

Posttraumatic Stress and Trauma History in Adolescents and Young Adults with HIV

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ABSTRACT

This study examined trauma history and posttraumatic stress in a sample of 30 adolescents and young adults with HIV/AIDS, recruited from December 14, 2004 through May 3, 2005. Overall, participants reported a mean of 5.63 traumatic events, with 93% of the sample reporting that receiving a diagnosis of HIV was experienced as traumatic. Of these, 13.3% met criteria for posttraumatic stress disorder in response to HIV diagnosis, while an additional 20% showed significant post-traumatic stress symptoms. Even greater rates of posttraumatic stress were reported in response to other trauma, with 47% of youth surveyed reporting symptoms of posttraumatic stress in response to such traumatic events as being a victim of a personal attack, sexual abuse, or being abandoned by a caregiver. These findings may inform professionals about the potential impact of the HIV diagnosis on adolescents and young adults, particularly as this may impact participation in medical care and need for mental health support.

INTRODUCTION

IN THE PAST 5 YEARS ALONE, approximately 100,000 adolescents and young adults between the ages of 13 and 24 have become infected with HIV.¹ Development of highly active antiretroviral therapy (HAART) has greatly reduced HIV mortality, but treatment requires significant self-management.² The extent of new HIV infections among this age group and the challenges they face in managing their disease underscores the need for research to improve care and prevention. Understanding and addressing key psychological factors impacting disease adjustment for young

people who are HIV positive is critical for providers to increase their effectiveness in providing health care to this highly vulnerable population.

Posttraumatic stress may be an important psychological variable to explore in individuals with HIV/AIDS. As defined by the *Diagnostic and Statistical Manual-IV (DSM-IV)*, posttraumatic stress disorder (PTSD) is characterized by having experienced an event in which body integrity and life are threatened; reactions of extreme fear, helplessness, or horror; and specific symptoms related to reexperiencing the event, avoidance of reminders of the event, and hyperarousal.³ The symptoms must

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be present for at least 1 month after the traumatic event, and must cause functional impairment. For an individual living with HIV, body integrity and life are clearly at risk, both from the diagnosis as well as the treatment. Re-experiencing symptoms cause distress that can interfere with daily function, including distress at returning to the site of the original diagnosis or where medical care is provided. Avoidance symptoms can lead to failure to return to a health care setting to obtain medical care, unwillingness to adhere to medical care regimens, and refusal to disclose one's status to significant others, including sexual partners. Hyperarousal can interfere with sleep as well as relationships with others; these include health care providers as well as family, friends, and significant others, who might offer emotional support to a young person living with HIV. Posttraumatic stress symptoms (PTSS), though not meeting full diagnostic criteria for PTSD, have also been found to interfere with psychological well-being. Severe and debilitating posttraumatic stress from trauma commonly experienced by young people such as significant injuries requiring hospitalizations, being physically attacked, or being physically threatened has been reported.^{4,5} Those who have experienced trauma have been found to be at greater risk for impaired social relationships, substance abuse, suicide attempts, personality disorders, delinquent behavior, physical injuries, and major depression.⁴⁻⁷ Thus, through its profound impact on psychological well-being, posttraumatic stress may interfere significantly with adolescents' and young adults' adjustment to receiving a diagnosis of HIV. In addition, posttraumatic stress affects the resulting lifestyle changes necessary to maintain their own health as well as to reduce secondary infections to others.

Because HIV/AIDS frequently strikes families already struggling with multigenerational histories of victimization and trauma, individuals with HIV may be at higher risk for mental health difficulties, including posttraumatic stress reactions.⁸ Limited evidence for understanding possible posttraumatic stress among adolescents and young adults with HIV is available from studies of HIV-infected adults. HIV-infected adults have been found to present

with high rates of post-traumatic stress (10.4% to 42%).⁹⁻¹² Posttraumatic stress disorder has been linked both to receiving the HIV diagnosis itself as well as to other life stressors associated with HIV such as a history of sexual abuse and assault.^{9-11,13} Strikingly, symptoms of posttraumatic stress have been found to persist for long periods of time postdiagnosis, with one study reporting posttraumatic symptoms even after 8 years, on average, postdiagnosis.¹⁴ Despite the likelihood of posttraumatic stress occurring among adolescents and young adults who have been diagnosed with HIV, this has not yet, to our knowledge, been characterized.

Young people with HIV/AIDS face the challenge of managing a highly stigmatizing chronic illness that may potentially cause or exacerbate existing mental health difficulties. The one major study of adolescents and young adults with HIV, Reaching for Excellence in Adolescent Care and Health (REACH), found that among 230 adolescents between the ages of 12 and 19 who became HIV infected through sexual behavior or injection drug use, life events with high impact such as being prescribed HIV medications (74%) or family financial problems (61%) were associated with higher levels of depression and anxiety.¹⁵ Although the REACH study did not include posttraumatic stress among the mental health conditions investigated, they did find an association between adherence and depression. Murphy and colleagues found that among HIV-infected adolescents, higher levels of depression were significantly associated with decreased adherence to taking antiretroviral medications.¹⁶ Within this sample, while 55% of the nondepressed group was self-reported as fully adherent with medications, only 29% of depressed individuals described themselves as fully adherent to their medication regimen. In a prospective study of adherence, depression among HIV-infected adolescents and young adults was found to be associated with failure to maintain adherence to HIV medication.¹⁷ Thus, comorbid mental health conditions, in this case, depression, may compromise the ability of young people with HIV to manage their disease as well as complicate efforts by the health care team to provide effective medical care.

This study proposes to add to the understanding of adolescents and young adults with HIV by examining trauma history and posttraumatic stress reactions. Earlier work has found that more than two fifths of individuals in this age range experience trauma including seeing someone hurt or killed, sudden injury or accident, news of another's sudden death/accident, or physical assault.¹⁸ An examination of trauma and its linkage to posttraumatic stress has not yet been extended to adolescents and young adults with HIV/AIDS. We hypothesize that, for adolescents and young adults living with HIV/AIDS, the extent of those experiencing traumatic events will be greater than 40% because of the expected impact of the diagnosis itself, as well as other risk factors associated with HIV such as exposure to violence and poverty, which are prevalent among urban settings. Furthermore, from the literature on the extent of PTSD among adults with HIV, where rates of 10%–42% are reported, we would expect to find rates of PTSD that are greater than 14.5%, which is the lifetime estimate of posttraumatic stress within a general population of adolescents and young adults.¹⁸

We also address limitations in the literature regarding the impact of receiving a diagnosis of HIV for adolescents and young adults. We will do this by examining to what extent receiving an HIV diagnosis is (1) perceived as traumatic and (2) associated with PTSS. Finally, we will expand the literature on posttraumatic stress among individuals with HIV by comparing posttraumatic stress reactions to receiving an HIV diagnosis to those associated with other life stressors. To summarize, this study examines: (1) the extent to which individuals with HIV experience potentially traumatic events, including the HIV diagnosis; (2) the extent to which receiving a diagnosis of HIV is perceived as traumatic; and (3) the extent of PTSS associated with HIV-diagnosis compared to other-related trauma, and how these relate to the number of traumatic events experienced.

MATERIALS AND METHODS

Participants were drawn from an outpatient HIV clinic in an urban pediatric hospital in the

northeastern United States. Inclusion criteria were: ages 18–24 years; HIV diagnosis; fluency in English; and willingness to provide written informed consent. The Institutional Review Board of the hospital gave approval for the conduct of this study.

Procedure

From 2004 to 2005, potential participants coming to clinic for a regular medical visit were approached by a member of the clinic team and asked if they wished to participate in a study seeking to understand what stressful and traumatic events young people have experienced and how young people feel following these events. If the youth agreed, a member of the investigative team explained the study in more detail and asked for formal consent. Once consent was obtained, a trained research assistant administered study questionnaires in a private office.

Measures

Trauma history. Participants were asked about their prior exposure to trauma, via the Traumatic Events Screening Inventory (TESI).^{19,20} This is a semistructured interview that includes a survey of potentially traumatic events including injuries or accidents, hospitalizations, disasters, domestic and community violence, physical and sexual abuse, as well as questions regarding reactions to the event. One additional item, receiving a diagnosis of HIV, was added for the present study, for a total of 15 events. The criteria for an event to be scored as “traumatic,” in accordance with *DSM-IV* criteria, were that a participant had to report, at the time of the event, experiencing intense fear, a sense of helplessness, or feeling horrified. Trauma history was scored as a count (0 to 15) of the number of traumatic events experienced. Interrater reliability κ for TESI summary scores at 2- and 4-month intervals with pediatric patients have been reported from 0.73 to 1.00.¹⁹ Validity has been established between parent and child/adolescent trauma ratings, ranging from 0.64 to 0.79.

Posttraumatic stress (PTSD, PTSS). PTSD and PTSS were assessed with the Posttraumatic

Stress Disorder Checklist-Civilian Version (PCL-C), a 17-item measure of symptoms keyed to DSM-IV diagnostic symptoms of PTSD.^{21,22} The PCL-C was administered twice; first, referencing the participant-identified “biggest, hardest” event they had ever experienced, and a second time referencing either receiving their HIV diagnosis (if that was not identified initially) or their “next hardest” experience. In accordance with standard symptom cluster scoring rules, participants who reported moderate distress by one or more reexperiencing symptoms, three or more avoidance symptoms, and two or more arousal symptoms over the past month were identified as meeting symptom criteria for PTSD. These criteria were used to evaluate PTSD both for HIV diagnosis and for the participant-identified other significant traumatic stressor. Consistent with previous studies, PTSS was defined by at least one severe rating in each symptom category (reexperiencing, avoidance, and arousal) as well as assessed impairment from these symptoms.^{23,24} Reliability has been established through test-retest, with a correlation coefficient of 0.96 in a sample of Vietnam veterans.²² Validity for the PCL-C has been established by comparing PCL-C-determined PTSD diagnoses with those from the SCID (Structured Clinical Interviews for DSM-III-R), one of the gold standards for diagnosing PTSD; the correlation statistic was found to be 0.64.^{22,25} Blanchard and colleagues²⁶ report a correlation with the CAPS (Clinician Administered PTSD Scale) of 0.929 in a sample of adult trauma victims. A confirmatory factor analysis of the PCL-C found that a hierarchical four-factor model supported an overall factor and as well as three symptom clusters of re-experiencing, numbing, and hyperarousal.²⁷ For this study, the coefficient alphas of the PCL-C factors ranged from 0.87 to 0.89.

Data analysis

Descriptive analyses were conducted to summarize exposure to traumatic events, HIV diagnosis-related and other trauma-related post-traumatic symptom severity, as well as prevalence of PTSD and PTSS. Relationships among trauma history and PTSD symptoms were examined using Pearson product-mo-

ment correlation analyses. Differences in PTSD rates per type of trauma (HIV diagnosis versus other) were tested through *t* tests. *t* tests were also used to compare symptom levels associated with types of trauma (HIV and other). Analyses were conducted using SPSS version 14.0 (SPSS, Inc., Chicago, IL).

RESULTS

Participants

Thirty youth participated in this study. Mean age of the sample was 21.4 years (range, 18–24 years), with 83% African American, 10% European American, and 7% biracial. The sample was 70% male, 23% female, and 7% transgender (male-to-female). With regard to sexual orientation, among the males, 67% were men who have sex with men (MSM), 14% heterosexual, and 19% bisexual; among the females, 71% were heterosexual, and 29% lesbian. All but one of the participants was infected with HIV through unsafe sex; the other was infected perinatally. Mean time since diagnosis was 4.6 years (range, 1.9–11.5). Most (63%) participants were employed or attending school or college.

Trauma history

All participants reported experiencing at least one potentially traumatic event and, on average, participants reported enduring 5.6 events they identified as traumatic (range, 1–10). Table 1 reports potentially traumatic events and participants' responses. Among these, by definition, all participants reported that they had received a diagnosis of HIV; other traumatic events most frequently endorsed included having a person close to the participant become seriously ill or injured, being a victim of a physical attack or abuse, involvement in a serious accident, and witnessing domestic violence. Almost all participants (93%) indicated that receiving their HIV diagnosis was traumatic, but high percentages of trauma were also reported in response to sexual abuse (100%), being separated from a caregiver, such as being placed in foster care (100%), physical attack (94%), and having someone close to them sick or hurt (92%). Not all frequently oc-

TABLE 1. TRAUMATIC EVENTS AND RESPONSES REPORTED BY STUDY PARTICIPANTS ($N = 30$)

<i>Event</i>	<i>n experiencing</i>	<i>% experiencing as traumatic</i>
Receiving a HIV diagnosis	30	93
Someone close to me sick or hurt	24	92
Neighboring violence	23	52
Been in or saw bad accident	17	82
Family violence	17	82
Family member incarcerated	17	53
Physical attack to me	16	94
Thought I might die	12	75
Separated from caregiver	10	100
Physical neglect by caregiver	10	90
Sexual abuse	9	100
Someone close suicide attempt	8	88
Family violence life threatening	5	60
Been in natural disaster	3	100
Emotional abuse	2	100

curing events were described as traumatic to this degree, e.g., neighborhood violence (52%) or having a family member incarcerated (53%).

When asked to name their "worst" event, 59% of the sample reported that receiving the HIV diagnosis was "hardest" or "worst" ever. The remaining 41% of the participants named another event as the "worst"; these included physical attacks or other serious illnesses.

Postrumatic stress

The majority of participants (57%) reported traumatic stress symptoms consistent with PTSD or PTSS in response to at least one traumatic stressor among the 15 potentially traumatic events surveyed. An average of each participant's most severe traumatic stress symptoms was calculated which revealed a moderate level of symptoms ($M[SD] = 36.87 [14.29]$).

HIV-related PTSD and PTSS

In response to the HIV diagnosis, 20% of participants reported symptoms consistent with PTSS, with an additional 13.3% meeting full symptom criteria for PTSD. Thus, for the sample overall, 33% showed a notable degree of posttraumatic stress in response to the HIV diagnosis. Participants reported moderately severe levels of post-traumatic stress in response to HIV diagnosis ($M[SD] = 33.03 [13.27]$). There was no significant relationship between

post-traumatic stress and length of time since diagnosis ($r = -0.16, p = 0.39$), nor between extent of HIV-related posttraumatic stress and the number of traumatic stressors experienced ($r = 0.01, p = 0.98$).

Other-related PTSD and PTSS

In response to the "other" most traumatic events, 47% of the participants reported traumatic stress reactions, with 23.3% reporting symptoms consistent with PTSS, and an additional 23.3% meeting symptom criteria for PTSD. Participants additionally reported moderately severe levels of post-traumatic stress in response to the other-related trauma ($M[SD] = 31.69[12.93]$). There was no significant relationship between extent of post-traumatic stress related to another traumatic event and the number of traumatic stressors experienced ($r = 0.08, p = 0.70$).

Comparing HIV-related with other-related stressors

HIV-related trauma symptoms were compared to non-HIV trauma symptoms, based on responses to the HIV diagnosis (whether assessed first or second) and to the "other" trauma (whether assessed first or second). As presented in Table 2, the levels of traumatic stress symptoms related to HIV diagnosis did not differ from those related to another traumatic event. Furthermore, no significant dif-

TABLE 2. DIFFERENCES FOR POSTTRAUMATIC DISORDER CHECKLIST SYMPTOM SCORES FOR HIV- AND OTHER-RELATED TRAUMA TYPES

Symptom scores	HIV		Other		t (25)
	M	SD	M	SD	
Reexperiencing	8.61	(4.20)	10.08	(5.31)	-1.780
Avoidance	14.15	(6.53)	12.92	(5.87)	0.873
Arousal	9.31	(4.68)	8.69	(4.34)	0.831
Total	32.08 (12.33)	31.69 (12.94)	0.160		

^a*p* < 0.05.^b*p* < 0.01.

ferences existed between extent of HIV diagnosis-related symptoms as compared to other trauma-related symptoms in each symptom category, although there was a trend toward re-experiencing symptoms being more severe for other-related as opposed to HIV-related trauma [$t(25) = -1.780, p = 0.09$]. Thus, generally, participants were similarly distressed across type of traumatic stressors.

Posttraumatic stress, functional impairment, and traumatic stress symptoms

Meeting symptom cluster criteria plus functional impairment is the most stringent standard for evaluating PTSD, and the relationship between this standard and the number of traumatic stressors was examined. Of the participants who met PTSD criteria, all but one met criteria for functional impairment as well. See Table 3 for results. No significant differences were found between the average number of stressors experienced, for both types of stressors combined, or for HIV-related traumatic stress alone, although the sample sizes are quite small. We were unable to compute a *t* test for other-related traumatic stress because one cell was empty.

TABLE 3. NUMBERS OF TRAUMATIC EVENTS EXPERIENCED BY CATEGORY OF STRESSOR (ALL TYPES, HIV OR OTHER) AND LEVEL OF SYMPTOMATOLOGY (PTSD ALONE OR WITH FUNCTIONAL IMPAIRMENT)

Trauma type	With PTSD alone			With PTSD + functional impairment			(df) t
	n	M	SD	n	M	SD	
All	1	3	0	7	5	1.63	(6) -1.15
HIV	1	3	0	3	5.67	1.53	(2) -1.51
Other	0	0	0	4	4.5	1.73	—

^a*p* < 0.05.

DISCUSSION

This study is the first to our knowledge to characterize posttraumatic stress among adolescents and young adults living with HIV. As hypothesized, individuals in this study reported having experienced high levels of potentially traumatic events in addition to receiving a diagnosis of HIV. Though receiving a diagnosis of HIV was almost universally experienced as traumatic, 20% reported diagnosis-related PTSS while approximately 13% of the sample met criteria for PTSD related to HIV diagnosis. Other life stressors were more frequently associated with both PTSD and PTSS, with 23.3% of the sample reporting PTSD and an additional 23.3% reporting PTSS. Reactions to receiving a diagnosis of HIV were as intense as reactions to other life stressors, with relatively high levels of reexperiencing, hyperarousal, avoidance, and functional impairment.

The numbers of traumatic events experienced by the individuals in this study are increased relative to community samples. Although an open population study of 2997 adults found an incidence of 0.8 traumatic events experienced per participant, on average, studies of clinical groups of adolescents and young adults typically report higher rates of traumatic events.²⁸ For example, in a sample of adolescents in long-term residential substance abuse treatment, Jaycox and colleagues⁴ reported a mean of 4.12 (of a possible 9) traumatic events experienced. Similarly, Zatzick and colleagues⁵ report that among hospitalized injured adolescents, a mean of 2.5 serious traumatic life events were reported by the injured adolescents prior to their injury, with 30% of the sample reporting 4 or more traumatic stres-

sors. Finally, Gianconia and colleagues¹⁸ determined that 43% of their sample of 18-year-olds in a longitudinal study reported at least one traumatic stressor by age 18 years. Despite these reports of higher rates of reported traumas among clinical samples of adolescents, the average number of 5.6 traumatic events experienced by the adolescents and young adults with HIV in this sample remains notable.

The remarkably high rate of posttraumatic stress symptoms related to HIV diagnosis and other events is consistent with the adult HIV literature. Kelly and colleagues¹⁰ report a 30.2% rate of current or lifetime PTSD among MSM with HIV and Katz and Nevid⁹ report a rate of 35% scoring in the syndromal or subsyndromal range among HIV-infected women. In these two studies, both receiving an HIV diagnosis and other traumatic life events were found to be associated with post-traumatic stress.

With regard to the adolescent/young adult literature, Murphy et al.¹⁵ found that life events with high impact were associated with depression and anxiety among adolescents with HIV; PTSD was not examined. Relatively low rates of PTSD have been found among clinical samples of adolescents. Among a sample of 898 youth in juvenile detention; only 11.2% met criteria for PTSD within the past year, with witnessing violence as the most frequent precipitating traumatic event.²⁹ In a community sample of 384 adolescents participating in a longitudinal study, Gianconia, and colleagues¹⁵ report that 6.3% of the overall sample developed PTSD, including 14.5% of those who had experienced at least one traumatic stressor. Thus, again, the rates of posttraumatic stress and PTSD within this sample appear quite high for an adolescent/young adult sample.

The relatively small number of participants included, especially females, is a limitation of the present study. Since females represent the fastest growing population of individuals being diagnosed with HIV, and women with HIV have been found to present with high rates of trauma history, including sexual abuse and violence, including a greater number of females in this study would have allowed for more detailed analysis of the effects of trauma on adolescent and young adult women with HIV. An additional limitation of the current study was that in the interest of assessing a broad range

of information about trauma and traumatic stress in this sample, a questionnaire format was used to assess posttraumatic stress reactions. A structured clinical interview is considered the gold standard for assessing posttraumatic stress symptomatology and would have provided greater diagnostic clarity. Other study limitations are the use of cross-sectional data, a lack of information on illness severity at the time of interview, and the sequence of stressors reported, especially in relation to receiving the HIV diagnosis.

Clinical implications for this study are that care providers need to be aware of the traumatic nature of receiving a diagnosis of HIV/AIDS among adolescents and young adults. This may be particularly true among those youth who have already experienced multiple traumas. The symptoms associated with posttraumatic stress, reexperiencing, hyperarousal, and avoidance, may interfere with adherence to medical care, in that youth may miss clinic visits due to these mental health symptoms. Having counseling resources available or making referral to mental health professionals is an important component of providing comprehensive care to adolescents and young adults with HIV.

In the future, research needs to examine the prevalence of posttraumatic stress among adolescents and young adults with HIV/AIDS through larger scale studies. It would be helpful to expand the study to include the effects of posttraumatic stress on adherence to medical care, including highly active antiretroviral therapy. Finally, the development of effective clinic-based interventions to reduce PTSS in youth with HIV/AIDS will facilitate their overall competence in living with HIV/AIDS.

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