

HIV-related distress and personal growth research report

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Acknowledgement and Citation

Acknowledgement

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Detailed statistical data is not reported in this report but can be obtained by contacting the researchers (details on the website).



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Project background and sample



This research aimed to investigate:

1. Which HIV-related events (like receiving the diagnosis, getting treatment, coming out) could be experienced as intensely distressing and lead to trauma symptoms,
2. Which factors contribute to HIV-related trauma,
3. Whether positive growth occurs in response to HIV adversity and how it affects distress.



100 gay men living with HIV took part in the research study

- Self-report questionnaires were returned by freepost
- Participants were recruited through advertising, voluntary agencies, and the research website (www.stress-hiv-research.org.uk) [questionnaires had to be printed from the website and returned by freepost].
- Individuals who participated in this research study were majority White British (76%), and educated at tertiary level (68%).
- About half were single (56%), in full-time employment (49%), and lived in London (51%), the rest were well spread across the British Isles.
- The average age was 43 (range 23 to 65 years old).
- The average number of years since diagnosis was 8 years (range: from less than 1 year to 23 years).



Sample

	%		%
Relationship status		Employment	
Single	56	Full-time	47
Have a partner	40	Unemployed/medically retired	25
Other	4	Part-time, volunteer, student	20
Education		Retired	7
Postgraduate degree	33	Not specified	1
Undergraduate degree/ Higher National Diploma	35		
A-level or less	29		
Not specified	3		
Ethnicity			
White British	76		
White Other	19		
Asian/Black	5		



Sample

Geography	%		%
North London	13	North East	4
South London	10	Yorkshire and the Humber	4
East London	13	North West	8
West London	15	North Country total	16
London total	51		
East of England	4	South West	8
South East	9	West Midlands	3
East Country total	13	West Country total	11
Scotland	2	Non-specified	3
Ireland	2		
Wales	2		
Ireland, Wales and Scotland total	6		



Which HIV-related events were traumatic?



What is a traumatic event?

An event is considered to be traumatic when an individual* :

- experiences or witnesses a severe physical threat or threat of death
- AND
- responds with intense emotional reaction to the event that includes either intense fear, helplessness, or horror

* Definition adapted from Diagnostic and Statistical Manual of Mental Disorders 4th edition text revision (DSM-IV-TR), 2000



What are posttraumatic stress symptoms?

- The diagnosis of posttraumatic stress disorder (PTSD) defines posttraumatic stress as *experiencing at least*:
 - **one reexperiencing symptom**
 - Intrusive distressing memories or recurring distressing dreams of the event
 - Acting/feeling as if event is happening again (e.g. flashbacks)
 - Emotional distress or physiological reaction to reminders of the event
 - **three avoidance and numbing symptoms**
 - Avoiding thoughts, feelings, activities, places, or people connected with the event
 - Unable to remember important parts of the event
 - Reduced interest in activities or restricted feelings
 - Feeling detached from others
 - Sense of foreshortened future
 - **two increased arousal symptoms**
 - Difficulty with sleep or concentration, being irritable or angry
 - Being hypervigilant or startling easily



Adapted from DSM-IV-TR (2000) definition

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Posttraumatic stress disorder

33% of gay men living with HIV had PTSD
in response to a HIV-related event

- Individuals experience PTSD if they have experienced a traumatic event and meet the criteria for posttraumatic stress symptoms.



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Stressful HIV-related events

A number of HIV-related events were measured which were *potentially* stressful or traumatic.

Event	% who experienced this event
– Receiving the HIV diagnosis	100%
– Coming out as HIV positive	93%
– Witnessing someone die from HIV-related illness	84%
– Receiving HIV treatment	78%
– Experiencing physical symptoms associated with HIV	72%
– Experiencing side-effects from the treatment	63%



Stressful HIV-related events

- Reactions to these events were measured.
- The percentage of individuals who *intensely* experienced the following reactions for each event were: %

Reaction:\nEvent:	HIV diagnosis	Coming Out as HIV+	Witnessing death due to HIV	Receiving treatment	Physical symptoms	Side effects
experience event as a physical threat	33	9	12	15	43	33
thought that I might die	61	15	36	21	40	19
intense fear	52	25	24	23	33	24
helplessness	56	27	36	18	39	40
horror	42	13	30	12	22	14
shame	34	27	11	10	13	13
humiliation	28	20	10	12	19	18
guilt	35	28	17	15	17	13

N = 100 93 84 78 72 63



Which HIV-related events were traumatic?

*Individuals who reported that they found the event threatening and experienced intense fear, or helplessness or horror during the event, were considered to have had a traumatic reaction to the event.

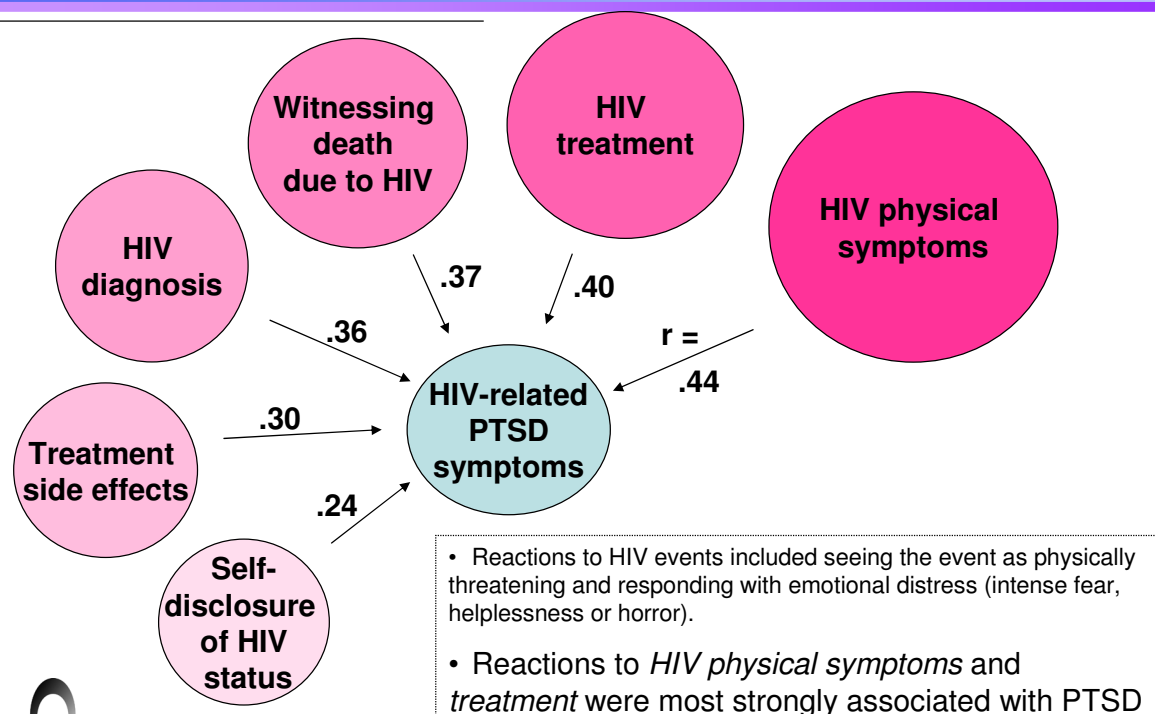
Event	% who experienced this event	% of whom had trauma reactions*
Receiving the HIV diagnosis	100	65
Coming out as HIV positive	93	15
Witnessing someone die from HIV-related illness	84	30
Receiving HIV treatment	78	19
Experiencing physical symptoms associated with HIV	72	40
Experiencing side-effects from the treatment	63	29

- 65% of gay men living with HIV experienced at least *ONE* HIV event as fulfilling the criteria for a traumatic event
- Excluding the diagnosis, between 15% and 40% of individuals found HIV-related events traumatic



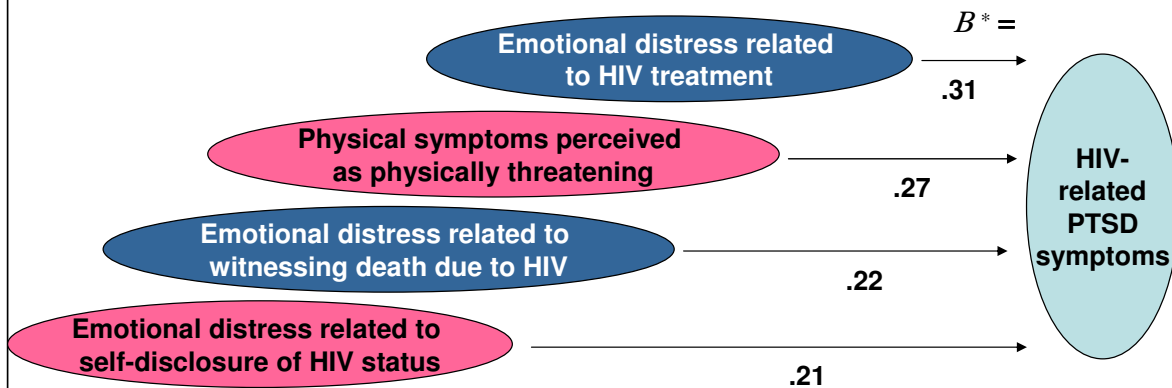
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HIV-related events and PTSD symptoms



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Reactions to HIV-related events that most linked to HIV-related PTSD



- FOUR events *independently* contributed to PTSD symptoms
- Emotional distress to treatment, witnessing someone die from HIV-related illness, and coming out as HIV positive were associated with PTSD
- Feeling physically threatened by physical symptoms also associated with PTSD

* = strength of association with PTSD symptoms
(stepwise regression of reactions to events on PTSD symptoms)



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Other reactions to HIV-related events

- Participants were asked to list what other reactions they experienced in response to HIV-related events.
- Other reactions in response to HIV-related events included:
 - Relief & empathy
 - Sadness & grief
 - Despair, hopelessness, abandonment
 - Disbelief, denial
 - Annoyance, anger
 - Anxiety, worry, shock
 - Regret
 - Numbness



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Other stressful HIV-related events

- Some participants also described other HIV-related events which they found highly distressing.
- These included:
 - Being outed
 - Poor doctor-patient relationships
 - Lack of available health services
 - Being prevented from travelling internationally
 - Experiencing or witnessing prejudice and discrimination
 - Experiencing HIV-related mental health problems
 - Being alone with the experience of HIV
 - Relationship or friendship problems
 - Employment and financial difficulties



HIV-related stress events: Summary

- Multiple HIV-related events were experienced as traumatic that included both physical illness and social events.
- Whilst HIV diagnosis was distressing for most, it did not have the strongest link with PTSD symptoms.
- HIV treatment, physical symptoms, witnessing someone die from HIV-related illness and coming out as HIV+ were most associated with PTSD symptoms.
- Mostly emotional distress in response to HIV-related events associated with PTSD, and in the case of physical symptoms, perceived threat was traumatic.
- A significant proportion of participants (33%) met criteria for HIV-related PTSD.



What were the HIV-related PTSD symptoms?

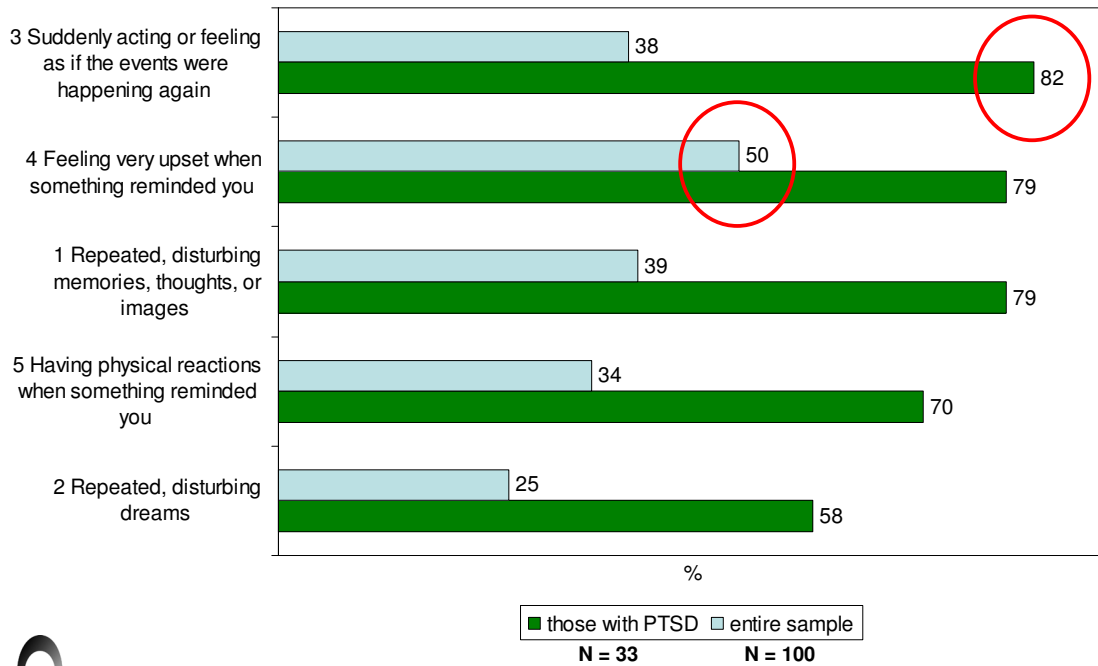


Individual PTSD symptoms

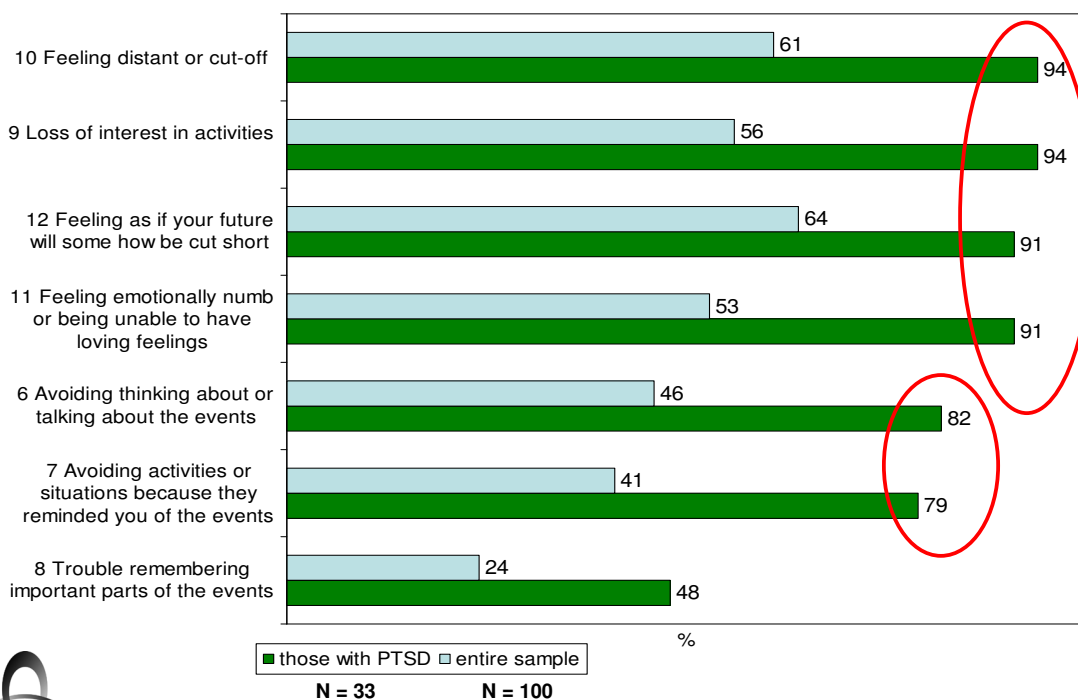
- We considered which individual PTSD symptoms were experienced at a clinical level of distress.
- Clinical distress was defined as a symptoms which was rated as bothering an individual moderately to extremely in the last month.



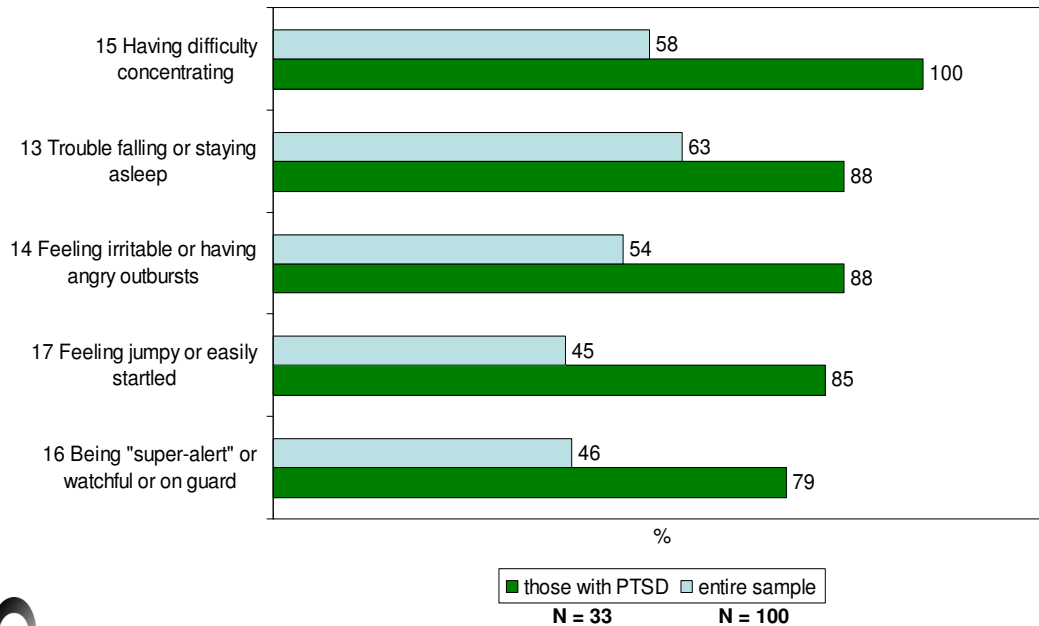
Re-experiencing symptoms



Avoidance and Numbing symptoms



Hyper-arousal symptoms



PTSD symptom profile

- Of the reexperiencing symptoms, classic PTSD reliving symptoms were experienced most frequently, by those meeting criteria for PTSD.
 - For the sample as a whole, heightened emotional distress was the most frequent reexperiencing symptom.
- Numbing symptoms were experienced more frequently than avoidance symptoms amongst those with PTSD
- Hyperarousal symptoms were experienced more frequently than reexperiencing symptoms
 - Difficulty concentrating was the most frequently experienced hyperarousal symptom for those with PTSD
 - This may be influenced by the physical illness effects of HIV rather than traumatic stress.
 - Classic hyperarousal symptoms such as being super-alert or jumpy were experienced least.



PTSD symptoms: Summary

- All the typical PTSD symptoms are present in HIV-related PTSD.
 - Reliving symptoms
 - Emotional numbing
 - Avoidance of reminders of the event
 - Hyperarousal
- There appears to be a symptoms trend of experiencing mostly emotional numbing, then avoidance, followed by arousal symptoms, and lastly reexperiencing symptoms.

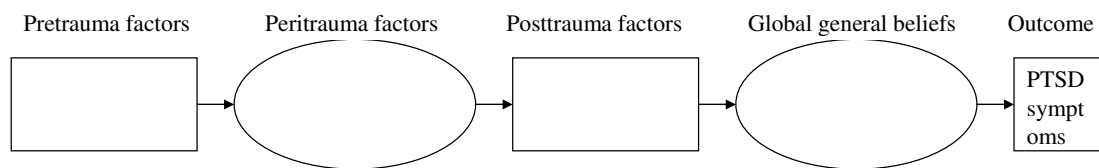


What influences HIV-related posttraumatic stress symptoms?



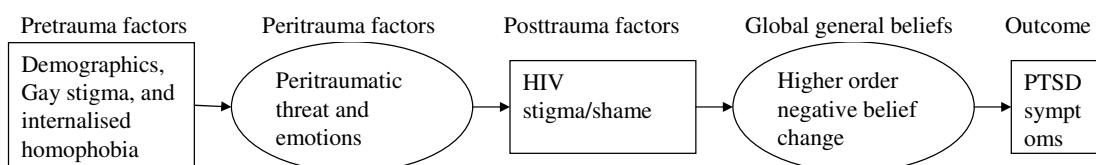
Theory of different factors affecting PTSD

- Trauma models suggest that factors before a traumatic event (pretrauma), factors during the trauma (peritrauma) and factors after the event (posttrauma) shape whether a person develops PTSD.
- Trauma is created through:
 - A) the impact that intense emotional arousal has on a person, e.g. fear affecting the ability to respond and process mentally what happens during an event, and
 - B) the extent to which positive beliefs about self, others, and the world are undermined (i.e. positive global general beliefs are undermined).



Theory of different factors affecting PTSD

- The following factors were measured in this study in order to develop a model for understanding some of the processes that are involved in HIV-related PTSD.
- The aim was to consider the extent to which fear, shame, and negative belief change affected HIV-related PTSD.
- The following factors were measured:
 - Pretrauma factors: gay stigma, internalised homophobia, and demographics
 - Peritrauma factors: reactions to HIV-related events
 - Posttrauma factors: HIV stigma and self-devaluation because of having HIV



Factors associated with HIV-related PTSD

The research model showed that:

- **Individuals who experienced their sexuality as devalued by others were vulnerable to being traumatised especially if they also devalued their own sexuality.**



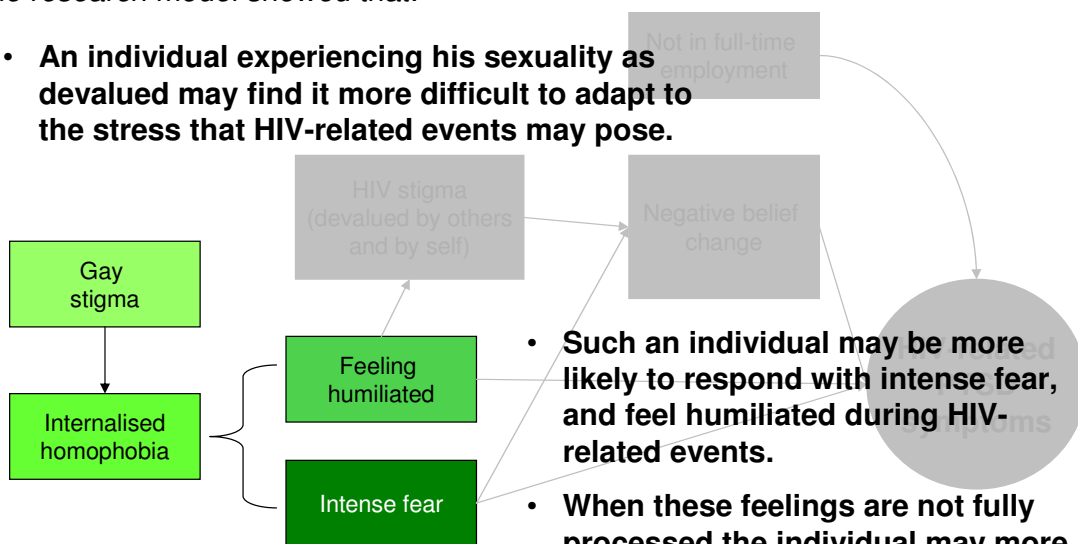
based on hierarchical stepwise regression



Factors associated with HIV-related PTSD

The research model showed that:

- **An individual experiencing his sexuality as devalued may find it more difficult to adapt to the stress that HIV-related events may pose.**



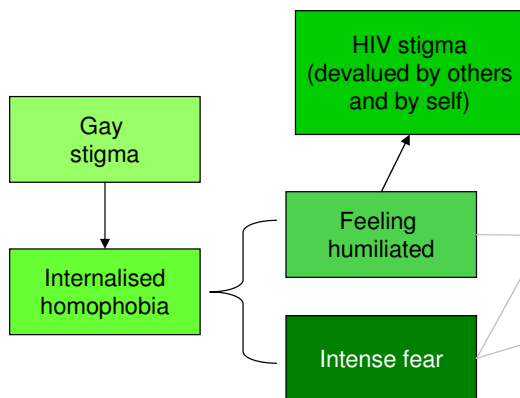
- **Such an individual may be more likely to respond with intense fear, and feel humiliated during HIV-related events.**
- **When these feelings are not fully processed the individual may more likely become traumatised.**

based on hierarchical stepwise regression



Factors associated with HIV-related PTSD

The research model showed that:



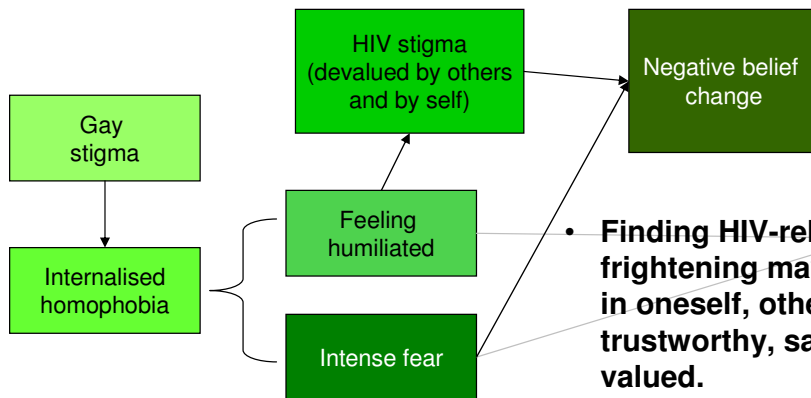
- Individuals who felt humiliated during an HIV-related event were more likely to experience their HIV status as devalued by others and by themselves, creating vulnerability to trauma symptoms.
- One possibility is that a person who felt humiliated is more likely to be finely tuned into and pick up social signals of devaluation.
- Experiencing a devalued sexuality may also make it more likely to experience HIV status as devalued.

based on hierarchical stepwise regression



Factors associated with HIV-related PTSD

The research model showed that:



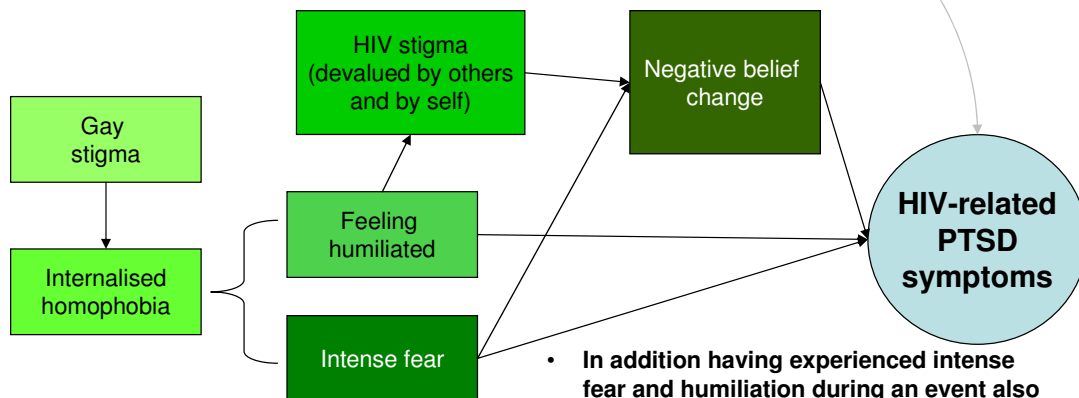
- Experiencing stigma (e.g. social rejection and blame) may undermine positive beliefs about self, others and the world.
- Finding HIV-related events intensely frightening may also threaten beliefs in oneself, others, and the world as trustworthy, safe, predictable, and valued.

based on hierarchical stepwise regression



Factors associated with HIV-related PTSD

The research model showed that:



- Holding negative beliefs about self, others and the world was shown to be one of the strongest explanations for PTSD symptoms.

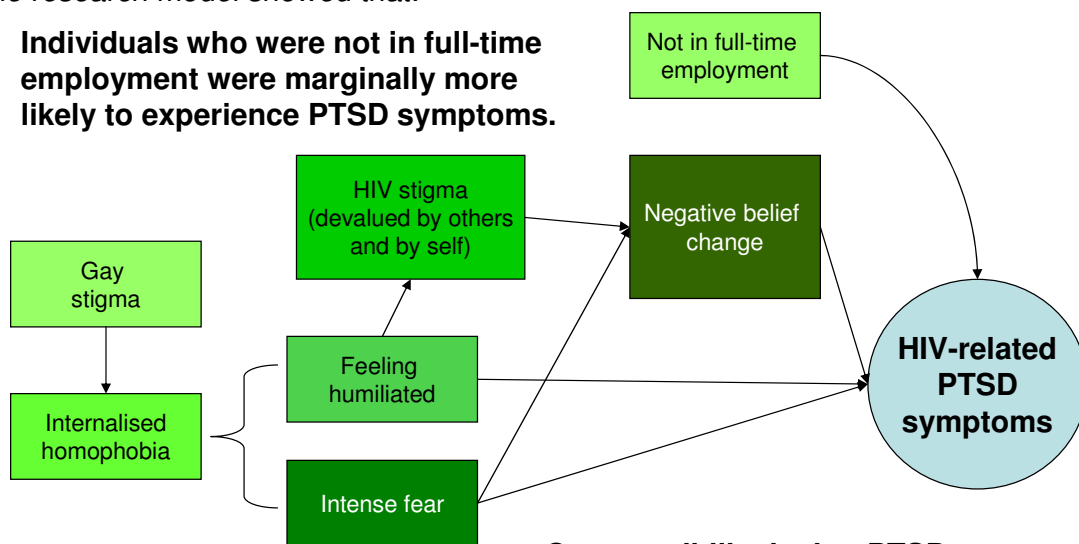
- In addition having experienced intense fear and humiliation during an event also contributed to PTSD symptoms.
- Such emotions are likely to interfere with a person's ability to process the stress they experienced.



Factors associated with HIV-related PTSD

The research model showed that:

- Individuals who were not in full-time employment were marginally more likely to experience PTSD symptoms.



- One possibility is that PTSD symptoms might make it more difficult to manage full-time work.



HIV-related PTSD influences: Summary

- An individual is more likely to experience HIV-related PTSD symptoms if he has experienced shame concerning his sexuality and HIV status.
- Shame and humiliation can occur as a result of being devalued by others as well as devaluing oneself.
- Shame appears to make PTSD symptoms more likely if positive global beliefs about self, others, and the world are undermined.
- Intense fear (and to a lesser extent humiliation) experienced *during* a trauma event contributed independently to PTSD symptoms.
 - intense emotional reactions may impact on a person in a manner that makes PTSD more likely.
- The statistical model supports both a fear-based and schema(meaning)-based model of traumatic stress.



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Do individuals grow in response to HIV adversity?



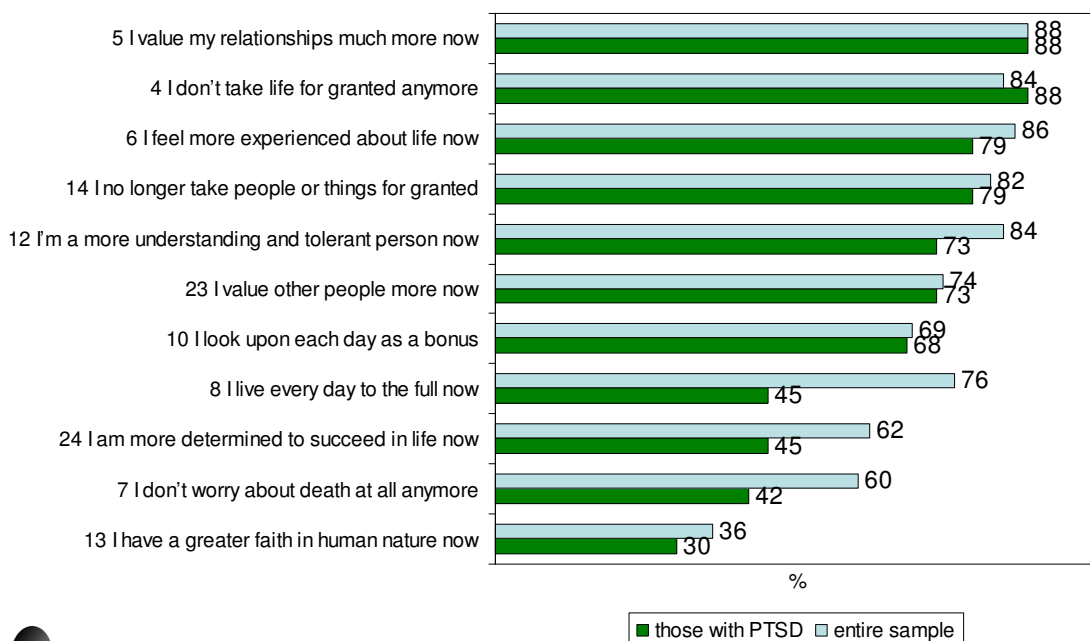
Positive growth following HIV-related events

- We measured the extent to which individuals had developed positive beliefs following HIV-related events.
- These beliefs reflected the positive changes that have come about as a result of adapting to the challenges posed by living with HIV.

The positive beliefs of individuals meeting PTSD criteria were compared with positive beliefs for the whole sample. (see next slide).

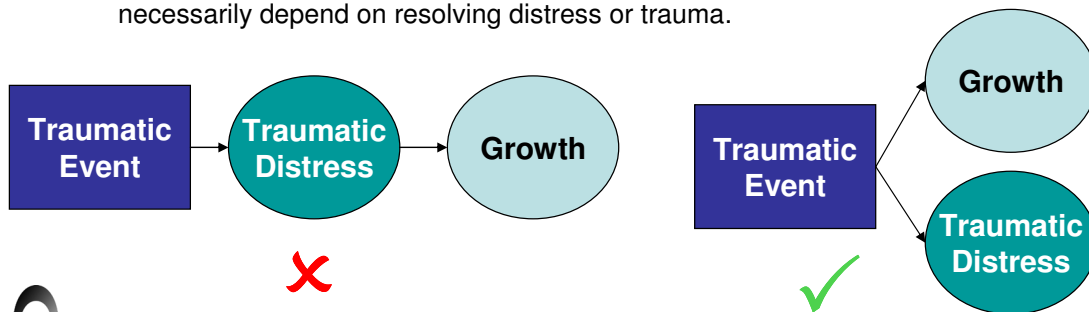


Positive growth following HIV-related events



Positive growth following HIV-related events

- Most individuals had positively grown from dealing with HIV-related adversity.
- Individuals with PTSD had made as many positive changes as those without PTSD.
 - Despite intense distress, people living with HIV show resilience and resourcefulness in responding to the demands of HIV-related stress events.
 - The results suggest that a person could therefore achieve both positive growth, whilst having distress.
 - Achieving positive changes or growth following trauma may therefore not necessarily depend on resolving distress or trauma.



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Positive growth following HIV-related events

- Individuals who grew positively in response to adversity were found to have *marginally* fewer deeper negative beliefs about themselves, others and the world (correlation between positive and negative beliefs: $r = -.21$, $p = .036$).
- This suggests that having made positive changes a person is somewhat less likely to hold deep negative beliefs.
- However, it is also possible that holding deep negative beliefs may make it somewhat more difficult to respond positively to adversity.



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Positive growth: Summary

- Most individuals had positively grown following stressful HIV-related events.
- It appears that positive growth did not depend on resolving distress, but also did not reduce traumatic distress.
- It is possible for individuals to simultaneously experience both distress and positive growth following traumatic HIV events.
- Holding greater negative beliefs were found to make it somewhat more difficult to grow from adversity.



Summary findings and recommendations



Summary findings

Posttraumatic stress disorder (PTSD)

- 33% of gay men living with HIV experienced distressing HIV-related events and distress symptoms that met PTSD criteria.

Trauma events

- The majority of people (65%) were intensely distressed during receiving the HIV diagnosis.
- However, the HIV diagnosis was *NOT* the most likely event to associate with PTSD symptoms.
- Reactions to *HIV treatment, HIV-related physical symptoms, witnessing someone die from HIV-related illness, and coming out as HIV positive* were directly associated with PTSD symptoms.



Summary findings

Trauma events (cont.)

- Both HIV events that threaten *physical well-being* and events that threaten *social well-being* associated with traumatic stress.
- HIV-related PTSD associated with *multiple HIV-related events*.

Trauma process

- Shame based factors before, during, and after trauma events associated with PTSD symptoms.
- Gay stigma and internalised homophobia accounted for a vulnerability to being traumatised by HIV-related events.
- Feeling intense fear and feeling humiliated during an HIV-related event associated with greater trauma symptoms.



Summary findings

Trauma process (cont.)

- HIV stigma and self-devaluation for having HIV associated with greater trauma symptoms.
- Breakdown in positive global beliefs about self, others, and the world was most predictive of PTSD symptoms.
- The results support the view that traumatic stress symptoms may be maintained by a breakdown in beliefs and a response to intense fear that was experienced during a traumatic event.



Summary findings

Positive growth

- Most individuals had grown positively in response to HIV adversity, despite the distress they may have experienced.
- Some individuals therefore seemed to have grown and made positive changes in their life, whilst at the same time, being traumatised by HIV-related experiences.
- This suggests resilience in the face of adversity.
- Those who were able to make positive changes following HIV, had a *tendency* to hold fewer negative beliefs.
- However, positive growth did not lower traumatic distress.



Summary findings

Treatment recommendations

- A number of HIV-related events, most notably HIV treatment and physical symptoms, associated with PTSD.
 - additional support may be required for some individuals who experience intense distress during these events.
 - Services may be able to identify individuals at risk of trauma by screening for those who experience intense fear or humiliation during such times.
- Experiencing prejudice from others and internalised prejudice increase risk of traumatisation.
 - Services that support people in coping with prejudice may help improve resilience to being traumatised.
 - Individuals may benefit from support in growing from adversity, which may decrease their chances of holding deep negative beliefs that may compromise resilience.



Summary findings

Treatment recommendations (cont.)

- Gay men who are traumatised by HIV-related events may require specialist PTSD treatment focusing on these events.
- Treatment for HIV-related PTSD may benefit from focusing on:
 - developing or maintaining a realistically positive view of self, others, and the world.
 - exploring the experience and effects that intense fear and humiliation during the event had.
- These treatment recommendations may apply to all people living with HIV for whom some HIV-related events were intensely distressing. However current study findings can only scientifically be generalised to gay men living with HIV.



Summary findings

Research recommendations

- Further research is needed to explore HIV-related PTSD amongst diverse groups of people living with HIV.
- HIV treatment associated most strongly with PTSD. Further research could examine which treatment experiences are most distressing (e.g. treatment initiation).
- This study supports examining the role of social threat in future research on minority groups living with HIV.
- The experiences related to HIV may require greater study to determine how individuals living with HIV can be supported before, during, and after such events.
- The role of fear and humiliation require greater study to understand the processes by which these feelings occur and how they make PTSD more likely in some individuals living with HIV.
- Further research on posttraumatic growth is required to understand what promotes growth and whether there are ways in which it may reduce distress.

