Stress Test

How HIV can both lead to post-traumatic stress disorder and be the result of the syndrome itself.

December 1, 2010 By David Evans

Writers frequently describe the AIDS epidemic in military terms, referring to battles waged and lost. Perhaps those war metaphors are apt. In fact, a syndrome commonly associated with soldiers, post-traumatic stress disorder (PTSD), is deeply linked to HIV—and the connection runs both ways. While some people are so traumatized by their HIV diagnosis that they develop PTSD, for others the situation is reversed: They experienced the stress disorder before contracting the virus.

That was the case for Jeff Nehrbas, who tested HIV positive in 1984 at the age of 26. His trauma began when he was barely a teenager. “When I was 14 I was [sexually] molested by [a close relative],” he says.

The resulting stress was amplified in his junior year of high school when word got out that the relative was molesting other boys too. Aside from the horror of learning that his own private hell was being visited on his classmates, Nehrbas also had to deal with stigma and rejection from others in his community. His best friend tapped him on the shoulder one day in basketball practice and said, “We heard about your family, you fucking faggot.”

Nehrbas spent nearly seven years in therapy coming to terms with what had happened to him. He feels that the trauma he experienced and his inability to cope with it prompted him to take sexual risks in his early 20s. Those risks in turn led to his contracting HIV.

Conall O’Cleirigh, PhD, is a behavioral scientist at The Fenway Institute, an LGBT health center, and instructor in psychiatry at Harvard Medical School in Boston. Sexual trauma and HIV often go hand in hand, he says, creating a dangerous intersection of PTSD and HIV.

According to O’Cleirigh, “PTSD is a complex disorder. One of the core features of its diagnosis is that it’s a reaction to a traumatic event—and not just losing your job or breaking up with your girlfriend or your boyfriend.” Dramatically traumatic events trigger PTSD and produce feelings of helplessness, terror or horror. Most experts specify that such trauma causes the sufferers to believe they or someone close to them is going to be killed or seriously injured.

Until 1980, PTSD didn’t have its own formal diagnostic criteria. But the syndrome has long been

known to those who treat veterans; it was called “soldier’s heart” during the Civil War and “shell shock” after World War II. Since 1980, however, clinicians have increasingly found that many kinds of trauma—ranging from plane crashes to rape, sexual abuse and assault—can provoke the same symptoms that plague soldiers returning from the battlefield.

O’Cleirigh says most people who survive traumas experience three types of symptoms. These include: intrusive thoughts, memories and emotions about the event; the strong desire to avoid places and things that provoke those memories and emotions; and a hyper-aroused state in which a person is vigilantly guarding against danger and is easily startled. For most people, O’Cleirigh says, these symptoms gradually subside over time. In someone with PTSD, however, they persist and may even worsen. “Some people can be very severely distressed, and their [attempts at] avoidance take up all their [time and energy],” he says.

We don’t yet fully know why some people end up with PTSD while others handle trauma without lasting effects, but researchers are looking at a number of factors. Most of these involve a complex interplay between the way the brain is wired and the chemical soup that controls brain function. In simplified form, O’Cleirigh explains it this way: “[People with PTSD] just remember [the event] in the wrong place in the brain, and there’s too much emotion attached to it.”

“I think one of the reasons why PTSD ends up being so important in HIV,” O’Cleirigh says, “is that HIV [often] affects people who have a fairly substantial trauma history.” Studies do show that people living with HIV are as much as 30 to 50 percent more likely than the general population to have been sexually abused as children or teens, or subjected to sexual violence as adults. PTSD can lead to drug and alcohol binges and heightened risk-taking, making for a dangerous combination.

But which came first, the virus or PTSD? While it’s been clear for some time that PTSD can increase a person’s risk for contracting HIV, researchers have lately wondered whether the reverse might also be true: that an HIV diagnosis, or the stress of living and surviving HIV, might actually lead to PTSD. That question is more than theoretical for Joe Killfoile, 56, a Montreal resident who is HIV positive and was recently diagnosed with PTSD.

For Killfoile, the worst symptom of his PTSD has been unrelenting night and day terrors, where the faces of countless friends who died of HIV flood his mind. “[When it happens] I recognize every single face, and I’ve even had [the terrors] while standing in line at the grocery store,” he says. “Somebody will bump me to move up, and it’s like I’ve woken up from this deep fog.”

Killfoile says the intrusive memories got so bad a couple of years ago that he couldn’t sleep and had a hard time functioning. He thinks a lot of the trauma comes from the helplessness he felt when his friends were dying. He also says that these losses were a constant reminder of his own mortality.

Killfoile’s story is not unique. O’Cleirigh says a number of causes can trigger PTSD in people with HIV, including illness, bereavement and stigma. He points to one study where the defining

traumatic event for 40 percent of a group of HIV-positive people with PTSD was receiving an HIV diagnosis.

Another recent study in HIV-positive men in England found, surprisingly, that the most significant factor associated with the onset of PTSD symptoms was starting to take HIV medication.

One of the study's authors, Anthony Theuninck, PhD, a researcher at the Oxleas NHS Foundation Trust in London, says more research is needed to understand precisely what it is about treatment that is so traumatic for some. He offers a possible explanation: "Taking medication may be perceived as signaling HIV's defeat of the body's resilience, and the person may become fixed on thinking about the virus killing them.

"If a person believes that a healthy lifestyle, or religious devotion for that matter, will assure them health," Theuninck adds, "the start of antiretrovirals may be perceived as undermining the very bedrock of how their world works."

A hallmark of PTSD is needing to avoid painful memories. That can pose particular danger for people with HIV, if, say, lifesaving activities such as visiting a doctor and taking meds reawaken trauma. That could push people to avoid their drugs and health care providers.

"Say somebody is afraid for their life, or is ashamed or guilty, or is feeling the full brunt of societal stigma and they want to avoid that sort of stuff," O'Cleirigh says. "[Those feelings could lead them] to avoid reminders of HIV. That could mean they'll be less likely to get connected into care, and they may avoid taking a look at their medications. Their adherence is going to suffer."

The core of most PTSD therapy involves changing how a person relates to memories of the events that shattered his or her world. Joshua Matacotta, a graduate student and therapist in training in San Francisco, has used this approach in working with PTSD sufferers. "The goal of treatment," he says, "is finding a way for people to acknowledge the reality of what happened to them, to integrate the experience into autobiographical memory, and to do so without having to re-experience the trauma all over again."

For Jeff Nehrbas, healing involves writing down his story. Originally he intended to focus mostly on how he's survived multiple tragedies over the years. He's since realized, however, that the molestation is where it all began, and that talking about it could help him heal—both himself and others who've been through the same thing.

Both Nerhbas and Killfoile have relied heavily on therapy to get them through, and Matacotta thinks this is vital. "I can't stress enough," he says, "the importance of finding a therapist who is a good match for you and is trained in working with PTSD and HIV-related PTSD."

Killfoile's recovery now includes pulling out his photo albums and remembering his lost friends in a different way. Instead of recalling them on their deathbeds, he now tries to remember the joy and the love he shared with him. He also finds meaning—and healing—on the POZ online forums

(poz.com/forums). There, he helps newly diagnosed people navigate the terrain of learning to live with HIV.

When asked what he would tell someone who reported symptoms of PTSD, he doesn't hesitate. "There's still a lot of stigma with HIV, but there's also a lot of stigma about mental health," he says. "And even if you don't fit the mold of some diagnosis, if you feel that you need some help, you need to get that help," he says.

The Basics

Defining (and treating) post-traumatic stress disorder

What It Is: Post-traumatic stress disorder (PTSD) is an anxiety disorder caused by a traumatic experience, provoking feelings of terror that your life or the lives of those around you are in peril.

Symptoms: Flashbacks of the event, nightmares, avoiding things that arouse painful memories, being easily startled, feeling constantly on edge, difficulty sleeping, angry outbursts.

Treatment: Ask your health care provider about specific therapies for PTSD (for a list of recommended techniques, see "Removing Memory's Sting," next page). Your doctor may prescribe medications for depression or anxiety.

Finding Help: To learn more about PTSD and other anxiety disorders, and to find a mental health provider near you, contact:
Anxiety Disorders Association of America, adaa.org, 240.485.1001
Association for Behavioral and Cognitive Therapies, abct.org, 212.647.1890

Removing Memory's Sting

The National Institute of Mental Health recommends three types of cognitive therapy for healing from PTSD:

Exposure therapy re-exposes people to the trauma they experienced, but in a safe way, using mental imagery, writing or visits to the place where the event happened. The therapist uses these tools to help people with PTSD face and cope with the feelings triggered by the traumatic event.

Cognitive restructuring helps people reinterpret and understand bad memories and the negative emotions—such as guilt or shame—they associate with the event. The therapist helps people with PTSD look at what happened in a realistic way.

Stress inoculation training tries to reduce PTSD symptoms by teaching a person how to reduce anxiety. As with cognitive restructuring, this treatment helps people handle their memories in a healthier way.

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