



Posttraumatic stress disorders among people living with HIV/AIDS



Questions

- What is the prevalence of posttraumatic stress disorders among people living with HIV in Ontario?
- Are there any guidelines or articulated competencies for providing services to people living with HIV who have posttraumatic stress disorder?

Key Take-Home Messages

- A high proportion of men and women with HIV have experienced psychological trauma.(2;5;8) Although there are no estimates of the prevalence of posttraumatic stress disorder (PTSD) in people living with HIV in Ontario or Canada, in the US estimates range from a low of 10% to a high of 74%.(3-10) Women appear to have particularly high rates of abuse and trauma.(1;2;5;8)
- Traumatic stress is associated with poor physical and mental health outcomes, including poor adherence to medication, poor health-related functioning, more symptoms, faster progression of HIV disease, and lower quality of life.(1-7)
- A trauma-informed, trauma-sensitive care model that addresses barriers that people with a history of trauma experience when they access health care may help HIV care providers recognize and appreciate their patients' distinct needs.(1)
- Screening and assessment of posttraumatic stress disorder – as well as referrals to evidence-based treatments – should be a standard of practice in HIV care settings, including emergency rooms, clinics and physician offices.(8)
- When caring for people who have experienced trauma, it is important for care providers to give patients a sense of control, allow them to make choices whenever possible and move at a speed that is acceptable to them – thereby fostering a sense of self-efficacy.(1;8)
- Most interventions for people living with HIV who have experienced posttraumatic mental illness incorporate psycho-education and strive to help patients develop adaptive coping and behavioural skills.(1)

EVIDENCE INTO ACTION

The OHTN Rapid Response Service offers HIV/AIDS programs and services in Ontario quick access to research evidence to help inform decision making, service delivery and advocacy.

In response to a question from the field, the Rapid Response Team reviews the scientific and grey literature, consults with experts, and prepares a brief fact sheet summarizing the current evidence and its implications for policy and practice.

Suggested Citation:

Rapid Response Service. *Rapid Response: Posttraumatic stress disorders among people living with HIV/AIDS*. Toronto, ON: Ontario HIV Treatment Network: November 2014.

Prepared by:

Kira Gangbar
Jason Globerman

Program Leads / Editors:

Jason Globerman
Sean B. Rourke, PhD
Jean Bacon

Contact:

rapidresponse@ohntn.on.ca

References

1. Aaron E, Criniti S, Bonacquisti A, Geller PA. Providing sensitive care for adult HIV-infected women with a history of childhood sexual abuse. *Journal of the Association of Nurses in AIDS Care* 2013;24(4):355-67.
2. Brief DJ, Bollinger AR, Vielhauer MJ, Berger-Greenstein JA, Morgan EE, Brady SM et al. Understanding the interface of HIV, trauma, post-traumatic stress disorder, and substance use and its implications for health outcomes. *AIDS Care* 2004;161(Suppl 1):S97-120.
3. Gore-Felton C, Ginzburg K, Chartier M, Gardner W, Gnew-Blais J, McGarvey E et al. Attachment style and coping in relation to posttraumatic stress disorder symptoms among adults living with HIV/AIDS. *Journal of Behavioral Medicine* 2013;36(1):51-60.
4. Machtiger EL, Wilson TC, Haberer JE, Weiss DS. Psychological trauma and PTSD in HIV-positive women: a meta-analysis. *AIDS & Behavior* 2012;16(8):2091-100.
5. Seedat S. Interventions to improve psychological functioning and health outcomes of HIV-infected individuals with a history of trauma or PTSD. *Current HIV/AIDS Reports* 2012;9(4):344-50.
6. Sherr L, Nagra N, Kulubya G, Catalan J, Clucas C, Harding R. HIV infection associated post-traumatic stress disorder and post-traumatic growth—a systematic review. *Psychology Health & Medicine* 2011;16(5):612-29.
7. Whetten K, Reif S, Whetten R, Murphy-McMillan LK. Trauma, mental health, distrust, and stigma among HIV-positive persons: implications for effective care. *Psychosomatic Medicine* 2008;70(5):531-8.
8. Beckerman NL, Auerbach C. Post-traumatic stress disorder and HIV: a snapshot of co-occurrence. *Social Work in Health Care* 2010;49(8):687-702.
9. Radcliffe J, Fleisher CL, Hawkins LA, Tanney M, Kassam-Adams N, Ambrose C et al. Posttraumatic stress and trauma history in adolescents and young adults with HIV. *AIDS Patient Care & STDs* 2007;21(7):501-8.

The Issue and Why It's Important

Posttraumatic stress has been well documented in the literature as a lasting mental health condition associated with exposure to a traumatic life event. Posttraumatic stress disorder (PTSD) is a psychiatric illness that may emerge after a person experiences, witnesses or is confronted with an event involving actual or perceived threat of death, serious injury or harm to the integrity to self or others.(6;11)

Individuals living with HIV often have complicated histories, including negative experiences such as traumatic events, mental illness and stigma.(7) Among people with HIV, trauma can have devastating mental and physical health consequences, including:

- depression, PTSD, and alcohol and drug use issues (5)
- poor physical and mental health outcomes, including poor adherence to medication, poor health-related functioning, more symptoms, faster progression of HIV disease, and lower quality of life.(1-7)
- higher risk of HIV transmission associated risk behaviours.(3;5;7)

For example, women with HIV who have a history of childhood sexual abuse are more likely to miss medical appointments, less likely to take their medications as prescribed and more likely to engage in risk behaviours such as using alcohol or drugs during sex, engaging in unprotected sex and having more sexual partners.(1;3;4) The impact of trauma on people's health can be compounded by stigma, discrimination, poverty and minimal social support.(5)

To improve health outcomes for people with HIV and a history of trauma, the health care systems need effective tools, treatments and interventions that recognize and reduce traumatic stress and other mental health problems.(5)

What We Found

Prevalence

In this review, we look specifically at the prevalence of post-traumatic stress disorder (PTSD) among people living with HIV.

Despite a thorough search of the literature, we were unable to find any estimates of the prevalence of posttraumatic mental illness among people with HIV in Ontario or Canada. US prevalence rates range from 10% to 74%, (3-10) which is considerably higher than the 7% to 10% prevalence of posttraumatic stress the general population.(3;6) As both the US and Canada share similar epidemics, the prevalence of posttraumatic stress should be comparable.

People living with HIV experience higher rates of PTSD than the general population.

PTSD is perhaps the most extensively documented post-trauma issue in people living with HIV.(10) PTSD can arise following a traumatic event or in response to receiving an HIV diagnosis. (3;5;6) The Diagnostic and Statistical Manual (DSM-IV) classifies the discovery of a life-threatening illness such as HIV as a traumatic event.(3;6;8) However, it is relatively unclear whether the diagnosis itself causes PTSD or whether it contributes to the collapse of an already traumatized individual. Some studies found PTSD to occur after HIV diagnosis but no studies found HIV diagnosis to exclusively contribute to PTSD; instead it seemed the diagnosis caused individuals who had already had a traumatic life to reach a breaking point.(3;6) The rate of PTSD diagnosis appears to be higher in HIV than

in other chronic illnesses, (8) which may be due to the stigma associated with HIV as well as pre-existing trauma.

In a Philadelphia study of adolescents and young adults with HIV, 93% reported a traumatic experience upon receiving their HIV diagnosis.(9) Of these, 13% met the criteria for PTSD, while another 20% showed significant posttraumatic stress symptoms.(9) Even greater rates of posttraumatic stress were reported in response to other trauma: 47% of participants reported symptoms of posttraumatic stress in response to events such as being a victim in a personal attack, experiencing sexual abuse or being abandoned by a caregiver.(9) In a study of people living with HIV in New York City, 34% met the screening criteria for PTSD (8) and, of those, 43% reported receiving no concurrent mental health treatment.(8)

PTSD may mask concomitant or pre-existing disorders including major depression, phobias, panic disorders, complicated traumatic grief, dissociative disorders, agoraphobia, obsessive compulsive disorders, social and other phobias, anxiety disorders, depression, and/or disorders of extreme stress not otherwise specified.(8) PTSD is highly linked with major depression, other anxiety disorders, and substance use issues.(5) In one US study, 37% of participants had both depression and PTSD.(7)

Women with HIV are twice as likely as women in the general population to experience PTSD

Women experience particularly high rates of abuse and trauma. (1;2;5;8) Trauma is recognized as a factor in the increasing prevalence of HIV in women as well as poorer health outcomes. Women living with HIV are twice as likely as women in the general population to have experienced trauma.(5) Women who have been exposed to trauma experience high rates of anxiety, depression, dissociation and PTSD.(1)

- A meta-analysis that estimated rates of psychological trauma and PTSD in women living with HIV in the US found very high rates in all categories of trauma exposure and PTSD.(4) The estimated rate of PTSD among HIV-positive women was 30% - over five times the rate of recent PTSD reported in a national sample of women.(4)
- In a study examining PTSD in ethnically diverse women with HIV in California, 42% met the full criteria for a PTSD diagnosis and another 22% met the criteria for partial PTSD.(12) Of the women with full PTSD, 59% were not receiving any psychiatric treatment, and of those with partial PTSD, 78% were not receiving any psychiatric treatment.(12)
- A study describing prevalence of trauma-related mental health issues among a cohort of Haitian women living with HIV in the US found that 34% reported PTSD, 49% reported depression and 43% reported anxiety.(13) The women in the study who reported a history of abuse were more likely than those without a history of abuse to report anxiety, PTSD and PTSD-related to HIV symptoms.(13)

The importance of trauma-sensitive care

Given high rates of PTSD among people living with HIV and lack of access to mental health treatment, it is important for health care systems to, at the least, provide trauma-informed services and, at best, develop trauma-specific services for patients/clients with HIV.

Both these terms refer to integrated models of care that involve organizational change, including staff training, service-delivery processes, client interactions, (1) formal links with other services, such as mental health and substance use

10. Theuninck AC, Lake N, Gibson S. HIV-related posttraumatic stress disorder: investigating the traumatic events. *AIDS Patient Care & STDs* 2010;24(8):485-91.
11. Glover DA, Williams JK, Kisler KA. Using novel methods to examine stress among HIV-positive African American men who have sex with men and women. *Journal of Behavioral Medicine* 2013;36(3):283-94.
12. Martinez A, Israelski D, Walker C, Koopman C. Posttraumatic stress disorder in women attending human immunodeficiency virus outpatient clinics. *AIDS Patient Care & STDs* 2002;16(6):283-91.
13. Glemaud M, Illa L, Echenique M, Bustamente-Avellaneda V, Gazabon S, Villar-Loubet O et al. Abuse and mental health concerns among HIV-infected Haitian women living in the United States. *Journal of the Association of Nurses in AIDS Care* 2014;25(Suppl 1):S62-9.
14. Williams JK, Glover DA, Wyatt GE, Kisler K, Liu H, Zhang M. A sexual risk and stress reduction intervention designed for HIV-positive bisexual African American men with childhood sexual abuse histories. *American Journal of Public Health* 2013;103(8):1476-84.
15. Sikkema KJ, Hansen NB, Kochman A, Tarakeshwar N, Neufeld S, Meade CS et al. Outcomes from a group intervention for coping with HIV/AIDS and childhood sexual abuse: reductions in traumatic stress. *AIDS & Behavior* 2007;11(1):49-60.
16. Pacella ML, Armelie A, Boarts J, Wagner G, Jones T, Feeny N et al. The impact of prolonged exposure on PTSD symptoms and associated psychopathology in people living with HIV: a randomized test of concept. *AIDS & Behavior* 2012;16(6):1327-40.

and the use of case managers to coordinate care.(2) In these models of care, PTSD screening, assessment and referrals to treatment should be standard practice in all settings where people with HIV receive care.(8) Infectious disease providers would benefit from standardized trauma protocols that assume most patients have experienced some form of trauma and would benefit from sensitivity to potential trauma triggers.(7)

Definitions

Trauma-informed services: staff members have been trained to be sensitive to the trauma-related health and psychological issues often present in trauma survivors(1)

Trauma-specific services: treatment of the sequelae of trauma(1)

The introduction of trauma-sensitive practices can benefit both providers and patients by reducing the effects that trauma may have on adherence to care and health outcomes. Providers have an opportunity to interrupt the cycle of abuse by creating new patterns of health and well-being for patients.(1) Important elements of trauma-sensitive care include:(1)

- Recognizing the psychological consequences of trauma
- Routinely screening for mental health symptoms
- Referring for trauma-specific psychological interventions

Screening

Screening – that is, including questions about traumatic experiences as part of history-taking – is an important step in trauma-sensitive care. It helps identify those with PTSD, including those who are not experiencing symptoms.(1)

Routine screening for trauma exposure or PTSD within the context of primary medical care may help to:

- Introduce the topic of mental health symptoms(1)
- Identify trauma survivors in need of specialized treatment(2)
- Provide opportunities to discuss treatment options. (1)

Despite evidence that patients accept routine trauma screening and physicians' belief that they can help patients with problems stemming from trauma, one study found that providers inquired about trauma history at only 11% of initial visits or 15% of annual visits.(1)

Screening can occur through self-administered questionnaires or interviews conducted by health care providers.(1) Tips for screening include:

- Incorporate questions about specific actions to allow patients to accurately disclose their history even if they do not identify themselves as abuse survivors, such as: "Has anyone ever touched you sexually against your will?"(1)
- Acknowledging the high prevalence of trauma helps the person feel more comfortable when asked about trauma history.
- Explaining that the same questions are asked of all patients is an important step in creating a safe environment for the patient.(7)

Disclosure of abuse to health professionals is most likely to occur when patients feel they will be believed and responded to with calm compassion and overall sensitive care, including respect for personal boundaries and awareness of the effects of trauma.

Assessment

Clinicians working with people with HIV will need to make a differential diagnosis, assessing the many complex affective disorders that may be at play and using the assessment to determine appropriate individual treatment.(8)

Providing trauma-sensitive care and examinations

People who have survived trauma or violence may have experienced power abuses, and any misuse of power in the health care system may add to their distress. Trauma may have damaged their trust, which means the provider must be willing to take steps to build a therapeutic alliance, (8) such as:

- Seeing the patient clothed before an examination, encouraging questions and explaining all parts of a physical examination and any procedures, and allowing patients to opt out of any or all parts of a physical examination.(7)
- Giving patients a sense of control, allowing them to make choices whenever possible, and moving at a pace that is acceptable to the patient – thereby fostering a sense of self-efficacy.(1;8)
- Acknowledging that the patient has ultimate decision-making power and developing care options based on the patients' expressed needs and desires.(1)
- Consulting individuals about their experiences with the health care system and inquiring how health care providers can be more sensitive to their needs.(1)

When HIV-positive adult women survivors of childhood sexual abuse were asked to define components of sensitive care, they identified the following themes:(1)

- a sense of control during appointments that increased patients' sense of safety
- providers who can respond to the disclosure of a traumatic history with assurances of confidentiality, empathetic and empowering responses, and nonjudgmental and non-stigmatized treatment
- providers who are able to express their willingness to help patients with a history of trauma
- regular verbal check-ins with patients throughout clinical care interactions
- providers who were aware of:
 - ◇ the potential negative impact of language and tone of voice
 - ◇ the fact that any aspect of the medical interaction – even a smell - can trigger fear or flashbacks
 - ◇ patients' body language throughout the interactions.

Interventions and treatments

The disproportionately high rates of trauma and PTSD among people living with HIV reinforce the urgent need for studies of trauma-prevention and trauma-recovery interventions.(4;6) Relatively few interventions have been reported in the literature.(3-6) However, the literature does highlight components of effective interventions including:

- addressing the abuse in a sensitive and nonjudgmental manner in order to reduce anxiety.(1) Integrating mental health and physical care, in order to help people with HIV and a history of trauma engage in health care services.(1)
- providing more intensive interventions to help people engage in health care, including: the use of case managers and social workers who have specific training in abuse; adherence counselors who can follow up with patients closely to assist with medication adherence; and on-site psychological services, outreach and retention specialists and peer educators.(1)

- using peer educators who share a similar serostatus or background with program recipients who can be trained to provide education and social support, act as client advocates and facilitate behavioural changes.(1) Because of their shared experiences, peers can enhance the relevance and credibility of health messages.(1)
- incorporating psycho-education that helps patients/clients develop adaptive coping and behavioural skills. It is important that mental health providers attempt to fully understand the presenting problems and their underlying issues in the context of the person's life, including any significant cultural, spiritual, religious, political, economic, familial and medical factors.

It is also helpful for patients when care providers are familiar with existing treatments for PTSD so, when they are making referrals, they can help patients make decisions about their treatment options. (2) Providers should also share information with mental health professionals about the factors affecting the person.(1) The development of collaborative networks between medical providers and trauma specialists may also help improve access to care and referrals to specialized treatment programs.(2)

Psychotherapy and pharmacological interventions for people with PTSD typically focus on emotional dysregulation.(3) Many current psychotherapeutic interventions focus on providing a safe and secure environment, establishing and maintaining interpersonal boundaries, developing self-efficacy, building self-esteem and establishing a sense of personal agency and control.(3)

Research exploring whether stress reduction interventions can improve mental and physical health is still in its infancy.(14) Social cognitive models emphasizing relaxation skills, cognitive coping strategies and social support have been effective in mediating mood effects and stress-related neurohormones in people with HIV.(14;15) Group cognitive-behavioural strategies, including prolonged exposure, coping skills training and stress management have shown some evidence of efficacy in people with HIV who have a history of trauma and PTSD.(5;15) Brief motivational interviewing interventions may also help facilitate follow-through with referrals for specialized treatment. In addition, offering PTSD treatment where HIV primary care is provided may help to engage patients in PTSD treatment.(2) Prolonged exposure therapy – or repetitive exposure to stimuli associated with the original trauma - has been shown to be efficacious in treating PTSD.(3;16)

Among adults with HIV who have trauma symptoms, combining exposure-based paradigms with psychotherapeutic interventions that improve HIV-related coping may reduce trauma-related symptoms.(3)

Conclusion

Given high rates of trauma and PTSD among people living with HIV, it is important for providers to offer trauma-sensitive services that help diagnose people as early as possible, overcome any barriers to them engaging in their own care, and make appropriate referrals to evidence-based treatment and interventions.(1) Delivery of care and services that acknowledge and address the psychosocial sequelae of abuse and violence may help increase treatment and medication adherence rates for people with HIV, and improve health outcomes.(1;2)

Care providers need to be more rigorous in diagnosing, referring and treating PTSD.(2;7;8) Trying to address PTSD symptoms without understanding and targeting the underlying factors will have limited effects on the person's long-term health and well-being. A more complex approach to the treatment of PTSD

is likely to be more effective in reducing morbidity and improve health and quality of life – particularly in people with HIV.(3)

More research is needed to fully understand why there are such high rates of PTSD symptoms among adults living with HIV.(3)

Factors That May Impact Local Applicability

All studies included in this summary were conducted within the US. Non-uniform definitions of psychological trauma, inconsistent delineation between childhood and adult exposures and methodological heterogeneity in trauma measurement, among other factors, complicate the comparison of rates of trauma and health outcomes across studies,(5) therefore caution should be used when interpreting findings or generalizing to other populations.

What We Did

We searched Medline and PsychINFO for articles using a combination of text terms [(HIV) or (human immunodeficiency) or (acquired immunodeficiency syndrome) or (acquired immune deficiency syndrome) or (AIDS)] AND text terms [(post-traumatic stress disorder) or (stress disorders, post-traumatic)]. The search was limited to articles published since 1996 onwards, in English.

Suggested Citation: Rapid Response Service. *Rapid Response: Posttraumatic stress disorders among people living with HIV/AIDS.* Toronto, ON: Ontario HIV Treatment Network; November 2014.