have faced (Radcliffe et al., 2007). In relation to their HIV diagnosis, 20% of participants associated their PTSS with their HIV diagnosis, and 13% met full symptom criteria for PTSD (Radcliffe et al., 2007).

Davey and colleagues (2009) also conducted a study with youth (ages 14 to 24) infected with HIV in which the researchers retrospectively examined family support among urban minority youth. The researchers found that youth infected via their behavior choices tended to have poor family support both before and after HIV diagnosis, and HIV-positive youth frequently experienced family-associated harm after disclosing their diagnosis, such as getting kicked out of their homes (Davey et al., 2009). The family support generally ranged between mixed and unsupportive levels at both pre- and post-diagnosis, and Davey and colleagues (2009) concluded that lack of family support could have contributed to the individuals' acquisition of HIV and could also put these youth at greater risk for poor treatment adherence. Because Davey and colleagues (2009) only assessed children who acquired HIV via behavior choices, the level of family support for perinatally infected children is unknown.

Finally, another study performed by Radcliffe and colleagues (2011) explored trauma as a potential factor that contributes to high risk sexual behavior in African American young men who have sex with men (YMSM). The participants ranged in age from 16 to 24 years and were HIV positive. Fifty-five percent of the YMSM identified HIV as the "hardest" or "worst" trauma they had experienced in their lifetime. Thirty-eight percent met criteria for PTSS associated with the stressors the YMSM classified as being the "worst" (Radcliffe et al., 2011). Furthermore, higher levels of PTSS were related to increased depressive symptoms. Other research has

documented the high rates of comorbidity with PTSD and depression among adolescents (ages 12 to 17) exposed to trauma, though little is known about these diagnostic relationships in children and adolescents infected with HIV (Kilpatrick et al., 2003). Because young men in Radcliffe and colleagues' study (2011) reported higher rates of lifetime trauma than other clinical and community samples, the authors theorized that youth who experience more traumatic events during their lifetime may experience more severe posttraumatic reactions in response to future traumas. This is consistent with the "two-hit hypothesis" of trauma noted by other researchers, such as Nightingale and colleagues (2011), in which earlier traumas produce a vulnerability that exacerbates the mental health effects of a later trauma (Radcliffe et al., 2011). If an HIV/AIDS diagnosis is equivalent to a criterion A1 event according to the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM-5; APA, 2013) this has a number of deleterious implications for the likelihood that HIV- and AIDS-infected children and adolescents suffer from posttraumatic stress.

Notably, the few studies that have been conducted on youth infected with HIV utilized the PTSD criteria from the *Diagnostic and Statistical Manual, 4th Edition Text Revision* (DSM-IV-TR; APA, 2000). With the recent release of the DSM-5 (APA, 2013), the American Psychiatric Association has updated the diagnostic criteria for PTSD. Criterion A for PTSD now requires that individuals experience "exposure to actual or threatened death, serious injury, or sexual violence" through "directly experiencing the traumatic event(s), witnessing (in person) the event(s) as it occurred to others, or learning that the traumatic event(s) occurred to a close family member or close friend" (APA, 2013, p. 271). Criterion B necessitates that "intense or prolonged psychological distress at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event(s)" and/or "marked physiological reactions to internal

or external cues that symbolize or resemble an aspect of the traumatic event(s)" must be associated with the traumatic event(s) after the traumatic event(s) have occurred (p. 271). Criterion C includes "persistent avoidance of stimuli associated with the traumatic event(s)," and Criterion D involves "negative alterations in cognitions and mood associated with the traumatic event(s)" (p. 271). Criterion C could be expressed through avoidance of distressing memories, thoughts, or feelings associated with the traumatic event(s) or avoidance of external reminders, such as people, places, activities, or situations, that elicit distressing memories, thoughts, or feelings associated with the traumatic event(s). "Persistent and exaggerated negative beliefs or expectations about oneself, others or the world," "persistent negative emotional state (e.g., fear, horror, anger, guilt, or shame)," or "feelings of detachment or estrangement from others" are all examples of potential negative alterations in cognitions or moods that fall under Criterion D (p. 272). The duration of the disturbance must be more than one month, and as with DSM-IV-TR criteria, the disturbance must cause "clinically significant distress or impairment in social, occupational, or other important areas of functioning" (APA, 2013, p. 272).

Although many of the diagnostic criteria for PTSD are similar to those in the previous edition of the DSM, the diagnosis has, by definition, been expanded. To date, there is no research examining a diagnosis of PTSD in relation to HIV based on the new criteria in the DSM-5. Though the relatively few changes to the diagnostic criteria suggest that the previously identified associations between DSM-IV-TR criteria for PTSD with an HIV diagnosis are likely applicable, the overall paucity of research in HIV-infected children and adolescents and PTSD remains an important area for further inquiry. In addition, the removal of PTSD from anxiety disorders in the DSM-5 suggests that trauma-related disorders and anxiety disorders should be analyzed separately, and no research has been conducted to understand the relationships between

internalizing symptoms (i.e., anxiety, depression) and PTSD in HIV-infected children and adolescents. Furthermore, in the studies that have been conducted with adolescents and the DSM-IV, there were limitations in sample size, population diversity, and potential confounds due to the participants experiencing a high number of other traumatic events. In addition, the majority of psychological HIV research conducted is centered on adults, which cannot necessarily be generalized to children and adolescents (Melvin & Sherr, 1995). The burdens of secrecy, bereavement, and illness are challenges many children and adolescents are not equipped or experienced in facing (Melvin & Sherr, 1995). Children and adolescents who have experienced trauma, generally, are at a greater risk for major depression, suicide attempts, personality disorders, impaired social relationships, substance abuse, delinquent behavior, and physical injuries (Radcliffe et al., 2007). The specific threatening or overwhelming aspects of the experience of living with HIV are relatively unknown as well as which aspects of the experience could qualify for a PTSD diagnosis (Theuninck et al., 2010). Given past research that posits adolescents exposed to trauma early in childhood are more at risk of developing PTSD in response to their HIV diagnosis, the exploration of mental health needs in children and adolescents with HIV is vital and could have specific implications for treatment adherence and disease progression (New et al., 2007).

Finally, although there is research documenting a strong relationship between PTSD and gender, such that Kilpatrick and colleagues (2003) demonstrated that approximately twice the proportion of girls than boys met PTSD criteria (6.3% vs. 3.7%), it is unknown how the role of gender may contribute to a relationship between PTSD and HIV status in children and adolescents. Thus, these types of exploratory analyses are warranted in this population.

Hypotheses

The current project focused on the extent to which HIV-infected and HIV-affected children and adolescents experience potentially traumatic events related to their disease experience, such as receiving an HIV diagnosis, receiving treatment, treatment adherence, physical symptoms, self-disclosing HIV status, stigmatization and discrimination, and witnessing HIV-related death. Children and adolescents were also assessed for other, non-HIV-related traumatic events. The magnitude to which posttraumatic stress symptoms (PTSS) are experienced in this population was explored. It was hypothesized that HIV-infected and HIV-affected children and adolescents experience elevated levels of PTSS compared to a broadly traumatized clinical and community pediatric sample. Further, it was hypothesized that HIV-infected and HIV-affected children and adolescents experience a greater number of non-HIV-related traumatic events, on average, than a broadly traumatized pediatric clinical sample. An exploratory frequency count was also conducted to examine the proportion of children and adolescents living with HIV who identify an HIV-related traumatic event as their "most bothersome" event in relation to their PTSS.

Furthermore, it has been suggested by past research, primarily in adults, that there is a connection between HIV and other mental health disorders. The current study examined the potential link between HIV and internalizing symptoms of anxiety and depression. It was hypothesized that there are higher rates of anxiety and depression symptoms in HIV-infected and HIV-affected children and adolescents when compared to broadly traumatized clinical and community pediatric samples. Additionally, it was hypothesized that there are lower levels of psychological adjustment (i.e., higher risk for emotional and behavior problems), as measured by the SDQ, in HIV-infected and HIV-affected children and adolescents when compared to a clinical and community pediatric sample.

Finally, examination of differences in method of disease transmission (perinatal vs. acquired), gender, race/ethnicity, age, location, and sexual orientation were exploratory as there were no data regarding significant differences within these factors in the occurrence of PTSS or PTSD in children and adolescents infected with or affected by HIV.

Method

Participants

Participants were recruited from One Heartland, a national nonprofit organization dedicated to improving the lives of children, youth, and their families facing HIV/AIDS. One Heartland was founded in 1993 when it began its mission to help children and families confronting HIV/AIDS. Camp Heartland and Camp Hollywood Heart are camps sponsored by One Heartland that are offered to children and adolescents, ages 7 to 20, who are infected with or affected by HIV/AIDS. HIV-infected participants are those who are HIV-positive, and HIV-affected participants are HIV-negative but have an infected family member. The first author (Ahlers) worked in a volunteer role with this organization in the past, and the Program Director agreed to assist with this project.

Packets with study materials were mailed to 468 HIV-infected and HIV-affected children and adolescents. Further, due to low participation, One Heartland staff distributed measures electronically to a listserv of current and past camp participants. Forty-four children and adolescents between the ages of 8 and 19 ($M = 14.47$; $SD = 3.053$) participated in this study. Participants attended between 0 and 11 years of a One Heartland camp ($M = 4$; $SD = 2.77$). Of the 44 participants, 31.8% ($n = 14$) of the sample was HIV-positive and 68.2% ($n = 30$) was HIV-negative but had a close family member who was infected. All HIV-positive participants were infected perinatally. Participants identified primarily as Black or African American

(70.5%) and the majority identified as female (68.2%). Participants were primarily heterosexual (79.5%), with a minority identifying as bisexual (6.8%), questioning (6.8%), and gay/lesbian (2.3%). See Table 1 for a summary of sociodemographic information.

Of the 30 HIV-affected participants, 76.7% live with an infected family member. All but one participant living with an infected family member provided data on the identity of that family member. The majority (63.6%) live with an infected parent; specifically, 12 out of 14 (85.7%) of HIV-affected children and adolescents are living with an infected mother. Other participants are living with an infected grandparent (18.2%), sibling (4.5%), or aunt/uncle (4.5%). A minority of the sample (9.1%) is living with more than one infected family member. Both HIV-infected and HIV-affected study participants also reported on whether or not they have experienced the loss of an immediate family member to HIV/AIDS. Seventeen (38.6%) participants had lost a family member and 13 (76.5%) of those children and adolescents were aware of the HIV status of their family member. Of the participants who lost a family member, the majority (53.3%) lost a parent and 33.3% experienced the loss of multiple family members.

Both HIV-infected and HIV-affected children and adolescents had between 2 and 7 people ($M = 4.29$; $SD = 1.418$) living in their household, themselves included. Thirty-two of the 44 participants provided information regarding their family's yearly income, which ranged from $0 to $360,000. The median yearly income was $43,300. According to Census data, the median household income in 2014 was $53,657; although, this number is lower for Black ($35,398) and Hispanic ($42,491) families (DeNavas-Walt & Proctor, 2015). For a family of four, a yearly income below $24,000 is considered "in poverty" (DeNavas-Walt & Proctor, 2015). Nearly 30% of the sample met the federal criteria for living below the poverty line. For further comparisons, participants were grouped into three categories based on income (see Table 1). Lastly,

participants and their families were relatively evenly distributed throughout the United States with 31.8% in the West, 22.7% in the Northeast, 22.7% in the South, and 20.5% in the Midwest. Further region breakdown according to the Census is provided in Figure 1.

Measures

UCLA PTSD Reaction Index for Children/Adolescents – DSM-5 (PTSD-RI-5; Steinberg, Brymer, Decker, & Pynoos, 2004 updated for DSM-5). In order to evaluate the presence of PTSS and whether the participants qualify for a PTSD diagnosis, the PTSD-RI-5 was administered. The PTSD-RI-5 is a 45-item self-report instrument, which assesses 13 types of trauma exposure, including illness/medical trauma. For the purposes of the current study, items regarding receiving an HIV diagnosis, receiving treatment, treatment adherence, physical symptoms, self-disclosing HIV status, stigmatization and discrimination, and witnessing HIV-related death were added to the PTSD-RI-5. In addition, the item "finding out about the HIV diagnosis of someone close to you" was added (see Appendix B for the self-report trauma history including the added items). Importantly, the PTSD-RI-5 asks the participant to list the 'most bothersome' experiences out of the 13 trauma types they may endorse, and to answer the symptom items with the 'most bothersome' event in mind. Norms and psychometric properties are not yet available for the DSM-5 version; therefore, DSM-IV norms were used. The UCLA PTSD Reaction Index for *DSM IV* (PTSD-RI) was designed for use with children and adolescents aged 7 to 18 years (Steinberg et al., 2004). Cronbach's alpha for the PTSD-RI was 0.90 and the test-retest reliability coefficient was 0.84 in previous studies (Roussos et al., 2005). Further, Steinberg and colleagues (2013) demonstrated that internal consistency for the PTSD-RI was uniformly high across age ranges, sex, and racial/ethnic groups (Cronbach's alpha 0.88-

0.91), which supports the use of the PTSD-RI across diverse populations. Internal consistency was 0.95 for the current study.

Revised Children's Anxiety and Depression Scale (RCADS; Chorpita, Yim, Moffitt, Umemoto, & Francis, 2000). The RCADS was used to measure specific anxiety and depression symptoms. The RCADS was developed using items on the Spence Children's Anxiety Scale (Spence, 1998). The RCADS is a 47-item self-report questionnaire with subscales corresponding to separation anxiety disorder (SAD), social phobia (SP), generalized anxiety disorder (GAD), panic disorder (PD), obsessive-compulsive disorder (OCD), and major depressive disorder (MDD), and it is utilized for youth ranging from 3rd to 12th grade. There are two total scores (Total Anxiety and Total Depression and Anxiety) as well. The Total Depression and Anxiety score was the primary variable of interest for the current study. The measure has been shown to have good internal consistency with Cronbach alpha coefficients ranging from 0.78 (SAD subscale) to 0.88 (panic disorder subscale) (Chorpita, Mofitt, & Gray, 2005). Internal consistency for the current study was 0.95. Specifically, Cronbach alpha coefficients were 0.88 for the social phobia subscale, 0.85 for panic disorder, 0.86 for major depression, 0.79 for generalized anxiety, 0.62 for obsessive-compulsive, and 0.67 for separation anxiety.

Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997). In order to assess general internalizing and externalizing distress, conduct problems, attention problems, peer relationships, as well as prosocial behavior, the SDQ was administered to participants. The SDQ is a 25-item behavioral screening questionnaire for children ages 4 to 17 years (Goodman & Goodman, 2009). There are five subscales to measure each of these issues described above separately and a Total Difficulties score, which includes all scales except the prosocial scale. The SDQ had a mean Cronbach alpha coefficient of 0.73 in past research, and it has been found

that children with higher difficulty scores have a greater likelihood of psychopathology (Goodman, 2001). Internal consistency for the current study was 0.64. The SDQ has been noted as being useful for researchers who want to determine "high-risk" samples (Goodman et al., 2003).

     Demographic Questionnaire (Unpublished measure). Demographic information was collected from participants using a demographic questionnaire developed for the current study (see Appendix A). The demographic measure was adapted from the One Heartland camp application form and gathered identical information, using the same language and format. The form included items on gender, race, location, age, sexual orientation, disease status (+/-), income, method of transmission, current medications, treatment history, diagnosed mental disorders, any other diagnosed medical conditions, and years in the camp program.

Procedure

     The One Heartland organization sends intake paperwork to all children and adolescents who participate in their camp programs. Measures for the current study were integrated into the campers' regular paperwork process with One Heartland, specifically between the mailing of the preregistration packet and the camp application form. One Heartland mailed preregistration packets to their campers in early January of 2014 in order to reestablish contact with the campers and their families. Later in the spring, One Heartland mailed out a camp application form, which is a 19-page document that is required for participation in camp. In between these mailings, in April, One Heartland mailed out the experimental assessment packet for the current study. Staff at the organization compiled a participant list of both infected and affected campers from their confidential files regarding the youth's demographic information, disease status, and physical location around the country. One Heartland mailed the experimental materials to the participants

along with the study consent form for their legal guardians and assent forms for child and adolescent participants. One Heartland maintained the consent forms with names, assigned a code number to each participant's packet, and sent the deidentified experimental measures to the first author for analysis. In order to help inform and tailor One Heartland services for participating children and adolescents, scores were calculated and communicated back to One Heartland staff. Permission for this deidentified transmission of information was included in the consent form.

Despite mailing study materials to 468 participants, only 17 surveys were returned, which is a response rate of approximately 3.6%. While current and past camp participants could have moved, the response rate was significantly lower than anticipated. As the Program Director had experienced recent success with email surveys, One Heartland staff compiled a list of infected and affected participants' email addresses. In order to maximize study participation, study materials were entered online in a secure data collection program, Qualtrics. Survey links and a letter inviting participation were distributed to a listserv of past and current camp participants by One Heartland staff. Study consent forms and assent forms for children and adolescents were included along with all measures. Participants provided no identifying information via Qualtrics.

All participants were offered the opportunity to participate in a gift card raffle for a chance to win one of three $20 VISA gift cards. Hardcopy participants were automatically entered with submission of their packet to One Heartland. Each participant who completed the survey via Qualtrics was assigned a random number upon completion. The participants were prompted to email this number to a One Heartland staff member who maintained a list linking participants to their random number. An online randomization program was used to select three

winners, and gift cards were mailed to One Heartland to distribute. Institutional Review Board approval was obtained prior to beginning the study.

Data Analytic Strategy

In the adult literature on the relationship between HIV-related traumatic events and posttraumatic stress disorder, past research has reported medium effect sizes though notably this research has primarily been done in adults (e.g., Bogart et al., 2011). According to G*Power with an alpha of 0.05, a power of 0.80, and the ability to detect a medium effect size (Cohen's d of 0.5), 128 participants are needed to conduct independent sample t tests.

As there were not enough HIV-infected participants to compare their experiences to those of HIV-affected participants, HIV-infected and HIV-affected participants were combined into one group for data analysis. This combined group will be referred to as children and adolescents "living with HIV" hereafter. As participants living with HIV directly or indirectly experience living with a chronic illness, samples drawn from a pediatric population were used for comparisons to capture other children and adolescents with exposure to medical trauma or chronic illness. Two computerized databases (PubMed and PsycINFO) were systematically searched for research studies conducted with samples drawn from a pediatric population using the PTSD-RI-5, RCADS, and SDQ. Notably, there is no published research using the updated PTSDI-RI-5 as opposed to the DSM IV version (PTSD-RI); therefore, research studies using the PTSD-RI were utilized. Articles were selected for comparison groups based on the following factors: 1) drawn from a pediatric population, 2) large sample size, 3) demographic similarity (i.e., identify as female and Black or African American and between the ages of 8 and 19), and 4) whether the authors published the necessary mean and standard deviation data. Lastly,

normative data from the measure publishers or other large normative samples were prioritized for community (non-treatment seeking) comparisons.

Multiple independent sample *t* tests were conducted to compare children and adolescents who are living with HIV to a pediatric sample. First, the symptom score on the PTSD-RI-5 was calculated for each participant using the recommended scoring procedure (Steinberg et al., 2004). The mean symptom score was compared to means from a clinical pediatric sample and a community (i.e., non-treatment seeking) sample, which included pediatric participants.

Additionally, frequency scores were calculated for non-HIV specific events and HIV-specific events, creating total subscale scores. Mean scores were calculated to derive both the average number of HIV-specific events and non-HIV-specific events experienced by HIV-infected participants, HIV-affected participants, and the combined group of participants living with HIV. The mean frequency scores for non-HIV specific trauma exposure of children and adolescents living with HIV were compared to a pediatric sample using an independent samples *t* test.

Multiple independent sample *t* tests were used to explore the internalizing symptoms of HIV-infected and HIV-affected children and adolescents. The mean T-score on the RCADS Total Depression and Anxiety scale was compared to a mean T-score from a clinical pediatric sample and a community sample. To assess overall psychological adjustment of children and adolescents living with HIV, the mean score on the Total Difficulties scale of the SDQ was compared to a mean score from a clinical pediatric and community sample.

Lastly, in order to examine the relationship between HIV diagnosis and PTSS, while controlling for non-HIV specific stressors and other mental health symptoms, stepwise multiple regression analysis was used. According to G*Power with an alpha of 0.05, a power of 0.80, the

ability to detect a medium effect size (Cohen's d of 0.5), and three predictors, 27 participants are needed. First, bivariate correlations were examined among all variables of interest (demographic variables, PTSD-RI-5 exposure frequency scores, PTSD-RI-5 symptom scores, SDQ total scores, RCADS total depression and anxiety scores.) Total scores on the non-HIV specific events were entered on the first step along with the RCADS Total Depression and Anxiety score and the SDQ Total Difficulties score, while scores on the HIV-specific events were entered on the second step. The PTSD-RI-5 symptom score total was the dependent variable. Finally, an exploratory frequency count was conducted on the item in which youth indicate their 'most bothersome' event.

Results

Trauma History

HIV-positive participants reported experiencing at least three traumatic events and, on average, participants reported experiencing 7.33 events (range, 3-12). HIV-positive participants reported experiencing 6.00 HIV-related traumatic events, on average, and 1.33 non-HIV related events. HIV-affected participants reported experiencing 1.30 HIV-related traumatic events, on average, and 2.78 non-HIV related events. In the combined sample, youth living with HIV, participants reported experiencing an average of 5.20 traumatic events (range, 0-12). Specifically, within the combined sample ($n = 35$), participants reported experiencing an average of 2.91 HIV-related traumatic events and 2.29 non-HIV related traumatic events. See Table 2 for a summary of trauma exposure history.

An independent samples t-test was conducted to compare the mean number of non-HIV-related traumatic events in children and adolescents living with HIV with a clinical sample. Wilcox and colleagues (2016) utilized a sample drawn from the National Child Traumatic Stress

Network (NCTSN) Core Data Set (CDS) and identified children and adolescents whose

parent/caregiver endorsed the presence of "medical problems or disabilities (e.g., chronic or

recurrent condition that affects the child's ability to function)." A dataset from the NCTSN CDS

was selected for comparison because the CDS represents the largest data sample on trauma-

exposed children and adolescents in the world. Trauma exposure was measured using the

Trauma History Profile (THP) of the PTSD-RI for DSM-IV, which is a clinician based interview

assessing 20 types of trauma exposure. The researchers identified 2,103 participants with

chronic or recurrent medical conditions and disabilities between the ages of 0 and 18 ($M = 10.4$,

$SD = 4.2$) and 41.6% identified as Black. The mean number of trauma types experienced was

3.2 ($SD = 2.3$). The difference between mean scores was significant t (2136) = -2.32, p = .020,

with an effect size of $d = .396$, as the comparison sample experienced a significantly greater

number of trauma types, on average, than children and adolescents from the current sample who

are living with HIV.

The most commonly reported traumatic event was receiving the HIV diagnosis of

someone close to the participant (74.3%). Fifty percent of participants have had someone close

to them die from HIV/AIDS. The three most frequently occurring non-HIV-related traumas

experienced by participants included witnessing or hearing of the violent death of a loved on

(41.2%), experiencing another really scaring or upsetting event (32.4%), and witnessing physical

violence of a family member (25.7%). See Table 3 for a complete list of the number of

participants who experienced specific traumatic events.

Posttraumatic Stress Symptoms and Diagnosis

The PTSD-RI-5 was used to measure the level of posttraumatic stress symptoms in

children and adolescents living with HIV and to determine whether participants met criteria for a

diagnosis of PTSD. Researchers have previously demonstrated that a cutoff of 38 has the greatest sensitivity and specificity in detecting PTSD (Steinberg et al., 2004). According to this cutoff, 4 out of 33 participants (12.1%) met diagnostic criteria for PTSD, which is above the average lifetime prevalence for children and adolescents according to the DSM-5 (APA, 2013).

To further explore PTSS in the current sample, scores were subdivided into groups according to severity. Goenjian and colleagues (2011) created symptom categories, including "mild" (12-23), "moderate" (24-37), and "severe" (greater than 38). These categories were used to divide participants' scores based on varying levels of severity. Six participants (12.5%) each had "moderate" and "severe" symptom levels and five (10.4%) had mild symptoms. Therefore, while 12.1% of participants met criteria for PTSD, 51.5% of participants had at least mild levels of symptoms and 36.4% had at least moderate symptoms.

The mean symptom score for participants who completed the PTSD-RI-5 was 20.36 (*SD* = 18.292), which fell into the "mild" symptom range as designated by Goenjian and colleagues (2011). The PTSD-RI-5 was designed for use with children and adolescents between 7 and 18 years of age. Due to sampling limitations, participants who were 19 years of age were included in the sample. When participants who were 19 years of age were removed from the sample, the mean symptom score for the PTSD-RI-5 was 19.37 (*SD* = 18.672), which is not significantly different from the mean PTSD-RI-5 score with the 19-year-old participants included in the sample; thus, the full sample was utilized in any analyses involving the PTSD-RI-5.

An independent samples *t*-test was conducted to compare the mean PTSD-RI-5 symptom score in children and adolescents living with HIV with a clinical sample. Ingerski, Shaw, Gray, and Janicke (2010) examined traumatic stress symptoms using the PTSD-RI in youth being considered for solid organ and bone marrow transplantation, youth diagnosed with HIV, and

youth diagnosed with sickle cell disease (SCD). Youth diagnosed with SCD (n = 19) who

completed the PTSD-RI were selected as the comparison group, and participants were between

the ages of 8 and 17 (M = 10.1; SD = 5.5). Youth with SCD were separated out and selected for

comparison as they did not include any HIV-positive children or adolescents, were drawn from a

pediatric population, and were the best demographic match (58.3% female, 100% Black). The

mean PTSD-RI score for youth diagnosed with SCD was 15.5 (SD = 12.9). The difference

between mean scores was not significant t (50) = 1.012, p = .313, which represented a small

effect size, d = .294. A summary of mean PTSD-RI scores from studies conducted with a

pediatric sample is included in Table 4.

In order to compare the PTSD-RI symptom scores with a larger, medically traumatized

sample of children and adolescents, scores from the current study were also compared with

scores from a study by Wilcox and colleagues (2016), who conducted a research study with a

sample of NCTSN CDS participants to compare posttraumatic stress symptoms in children with

and without medical problems who were also receiving trauma-related care. The mean PTSD-RI

score for the medically traumatized sample (n = 1139) was 25.5 (SD = 14.8). The difference

between mean scores was not significant t (1170) = -1.953, p = .051, which represented between

a small and medium effect size, d = -.345. As previously mentioned, the NCTSN CDS was also

selected for comparison as it represents the largest data sample on trauma-exposed children and

adolescents from community and clinical samples.

Given that the prevalence of PTSS and PTSD in youth living with HIV have not been

established compared to community (non-treatment seeking) samples, an additional independent

samples t-test was conducted using the mean PTSD-RI-5 score. A subsample of the CDS of the

NCTSN was used as a combined clinical and community sample because, as previously

mentioned, the CDS is the largest data sample on trauma-exposed children and adolescents in the world. Steinberg and colleagues (2013) administered the PTSD-RI to 6,291 participants between 7 and 18 years of age (M = 12.7; SD = 3.08). Participants were exposed a broad range of traumatic experiences, and, specifically, 10.6% of participants experienced living with serious illness or medical trauma. Approximately 55.6% of participants identified as female and 23% were Black/African American. The mean PTSD-RI score across participants was 26.6 (SD = 14.9). The difference between mean scores was significant t (6322) = -2.40, p = .017, which represented nearly a medium effect size, d = .418. The combined clinical and community sample obtained from the NCTSN had a higher mean score on the PTSD-RI than children and adolescents from the current sample living with HIV.

The PTSD-RI-5 includes an item for participants to identify the "most bothersome" event of their traumatic experiences and to provide a qualitative description of this event. Overall, 40% of participants who identified their "most bothersome" event identified an HIV-related trauma as opposed to a non-HIV-related trauma. Two participants identified taking medications, one participant identified stigma and discrimination related to HIV status, and five identified loss of a family member or fear of loss of a family member as their most bothersome event. Further, two additional participants identified non-HIV-related traumas as "most bothersome" and provided additional description suggesting that the events were, indeed, HIV-related. For instance, one participant endorsed witnessing "violent death or serious injury of a loved one or friend" as his/her "most bothersome" event and added, "My birth mother died of HIV." Additionally, another participant selected the exposure event "other" as his/her "most bothersome" trauma exposure and added, "My sister almost died three times from being so sick with AIDS. It scared me, and it hurts so bad to see my sister suffer from AIDS, going forth and

back to the hospital. I lost my father to AIDS I don't want to lose my sister to AIDS." Therefore, when including these additional participants in the proportion of participants who identified their "most bothersome" event as HIV-related, the adjusted percentage is 50% of the sample.

Predictors of Posttraumatic Stress

A stepwise multiple regression was used to examine the relationship between living with HIV and PTSS, while controlling for non-HIV specific stressors and other mental health symptoms. First, bivariate correlations were examined among all variables of interest including: demographic variables (e.g., age, gender, racial group, sexual orientation, income), PTSD-RI-5 exposure frequency scores, PTSD-RI-5 symptom scores, SDQ Total Difficulties scores, and RCADS Total Depression and Anxiety scores. The RCADS Total Depression and Anxiety score $(r = 0.668; p < 0.001)$ and the SDQ Total Difficulties score $(r = 0.605; p < 0.001)$ were both correlated with the PTSD-RI-5 total symptom score. There were no significant correlations between demographic variables and the PTSD-RI-5 total symptom score.

Therefore, total scores on the non-HIV-specific events were entered on the first step along with the RCADS Total Depression and Anxiety scores and the SDQ Total Difficulties scores, while scores on the HIV-specific events were entered on the second step. The PTSD-RI-5 symptom score total was used as the dependent variable.

The scores on the non-HIV-specific events, RCADS Total Depression and Anxiety scale, and SDQ Total Difficulties scale accounted for a significant proportion of the variance in the model with an adjusted R square of 0.557 $(p < 0.001)$. The addition of frequency scores from HIV-specific events did not significantly contribute to the overall regression model and only accounted for an additional 1% of the variance observed in PTSS as measured by the PTSD-RI-5 symptom scale.

Internalizing Symptoms

The RCADS was used to measure internalizing symptoms, specifically symptoms of depression and anxiety, in children and adolescents living with HIV. Scores were divided into a "normal" (T-score < 65), "borderline" (T-score between 65 and 70), and "clinical" (T-score ≥ 70). The Total Depression and Anxiety scale combines five anxiety subscales and a depression subscale for a measure of total internalizing difficulties. The majority of the sample who completed the RCADS fell in the "normal" range; however, 8.1% reported clinically significant levels of internalizing symptoms. Of the 37 participants who completed the RCADS, 10.8% fell in the "clinical" range on the depression subscale whereas 5.4% had clinically significant levels of anxiety across the five anxiety subscales. For the anxiety subscales, the greatest percentage of participants had "borderline" or "clinical" symptom levels for the panic disorder (5.4%; 8.1%, respectively) subscale and the separation anxiety (2.7%; 8.1%) subscale. The mean T-scores were not elevated for any scale or subscale. See Table 5 for a summary of T-scores.

The RCADS is designed for use in children and adolescents between 3rd and 12th grade. Six participants were beyond the 12th grade. Frequencies and descriptive statistics were calculated both with and without those beyond 12th grade included in the sample. Mean scores for the two primary scales and underlying subscales did not appear to differ significantly based on the inclusion of participants beyond 12th grade. Mean T-scores did not differ beyond one point for each scale or subscale. When participants beyond 12th grade were excluded from the sample, the percentage of participants falling into the "borderline" and "clinical" classifications increased slightly. For instance, without those beyond 12th grade, 9.7% of participants reported clinically significant levels of internalizing difficulties. Further, 12.9% fell in the "clinical" range on the depression subscale; whereas, 6.5% had clinically significant levels of anxiety

across the five anxiety subscales. While the RCADS may underestimate the levels of

internalizing symptoms in adolescents beyond the 12th grade, inclusion of these individuals in the

sample did not appear to significantly alter results.

An independent samples *t*-test was conducted to compare the mean Total Depression and

Anxiety T-score in children and adolescents living with HIV with a clinical sample. As neither

age nor gender was correlated with the Total Depression and Anxiety T-score, the mean T-score

for the entire sample was utilized ($M = 43.84$; $SD = 12.41$). Hourigan, Southam-Gerow, and

Quinoy (2015) administered the RCADS to a sample of participants from an urban pediatric

primary care clinic in the mid-Atlantic region of the United States. This study was selected as

the largest sample drawn from a pediatric population using the RCADS that most closely

matched the demographic data (i.e., primarily minority and female). Participants ranged from 8

to 17 years of age ($M = 12.36$; $SD = 2.55$), 73% identified as African American, and 60.9%

identified as female. The mean Total Depression and Anxiety T-score across participants ($n =$

197) was 43.09 ($SD = 9.75$). The difference between mean scores was not significant $t(232) =$

0.41, p = .680 with an effect size of $d = .077$.

An additional independent samples *t*-test was conducted to compare the internalizing

difficulties of children and adolescents living with HIV against a community sample. Trent and

colleagues (2013) administered the RCADS to a sample of children and adolescents in Grades 2

to 12 in public schools across the state of Mississippi. This study was selected as the community

(non-treatment seeking) sample as a large sample that matched the demographic characteristics

most closely. Fifty-one percent of the 12,965 participants identified a female and 38.6% were

African American. The mean Total Depression and Anxiety T-score was 51.41 ($SD = 10.32$).

The difference between mean scores was significant $t(12730) = -4.45$, p < 0.001, which

represented a large effect size, $d = .733$, and the sample from Trent and colleagues (2013) experienced a significantly higher level of total depressive and anxiety symptoms than children and adolescents living with HIV.

Psychological Adjustment

The SDQ was utilized to assess the overall psychological adjustment of children and adolescents living with HIV. Parent-report was utilized for participants between 4 and 10 years of age, and self-report was utilized for participants older than 11. Scores were compared across measures using bandings, which included "close to average," "slightly raised," "high," and "very high." For the prosocial scale, "slightly raised" is replaced with "slightly lowered" and "high" is replaced with "low." Guidelines are provided to split both parent- and self-report SDQ scores into identical banding categories (sdqinfo.com).

A measure of total difficulties combines scores from four subscales, including emotional symptoms, conduct problems, hyperactivity/inattention, and peer problems. Overall, the majority of participants fell in the "close to average" (75.0%) category for the total difficulties scale. Interestingly, only 50% of participants fell in the "close to average" range for the peer problems subscale and 19.4% of participants fell into the "very high" category (meaning they are experiencing high levels of negative peer interactions). See Table 6 for the percentage of participants who were divided into each category.

The SDQ questionnaires are normed for use on children and adolescents between 4 and 17 years of age. As participants who were above 17 years of age were included in the sample, descriptive statistics were calculated for those 17 and under and compared to those for the total sample. The percentage of participants who fell in the "close to average" range was lower when 18- and 19-year-old participants were removed from the sample; however, differences were not

greater than 1% for total difficulties. Therefore, while the SDQ might underestimate difficulties

in adolescents over the age of 17, it did not appear to significantly alter the results. One

exception was that the percentage of participants in the "very high" category on the peer

problems subscale dropped from 19.4% to 12.9% when the 18- and 19-years olds were removed

from the sample. See Table 7 for a summary of mean total and subscale scores on the parent-

and self-report SDQ.

      An independent samples *t*-test was conducted to compare the mean Total Difficulties

score in children and adolescents living with HIV with a clinical and community sample. As

only three participants' caregivers completed the parent SDQ, analyses are exclusively based on

the self-report SDQ (i.e., participants 11 and older). The mean Total Difficulties score for the

self-report SDQ was 10.79 (*SD* = 7.28). Madden, Hastings, and V'ant Hoff (2002) examined the

psychological adjustment of children with end stage renal disease attending nephrology clinics at

a pediatric hospital in the UK. These data were selected as the largest pediatric sample with

available self-report SDQ data that most closely matched the demographic data of the current

sample of participants living with HIV despite the lack of data on race/ethnicity. Participants

were between the ages of 11 and 16 (*M* = 14.22; *SD* = 1.77) with an average of 10.59 years (*SD*

= 4.22) of receiving treatment for renal disease. Seventeen participants identified as female. The

mean SDQ Total Difficulties score across participants (*N* = 43) was 11.7 (*SD* = 5.6). The

difference between mean scores was not significant *t* (74) = -0.616, p = 0.540, which almost

represented a small effect size, *d* = -.143.

      An additional independent samples *t*-test was conducted to compare the psychological

adjustment of children and adolescents living with HIV against a community epidemiological

sample. The British normative sample for the self-report SDQ was comprised of children and

adolescents living in private households in England, Scotland, and Wales (Meltzer, Gatward, Goodman, & Ford, 2000). These data were selected for the community comparison based on availability of self-report SDQ data and as the normative sample for the measure. Individuals between the ages of 11 and 15 completed the self-report SDQ ($n = 4{,}228$) and had a mean Total Difficulties score of 10.3 ($SD = 5.2$). The difference between mean scores was not significant t (4259) = 0.54, p = 0.591 with an effect size of $d = .094$.

Exploratory Analyses

Participants were classified categorically regarding whether they met criteria for a diagnosis of PTSD using the cutoff score recommended by Steinberg and colleagues (2004). There were several variables correlated with an increased likelihood of exceeding the cutoff score. Loss of an immediate family member to HIV/AIDS was correlated with meeting diagnostic criteria for PTSD (r = 0.407; p = 0.019). Further, higher scores on the RCADS Total Depression and Anxiety scale was correlated with exceeding the clinical cutoff on the PTSD-RI-5 (r = 0.444; p = 0.011).

There were several additional trends linked with participants' camp experiences. For instance, participant scores on the SDQ Total Difficulties scale and SDQ Conduct Problems subscale were negatively correlated with the number of years that participants attended One Heartland camp programs (r = -0.503, p = 0.003; r = -0.487, p = 0.004, respectively). Further, participant scores on the SDQ Prosocial subscale were positively correlated with years attending camp (r = 0.386; p = 0.026).

Discussion

The current study examined the relationships between HIV-related traumatic events and the experience of PTSS, PTSD, and other mental health outcomes in children and adolescents

living with HIV. First, while 12.1% of children and adolescents living with HIV met diagnostic criteria for HIV, the majority of the sample demonstrated mild (51.5%) to moderate (36.4%) symptoms of posttraumatic stress. This was similar to the previous finding by Radcliffe and colleagues (2007) that 13% of HIV-infected participants met full symptom criteria for PTSD and the majority (57%) reported PTSS in response to at least one traumatic stressor. Contrary to the hypothesis, children and adolescents living with HIV did not differ significantly in their levels of PTSS as measured by the PTSD-RI-5 from a clinical pediatric sample. Further, children and adolescents living with HIV did experience significantly different levels of PTSS when compared to a combined clinical and community sample derived from the CDS of the NCTSN, and the CDS sample experienced higher levels of symptoms, on average. This finding contradicts limited research in HIV-infected children and adolescents that indicate elevated levels of PTSS and PTSD in connection to HIV-related traumatic events (Radcliffe et al., 2007; Radcliffe et al., 2011). However, the levels of PTSS and PTSD in children and adolescents in the current sample was greater than that outlined in the DSM-5 (APA, 2013).

In the examination of overall trauma exposure, contrary to the hypothesis, children and adolescents living with HIV experienced significantly different levels of non-HIV-related traumatic events when compared with a clinical sample, as the clinical CDS sample experienced, on average, a greater number of lifetime traumatic events. While children and adolescents with HIV did differ significantly from the CDS participants with chronic or recurrent medical conditions and disabilities, the trauma history gathered was more extensive, as the THP evaluated children and adolescents' exposure to 20 traumatic events whereas the PTSD-RI-5 self-report trauma history only evaluates exposure to 13 traumatic events (though both measures allow for an 'other' write-in category). Further, as there is no past research on exposure to HIV-

related events in youth, there was no comparison sample to evaluate levels of trauma exposure when taking into account HIV-related traumatic experiences. As the most commonly reported traumatic event was receiving the HIV diagnosis of someone close to the participant, it is extremely important to consider the effect of exposure to HIV-related events. Further, half of participants who identified their "most bothersome" traumatic event identified an HIV-related event, such as taking their medications, experiencing stigma/discrimination, and experiencing loss or fear of loss of someone close to them who is infected with HIV/AIDS.

As expected, higher levels of general distress, as indicated by SDQ scores, and higher levels of anxiety and depression, as indicated by RCADS scores, were positively correlated with higher scores on the PTSD-RI-5 for PTSS. Further, the scores on the PTSD-RI-5 for non-HIV-related traumatic events was correlated with higher scores as well. Higher levels of distress, anxiety, and depressive symptoms as well as greater exposure to non-HIV related events accounted for a significant percentage of the variance observed in PTSS. Contrary to the hypothesis, the addition of frequency scores for HIV-specific events did not significantly contribute to the prediction of levels of PTSS in children and adolescents living with HIV and it only accounted for an additional 1% of the variance. Given the inclusion of those who are affected by HIV in the sample utilized for the regression analysis and that these participants inherently experienced fewer HIV-related events (i.e., have not been diagnosed with HIV, no physical symptoms, do not take HIV medication regimen), this result was not surprising.

The examination of demographic variables, anxiety and depressive symptoms, and psychological adjustment in children and adolescents living with HIV was exploratory. There is little consistent evidence of a significant relationship between demographic variables and PTSD, with the exception of gender. Contrary to past research findings (e.g., Hanson et al., 2008;

Kilpatrick et al., 2003), gender was not correlated with participants' levels of PTSS, although gender was correlated to major depressive symptoms as measured by the RCADS MDD subscale. There were no other demographic variables correlated with levels of PTSS. Contrary to the hypothesis, children and adolescents living with HIV did not differ significantly from a pediatric clinical sample in their rates of anxiety and depressive symptoms nor did they differ from a pediatric and community sample in their level of psychological adjustment.

Importantly, exploratory analyses related to the participants' camp experiences suggest that attending camp may be protective and beneficial for children and adolescents living with HIV. Specifically, more years attending One Heartland camps was related to lower levels of difficulties and conduct problems and higher levels of prosocial behaviors as measured by the SDQ.

This study was the first to examine measures of posttraumatic stress, anxiety and depressive symptoms, and psychological adjustment in a sample of children and adolescents who were both infected with and affected by HIV. Further, this is the first study to the researcher's knowledge that examines disease-related experiences in such a young sample and an HIV-infected sample that was exclusively infected via perinatal transmission. Given the abundance of research suggesting a link between trauma exposure during developmentally sensitive periods, such as early childhood and adolescence, and long-term adverse consequences (Layne et al., 2014), it is critical to understand the effect of living with HIV on individuals during childhood and adolescence. Importantly, despite finding elevated levels of PTSS and PTSD in this sample, participants did not differ significantly from other clinical samples of children and adolescents living with chronic illness. Therefore, despite the added burden of living with a highly stigmatized illness, children and adolescents with HIV do not seem to suffer additional

psychopathology. Kazak and colleagues (2006) proposed a Pediatric Medical Traumatic Stress (PMTS) model to describe the arousal, re-experiencing, and avoidance symptoms that children and families may experience in response to living with a chronic illness. The researchers suggested that PMTS is characterized by PTSS and the symptoms might not result in meeting diagnostic criteria for PTSD or acute stress disorder (Kazak et al., 2006). Kazak and colleagues (2006) identified that traumatic stress may develop at various points throughout the course of illness and treatment, and it is, therefore, critical to understand and monitor psychological reactions to pediatric illness and injury. Given that children and adolescents living with HIV do not appear to differ significantly from those living with other chronic illnesses, HIV-related experiences can be conceptualized within this framework as potential stressors leading to PTSS.

Despite the lower levels of non-HIV-related trauma exposure when compared to clinical or community samples, this finding in particular should be interpreted with caution. Given the extremely low response rate, there might have been particular characteristics of participants that completed surveys, such as a change in home environment following HIV-related loss resulting in increased stability, which were protective factors against additional trauma exposure. Further, participants who responded may just be functioning better (i.e., lower levels of PTSS and depressive and anxiety symptoms and higher levels of psychological adjustment) than those who did not respond. As avoidance is a hallmark diagnostic feature of PTSD, those experiencing higher levels of PTSS, possibly meeting criteria for PTSD, may have been less likely to complete measures describing their traumatic experiences.

Researchers have consistently identified that multiple episodes of trauma exposure occur more commonly than a single incident trauma and, as a result, exert more potent effects than an isolated exposure (Pynoos et al., 2014). Therefore, additional research in children and

adolescents living with HIV conducted with a larger sample is of high importance. Further, it is important to consider the role of camp-related experiences as a protective factor for children and adolescents living with HIV. Future research could examine years at camp as a moderator of the relationship between HIV-related traumatic experiences and psychopathology.

Limitations and Future Directions

The limitations of this study include the use of self-report, using measures beyond the ages identified in the normative sample, and a small sample size to evaluate the prevalence of PTSS in children and adolescent with a chronic illness. That said, past research on PTSD using self-reports of children and adolescents suggest that self-reports can be accurate measures of symptoms and distress. Further, some children and adolescents may feel more comfortable reporting their difficulties on questionnaires as opposed to verbal reports. In order to include more participants living with HIV in the sample, the measures were administered to participants that were older than is identified in the normative sample. Specifically, the PTSD-RI-5 and SDQ was administered to 18- and 19-year olds and the RCADS was administered to participants beyond the 12th grade. Despite the expansion of measure use beyond the recommended age range, the results did not appear to be significantly affected by including these participants.

The most significant limitation was a small sample size. Despite multiple recruitment attempts to increase the sample size, the proposed data analyses could not be performed as originally intended, which was to compare the experiences of HIV-infected and HIV-affected children and adolescents with a pediatric clinical sample. Unfortunately, difficulty recruiting trauma-exposed youth in research is not uncommon; thus, due to the extremely low response rate, HIV-infected and HIV-affected participants were combined into one group for comparisons. Further, despite combining participants into a living with HIV group, many of the analyses

conducted were still underpowered, potentially limiting the ability to identify significant differences.

Due to the limitations in sample size, there were many comparisons that were unable to be explored. Specifically, future research could seek to identify whether HIV-related experiences differ for those who are infected with HIV and those who are affected by HIV. Additionally, all participants in this study were infected with HIV perinatally. There may be important differences in the experiences of HIV-infected individuals linked with method of transmission that could not be examined in this study. Unlike with other chronic illnesses, an HIV diagnosis, particularly if HIV is acquired through high-risk behaviors, does not guarantee that the child or adolescent's family will be supportive, helpful, and consolatory (Radcliffe, Hawkins, & Buchanan, 2014). Future research could compare the experiences of HIV-infected individuals linked with method of transmission as well as more targeted exploration of family-related variables and psychological symptoms.

Further, past researchers have noted that children and adolescents with medical problems or disabilities tend to use medical and behavioral health services for trauma or emotional/behavioral concerns at an elevated rate, specifically costly services such as the emergency department and inpatient psychiatric services, when compared to those without medical problems or disabilities (Wilcox et al., 2016). Service utilization in children and adolescents with HIV has yet to be examined.

While the sample size for the current study might have been small for an evaluation of prevalence, it contributes to the literature in significant and important ways given the preliminary nature of the study and the nascent stage of the field with this population. Given the scarcity of research among children and adolescents living with HIV, the current study contributes to the

field in several ways. Patient care may be enhanced by informing education initiatives that

enrich care professionals' awareness of the potential link between HIV, posttraumatic stress, as

well as other mental health issues, in children and adolescents and how to identify vulnerability,

offer follow-up, and refer patients for specialist psychological treatment (Theuninck et al., 2010).

Furthermore, both parents and children will benefit from education to help HIV-positive youth

recognize their vulnerability and identify posttraumatic symptoms (Theuninck et al., 2010).

Findings from the current study may also directly benefit One Heartland relative to their

programming and treatment offerings. Future treatments or trainings for employees that work

with children and adolescents infected with HIV may be developed as a result of this research,

which can improve the ability of HIV-positive children and adolescents to live with and manage

their chronic illness. Given that children and adolescents living with HIV may not differ

significantly from those living with other chronic illnesses, existing evidence based practices for

a pediatric population may not need to be significantly modified and can be directly applied to

children and adolescents living with HIV. The findings of this study may also inform future

versions of the DSM-5. The DSM-5 is intended to be a "living document," and the present study

may provide evidentiary support in favor of including the experience of living with a chronic

illness as a potential traumatic stressor for PTSD (APA, 2013).

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Table 1

Sociodemographic Variables

Characteristics	Frequency (%)
Gender (*N* = 44)	
Female	68.2
Male	31.8
Race (*N* = 44)	
American Indian/Alaskan Native	4.5
Asian	2.3
Black or African American	70.5
Hispanic or Latino/a	15.9
Multiracial	6.8
Sexual Orientation (*n* = 42)	
Heterosexual	79.5
Gay/Lesbian	2.3
Bisexual	6.8
Questioning	6.8
HIV Status (*N* = 44)	
Positive	31.8
Negative	68.2
Yearly Household Income (*n* = 33)	
Below $24,000	22.9
Between $24,000 and $100,000	35.4
Above $100,000	10.4
Poverty Status (*n* = 33)	
In poverty	29.5
Not in poverty	45.5

Table 2

Participant Trauma Exposure

	M	*SD*	Range
HIV-related trauma			
HIV-Positive (*n* = 12)	6.00	1.758	3-8
HIV-Negative (*n* = 23)	1.30	0.876	0-4
Combined sample (*n* = 35)	2.91	2.571	0-8
Non-HIV-related trauma			
HIV-Positive (*n* = 12)	1.33	1.371	0-4
HIV-Negative (*n* = 23)	2.78	2.275	0-9
Combined sample (*n* = 35)	2.29	2.108	0-9
Combined trauma exposure			
HIV-Positive (*n* = 12)	7.33	2.902	3-12
HIV-Negative (*n* = 23)	4.09	2.485	0-10
Combined sample (*n* = 35)	5.20	3.027	0-12

Table 3

Self-report of Trauma History (*n* = 35)

Event	*N* experiencing	*% experiencing*
Discovered HIV diagnosis of someone close	26	74.3
Known someone who has died from HIV/AIDS [a]	17	50.0
Witnessed or heard of violent death/injury of loved one [a]	14	41.2
Received HIV treatment [a]	13	38.2
HIV medication regimen [a]	13	38.2
Received HIV diagnosis	12	34.3
Experienced other scary or upsetting event	11	32.4
Witnessed physical family violence	9	25.7
Witnessed neighborhood violence	8	22.9
Treated differently because of HIV [a]	7	20.6
Been in a natural disaster	7	20.0
Disclosed HIV status [a]	6	17.6
Experienced physical symptoms of HIV	6	17.6
Experienced medical trauma	6	17.1
Experienced child sexual abuse	5	14.3
Experienced neighborhood, school, or community violence (e.g., beaten up, shot at)	5	14.3
Been in a bad accident	5	14.3
Experienced child physical abuse	5	13.3
Seen a dead body (not at funeral)	4	11.4
Experienced meanness due to HIV	2	5.9
Experienced sexual assault/rape [a]	1	2.9
Lived in a warzone	0	0.0

[a] *n* = 34

Table 4

PTSD-RI Mean Symptom Scores of Pediatric Samples Considered for Comparison Group

	N	*M (SD)*	Reference
Pediatric chronic illness groups (transplant, HIV, sickle cell disease)	45	17.2 (13.5)	Ingerski, Shaw, Gray, & Janicke (2010)
Pretransplant	18	18.8 (13.6)	
HIV-positive	12	18.1 (15.2)	
Sickle cell disease	19	15.5 (12.9)	
Children with burns	72	16.82 (13.13)	Saxe et al. (2005)
Pediatric patients (type 1 diabetes, cancer, accident-related injury)	209	12.9 (9.8)	Landolt, Vollrath, Ribi, Gnehm, & Sennhauser (2003)
Children with chronic or recurrent medical conditions or disabilities	1139	25.5 (14.8)	Wilcox et al. (2016)
Siblings of pediatric cancer patients			
4-6 weeks post-diagnosis	16	15.57 (11.89)	Prchal, Graf, Bergstraesser, & Landolt (2012)
4 months post-diagnosis	16	12.71 (11.36)	
7 months post-diagnosis	16	11.64 (11.45)	

Note. Values in parentheses represent standard deviations

Table 5

Participant T-scores on the RCADS Scales & Subscales (*n* = 37)

	M	SD	Range
RCADS Total Internalizing (Depression & Anxiety)	43.84	12.41	28.5-75.6
Depression	45.15	13.73	29.83-88.99
Anxiety	43.96	11.22	28.75-73.51
Generalized Anxiety Disorder	43.98	9.62	29.68-63.72
Obsessive-Compulsive Disorder	40.99	7.96	29.29-56.74
Panic Disorder	48.33	12.70	36.01-85.24
Separation Anxiety Disorder	50.40	11.55	37.46-80.05
Social Phobia	44.23	10.04	26.20-69.46

Table 6

SDQ Scale Scores for Percentage of Participants (*n* = 36)

	Close to average	Slightly raised (Slightly lowered)	High (Low)	Very high (Very low)
Total Difficulties	75.0	8.3	2.8	13.9
Emotional symptoms	69.4	11.1	8.3	11.1
Conduct problems	80.6	8.3	5.6	5.6
Hyperactivity/Inattention	83.3	2.8	0.0	13.9
Peer Problems	50.0	22.2	8.3	19.4
Prosocial	83.3	5.6	2.8	8.3

Table 7

Participant scores on the Parent- and Self-report SDQ Scales & Subscales (*n* = 36)

	M	SD
<u>Parent-report SDQ</u> (*n* = 3)		
Emotional problems	5.00	1.00
Conduct problems	1.00	.00
Hyperactivity	3.33	1.53
Peer problems	1.33	1.16
Pro-social behavior	8.67	1.53
Total difficulties	10.67	3.22
<u>Self-report SDQ</u> (*n* = 33)		
Emotional problems	3.09	2.43
Conduct problems	1.82	2.04
Hyperactivity	3.00	2.92
Peer problems	2.88	1.97
Pro-social behavior	8.09	2.26
Total difficulties	10.79	7.28

Figure 1

Geographic Location of Participants by Census Region

Distribution of Participants According to Census Region

- Middle Atlantic — 22.7%
- East North Central — 18.2%
- West North Central — 2.3%
- South Atlantic — 18.2%
- East South Central — 2.3%
- West South Central — 2.3%
- Mountain — 15.9%
- West — 15.9%
- Missing data — 2.3%
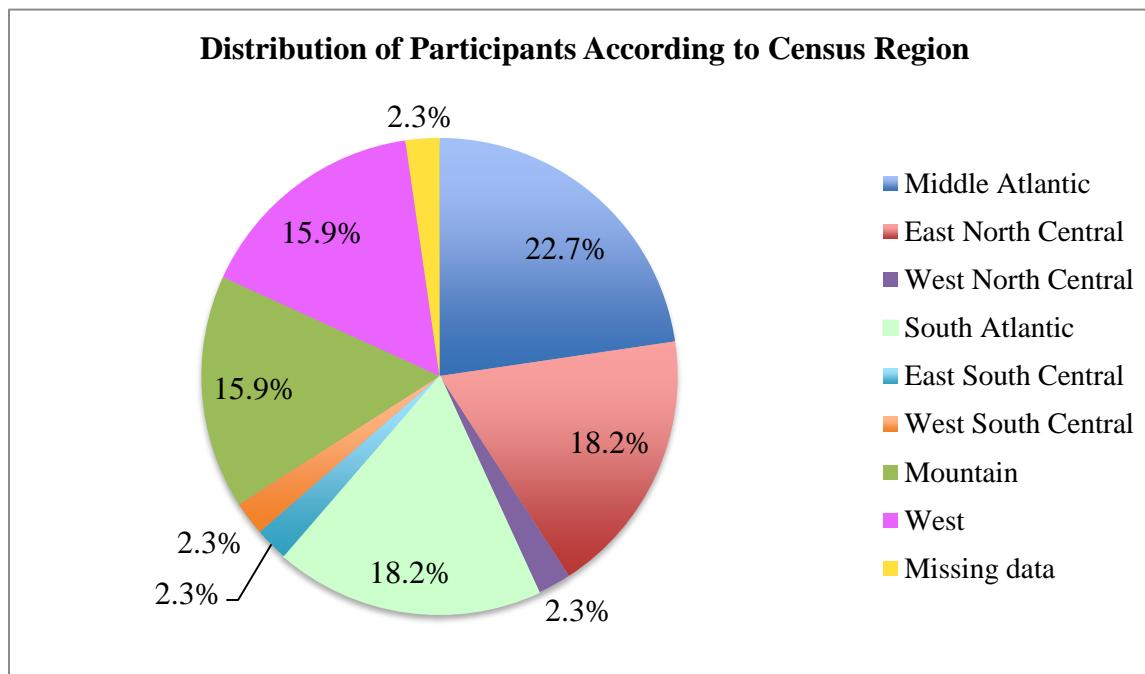
Appendix A

Demographic Form

Please complete this form to the best of your ability. You are welcome to fill this out with the help of your parent/guardian, or you can have him/her fill it out for you. Please do not include your name or any other personal information other than what the questions ask. Thank you!

1. What is your age? _____

2. How would describe your gender?
    ☐ Female
    ☐ Male
    ☐ Transgender
    ☐ Gender neutral
    ☐ Intersex
    ☐ Other: Please describe _____

3. What is your racial group? *(You may check more than one)*
    ☐ American Indian/Alaska Native
    ☐ Asian
    ☐ Native Hawaiian or Other Pacific Islander
    ☐ Black or African American
    ☐ Hispanic or Latino
    ☐ White, non-Hispanic or Latino
    ☐ Other: _____

4. How do you describe your sexual orientation?
    ☐ Heterosexual
    ☐ Gay / Lesbian
    ☐ Bisexual
    ☐ Questioning

5. What is the name of the city and state where you live:
    _____

6. How many people are living in your household (including yourself): _____

    What is the yearly income of the household:
    _____

7. How many years has the participant attended a One Heartland camp program related to HIV/AIDS (e.g., Camp Heartland, Hollywood Heart)? If this is the first year please write zero.

    _____
    _____

8. Has a medical professional ever diagnosed the participant with a medical condition (e.g., asthma, diabetes)? Please list below. If the participant does not have a diagnosable medical condition, please write "NONE."

    _____
    _____
    _____
    _____

9. Please list all medication(s) the participant is taking. If the participant is not taking any medications, please write "NONE."

    _____
    _____
    _____
    _____
    _____
    _____

10. The participant is HIV Positive _____ HIV Negative _____

    If the participant is HIV positive, does the participant know their HIV status?
    Yes _____ No_____

    If the participant is HIV positive, how many years has the individual been living with (and aware) of his/her HIV status?
    _____

    If the participant is HIV positive, how was he/she infected?
    Perinatal:
    Infected parent (pregnancy, childbirth, breastfeeding) _____

    Acquired:
    Sexual contact _____

    Injection drug use _____

Blood transfusion _____

Other _____

11. If the participant is HIV Negative, is the participant living with an infected family member?
      Yes _____ No_____

      If yes, what is the relationship to the participant?
      _____

      Does the participant know the HIV status of the infected family member?
      Yes _____ No_____

12. Has the participant lost an immediate family member to HIV/AIDS?
      Yes _____ No_____

      If yes, what was the relationship to the participant?
      _____

      Did the participant know the family member had HIV/AIDS?
      Yes _____ No_____

13. Has a medical or mental health professional ever diagnosed the participant with any of the following mental health disorders?

Depression: ☐ Yes ☐ No	**Bipolar Disorder:** ☐ Yes ☐ No
If Yes, ☐ does the participant receive counseling? ☐ is the participant being treated with medication?	If Yes, ☐ does the participant receive counseling? ☐ is the participant being treated with medication?
Generalized Anxiety Disorder: ☐ Yes ☐ No	**Panic Disorder:** ☐ Yes ☐ No
If Yes, ☐ does the participant receive counseling? ☐ is the participant being treated with medication?	If Yes, ☐ does the participant receive counseling? ☐ is the participant being treated with medication?
Attachment Disorder/Separation Anxiety: ☐ Yes ☐ No	**Obsessive Compulsive Disorder:** ☐ Yes ☐ No
If Yes, ☐ does the participant receive counseling? ☐ is the participant being treated with medication?	If Yes, ☐ does the participant receive counseling? ☐ is the participant being treated with medication?
Attention Deficit/Hyperactivity: ☐ Yes ☐ No	**Oppositional Defiant Disorder:** ☐ Yes ☐ No
If Yes, ☐ does the participant receive counseling? ☐ is the participant being treated with medication?	If Yes, ☐ does the participant receive counseling? ☐ is the participant being treated with medication?
Eating Disorder: Anorexia or Bulimia: ☐ Yes ☐ No	**Learning Disability:** ☐ Yes ☐ No
If Yes, ☐ does the participant receive counseling? ☐ is the participant being treated with medication?	If Yes, ☐ does the participant receive counseling? ☐ is the participant being treated with medication?
Autism or Developmental Disorders: ☐ Yes ☐ No	**Tourette's Syndrome:** ☐ Yes ☐ No
If Yes, ☐ does the participant receive counseling? ☐ is the participant being treated with medication?	If Yes, ☐ does the participant receive counseling? ☐ is the participant being treated with medication?
Please list any other conditions and helpful insights to the above:	

Appendix B

UCLA PTSD REACTION INDEX FOR CHLDREN/ADOLESCENTS - DSM-5©

SELF-REPORT TRAUMA HISTORY: *Sometimes people have scary or violent things that happen to them where someone could have been or was badly hurt or killed. Has anything like this ever happened to you?*

1. Provide a brief description of what happened:

_____

_____

_____

_____

_____

*Below is a list of other scary or violent things that can happen. For each question, check **"Yes"** if this has **happened to you**; check **"No"** if this **did NOT happen to you**.*

1. Were you in a disaster, like an earthquake, wildfire, hurricane, tornado or flood?	□Yes	□No
2. Were you in a bad accident, like a serious car accident or fall?	□Yes	□No
3. Were you in a place where a war was going on around you?	□Yes	□No
4. Were you **hit, punched, or kicked very hard** at home? (**DO NOT INCLUDE** play fighting between brothers and sisters.)	□Yes	□No
5. Did you see a family member being **hit, punched or kicked very hard** at home? (**DO NOT INCLUDE** play fighting between brothers and sisters).	□Yes	□No
6. Were you **beaten up, shot at, or threatened to be hurt badly** in your school, neighborhood or town?	□Yes	□No
7. Did you see someone who was **beaten up, shot at or killed?**	□Yes	□No
8. Did you see a **dead body** (do not include funerals)?	□Yes	□No
9. Did someone touch your **private parts** when you did not want them to?	□Yes	□No
10. Did you see or hear about the **violent death or serious injury** of a loved one or friend?	□Yes	□No
11. Did you have a **painful or scary medical treatment** when you were very	□Yes	□No

sick or badly injured?		
12. Were you ever **forced to have sex** with someone when you didn't want to?	□Yes	□No
13. Have you ever been **diagnosed with HIV**?	□Yes	□No
14. Have you ever **received treatment** for your HIV diagnosis?	□Yes	□No
15. Have you ever had to **take medication for your HIV diagnosis** a certain number of times per day or per week?	□Yes	□No
16. Have you ever had to **tell someone about your HIV status**?	□Yes	□No
17. Have you ever had **physical (body) symptoms** because of HIV?	□Yes	□No
18. Has anyone ever **treated you differently** because you have HIV?	□Yes	□No
19. Has anyone ever **been mean** to you because you have HIV?	□Yes	□No
20. Has anyone you know ever **died from HIV/AIDS**?	□Yes	□No
21. Have you ever found out about **the HIV diagnosis of someone close to you**?	□Yes	□No
22. OTHER than the things described above, has **ANYTHING ELSE** ever happened to you that was **REALLY SCARY OR UPSETTING?**	□Yes	□No