

HIV: Psychological Trauma and the Ameliorating Factors

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Abstract

A study was conducted to explore the traumatic nature of HIV diagnosis and to investigate which factors best and most efficiently lead to trauma recovery. A questionnaire was distributed via HIV organisations in Norway and Poland. Trauma was assessed twice using the Impact of Event Scale – Revised by first asking participants to recall the time just after diagnosis and then at present time. A trauma development score was derived from the difference. Participants were also asked to rank variables in order of experienced importance and effectiveness. Participant sample ranged in age from 21-71. All participants were Scandinavian. Because of a small participant sample, no valid results could be derived.

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The history of human immunodeficiency virus (HIV) treatment can, in general, be looked at as a spectacular success (Deeks, Lewin, & Havlir, 2013). From the early stages of HIV discovery with mass fatalities and an expected life duration of 11 years following infection (UNAIDS Reference Group on Estimates, Modelling, and Projections, 2006), the current expectation is a chronic condition with a near-normal life and relatively manageable health effects (Knoll, Lassmann, & Temesgen, 2007). The success of antiretroviral treatment can be considered a triumph of modern pharmaceutical development (Deeks, Lewin, & Havlir, 2013).

This, however, gives rise to a new challenge for health-care professionals. As stated by Deeks, Lewin and Havlir (2013, p. 1533): “Rather than dealing with acute potentially life-threatening complications, clinicians now are confronted with managing a chronic disease that in the absence of a cure will persist for many decades”. What should be modern healthcare’s approach to provide adequate support in face of HIV as a chronic condition? Can modern health care predict the needs of the HIV+ individuals of tomorrow? And in all this – what is the role of psychology?

Considerable evidence suggests that people with HIV are significantly more distressed than the general population, and research finds that a significant proportion of HIV+ individuals experience trauma or develop anxiety disorders based on basic criteria found in the *Diagnostic and Statistical Manual of Mental Disorders*, 5th Edition (American Psychiatric Association [APA], 2013; Beckerman & Auerbach, 2010). These criteria include *intrusive recollections*, *avoidance or numbing symptoms* and *hyper-arousal symptoms* (Rzeszutek, Oniszczenko, & Firląg-Burkacka, 2012). A study by Israelski et al. (2008) found that of a sample size of 210 HIV+ individuals, 34 % ($n = 71$) met the criteria for *posttraumatic stress disorder* (PTSD)

according to the PTSD Checklist (PCL) and 43 % ($n = 91$) met the criteria for *acute stress disorder* (ASD) according to the Stanford Acute Stress Reaction Questionnaire. Other studies found similar prevalence rates, ranging from 30 % to 64 % (Kelly, et al., 1998; Kimerling, et al., 1999; Martinez, Israelski, Walker, & Koopman, 2002; Safren, Gershuny, & Hendriksen, 2003). A major source hypothesised to underlie the psychological trauma symptoms is the highly stressful and potentially traumatic nature of receiving a positive HIV diagnosis, related to the potentially life-threatening nature of the disease (Nightingale, Sher, & Hansen, 2010; Martin & Kagee, 2008; Beckerman & Auerbach, 2010). Other traumatic aspects of HIV includes stigmatization (Breet, Kagee, & Seedat, 2014), deteriorating social and economic conditions (Rzeszutek, Oniszczenko, & Firląg-Burkacka, 2012) and the uncertainty of how the disease will progress (Theuninck, Lake, & Gibson, 2010). In a study by Olley et al. (2005, 2006), 36 % of recently diagnosed HIV+ individuals with related PTSD reported that being informed of their HIV-positive diagnosis was the index trauma.

In lieu of the considerable body of research pointing to HIV as a traumatic stressor potentially leading to PTSD, it is clear that psychology does have a role to play in providing adequate healthcare to HIV+ individuals. One should therefore expect great psychological emphasis and vigilance put on the HIV+ population, but this is alas not the case. Psychiatric disorders frequently go under-detected in HIV care settings (Gatz, Brownstein, & Taylor, 2005; Hembree & Foa, 2003). This could potentially be attributed precisely to the traumatic experience of receiving an HIV diagnosis. PTSD may obscure the expression of concomitant disorders, including major depression, phobias, panic disorder, 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 (Carlson, 2005; Gore-Felton & Koopman, 2002; Gatz, Brownstein, & Taylor, 2005; Hembree & Foa, 2003).

This study aims to shed further light on the traumatic nature of receiving and living with an HIV diagnosis. The literature review conducted showed ample support for the traumatic nature of HIV, but little in the way of distress relief. It was therefore necessary to look for analogous research. A study on the impact of social support on PTSD symptoms in a sample composed by motor vehicle accident victims found social support to be a significant moderating variable (Gabert-Quillen, et al., 2012). In a more general approach to PTSD treatment, Briere, Scott and Jones (2006, p. 31) emphasize the importance of social support and disclosure of the trauma event, but also point out that social response tend to vary from the type of traumatic event and victim characteristics – some traumas are more socially acceptable than others. Briere, Scott and Jones also underline the benefits of behavioural activation.

Method

In an attempt to better understand the nature of HIV related trauma, the following research question was devised: *Which factors most efficiently provide less trauma symptoms?* The following variables were generated, derived from the available research but also through personal experience and conversations with other HIV+ individuals about their experiences following a diagnosis; *support from health-care workers, support from family, support from friends, support from colleagues/employer(s), support from romantic partner, talk with other HIV+ individuals, new/more knowledge about HIV, therapy, diagnosis disclosure, medication and return to work/studies.*

Measures

A questionnaire was designed which aimed to measure traumatic stress symptoms, which types of support the participants had received, employed or otherwise engaged in, and to which level of importance and effect the participants themselves felt the factors had contributed in the time following their diagnosis. As searching for a specifically HIV related trauma questionnaire unfortunately proved futile, trauma symptoms were measured using the Impact of Event Scale-Revised (IES-R), which targets the behaviours, cognitions and emotions underlying the traumatic event, while also measuring the DSM-5 trauma criteria of avoidance, intrusion and hyperarousal into 3 subscales (Horowitz, Wilner, & Alvarez, 1979). Participants were asked at the start of the questionnaire to think back to the time immediately following their diagnosis and fill out the scale accordingly. Participants were then asked to submit whether they had received, employed or otherwise engaged in the variables, rank them in subjective order of effectiveness and indicate the variables' importance on a 1-7 Likert scale, 1 being "Not At All Important" and 7 being "Extremely Important". At the end of the questionnaire, participants were asked to fill out the IES-R again, but were this time instructed to only look back 1 month from the present day and answer accordingly. The survey is available in the appendix, although slightly modified in style to fit a document format. The difference from the initial to the subsequent assessment was then calculated, giving a trauma development score. As the initial trauma score and the development score varied, it was deemed possibly more indicative of the trauma development to look at the percentile trauma development score, thus this was also calculated. Otherwise, participants were asked to provide demographics such as gender, age, sexual orientation, education and time since diagnosis. Time since diagnosis was correlated with the trauma development score in an attempt to control for time as a main effect.

Participants

HIV organisations in Poland, Norway, England and Ireland were approached and asked if they had an infrastructure in place which allowed for recruitment of participants, such as social media sites, e-mail lists or physical offices where participants could be recruited. If the organisations acquiesced to supporting the study and had the infrastructure in place, they were asked to distribute the aforementioned questionnaire. In Norway, *HIVNorge* and *Aksept* distributed the questionnaire whereas *Jeden Świat* distributed in Poland. It was unfortunately not possible to establish a cooperation with any HIV organisations in the UK.

Over a period of 2 months, 32 participants responded. Of these, 15 were incomplete and had to be excluded from the study. Also unfortunate is that there were no Polish participants in the study, partly due to the difficulty experienced in trying to establish a dialogue with the Polish HIV organisations. This led to the Polish version of the questionnaire only being distributed for 2 weeks, during which no Polish participants responded. In the end, 17 valid, complete responses remained, all save 1 citing Norway as their country of residence, the remaining 1 citing Denmark as their country of residence. The participants' age ranged from 21 to 71 years old, with a mean and median age of 41. Four of the participants were female and thirteen were male. 6 participants identified as heterosexual, 9 identified as gay and 2 identified as bisexual. Time since diagnosis ranged from 7 months to 430 months (35 years and 10 months), with a mean of 96 months (8 years) and a median of 36 months (3 years). Of the participants, 1 reported an elementary school education, 7 reported a high school education, 5 reported a Bachelor level education, 2 reported a Master level education, 1 reported a PhD and 1 reported a technical certificate. A full overview of participant demographics as well as IES-R scores and trauma development scores can be found in table 1.

Table 1

Participant Characteristics and Trauma Scores

Age	Gender	Country of Residence	Education	Sexual Orientation	Months since Diagnosis	IES-R ₁	IES-R ₂	TraDev	TraDev Percentage
21	Male	Norway	High school	Bisexual	7	72	30	-42	-30.24
25	Male	Norway	High school	Gay/Lesbian	25	54	7	-47	-25
26	Male	Norway	Bachelor	Gay/Lesbian	26	59	12	-47	-28
28	Male	Norway	Bachelor	Gay/Lesbian	34	57	53	-4	-2
31	Male	Norway	Bachelor	Gay/Lesbian	93	19	0	-19	-4
33	Male	Norway	Elementary school	Heterosexual	8	64	50	-14	-9
34	Male	Norway	Bachelor	Gay/Lesbian	30	46	35	-11	-5
37	Male	Norway	Master	Gay/Lesbian	70	41	4	-37	-15
41	Female	Norway	High school	Heterosexual	36	64	27	-37	-24
41	Female	Norway	Bachelor	Heterosexual	194	24	23	-1	0
44	Male	Norway	High school	Bisexual	24	47	36	-11	-5
45	Female	Norway	High school	Heterosexual	12	61	55	-6	-4
50	Male	Norway	High school	Heterosexual	51	70	72	2	+1
52	Male	Norway	High school	Gay/Lesbian	82	32	3	-29	-9
58	Male	Denmark	Technical certificate	Gay/Lesbian	406	56	0	-56	-31
64	Male	Norway	Master	Gay/Lesbian	430	29	0	-29	-8
71	Female	Norway	PhD	Heterosexual	108	43	1	-42	-18

Note: IES-R₁ = initial trauma score; IES-R₂ = subsequent trauma score; TraDev = trauma development score; TraDev Percentage = trauma development percentage score.

Results

Descriptive analysis showed that initial trauma scores (IES-R₁) ranged from 19 to 72, with a mean score of 49.29 and a median score of 64. A score of 24 or above indicates that PTSD is a clinical concern and that some or partial PTSD symptoms are likely present (Asukai, et al., 2002). Sixteen participants (94.12 %) scored 24 or above. A score of 33 or higher indicates a probable PTSD diagnosis if symptoms persist over 6 months or more (Creamer, Bell, & Falilla, 2002). According to Kawamura, Yoshiharu and Nozomu (2001), a score of 37 or above in individuals with PTSD is high enough to suppress immune system functioning even 10 years after an impact event. All of the remaining 13 participants (76.47 %) scored 37 or above. In effect, only 1 participant scored less than the cut-off score. The subsequent trauma score (IES-R₂) ranged from 0 to 72, with a mean score of 24 and a median score of 23. 8 participants (47.05 %) scored 24 or above, 6 participants (25.29 %) scored 33 or above and 4 participants (23.53 %) scored 37 or above. The trauma development score ranged from 2 to -56, with a mean score of -25.29. The trauma development percentage score ranged from +1.40 % to -31.36 %, with a mean score of -12.76 %.

No significant correlation was found between time since diagnosis and trauma development score ($r = .19; p > .05$). This allows for the inference that something else than merely time accounts for the development in trauma scores.

No significant relationship was found between trauma score or trauma development score with gender, sexual orientation, level of education or age ($p > .05$).

When asked to order which variables had been experienced most to least effective in the time following diagnosis, participants reported the following (range 1 – 11, 1 being the most efficient): *medication* (M = 4.29), *support from friends* (M = 4.94), *support from health-care*

workers (M = 5.35), *support from family* (M = 5.41), *therapy* (M = 5.47), *support from romantic partner* (M = 5.59), *talk with other HIV+ individuals* (M = 5.71), *new/more knowledge about HIV* (M = 6.59), *diagnosis disclosure* (M = 6.94), *return to work/studies* (M = 7.12), and *support from colleagues/employer(s)* (M = 8.59). When asked which variables had been the most important in the time following their diagnosis, participants reported the following (range 1 – 7, 7 being the most important): *medication* (M = 6.63), *new/more knowledge about HIV* (M = 6.24), *support from friends* (M = 5.86), *support from health-care workers* (M = 5.76), *return to work/studies* (M = 5.67), *support from family* (M = 5.54), *support from romantic partner* (M = 5.33), *talk with other HIV+ individuals* (M = 5.08), *diagnosis disclosure* (M = 4.69), *therapy* (M = 4.27), and *support from colleagues/employer(s)* (M = 3.78). ANOVAs were conducted to see if importance or effectiveness had any effect on trauma development, with insignificant results ($p > .05$).

Discussion

Because of the low sample size, it is near-impossible to draw any statistically valid conclusions. A larger sample size could potentially have yielded more understanding on which factors provide more or less distress relief from the trauma symptoms HIV+ individuals experience after receiving a HIV diagnosis. As it stands, one can only derive tentative inferences from the descriptive statistics.

The main findings from this study are the trauma scores from the initial IES-R assessment, and the trauma development score. Analysis shows that the vast majority of participants were above the lower cut-off score, indicating partial trauma symptoms and a clinical concern for PTSD. The findings from this study then joins the already ample research maintaining the traumatic nature of receiving an HIV diagnosis (Kelly, et al., 1998; Kimerling, et

al., 1999; Martinez, Israelski, Walker, & Koopman, 2002; Safren, Gershuny, & Hendriksen, 2003; Israelski, et al., 2008).

The trauma development score shows that there is, for the majority of participants, a change in level of trauma over time, but not for everyone and not at a uniform rate. This supports the non-related correlation between trauma development score and time since diagnosis, suggesting that time itself is not enough. According to Briere (2006), there is a difference in the development of trauma symptoms and PTSD if the trauma is experienced as interpersonal rather than accidental. An interpersonal trauma, such as rape, assault or kidnapping, maintains its trauma severity and oftentimes escalates in intensity over time. HIV could potentially be considered both interpersonal and accidental depending on the circumstances of HIV contraction, and in ambiguous circumstances could potentially also depend on the person's perceived locus of control, hence possibly explaining some of the variance in trauma development. This was not addressed by the study and therefore remains speculation and inspiration for further study.

There was no major congruence between the reported importance and effectiveness of the variables. In general, participants reported medication as the most effective and important variable. This is consistent with research stating that the traumatic nature of HIV derives from the potentially life-threatening nature of HIV (Nightingale, Sher, & Hansen, 2010; Martin & Kagee, 2008; Beckerman & Auerbach, 2010).

There are many limitations to this study. First and foremost, the number of participants is far too low to yield any valid statistical meaning. The low number of participants makes it near impossible to draw valid statistical inferences, potentially even on the descriptive data as there is great variance in age cohort and amount of time since diagnosis. More participants could potentially have increased the statistical validity of the study. The participants were also solely

Scandinavian, and therefore users of a Scandinavian health-care system. Without a more diverse participant pool, it is possible that the consistently high scores of reported importance and effectiveness of *medication* and *support from health-care workers* reflects the particular characteristics of the Scandinavian health-care system more than the traumatic nature of HIV. Although superfluous after the aforementioned, the correlational nature of the data does not allow for causality. The IES-R is well-researched (Asukai, et al., 2002; Creamer, Bell, & Falilla, 2002; Kawamura, Yoshiharu, & Nozomu, 2001; Horowitz, Wilner, & Alvarez, 1979; Coffey & Berglind, 2006; Neal, et al., 1994; Weiss & Marmar, 1997), but is not a diagnostic tool and does not have a formal cut-off score. It is also possible that, because of the sampling procedure, the participant sample is biased towards those who stay up to date on HIV organisations. It is possible that some HIV+ individuals avoid such organisations for fear of stigma or trauma symptom evocation. Conversely, some HIV+ individuals might have no interest in HIV+ organisations because they see no reason to. As suggested by Deeks, Lewin and Havlir (2013), with medication, HIV is simply a chronic condition which makes little of its presence known. If a similar study was to be conducted, it might be beneficial to investigate whether such sub-populations exist.

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Appendix 1

HIV AND TRAUMA – SURVEY

Thank you for taking time to answer this survey about your experiences related to receiving an HIV diagnosis. This survey will take approx. 15 minutes. All responses are confidential and anonymous. No responses can be traced back to you, and all responses will be stored securely. All inquiries can be addressed to: j.matre@student.uw.edu.pl.

Personal Characteristics

Age in years: _____

Gender: Male
 Female
 Transgender
 Other: _____

Nationality: _____

Country of Residence: _____

Sexual orientation: Heterosexual
 Gay/Lesbian
 Bisexual
 Other: _____

Level of Education: Elementary school
 High school
 Bachelor
 Master
 Post-graduate diploma
 PhD
 Technical certificate

Month and year when you received your diagnosis: _____/_____

Please try to think back to the time period after you received your diagnosis. How well do the statements below reflect how you thought, felt or behaved?

Choices: Not At All – A Little Bit – Moderately – Quite A Bit – Extremely

1. Any reminder brought back feelings about it.
2. I had trouble staying asleep.
3. Other things kept making me think about it.
4. I felt irritable and angry.
5. I avoided letting myself get upset when I thought about it or was reminded of it.
6. I thought about it when I didn't mean to.
7. I felt as if it hadn't happened or wasn't real.
8. I stayed away from reminders of it.
9. Pictures about it popped into my mind.
10. I was jumpy and easily startled.
11. I tried not to think about it.
12. I was aware that I still had a lot of feelings about it, but I didn't deal with them.
13. My feelings about it were kind of numb.
14. I found myself acting or feeling like I was back at that time.
15. I had trouble falling asleep.
16. I had waves of strong feelings about it.
17. I tried to remove it from my memory.
18. I had trouble concentrating.
19. Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart.
20. I had dreams about it.
21. I felt watchful and on-guard.
22. I tried not to talk about it.

In the time following your diagnosis, which of the following items did you receive, seek out or engage in? Please tick the box which applies to you. If the item does not apply to you, please tick NA.

Support from health care professionals:	Yes	No	NA
Support from family:	Yes	No	NA
Support from friends:	Yes	No	NA
Support from co-workers or employer(s):	Yes	No	NA
Support from spouse/boyfriend/girlfriend/romantic partner:	Yes	No	NA
Meeting and talking to other HIV+ individuals:	Yes	No	NA
Talking to a therapist, alone or in a group setting:	Yes	No	NA
Education/learning about HIV:	Yes	No	NA
Disclosing HIV diagnosis to others:	Yes	No	NA
Receiving and taking medication:	Yes	No	NA

Please order the variables below from least to most effective – most effective on top and least effective on the bottom.

Choices: Drag-and-drop mechanic.

Support from health care professionals
 Support from family
 Support from friends
 Support from co-workers or employer(s)
 Support from spouse/boyfriend/girlfriend/romantic partner
 Meeting and talking to other HIV+ individuals
 Talking to a therapist, alone or in a group setting
 Education/learning about HIV
 Disclosing HIV diagnosis to others
 Receiving and taking medication

On a scale from 1 to 7 please indicate how important you have felt the following factors to be in the time following your diagnosis. If the question is not applicable to you, please mark the boxed named Not Applicable.

Choices: Not At All Important – Slightly Important – Somewhat Important – Moderately Important – Fairly Important – Very Important – Extremely Important – Not Applicable.

Support from health care professionals:

Support from family:

Support from friends:

Support from co-workers or employer(s):

Support from spouse/boyfriend/girlfriend/romantic partner:

Meeting and talking to other HIV+ individuals:

Talking to a therapist, alone or in a group setting:

Education/learning about HIV:

Disclosing HIV diagnosis to others:

Receiving and taking medication:

Going to work/studies:

From the present day, please think back over the last month. How well do the statements below reflect your thoughts, feelings or behaviour?

Choices: Not At All – A Little Bit – Moderately – Quite A Bit – Extremely

1. Any reminder brought back feelings about it.
2. I had trouble staying asleep.
3. Other things kept making me think about it.
4. I felt irritable and angry.
5. I avoided letting myself get upset when I thought about it or was reminded of it.
6. I thought about it when I didn't mean to.
7. I felt as if it hadn't happened or wasn't real.
8. I stayed away from reminders of it.
9. Pictures about it popped into my mind.
10. I was jumpy and easily startled.
11. I tried not to think about it.
12. I was aware that I still had a lot of feelings about it, but I didn't deal with them.
13. My feelings about it were kind of numb.
14. I found myself acting or feeling like I was back at that time.
15. I had trouble falling asleep.
16. I had waves of strong feelings about it.
17. I tried to remove it from my memory.
18. I had trouble concentrating.
19. Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart.
20. I had dreams about it.
21. I felt watchful and on-guard.
22. I tried not to talk about it.