

HIV-Related Posttraumatic Stress Disorder: Investigating the Traumatic Events

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Abstract

This study examined the relationship between the experience of various HIV-related events (receiving the diagnosis, receiving treatment, experiencing physical symptoms, self-disclosing HIV positive status, and witnessing HIV-related death) and posttraumatic stress symptoms in a sample of 100 gay men living with HIV. Self-report data revealed that 65% met criteria for having experienced a traumatic event in accordance with the *Diagnostic and Statistical Manual of Mental Disorders, 4th edition, Text Revision (DSM-IV-TR)* posttraumatic stress disorder (PTSD) criterion A. The experience of shame, humiliation, or guilt during an event was measured but not found to be a significant indicator of having been traumatized. A total of 33% qualified for a PTSD diagnosis. Stepwise multiple regression analysis showed that receiving medical treatment, experiencing physical symptoms, and witnessing HIV-related death were most associated with HIV-related PTSD symptoms. Given that multiple HIV-related events are potentially traumatic, the screening, assessment and treatment for HIV-related PTSD may need to be considered by HIV services.

Introduction

LIFE-THREATENING ILLNESS is recognized in the *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition Text Revision (DSM-IV-TR)* as a possible traumatic stressor that could give rise to a posttraumatic stress response.¹ Posttraumatic stress disorder (PTSD) prevalence rates in response to cancer have been found to range from 0% to 32%,² while PTSD in response to the experience of HIV has been found to range from 13% in adolescent and young adults,³ 15% in ethnic minority women,⁴ 30% among gay men⁵ to 64% for HIV-positive people who have difficulty adhering to medication.⁶

Life-threatening illnesses are frequently ongoing and over the course of the illness multiple instances may recur during which the illness poses a threat to physical integrity or causes physical harm. Such instances may include the diagnosis and prognosis, noxious treatment, disease and treatment side effects.^{2,7} In addition, these threats may be associated with compromised physical, social, and occupational functioning that threaten the integrity of the self. Each event may pose a different type and degree of threat. Therefore, many different illness-related events can be considered an index threat event or a trigger for PTSD. HIV researchers have accounted for such variability by designating the global experience of

"having HIV"⁶ or "being diagnosed and treated"⁴ as the traumatic event. While these definitions capture a breadth of potential stressors constituting the illness experience, they lack specificity. What is not known is what may be specifically threatening or overwhelming about the HIV-illness experience, and which aspects of the experience could meet diagnostic criteria for trauma exposure.

The *DSM-IV-TR* conceptualizes a traumatic event as involving physical threat and evoking strong emotional distress (criterion A for PTSD). This is more specifically defined as meeting subcriteria A1 and A2. According to A1 "the person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others," and according to A2 "the person's response involved intense fear, helplessness, or horror."¹

Research has established a link between receiving the HIV diagnosis and PTSD,⁵ signifying the degree to which this event is experienced by some people as threatening to physical integrity. However, over the duration of the illness various events may signal degrees of threat, some more immediately threatening than others, like physical illness symptoms. Chronic illness-related PTSD may therefore contain a broad range of possible index traumas, which could

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complicate measuring a *post*-trauma syndrome. However, in simple PTSD it has been observed that traumatised individuals struggle to describe posttraumatic symptoms as arising from a single aversive moment.⁸ Taking account of multiple possible trauma moments may therefore more accurately reflect the phenomenological trauma experience.

The objective threat an event poses to an individual's physical integrity is not the only criteria that designates an event as traumatic. Diagnostic criteria require that an emotional response occurs during an event which may account for variability in individual responses to objective events. Where emotional distress in response to a threat event is absent, developing PTSD is unlikely, although in a small minority of cases PTSD has been observed.^{9,10} Diagnostically, emotional responses that indicate a traumatic reaction have been limited to intense fear, helplessness or horror. There is evidence that other responses such as shame, anger, and numbing that occur during a traumatic event (i.e., that are peritraumatic) may also associate with and predict PTSD.^{10,11}

Peritraumatic emotional responses, other than those diagnostically recognized, may point to additional psychological processes leading to PTSD. Katz and Nevid⁴ found a strong association between stigma and HIV-related PTSD symptoms. While fear associated with physical threat is central to the diagnosis of PTSD, the authors suggest that shame, humiliation, and guilt may be central to HIV-related PTSD and interventions should be guided by schema models of trauma that focus on these emotions.¹² This alternative PTSD model potentially broadens the range of traumatic HIV-related stressors, which could include threats to the self such as acts of stigmatization that range from verbal aggression to discrimination.¹³

This study aimed to investigate whether a broad range of HIV-related events met criterion A for PTSD. We hypothesized that responses to more than one HIV-related event would associate with posttraumatic stress symptoms (PTSS), and that both perceived threat (criterion A1) and emotional distress such as fear, helplessness, or horror (criterion A2) would associate positively with PTSS. We explored which HIV-related events would associate more with PTSS in a model of multiple events, and hypothesized that diagnosis, as the seminal HIV-related event, would account for most of the independent variance in PTSS. We hypothesized that some participants would meet event and symptom criteria that would qualify for a PTSD diagnosis. We examined the role of shame and hypothesized that the associative strength between meeting criterion A and PTSS would increase if shame-associated responses were regarded as identifiers of trauma (criterion A2).

Methods

Participants

The sample consisted of 100 self-identified gay men living with HIV and resident in the British Isles. Self-report questionnaires were distributed through voluntary gay and HIV community support services and adverts for the study placed in the national HIV and gay press. Participants self-selected and could pick up a questionnaire at a service or print off a questionnaire from a dedicated website that had to be returned by post. This method ensured a wider geographic spread but did not allow for calculating return rates. The

mean age was 43 (range, 23–65), mean years since diagnosis was 8 years (range, <1–23 years). The majority were white (95%), approximately half defined themselves as single (56%), nearly half in full-time employment (47%), two thirds (68%) had tertiary education, and more than half lived in London (52%). The geographical and ethnic bias in the sample followed the same pattern of distribution as found in large scale research using national United Kingdom samples ($N = 16,365$) of gay men.¹³

Assessment of responses to HIV-related events (criterion A)

Responses to potentially distressing HIV-related events were measured, which included: receiving the diagnosis; receiving treatment; experiencing side effects; physical symptoms; self-disclosing HIV status; and witnessing HIV/AIDS-related death. Using a 3-point scale used by Brewin¹⁰ (0 = not at all, 1 = to some degree, 2 = intensely) the intensity of responses to each event were rated. Where events were experienced more than once, the most distressing time was rated. Ratings of 2 were scored as endorsing the criterion thus producing binary diagnostic variables. Responses were coded as meeting criterion A1 (experiencing the event as a physical threat or having thoughts of dying); meeting criterion A2 (experiencing either fear, helplessness, or horror), meeting criterion A (meeting both criterion A1 and A2); and responses coded to reflect having had a shame-associated response (experiencing either shame, humiliation, or guilt).

Assessment of PTSS

The Posttraumatic Checklist Civilian Version (PCL-C) measures the 17 diagnostic symptoms defined by the *DSM-IV-TR*.¹ It measures the 3 subsyndromes of reexperiencing, avoidance/numbing, and arousal on a 5-point scale (1 = not at all to 5 = extremely). The test was demonstrated to be reliable (Cronbach $\alpha r = 0.97$, test-retest $r = 0.96$),⁸ and in this study Cronbach $\alpha r = 0.94$. Convergent validity was demonstrated through correlations with standard measures of PTSD ranging between 0.77 and 0.93.¹⁴ The PCL-C has been used extensively in research on illness-related PTSD.² Participants were asked to rate their experience of symptoms in response to all of the above HIV-related events that they had experienced.

PTSD diagnosis

A cutoff score of 50 or more on the PCL-C has been shown to provide a putative PTSD diagnosis with a sensitivity of 0.82 and specificity of 0.83,^{8,14} offering a stricter diagnostic method than using endorsements of symptoms (score ≥ 3) according to *DSM-IV-TR* criteria.⁷ Where responses met criterion A for at least one event and the cutoff for posttraumatic symptoms, a PTSD diagnosis was assigned.

Data analysis

Descriptive analyses were conducted to examine the frequency of events meeting criterion A for PTSD and the number of participants meeting full criteria for PTSD. The relationship between traumatic events and PTSS was examined using Spearman's correlation analysis for the binary criterion A variables. Multivariate stepwise regression analysis was

used to examine which traumatic events best predicted traumatic stress symptoms. All these analyses were repeated after including shame in the criteria for a traumatic event (criterion A) to examine the peritraumatic role of shame in trauma. Analyses were conducted using SPSS version 17 (SPSS, Inc., Chicago, IL).

Results

Frequency of traumatic events and PTSS

Over half the sample (55%) found that receiving an HIV diagnosis was traumatic, followed by 40% experiencing HIV-related physical symptoms, 30% witnessing HIV/AIDS-related death, 29% having treatment side effects, 19% receiving medical treatment, and 15% self-disclosing HIV status (see criterion A frequencies, Table 1). A total of 65% experienced at least one HIV-related event as traumatic. Receiving the HIV diagnosis was more distressing than other events on most parameters but was not seen as more physically threatening. Physical symptoms of HIV were most likely to be experienced as physically threatening.

Using the PCL-C cutoff score of 50 or greater, 39% qualified for a putative PTSD diagnosis, and when combined with criterion A, a total of 33% of the sample met PTSD criteria.

Traumatic event experiences and PTSS

The correlations showed that traumatic experiences of all HIV-related events (criterion A) associated significantly with posttraumatic stress at significance level $p < 0.01$, except for the experience of self-disclosure, which was significantly associated at the $p < 0.05$ level (Table 2). For most events emotional distress (criterion A2) correlated more strongly with PTSS (range of $r = 0.35$ to 0.51) than perceived physical threat (criterion A1) (range of $r = 0.22$ to 0.47). The exception was the "experience of physical symptoms," where perceived physical threat correlated more strongly ($r = 0.47$) than emotional distress ($r = 0.35$) with PTSS, and for receiving the diagnosis the correlations of PTSS with emotional distress and physical threat were of a similar magnitude.

Predictors of PTSS

A stepwise regression calculated the relative association of HIV-related trauma events and PTSS. Demographics such as year of diagnosis, age, geography, ethnicity, education, relationship status, and employment were measured, of which only employment correlated with PTSS so that those who were in full-time employment were less likely to experience PTSS than those who were not. Employment was therefore controlled for in the analysis. All parametric assumptions were met, with low to moderate intercorrelations ($r = < 0.5$) among the stressor variables, posing no significant threat to the parametric assumptions.¹⁵ The first regression examined the associations between meeting criterion A for each event and PTSS. All findings were verified by backward regression analysis.

Criterion A for each event was entered stepwise (Table 3). Traumatic experiences of receiving medical treatment, having physical symptoms and witnessing HIV-related death associated to similar degrees with posttraumatic stress symptoms. The model explained 32% of the variance in PTSS.

Shame and trauma

When shame-related emotions were included in criterion A2, the percentage of people who could be said to have experienced a traumatic event (i.e., who met criterion A) increased between 1% and 4% across the different events (Table 1), and the proportion who met criterion A in response to at least one HIV-related event increased from 65% (without recognizing shame) to 66%. However, including shame-associated emotions in criterion A2 did not affect the number who qualified for a PTSD diagnosis, which remained at 33%.

Including shame-related emotions in meeting criterion A marginally increased the associative strength between criterion A and PTSS for most events by $r = 0.01$ or 0.02 . However, for treatment and witnessing HIV-related death, the inclusion of shame-associated responses reduced the association by $r = 0.04$ and 0.02 , respectively (Table 2).

Shame-associated responses were included as a possible criterion A2 reaction in a rerun of the stepwise regression

TABLE 1. PROPORTION (%) OF INDIVIDUALS WHO EXPERIENCED REACTIONS TO AN EVENT INTENSELY

	<i>HIV diagnosis</i>	<i>Physical symptoms</i>	<i>Receiving treatment</i>	<i>Side effects</i>	<i>Witnessing HIV-related death</i>	<i>Self-disclosing HIV + status</i>
n =	100	72	78	63	84	93
1 Experience event as a physical threat	33	43	15	33	12	9
2 Thought that I might die	61	40	21	19	36	15
<i>Criterion A1 (1 or 2)</i>	64	56	27	38	38	20
3 Fear	52	33	23	24	24	25
4 Helplessness	56	39	18	40	36	27
5 Horror	42	22	12	14	30	13
<i>Criterion A2 (3 or 4 or 5)</i>	65	47	30	44	42	37
6 Shame	34	13	10	13	11	27
7 Humiliation	28	19	12	18	10	20
8 Guilt	35	17	15	13	17	28
<i>Shame-associated emotions (6 or 7 or 8)</i>	44	25	19	21	18	41
<i>Criterion A (A1 and A2)</i>	55	40	19	29	30	15
<i>Criterion A (A1 and (A2 or shame-associated emotions))</i>	57	43	20	30	31	19

TABLE 2. CORRELATIONS OF CRITERIA A1 AND A2 FOR EACH EVENT WITH PTSS

	PCL-C
HIV-related events:	
Diagnosis	
Criterion A1	0.31 ^a
Criterion A2	0.35 ^a
Shame-associated emotions	0.33 ^a
Criteria A1 & A2	0.36 ^a
Criteria A1 & (A2 or shame-associated emotions)	0.37 ^a
Treatment	
Criterion A1	0.36 ^a
Criterion A2	0.51 ^a
Shame-associated emotions	0.29 ^a
Criteria A1 & A2	0.40 ^a
Criteria A1 & (A2 or shame-associated emotions)	0.36 ^a
Treatment Side Effects	
Criterion A1	0.32 ^a
Criterion A2	0.42 ^a
Shame-associated emotions	0.36 ^a
Criteria A1 & A2	0.30 ^a
Criteria A1 & (A2 or shame-associated emotions)	0.31 ^a
Physical Symptoms	
Criterion A1	0.47 ^a
Criterion A2	0.35 ^a
Shame-associated emotions	0.31 ^a
Criteria A1 & A2	0.44 ^a
Criteria A1 & (A2 or shame-associated emotions)	0.45 ^a
Self-disclosure	
Criterion A1	0.22 ^b
Criterion A2	0.45 ^a
Shame-associated emotions	0.42 ^a
Criteria A1 & A2	0.24 ^b
Criteria A1 & (A2 or shame-associated emotions)	0.26 ^a
Witnessing HIV-related death	
Criterion A1	0.29 ^a
Criterion A2	0.42 ^a
Shame-associated emotions	0.21 ^b
Criteria A1 & A2	0.37 ^a
Criteria A1 & (A2 or shame-associated emotions)	0.35 ^a

^a $p < 0.01$ (two-tailed).

^b $p < 0.05$ (two-tailed).

PCL-C, Posttraumatic Checklist Civilian Version; PTSS, posttraumatic stress symptoms.

analysis (Table 4), using the same stressors as entered in the first model. Overall, the inclusion of shame-associated responses within criterion A2 detracted from the explanatory power of the model down to 29% of the PTSS variance. The inclusion of shame did not affect which types of stressors were predictive of PTSS.

Discussion

Traumatic HIV-related events

Thirty-three percent of the participants in this study qualified for a PTSD diagnosis; a proportion that is in line with

previous research on HIV-related PTSD in gay men.⁵ For each HIV-related event a sizeable number of respondents met DSM-IV-TR PTSD criterion A (ranging from 15% to 55%). This suggests that a wide range of HIV-related events can be of traumatic intensity for some individuals.

The data supported the hypothesis that for all HIV-related events PTSS associated with the extent to which an event was perceived as a threat to physical integrity (criterion A1) and the extent to which the event inspired fear, helplessness or horror (criterion A2). The range of events include both illness-specific stressors, such as receiving medical treatment or having physical symptoms, as well as social stressors, such as self-disclosing HIV status and witnessing HIV-related death. The breadth of events that may threaten physical integrity and inspire traumatic fear therefore appears to extend beyond the disease itself. Traumatic HIV-related events can also include the interpersonal threat of being victimized when self-disclosing HIV or social reminders of the threat posed by HIV when witnessing HIV-related death.

When accounting for all the HIV-related events, three events stood out as predicting the experience of posttraumatic stress symptoms. These events included receiving treatment, experiencing physical symptoms, and witnessing HIV-related death. Each of these stressors captures a different aspect of living with HIV, ranging from the direct threat that physical symptoms pose to health to the challenges posed by medical treatment and the social reminders of HIV threat when witnessing a related death. The hypothesis that being diagnosed with HIV would be the seminal traumatic event, was not supported, despite the greatest proportion of participants (55%) rating the event as traumatic. This suggests that receiving the diagnosis may be more in keeping with the definition of an "information stressor" that does not constitute an imminent threat to life and physical integrity, but signals a future threat,¹⁶ whereas physical symptoms, treatment, and witnessing death may bring to mind a more immediate threat posed by HIV.

Receiving treatment was marginally the strongest predictor and an unexpected finding. The emotional distress evoked by receiving treatment was more highly correlated with PTSS ($r = 0.51$) than any other stressor. Such distress could partly be accounted for by the physical threat posed by treatment that correlated with PTSS, although treatment had a low incidence of being seen as physically threatening (27%). The distress evoked by treatment may therefore be attributable to other kinds of cognitive appraisals. Such appraisals could include catastrophic expectations about the limitations a medication regime may impose on social or occupational functioning thus leading to traumatic fear, or the perceived failure of alternative medicines and lifestyle remedies leading to traumatic helplessness.

The role of shame

The inclusion of shame, humiliation, or guilt in criterion A2 increased the number of individuals who could be considered to have experienced a traumatic event by only 1%. Moreover, including shame, humiliation, or guilt did not change the proportion of participants who qualified for a PTSD diagnosis. This suggests that extending the list of possible criterion A2 emotions to include shame-associated emotions provides no diagnostic advantage.

TABLE 3. STEPWISE REGRESSION OF TRAUMA REACTIONS (CRITERION A) PREDICTING HIV-RELATED PTSS

Variables	β	<i>t</i>	<i>p</i>	R ² change
Physical symptoms	0.259	2.88	0.005 ^a	0.185
Treatment	0.278	3.11	0.002 ^a	0.087
Witnessing HIV-related death	0.229	2.62	0.010 ^b	0.048
Not full-time employed	0.177	2.07	0.041 ^b	0.029

^a*p* < 0.01.

^b*p* < 0.05.

R² = 0.35, Adj R² = 0.32, F(4;95) = 12.76, *p* < 0.001.

PTSS, posttraumatic stress symptoms.

The correlations between shame-associated experiences and PTSD symptoms indicate that shame, humiliation, or guilt may play a role in HIV-related PTSD. However shame-associated responses detracted from the association between some stressful HIV-related events and PTSS. The role played by shame-associated responses thus appears to vary according to the particular event. Shame-associated emotions may therefore be part of the range of emotional responses to stressful HIV-related events. However, the results from this study do not support shame-associated emotions as a consistent primary factor in understanding the precipitation of PTSD. The current results therefore support the traditional view that HIV-related PTSD is a fear-based condition in line with accepted diagnostic indicators. The shame-based PTSD subtype as proposed by Katz and Nevid⁴ is not supported by the results from this study.

Treatment implications

Individuals living with HIV experience periods of good health interspersed with distinct episodes or reminders of HIV threat. Examples of such threatening reminders might be receiving test results of low immune function or high viral load, starting treatment, witnessing HIV-related deaths, or struggling with various HIV-related physical symptoms. The current results, while retrospective, concur with other research findings that peritraumatic distress such as intense fear, helplessness or horror could predict the development of PTSD symptoms.¹⁷ Individuals who rate themselves as feeling intensely fearful, helpless or horrified during an HIV-related event may be at risk of developing posttraumatic stress symptoms that include reexperiencing the event, behavioral avoidance or emotional numbing, and hypervigilance to threat cues. The experience of such heightened

emotions may therefore offer the treating clinician a potential screening indicator for individuals who may be at risk of developing HIV-related PTSD.

Where individuals develop such symptoms within 1 month of the event, routine monitoring, and supportive care is appropriate on a watchful waiting basis. However, specialized psychological care for posttraumatic stress within the first month is possibly contraindicated. In fact, specialist trauma intervention or “critical incident debriefing” during this first month is not recommended and has been shown to delay recovery from posttraumatic stress symptoms.¹⁸ However, individuals who continue to experience posttraumatic stress symptoms beyond this first month may benefit from specialist trauma assessment and evidence-based intervention.^{18,19}

Patient care may therefore be enhanced by education initiatives that enhance care professionals’ awareness of the link between HIV and PTSD, how to identify vulnerability, offering follow-up, and referring for specialist psychological treatment for PTSD. Individuals living with HIV may also benefit from education to help them recognize their vulnerability and identify symptoms of PTSD. Noting that PTSD often goes unrecognized especially for physical illnesses,²⁰ this research highlights the potential value of taking a proactive approach given the significant number of individuals who do report HIV-related PTSD symptoms.

Limitations and research implications

The methodology in this study has a number of limitations. First and foremost, the cross-sectional design and retrospective rating of peritraumatic emotions does not allow for causal conclusions. Prospective studies are required to assess emotional reactions during HIV-related events and their

TABLE 4. STEPWISE REGRESSION: TRAUMA REACTIONS (CRITERION A INCLUDING SHAME-ASSOCIATED REACTIONS AS POSSIBLE CRITERIA A2 EMOTION) PREDICTING HIV-RELATED PTSS

Variables	β	<i>t</i>	<i>p</i>	R ² change
Physical symptoms	0.337	3.77	0.000 ^a	0.199
Witnessing HIV-related death	0.234	2.66	0.009 ^a	0.072
Treatment	0.215	2.39	0.019 ^b	0.041

^a*p* < 0.01.

^b*p* < 0.05.

R² = 0.31, Adj R² = 0.29, F(3;96) = 14.54, *p* < 0.001.

PTSS, posttraumatic stress symptoms.

association with traumatic stress symptoms. Self-report measures of PTSD have also been noted to potentially overestimate diagnoses,²¹ whereas clinical interviews may allow for more accurate identification of the stressor event and establishing a diagnosis. Possible self-selection bias could not be ruled out because sampling was not randomized.

Factors such as physical symptoms of HIV, social support, non-HIV-related trauma, stigma, stressful life events, and past psychiatric morbidity have been found to associate with HIV-related PTSD in other studies.⁴⁻⁶ However, these possible confounding factors were not controlled for in the present analysis because this type of information was not gathered. Given that the appraisal of an event is central to the definition of posttraumatic stress, the present study prioritized this as its main focus. However, events are experienced in complex contexts. This can be examined in future work through comprehensive modeling of the relative contributions of different factors and their pathways of influence, using prospective measurement and pathway analysis.

The impact of HIV-related PTSD on overall well-being may also need to be considered. Kelly and colleagues⁵ found that HIV-related PTSD was associated with PTSD arising from other trauma, while PTSD in response to non-HIV-related events has been found to associate with lower medication adherence and risky sexual practices.^{22,23} Investigating the relationship between HIV-related PTSD, other types of PTSD and risk behavior may further clarify pathways of influence and guide future preventative interventions.

Conclusions

The findings from this study add to the growing base of empirical evidence that PTSD does occur in response to a variety of HIV-related events above and beyond the diagnosis itself. The results also support the view that HIV-related PTSD is primarily associated with fear, helplessness, or horror as opposed to shame, humiliation, or guilt.

Further research is needed to determine the conditions that contribute to some HIV-related events being more likely to be traumatic than others. Such research may benefit from being guided by psychological PTSD models to clarify cognitive appraisals of threat involved in the experience of HIV-related trauma. Investigating the specific appraisals of threat may help understand what aspects of HIV-related events are traumatic to inform further service and treatment development.

Acknowledgments

This research was partly funded by Salomons: Centre for Applied Social and Psychological Development, Canterbury Christ Church University, Canterbury, United Kingdom. This contribution is gratefully acknowledged.

Author Disclosure Statement

No competing financial interests exist.

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