



The Legacy of the Past

Gay Men in Mid-Life And the Impact of HIV/AIDS

By Spencer Cox
Executive Director

The Medius Institute
For Gay Men's Health

The Medius Institute is a non-profit organization dedicated to improving the health, well-being, and longevity of gay men.

The author is deeply indebted to Dr. Robert Kerzner and Dr. Walt Odets for their insights into these issues. See Kerzner RM. The adult life course and homosexual identity in midlife gay men. *Annu Rev Sex Res.* 2001;12:75-92 and Odets W. Survivor Guilt in HIV-Negative Gay Men. *Hath Cont Ed for Psych.* 4:15. 1994.

Special thanks to Founding Sponsor Broadway Cares/Equity Fights AIDS, David Corkery and The Corkery Group, GlaxoSmithkline, Mark M. Sexton & W. Kirk Wallace, and New York's Lesbian, Gay, Bisexual & Transgender Community Center.

Also thanks to: Lynda Dee, Dr. Alan Downs, Dr. Anthony Gaudio, Dr. Perry Halkitis, Michael Isbell, Michael Joyner, Jay Laudato, Mark Leydorf, Jon-David Nalley, Catherine McBride, Christopher Murray, David Nimmons, Laura Pinsky, Michele Pronko, David Richwine, Michael Shernoff, John Sirabella, Tom Viola, John Voelcker, Dr. Barbara Warren, Dr. Ron Winchell, and Mark Woodcock.

Our lifetime as gay men has been bewildering, to be honest. But we dealt with it through this terrible plague as well, this hideous illness that struck so many people down. And the current younger generation I don't think even understands what we went through, what we witnessed. For me that's the fuel. The ashes of all the people I loved who are dead keep me going. I promised one of my best friends that I would not give up. And that's still very much a part of my identity. I am a child of the plague and I will never, never forget that. For some of us, that changed us forever. It gave us a sort of intensity and drive that the younger generation cannot know because they are lucky enough to have escaped it.

Writer Andrew Sullivan in *Soul Searching: Andrew Sullivan's Quest to Reclaim Conservatism*. *Metro Weekly*. November 9, 2006

Introduction

The current generation of American gay men in mid-life has experienced remarkable losses. From the late 1970s until the end of 1999, when effective anti-HIV regimens became widely available, the AIDS epidemic ravaged America's gay communities: the Centers for Control and Prevention (CDC) estimate that more than 267,500 men who have sex with men died of AIDS in the United States during those early years.¹

Following the terrorist attacks of September 11th, 2001, there was immediate recognition of the urgent need for immediate and ongoing mental health evaluation and treatment for those exposed to and/or affected by the event.² In contrast, for gay men who lived for decades through an epidemic that killed hundreds of thousands of friends and family members, no systematic effort has been made to treat -- or even to identify -- the long-term psychological effects associated with such traumatic experiences and painful memories.

Self-harming behaviors have been identified in other survivors of mass trauma, and have also been associated with AIDS-related bereavement.^{3,4,5,6} Specifically, a number of risks have been identified for gay men in mid-life, defined roughly as thirty-five to fifty-five years of age, that may be directly or indirectly associated with traumatic experiences, including:

- Depression and anxiety
- Drug and alcohol addiction
- Sexual risk-taking
- Partner violence
- The inability to positively imagine or plan for the long-term future

¹ Centers for Disease Control and Prevention. *HIV/AIDS Surveillance Supplemental Report*. Vol. 8, No 1. 2001. Includes MSM and MSM/IDU.

² Resnick H, Galea S, et al. Research on Trauma and PTSD in the Aftermath of 9/11. *PTSD Res Quart*. 15(1) Winter 2004.

³ Krystal H & Danieli Y. Holocaust Survivor Studies in the Context of PTSD. *PTSD Res Quart*. 5(4) Fall 1994.

⁴ Martin, J., and L. Dean, "Effects of AIDS-Related Bereavement and HIV-Related Illness on Psychological Distress Among Gay Men: A 7-Year Longitudinal Study, 1985-91," *Journal of Consulting and Clinical Psychology* 61 (1993), pp. 94-103.

⁵ Pfefferbaum B & Doughty DE. Increased alcohol use in a treatment sample of Oklahoma City bombing victims. *Psychiatry*. 2001 Winter; 64(4):296-303

⁶ Bremner JD, Southwick SM et al. Chronic PTSD in Vietnam combat veterans: course of illness and substance abuse. *Am J Psychiatry*. 1996 Mar; 153(3):369-75

There is no question that, at the time, massive bereavement produced traumatic symptoms. In 1993, researchers at the Columbia School of Public Health attempted to quantify the psychological impact of AIDS-related bereavements. In a group of 746 gay men, scientists found "a direct dose-response relation between bereavement episodes and the experience of traumatic stress response symptoms, demoralization symptoms, and sleep disturbance symptoms."⁷ In this study, recreational drug use and sedative use also increased in proportion to the number of bereavement episodes.

Drug and alcohol use are common responses to trauma. For instance, after September 11, 2001, sustained increases were seen in use of cigarettes, alcohol and marijuana among residents of Manhattan living below 110th Street; these increases were associated with post-traumatic symptoms and depression.⁸ Researchers find very high rates of recreational drug use among urban gay men: more than 50 percent of respondents in the Gay Urban Mens' Health Study said they used recreational drugs.⁹ Almost 20 percent reported recent "frequent" use of powder drugs (ecstasy, ketamine, cocaine).¹⁰ While frequent or heavy drug use is not confined to gay men in mid-life, these men use and abuse recreational drugs in substantial numbers.^{11,12,13}

⁷ Martin, 1993. *Ibid.*

⁸ Resnick 2004. *ibid.*

⁹ Stall R, Paul JP et al. Alcohol Use, Drug Use and Alcohol-related Problems Among Men Who Have Sex With Men: The Urban Men's Health Study. *Addiction*. 96(11). Nov 2001. p. 1589

¹⁰ Stall 2001. *Ibid.*

¹¹ Sexual behavior patterns of methamphetamine-using gay and bisexual men. *Subst Use Misuse*. 2005;40(5):703-19

¹² Patterson TL, Semple SJ et al. Methamphetamine-Using HIV-positive Men Who Have Sex With Men: Correlates of Polydrug Use. *J Urban Health*. 2005 Mar;82(1 Suppl 1):120-6.

¹³ Halkitis PN, Green KA & Mourgues P. Longitudinal investigation of methamphetamine use among gay and bisexual men in New York City: findings from Project BUMPS. *J Urban Health*. 2005 Mar;82(1 Suppl 1):i18-25.

In addition, there is evidence that, in gay men, traumatic bereavement is associated with risky sexual behavior. Men who have sex with men and who lost a friend or relative in the September 11th attacks were significantly more likely to report unprotected anal intercourse, and more sexual partners after the disaster than those who did not.¹⁴ And there is compelling evidence of ongoing, increased risky sexual behavior among gay men: since 1999, dramatic increases in rates of syphilis have been reported among American men who have sex with men.¹⁵ Rates of new HIV infections in men who have sex with men in the United States are rising, and studies show that risk-taking is frequent among middle-aged gay men. Of newly reported HIV cases among men who have sex with men in New York City in 2004, the majority were in men over 30, and more than a third were in men over 40.^{16,17}

The development of effective HIV therapy seems to have interrupted the study of the psychological impact of the AIDS epidemic: very little research is available from the late 1990s onward. However, these current data on risk behaviors among gay men in mid-life offer ample cause for questions and concerns. Gay men now in mid-life came of age before or during the dark early days of the epidemic, and have survived to see the dramatic amelioration of its effects in the United States. It would be surprising if such experiences did *not* have long-standing effects on the lives of survivors. While it is by no means certain that current high-risk behaviors are related to the traumatic survival of AIDS-related loss, the question certainly merits more detailed exploration than it has been given.

¹⁴ Chiasson MA, Hirshfield S et al. Increased high risk sexual behavior after September 11 in men who have sex with men: an Internet survey. *Arch Sex Behav.* 2005 Oct;34(5):527-35.

¹⁵ Division of STD Prevention. *Sexually Transmitted Disease Surveillance 2004 Supplement: Syphilis Surveillance Report*. Atlanta: US Department of Health and Human Services, Centers for Disease Control and Prevention; 2005. Online at <http://www.cdc.gov/std/Syphilis2004/SyphSurvSupp2004.pdf>. Accessed 30 Jul 2006.

¹⁶ Centers for Disease Control and Prevention. *HIV/AIDS Surveillance Report, 2004*. Vol. 16. Atlanta: US Department of Health and Human Services, Centers for Disease Control and Prevention; 2005

¹⁷ Torian L. Director, HIV Surveillance and Epidemiology Program, Department of Health and Mental Hygiene, City of New York. Personal Communication. Dec 7 2004

The History of Loss

From 1979 until the late 1990s, urban gay men experienced unprecedented losses to HIV/AIDS. Unlike “normal” bereavements, these men often experienced multiple, repeated losses on an almost unimaginable scale:

As of 1994, up to 60 percent of gay men reported annual losses, and a third of these bereaved individuals described the multiple loss of family, friends, and neighbors. Some bereaved survivors have witnessed the extinction of their entire social support network, thereby reaching a level of isolation uncommon to most other bereaved groups. By 1988 gay males had already on average lost six lovers, friends, and/or family members.¹⁸

These experiences of intense, multiple losses have been described as forming a “multiple loss syndrome” in which the constant interruption of the grieving process by the additional loss prolonged the mourning process and prevented completion of the tasks of mourning.^{19,20}

In addition, the early days of the AIDS epidemic were marked by discrimination against people who had AIDS, and against those who were perceived to be at risk for the disease. This discrimination, coupled with the failure of society to recognize the importance of gay men’s relationships, exacerbated the pain of illness, caregiving and loss.²¹

¹⁸ Martin, J., and L. Dean, "Effects of AIDS-Related Bereavement and HIV-Related Illness on Psychological Distress Among Gay Men: A 7-Year Longitudinal Study, 1985-91," *Journal of Consulting and Clinical Psychology* 61 (1993), pp. 94-103.

¹⁹ Biller R & Rice S. Experiencing multiple loss of persons with AIDS: grief and bereavement issues. *Health Soc Work*. 1990 Nov;15(4):283-90

²⁰ Mallinson RK. The lived experience of AIDS-related multiple losses by HIV-negative gay men. *J Assoc Nurses AIDS Care*. 1999 Sep-Oct;10(5):22-31

²¹ cf. Monette P. *Borrowed Time: An AIDS Memoir*. Harvest Books. Reprint Edition: June 1998, and Shilts R. *And The Band Played On: Politics, People and the AIDS Epidemic*. St. Martins Press. 1987

Obviously, these multiple AIDS deaths were not experienced uniformly by all gay men; urban gay men, for example, were much more likely to report multiple deaths than non-urban men.²² However, for those men at the heart of the epidemic, the time was often apocalyptic: the late film critic Vito Russo famously described the experience in a speech in 1988:

[It's] like living through a war which is happening only for those people who happen to be in the trenches. Every time a shell explodes, you look around and you discover that you've lost more of your friends, but nobody else notices. It isn't happening to them. They're walking the streets as though we weren't living through some sort of nightmare. And only you can hear the screams of the people who are dying and their cries for help. No one else seems to be noticing.²³

At the Sixth International Conference on AIDS in 1990, San Francisco Mayor Art Agnos noted that more San Franciscans had died of AIDS than died in the four wars of the 20th century, combined and tripled.²⁴

In 1994, the magnitude of this disaster prompted psychologist Walt Odets to write

Many gay men in the United States have now suffered such severe, repeated losses that a psychological "recovery" (by non-epidemic standards), even with a therapy-assisted assimilation of the losses, is unlikely or impossible.²⁵

Given this grim assessment, it is surprising that, more than ten years later, we lack information on psychological outcomes. No one seems to have even asked the question: what happened to the survivors?

²² Stall R. Personal Communication. July 22, 2006

²³ Russo V. Why We Fight: Transcript of speech. October 10, 1988. Online at <http://www.actupny.org/documents/whfight.html>. Accessed May 1, 2006.

²⁴ Agnos A quoted in Scott J. Arrests, Pleas Mark Opening of AIDS Talks. *LA Times*. Jun 21 1990

²⁵ Odets W. Survivor Guilt in HIV-Negative Gay Men. *Hath Cont Ed for Psych*. 4:15. 1994

Post-Traumatic Stress Disorder (PTSD)

Post-Traumatic Stress Disorder (PTSD) is a type of anxiety disorder that develops in response to experiences involving intense feelings of fear, helplessness or horror.

PTSD is particularly associated with situations involving the threat of death to one's self or others, but can also be caused by violent attacks

The diagnosis of post-traumatic stress disorder was created to describe the symptoms seen in Holocaust survivors and veterans of the war in Vietnam. The disorder can cause flashbacks (vivid, disturbing memories of the traumatic event), sleep problems and nightmares. There may be outbursts of anger, and feelings of detachment, guilt, or paranoia. Alcohol and drug abuse is also associated with PTSD.^{26,27} In addition, PTSD is associated with functional impairments, such as difficulty or inability in working, compromised physical health and diminished sense of well-being.²⁸

In most people, full-blown PTSD is a transitory syndrome, however following traumatization, PTSD can become a chronic condition in a significant number of persons. For instance, immediately following a major earthquake in Turkey in 1999, a dramatic increase in rates of PTSD was observed, and symptoms persisted in about two-thirds of those diagnosed for more than three years.²⁹ Similarly, among those diagnosed with PTSD following a terrorist bombing in Oklahoma City, OK, 76% reported symptom onset on the day of the disaster, and 89% of cases still had symptoms 17 months after the disaster.^{30,31}

²⁶ Kessler RC, Sonnega A et al. Posttraumatic stress disorder in the National Comorbidity Survey. *Arch Gen Psychiatry* 1995; 52:1048-1060.

²⁷ Pfefferbaum 2001. *Ibid*.

²⁸ Zatzick DF, Marmar CR et al. Posttraumatic stress disorder and functioning and quality of life outcomes in a nationally representative sample of male Vietnam veterans. *Am J Psychiatry*. 1997 Dec; 154(12): 1690-5

²⁹ Onder E, Tural U et al. Prevalence of psychiatric disorders three years after the 1999 earthquake in Turkey: Marmara Earthquake Survey (MES). *Soc Psychiatry Psychiatr Epidemiol*. 2006 Aug 11

³⁰ North CS, Nixon SJ et al. Psychiatric disorders among survivors of the Oklahoma City bombing. *JAMA*. 1999 Aug 25;282(8):755-62

³¹ North CS, Pfefferbaum B, et al. The course of posttraumatic stress disorder in a follow-up study of survivors of the Oklahoma City Bombing. *Ann Clin Psychiatry*. 2004 Oct-Dec;16(4):209-15

Generally, primary PTSD symptoms can be divided into three “clusters:”

- Hyperarousal (constant feelings of being “on guard” and/or easily startled)
- Numbing/Avoidance (emotional deadening)
- Intrusive (flashbacks, nightmares)

In Vietnam veterans who developed chronic PTSD, symptoms typically begin at the time of exposure to combat trauma in Vietnam and increased rapidly during the first few years. Hyperarousal symptoms developed first, followed by numbing/avoidant symptoms and finally by symptoms from the intrusive cluster.³² These symptoms are additive, and all three clusters may be present at any point during the disorder. Symptoms plateaued within a few years after the war, following which the disorder became chronic and unremitting.³³

Rates of PTSD are surprisingly high in the general population: about eight percent of Americans are thought to develop PTSD at some point in their lives, and women are more than twice as likely as men to be diagnosed with PTSD.³⁴ However, in regions that have recently experienced wars, rates among the general population exceeded 35% in some areas.³⁵ Estimates of PTSD rates among Vietnam veterans, probably the most closely studied risk group, have varied widely, ranging from approximately fifteen percent post-war lifetime risk to more than thirty percent:

³² Bremner 1996. *Ibid.*

³³ Bremner 1996. *Ibid.*

³⁴ Kessler 1995. *Ibid.*

³⁵ De Jong, J., Komproe, et al. Lifetime events and Posttraumatic Stress Disorder in 4 postconflict settings. *JAMA*, 2001 286 (5), 555-562.

Major Estimates of PTSD Rates in Vietnam Veterans		
	PTSD Rates After Vietnam	PTSD rates in the late 1980s
National Vietnam Veterans Readjustment Study ³⁶	30.9%	15.2%
The CDC's Vietnam Experience Study ³⁷	14.7%	2.2%
Columbia University Study ³⁸	18.7%	9.1%

Variations among these findings are probably the result of differences in definitions of post-traumatic symptoms; in 2006, researchers from Columbia University reanalyzed data from earlier studies and found that estimates were highly sensitive to definitions: more restrictive definitions of symptoms produced lower estimates of incidence. In addition, lower estimates may have excluded some non-combat cases, such as medical personnel.³⁹ Estimates of PTSD following the Oklahoma City bombing had a more narrow range, from 31% to 41%.⁴⁰

PTSD in veterans is strongly associated both with combat exposure and with greater intensity of combat. Having been wounded in combat was also associated with higher rates of PTSD.⁴¹ Similarly, having been wounded in the Oklahoma City bombing predicted subsequent PTSD development.⁴²

³⁶ Kulka, R. A., Schlenger, W. E., Fairbank, J. A., Hough, R. L., Jordan, B. K., Marmar, C. R., et al. (1990b). *Trauma and the Vietnam War generation: Report of findings from the National Vietnam Veterans Readjustment Study*. New York: Brunner/Mazel.

³⁷ Centers for Disease Control. 1988. Health Status of Vietnam Veterans: I. Psychosocial Characteristics. *JAMA* 259: 2701-2707.

³⁸ Dohrenwend BP, Turner JB et al. The psychological risks of Vietnam for U.S. veterans: a revisit with new data and new methods. *Science*. 2006 Aug 18; 313(5789):979-82.

³⁹ *Ibid.*

⁴⁰ North 2004. *Ibid.*

⁴¹ Buydens-Branchey L, Noumair D, & Branchey M. Duration and intensity of combat exposure and posttraumatic stress disorder in Vietnam veterans. *J Nerv Ment Dis*. 1990 Sep;178(9):582-7

⁴² Tucker P, Pfefferbaum B et al. Predictors of post-traumatic stress symptoms in Oklahoma City: exposure, social support, peri-traumatic responses. *J Behav Health Serv Res*. 2000 Nov;27(4):406-16

PTSD in veterans was explained primarily by war stressors, including threat to life and exposure to grotesque death, but premilitary and postmilitary factors also contributed to the likelihood of a current diagnosis of PTSD.⁴³ For men, a history of pre-war trauma, such as accidents, assaults, and natural disasters, directly predicted PTSD and also increased PTSD symptoms for high combat-exposed veterans. Family instability, childhood antisocial behavior, and age had indirect effects on PTSD for men. For women, family instability predicted development of post-war PTSD.⁴⁴

To get a better grasp of PTSD in the “general population,” researchers in 1996 studied lifetime history of traumatic events and PTSD among a representative sample of 2,181 people aged 18 to 45 in Detroit. The highest risk of PTSD was associated with having been violently assaulted, with one in five victims reporting PTSD, while death of a loved one was the most often reported precipitating trauma among persons with PTSD, accounting for approximately one-third of all PTSD cases.⁴⁵

⁴³ Green BL, Grace MC et al. Risk factors for PTSD and other diagnoses in a general sample of Vietnam veterans. *Am J Psychiatry*. 1990 Jun; 147(6):729-33

⁴⁴ King DW, King LA et al. Prewar factors in combat-related posttraumatic stress disorder: structural equation modeling with a national sample of female and male Vietnam veterans. *J Consult Clin Psychol*. 1996 (Jun;64(3):520-31

⁴⁵ Breslau N, Kessler RC, et al. Trauma and posttraumatic stress disorder in the community: the 1996 Detroit Area Survey of Trauma. *Arch Gen Psychiatry*. 1998 Jul;55(7):626-32

Caregiving during a sustained illness can also be a risk factor for PTSD. In a study of family caregivers during the three years following a family member's heart transplant, almost one-fourth of caregivers developed PTSD.⁴⁶ This observation is important in the context of AIDS, because of the preponderance of gay men – often themselves HIV-infected – among caregivers for those who were ill.^{47,48} Several studies have demonstrated that HIV status predicts post-bereavement depression in caregivers, with HIV+ caregivers more likely to report depression for longer periods following bereavement.^{49,50}

Although Post-Traumatic Stress Disorder as defined by the DSM-IV is clearly a useful diagnostic description, a strict focus on PTSD diagnoses probably minimizes the impact of post-traumatic disorders, particularly after sustained, repeated trauma such as the multiple deaths associated with the AIDS epidemic.

In her book *Trauma and Recovery*, Dr. Judith Herman wrote:

The syndrome that follows upon prolonged, repeated trauma needs its own name. I propose to call it "complex post-traumatic stress disorder." The responses to trauma are best understood as a spectrum of conditions rather than as a single disorder. They range from a brief stress reaction that gets better by itself and never qualifies for a diagnosis, to classic or simple post-traumatic stress disorder, to the complex syndrome of prolonged, repeated trauma.⁵¹

⁴⁶ Dew MA, Myaskovsky L et al. Onset, timing and risk for depression in family caregivers to heart transplant recipients. *Psychol Med.* Aug;34(6):1065-82

⁴⁷ Turner HA & Catania JA. Informal caregiving to persons with AIDS in the United States: caregiver burden among central cities residents eighteen to forty-nine years old. *Am J Community Psychol.* 1997 Feb;25(1):35-59

⁴⁸ Turner HA, Catania JA, Gagnon J. The prevalence of informal caregiving to persons with AIDS in the United States: caregiver characteristics and their implications. *Soc Sci Med.* 1994 Jun;38(11):1543-52

⁴⁹ Folkman S, Chesney M et al. Postbereavement depressive mood and its prebereavement predictors in HIV+ and HIV- gay men. *J Pers Soc Psychol.* 1996 Feb;70(2):336-48

⁵⁰ Land H, Hudson SM & Steifel B. Stress and depression among HIV-positive and HIV-negative gay and bisexual AIDS caregivers. *AIDS Behav.* 2003 Mar;7(1):41-53.

⁵¹ Herman JL. *Trauma and Recovery*. Rivers Oram Press. 2001

A formal diagnosis of PTSD requires the presence of a specific set of symptoms (see appendix), however the impact of trauma is often more complex than simply the presence or absence of a PTSD diagnosis. Therefore researchers often classify responses to trauma based on the number of PTSD symptoms that are present. For instance, a survey of Americans immediately following the September 11th terrorist attacks found that the average respondent had five symptoms of acute PTSD-related stress; the average number of symptoms was reduced by more than half within six months of the disaster, but some symptoms did persist in many people.⁵²

In addition, trauma is associated with other mental health concerns, such as chronic anxiety, depression, alcohol/drug abuse, violence and suicidality.^{53,54,55,56} In Vietnam veterans, levels of depression, anxiety, alcohol/substance abuse and mood and anxiety disorders were elevated in direct relationship to combat exposure.^{57,58,59}

Rates of Non-PTSD Disorders in Veterans⁶⁰		
	Veterans	Non-Veterans
Depression	4.5%	2.3%
Anxiety	4.9%	3.2%
Alcohol/Substance Abuse	13.7%	9.2%

⁵² Silver RC, Holman EA et al. *Nationwide Longitudinal Study of Psychological Responses to September 11*. *JAMA*, 288, 1235-1244.

⁵³ Eisen SA, Griffith KH et al. Lifetime and 12-month prevalence of psychiatric disorders in 8,169 male Vietnam War era veterans. *Mil Med*. 2004 Nov;169(11):896-902.

⁵⁴ Savarese VW, Suvak MK et al. Relationships among alcohol use, hyperarousal, and marital abuse and violence in Vietnam Veterans. *J Trauma Stress*. 2001 Oct;14(4):717-32

⁵⁵ Price RK, Risk NK et al. Post-traumatic stress disorder, drug dependence, and suicidality among male Vietnam veterans with a history of heavy drug use. *Drug Alcohol Depend*. 2004 Dec 7; 76 Suppl:531-43.

⁵⁶ Zatzick DF, Jurkovich GJ et al. Posttraumatic stress, problem drinking, and functional outcomes after injury. *Arch Surg*. 2002 Feb;137(2):200-5.

⁵⁷ Centers for Disease Control. 1988. Health Status of Vietnam Veterans: I. Psychosocial Characteristics. *JAMA* 259: 2701-2707.

⁵⁸ Orsillo SM, Weathers FW, et al. Current and lifetime psychiatric disorders among veterans with war zone-related posttraumatic stress disorder. *J Nerv Ment Dis*. 1996 May;184(5):307-13

⁵⁹ Grayson D, Dobson M, & Marshall R. Current combat-related disorders in the absence of PTSD among Australian Vietnam veterans. *Soc Psychiatry Psychiatr Epidemiol*. 1998 Apr; 33(4):186-92

⁶⁰ Centers for Disease Control. 1988. Health Status of Vietnam Veterans: I. Psychosocial Characteristics. *JAMA* 259: 2701-2707.

These estimates may be low, reflecting the conservative estimates used by the Centers for Disease Control and Prevention, which conducted the study, but they clearly reflect the increased risks to veterans as compared to non-veterans.

Relative to veterans without PTSD, veterans with PTSD also had significantly higher rates of current major depression, bipolar disorder, panic disorder, and social phobia, as well as significantly higher rates of lifetime major depression, panic disorder, social phobia, and obsessive-compulsive disorder.⁶¹

In addition, PTSD is associated with other functional limitations. One veterans study found that risks of poorer outcomes were significantly higher in subjects with PTSD than in subjects without PTSD in five key measures of function:

- Diminished well-being
- Physical limitations
- Compromised physical health status
- Currently not working, and
- Perpetration of violence.⁶²

A study of survivors of the Oklahoma City bombing showed that PTSD significantly affects social and occupational functioning. More than half of survivors with PTSD and most of those with comorbid PTSD reported that their PTSD symptoms interfered with their normal activities; they also reported dissatisfaction with their work performance after the disaster. More than 75% said that the bombing had negative effects on their personal relationships.⁶³ PTSD was also associated with approximately 3.6 days of work impairment per month.⁶⁴

⁶¹ Orsillo SM, Weathers FW, et al. Current and lifetime psychiatric disorders among veterans with war zone-related posttraumatic stress disorder. *J Nerv Ment Dis.* 1996 May;184(5):307-13

⁶² Zatzick DF, Marmar CR, et al. Posttraumatic stress disorder and functioning and quality of life outcomes in a nationally representative sample of male Vietnam veterans. *Am J Psychiatry.* 1997 Dec;154(12):1690-6

⁶³ North CS, Nixon SJ, Shariat S, et al. Psychiatric disorders among survivors of the Oklahoma City bombing. *JAMA.* 1999;282:755-762.

⁶⁴ Kessler RC, Cuiu WT et al. Prevalence, severity and comorbidity of 12-month DSM-IV disorders in the National Comorbidity Survey Replication. *Arch Gen Psychiatry.* 2005. 62, 617-627

Vietnam-theater veterans with PTSD experienced more severe drug- and alcohol-abuse problems than did veterans without PTSD and were at greater risk for having both forms of substance abuse. The severity of substance abuse is linked to PTSD rather than to the severity of combat stress.⁶⁵

Among Vietnam theater veterans, postwar mortality risk for cardiovascular, cancer, and external causes of death (including motor vehicle accidents, accidental poisonings, suicides, homicides, injuries of undetermined intent) was associated with PTSD. Risk of death from any cause was also elevated in these veterans with PTSD.⁶⁶

In the face of sustained trauma, such as was presented by the early years of the AIDS epidemic, one could reasonably expect to see elevated levels of PTSD even decades after the events in question. But experience with other sustained traumas also suggest that the impact of these experiences may be more varied, and may include ongoing physical, emotional, behavioral and, for want of a better word, spiritual costs. These costs are not inconsequential, and any sustained effort to address the legacy of HIV/AIDS should approach the question broadly.

⁶⁵ McFall ME, Mackay PW, & Donovan DM. Combat-related posttraumatic stress disorder and severity of substance abuse in Vietnam veterans. *J Stud Alcohol*. 1992 Jul; 53(4):357-63

⁶⁶ Boscarino JA. Posttraumatic stress disorder and mortality among U.S. Army veterans 30 years after military service. *Ann Epidemiol*. 2006 Apr;16(4):248-56. Epub 2005 Aug 15.

Survivor Guilt and HIV/AIDS

Survivor guilt describes the feelings of guilt, responsibility and shame that people sometimes feel following a traumatic event involving loss of life, particularly mass deaths. It may be particularly common when the death involved someone close to them, such as a family member or friend. It is not a formal diagnostic term, but rather a description of feelings and behaviors commonly seen in survivors.

In 1994, Odets described evidence of survivor guilt, similar to that experienced by survivors of the Holocaust and other mass traumas, in his gay male patients in San Francisco. Dr. Odets' essay remains the most detailed clinical description of survivor guilt related to HIV/AIDS, and so his observations merit close attention.

Odets distinguished between "direct" or "reactive" responses to AIDS-related bereavement, and reactions that are mediated by guilt. The clinical presentation of these responses can be virtually identical:

Depression, anxiety, substance use and abuse, and sexual, interpersonal and occupational dysfunctions are all now commonly observed by the psychotherapist working with HIV-negative gay male populations. Such signs and symptoms, however, are seen in individuals both with and without survivor guilt, and the clinician must be able to identify and clarify survivor guilt, where it appears to exist, within such complex presentations.⁶⁷

However, when guilt related to survival is present,

therapies appear to "stall" to the bewilderment of the therapist who remains unaware of the major unaddressed issue of guilt that is underlying what is being treated as a traditional reactive "bereavement" problem...Survivor guilt is a feature that can substantially complicate, inhibit, or completely arrest the mourning process, and it often increases the risk of self-destructive behaviors.⁶⁸

⁶⁷ Odets, 1994 *Ibid.*

⁶⁸ *Ibid.*

Odets observed extremes of self-harming behaviors in his patients that he believed to be associated with guilt over surviving their loved ones:

Binges of unprotected sex, especially after the death of a friend or lover, are a phenomenon not uncommonly reported in therapy sessions conducted by the author. Other self-destructive behaviors now seen commonly in gay men may also be indicators of guilt about surviving the epidemic: substance abuse, self-generated financial problems, difficulty planning for the future, and avoidance of life-sustaining relationships are among those most commonly seen by the author in his psychotherapy practice.⁶⁹

Odets proposes that guilt-mediated responses can be distinguished from “normal” grieving by exploring the relationship to losses:

Anger at the deceased for leaving the survivor behind is a common experience in normal grieving. It is rarely among the feelings of the person experiencing survivor guilt. Rather, there is remorse and sadness at being left behind, the survivor often feels it is his fault, rather than the deceased’s, that this has occurred. Finally, those experiencing simple reactive grief usually wish the deceased back in life, while those experiencing survivor guilt more often wish to join the dead.⁷⁰

For Dr. Odets, this “wish to join the dead” is behind the urge to self-harming behavior:

The unconscious desire to *not* survive – because of depression, loss, and guilt about surviving – is surely an important, not uncommon motivation for unsafe sex. Also important is the unconscious belief that one *will not* survive – an expression of helplessness and resignation.⁷¹

⁶⁹ *Ibid.*

⁷⁰ *Ibid.*

⁷¹ Odets W. The Psychological Impact of AIDS on Uninfected Gay and Bisexual Men. Plenary address to the Sixth International Conference on AIDS. 1990. Online at http://www.waltonodets.com/Presentations/The_Psychological_Impact_of_AI/the_psychological_impact_of_ai.html

Odets also observes a “developmental predisposition’ for such feelings in some men, in the form of much earlier psychological conflict characterized by guilt and loss”. Several therapists have noted that such burdens of guilt and shame are common in gay men with respect to experiences in childhood and of coming out of the closet.^{72,73}

Dr. Odets’ observations focused on the experience of HIV-negative men, assuming that the pool of survivors would come primarily from that group. However, the development of effective treatment for HIV disease has meant that there is also a pool of HIV-positive survivors, whose experiences of traumatic loss may be similar to or even greater than those of HIV-negative men; this may explain the overrepresentation of HIV-positive men among the heaviest risk-takers.

⁷² Isay R. *Being Homosexual: Gay Men and Their Development*. Avon 1990.

⁷³ cf. Downs A. *The Velvet Rage*. De Capo Lifelong Books. 2005

Discussion

This essay is not intended to argue that the traumatic experience of the AIDS epidemic is solely responsible for high-risk behavior and/or emotional problems in some middle-aged gay men. Rather, we observe that there is a group of gay men in mid-life who have survived massive, traumatic loss, and who currently exhibit self-harming behaviors that are associated with traumatic loss. Surely a methodical exploration of possible connections between these observations is warranted.

Mid-life is, of course, challenging for many people, and there are strong reasons why mid-life would be particularly difficult for gay men. The HIV pandemic has created sociocultural and demographic changes within the gay community that may put particular stress on gay men in mid-life. The first wave of AIDS-related deaths in the early 1980s devastated the generation of gay men now in their mid-50s through late 70s. As a consequence, gay men currently in mid-life may have had few contacts with older men, and few sources for advice and modeling of successful aging. And while effectively no data exist on the subject, the death of a substantial portion of one generation of older gay men may contribute to the much-noted gay cultural emphasis on youth, and the absence of age-adjusted cultural institutions and practices for gay men in mid-life.⁷⁴

Additionally, gay culture has changed dramatically in the past few decades. While these changes have mostly increased acceptance and integration, gay men in mid-life encounter institutions and choices radically different from those available when they came out.⁷⁵ For instance, in the past ten years there has been a growing acceptance and visibility of gay marriage and adoption. Gay men who have made important life choices based on earlier relational models may find themselves confused and disoriented by these changes.

Finally, while great progress has been made in the social acceptance of homosexuality, there are still vast reservoirs of homophobia in American culture, as evidenced by efforts to amend the Constitution to prohibit gay marriage, and by the ongoing federal persecution of gay people serving in the military.

⁷⁴ Schope R. Who's afraid of growing old? Gay and lesbian perceptions of aging. *J Gerontol Soc Work.* 2005;45(4):23-38.

⁷⁵ Cf. Sullivan A. The End of Gay Culture. *New Repub* November 1 2005.

But given what we know, there are good reasons to be concerned that current mental health issues among gay men in mid-life may be related to survival of the early AIDS epidemic. We can document the occurrence of mass trauma and symptoms of post-traumatic reaction during the early days of the AIDS epidemic. We can also document current functional impairments and elevated risk-taking behaviors in middle-aged gay men today. What we lack are good data that measure the rates of post-traumatic symptoms in gay men who survived the early AIDS epidemic, or any good data evaluating the relationship of such symptoms to current mental health problems and/or risk-taking behaviors.

Since people with prior traumatic experiences are at higher risk for developing PTSD in response to new trauma, ongoing trauma can create a kind of cumulative escalation of risk: childhood trauma, the trauma associated with the AIDS epidemic, and even more generally collective traumas such as September 11th may each have contributed to the risk of PTSD or other post-traumatic symptoms for middle-aged gay men.^{76, 77}

In this population, defining the role of comorbid conditions – particularly depressive disorders – will also be important.⁷⁸ Gay men are at increased risk for depression, and depression often accompanies PTSD. These conditions are independent sequelae of trauma, and both exacerbate and are exacerbated by one another.⁷⁹

⁷⁶ King 1996. *Ibid.*

⁷⁷ Zatzick D, Jurkovich G et al. Posttraumatic distress, alcohol disorders, and recurrent trauma across level 1 trauma centers. *J Trauma*. 2004 Aug;57(2):360-6

⁷⁸ For a more complete discussion of depression in gay men, see Cox S. *Legacy of the Past: Gay Men, Risk-taking and Depression*. Online at www.mediusinstitute.org/Living%20On%20The%20Edge.pdf

⁷⁹ Pfefferbaum B, Stuben J et al. Panic reactions to terrorist attacks and probable posttraumatic stress disorder in adolescents. *J Trauma Stress*. 2006 Apr;19(2):217-28

Finally, when evaluating the overall health of a community, researchers usually look at readily quantifiable criteria: rates of disease or the frequency of risk factors such as smoking and obesity. In evaluating the health of gay men, diseases such as syphilis and HIV, or behaviors such as alcohol abuse and safer sex are commonly measured parameters.

However, understanding the legacy of the AIDS epidemic will require qualitative as well as quantitative studies and interventions. While risk-taking and its consequences may provide evidence of one kind of traumatic response, the literature also describe "numbing" symptoms in survivors, in which people become detached from their own emotions and have difficulty in sustaining relationships.⁸⁰ Such detachment may be more difficult to identify, but, where present, must surely play a key role in understanding survivors. For instance, in 1998, Dr. Bruce Kellerhouse reported on qualitative interviews with a group of gay men who had experienced ten or more losses due to AIDS. One participant told him:

Life seemed full of promise [before AIDS]. There was more fun in daily living, in being with friends, in sex. There was no big dread or fear like I feel now. AIDS has enfolded my entire life and closed it down.⁸¹

Rather than trying to identify a single "survivor syndrome" in gay men who survived the worst of the AIDS epidemic, it is probably more important to attempt to understand and describe the range of mental health issues in survivors -- including particular focus on risk behavior -- and to assess their correlation with loss. Qualitative descriptions, including oral histories, should also be undertaken to capture

⁸⁰ cf Herman J, *Trauma and Recovery* (op cit.) for a more complete discussion of these phenomena.

⁸¹ Quoted in Kellerhouse B. Consequences of Multiple, Traumatic AIDS-related Bereavement in HIV-Negative Gay Men. Presented at the 106th Annual Convention of the American Psychological Association. Aug 17 1998. San Francisco.

More likely, the legacy of HIV/AIDS in this population may serve as a contributor to a “syndemic,” a phenomenon described by Dr. Ron Stall in which multiple co-occurring epidemics mutually reinforce each other to increase risks (e.g. depression and substance abuse each increase risks for the other).⁸²

The AIDS epidemic is certainly far from over. With reports of rising rates of HIV infection among men who have sex with men, the HIV epidemic will be with us for the foreseeable future.⁸³ And, of course, the dramatic reduction of deaths has until recently been a phenomenon solely in the developed world.

We urgently need to study and understand the painful legacy of those early years of AIDS. Such research might well help us to create more effective responses to the challenges faced by gay men in mid-life. We owe it to those who have survived.

⁸² Stall R, Mills TC et al. Association of co-occurring psychosocial health problems and increased vulnerability to HIV/AIDS among urban men who have sex with men. *Am J Public Health*. 2003 Jun;93(6):939-42.

⁸³ Centers for Disease Control and Prevention. 2005. *Ibid*.

Appendix: DSM-IV Diagnostic Criteria for Post Traumatic Stress Disorder (PTSD)

- 1) The person has been exposed to a traumatic event in which both of the following were present:
 - a) The person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others.
 - b) The person's response involved intense fear, helplessness, or horror.
Note: In children, this may be expressed instead by disorganized or agitated behavior.

- 2) The traumatic even is persistently re-experienced in one (or more) of the following ways:
 - a) Recurrent and intrusive distressing recollections of the event, including images, thoughts, and/or perceptions.
Note: In young children, repetitive play may occur in which these or other aspects of the trauma are expressed.
 - b) Recurrent distressing dreams of the event.
Note: In young children, there may be frightening dreams without recognizable content.
 - c) Acting or feeling as if the traumatic event were recurring (includes a sense of reliving the experience, illusions, hallucinations, and/or dissociative flashback episodes, including those that occur on awakening or when intoxicated).
Note: In young children, trauma-specific re-enactment may occur.
 - d) Intense psychological distress at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event.
 - e) Physiological reactivity on exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event.

- 3) Persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness (not present before the trauma), as indicated by at least three of the following:
 - a) Efforts to avoid thoughts, feelings, and/or conversations associated with the trauma
 - b) Efforts to avoid activities, places, and/or people that arouse recollections of the trauma.
 - c) Inability to recall an important aspect of the trauma
 - d) Markedly diminished interest or participation in significant activities
 - e) Feeling of detachment or estrangement from others
 - f) Restricted range of affect (*e.g.*, inability to have loving feelings)
 - g) Sense of a foreshortened future (*e.g.*, does not expect to have a career, marriage, children, or a normal life span)

DSM-IV Diagnostic Criteria for PTSD (contd.)

- 4) Persistent symptoms of increased arousal (not present before the trauma), as indicated by at least two of the following:
 - a) Difficulty falling or staying asleep
 - b) Irritability or outbursts of anger
 - c) Difficulty concentrating
 - d) Hypervigilance
 - e) Exaggerated startle response
- 5) Duration of the disturbance (symptoms in Criteria B, C, and D) is more than one (1) month
- 6) The disturbance causes clinically significant distress and/or impairment in social, occupational, and/or other important areas of functioning.

Important Descriptive Terms

<i>Acute</i>	Duration of symptoms is less than three (3) months
<i>Chronic</i>	Duration of symptoms is more than three (3) months
<i>Delayed Onset</i>	Onset of symptoms is at least six (6) months after the incident

