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1 December 2007

Dear Participant/ Supporter,

I would like to thank you for the support you have shown to the HIV-related Distress and Personal Growth research project. This letter is a summary of some of the key findings from the project. More information can be obtained from the research website: www.stress-hiv-research.org.uk. The study took place between November 2006 and March 2007, and 100 gay men from across the British Isles took part.

The study found that 33% of gay men living with HIV experienced posttraumatic stress disorder (PTSD) in response to at least one stressful HIV event.

What is PTSD?

A person is said to have PTSD when they have:

1. experienced or witnessed a severe physical threat or threat of death
- AND**
2. responded with an intense emotional reaction to the event that included either intense fear, helplessness, or horror

The person will also have experienced *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

Which HIV-related events were traumatic?

Participants were asked to indicate what their reactions were to HIV-related events. 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. The results were as follows:

Event	% who experienced this event	% of whom had trauma reactions to the event
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

It is clear from these results that the majority of people (65%) had traumatic reactions to receiving the diagnosis. This raised the question whether receiving the diagnosis was most likely to contribute to developing PTSD?

The results showed that the events which *most* linked with PTSD were:

1. Receiving HIV treatment
2. Physical symptoms associated with HIV
3. Witnessing someone die from HIV-related illness
4. A difficult coming out as HIV positive

This suggests that whilst receiving the HIV diagnosis can be very distressing, it is not most likely to lead to experiencing trauma. People who were traumatised were more likely to have had distress about treatment, physical symptoms, seeing others die from HIV and having had a difficult coming experience. *However, this does not mean that everybody who has experienced these events experienced trauma.*

What seems to be important is whether a person had a *traumatic reaction* to the event. It was found that those who experienced *intense fear or humiliation* during the event were more likely to develop posttraumatic stress symptoms. In other words, people who experienced intense fear during HIV treatment appear to have been more likely to be traumatised by it. Similarly, if a person felt intensely humiliated during a coming out experience, they seem to have been more likely to be traumatised by the experience. However, whilst intense negative feelings (trauma reactions) might make it more likely, it does not mean that a person *will* be traumatised. Other influences may be necessary before a person experiences trauma.

What is the role of prejudice?

Homophobia and HIV stigma were found to make it more difficult for a person to cope with the stress of HIV. The extent to which others discriminated and devalued a person for being gay or HIV positive, *as well as*, the extent to which a gay HIV positive person devalued himself for being gay and HIV positive, made it more likely for that person to be traumatised by HIV-related events.

Experiencing prejudice from others and being prejudiced towards oneself for having HIV or being gay, are additional influences that might make it more likely that a person experiences some HIV events as traumatic.

What causes HIV-related PTSD?

A number of different influences were found to associate with PTSD in response to stressful HIV events. So far I have mentioned that these influences include:

- the *type* of HIV event experienced
- whether intense fear or humiliation was experienced during the event, and
- whether prejudice was experienced from others or towards oneself for being gay or HIV positive

But all the people who have had these experiences did not experience PTSD, although a significant amount did. The results showed that what seems key is whether a person's deeply held *positive* beliefs about themselves, others, and their world became *undermined* as a result of the experiences they had. When these experiences skew a person's deepest views to becoming negative, then a person is most vulnerable to being traumatised.

Although, the data showed that in addition to negative beliefs, intense fear during an event was also sufficient to contribute to posttraumatic stress symptoms.

One of the limitations of the research is that we cannot say exactly what causes HIV-related PTSD, but the information gives useful indications about what might be likely.

Positive growth

When faced with challenges and adverse experiences, people are able to respond positively and learn to live with adversity in a constructive way. The results showed that most people had made positive changes in their lives and grown from the challenges that HIV posed them.

The results showed, maybe surprisingly, that a person could experience both positive feelings and growth, whilst *also* experiencing intense distress in response to HIV. This indicates the complexity of human experiences when faced with adversity. It also highlights that during times of high stress people also have a lot of resilience and resourcefulness that they can draw on.

Treatment or Support

Receiving HIV treatment and having physical symptoms from HIV seemed to be the events that were most likely to contribute to trauma. For some people additional support may be required around the time when they need to start combination therapy or experience physical symptoms. For some such a time may be accompanied by intense fear and worry about their wellbeing. The threat that some people may associate with this time may make them more negative in their views. Social support, support from community volunteers, and in some cases professional counselling may be needed to help the person cope during that time.

For people living with HIV who experience traumatic stress (PTSD) a focused treatment may be needed that helps them address the specific symptoms. Psychological treatment that focuses on the effects of intense fear or shame experienced during HIV-related events might be useful to consider.

The ability for people to hold positive views and grow from dealing with HIV, indicates a resourcefulness that people could draw on in order to help them address the challenges that living with HIV may bring. HIV positive people may benefit from services that assist them in developing positive views and approaches to living with HIV.

Conclusion

This research study has shown that some HIV-related events can be intensely distressing and may traumatise some people. But people are able to grow and respond positively to adversity, despite the distress they experience.

A number of different influences were found to potentially make people more vulnerable to being traumatised by HIV-related events. These include the type of event a person experienced, whether they felt intense fear or humiliation during the event, and the extent to which they have experienced prejudice from others and towards themselves. The extent to which these experiences negatively skew a person's deeper beliefs about themselves, others and the world appeared to be one of the strongest influences in whether a person was traumatised.

Living with HIV is not inherently traumatic, but it seems that for some people some experiences linked to HIV can be overwhelming and lead to trauma (PTSD). Getting support during a difficult time might be helpful to prevent trauma. For people who are traumatised by their experience more professional psychological help may be needed to help them overcome the effects of trauma. Developing positive beliefs, and getting support in managing prejudice, may also be protective in helping people to cope with the challenges posed by HIV. Should you need support a list of services and a national helpline that can direct you to local services is attached to this letter.

Yours Sincerely,

Dr. Anthony C. Theuninck
Clinical Psychologist

SUPPORT SERVICES

NATIONAL HELPLINE

THT Direct helpline: 0845 12 21 200 (offers information, emotional support and guidance on local services available)

Terrence Higgins Trust and Lighthouse Service Centers

A national voluntary organisation offering a wide range of information and HIV services.

Website: www.tht.org.uk

Email: info@tht.org.uk

Body Positive

Body Positive organisations exist around the UK, offering diverse services specifically for people living with HIV. Find your local service by searching on the internet or contacting THT Direct.

PACE: promoting lesbian and gay health and wellbeing

A London based charity offering counselling and therapy, group work, mental health advocacy and youthwork amongst other services.

Address: PACE, 34 Hartham Road, London N7 9JL

Telephone: 020 7700 1323

Website: <http://www.pacehealth.org.uk>

E-mail: info@pacehealth.org.uk

Metro: A Lesbian, Gay and Bisexual Centre based in Greenwich South East London

A South-East London, Greenwich based service offering a range of services including counselling and information support.

Telephone: 020 8265 3311

Website: <http://www.themetro.dircon.co.uk/>

Email: info@t-metro.co.uk

NHS Direct

This England wide 24 hour helpline and website directory provides information on a range of medical issues and guidance on who to contact for services.

Telephone helpline: 0845 46 47 (24 hours)

Website: www.nhsdirect.nhs.uk