Wounded AIDS Warriors Suffering, Dying on Their Own

The death of Spencer Cox prompts a cofounder of the Medius Institute for Gay Men's Health to speak out.

January 9, 2013 By John Voelcker

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The death of notable AIDS activist Spencer Cox last month, at age 44, was a wake-up call -- a blaring alarm -- that highlighted once again the critical need for mental health programs and studies of the powerful trauma experienced by gay men in their 40s through 70s who've lived through the loss and destruction of entire communities due to AIDS.

A drama student in college, Cox was a brilliant and searingly smart activist, and he accomplished by age 35 what many of us never achieve over a lifetime. In 1995 he designed a drug trial for Ritonavir -- an early protease inhibitor -- that allowed for fast data collection and a quick approval process if warranted. After just six months the drug was approved. Cox was then only 26.

He was one of several activists featured in the current documentary How to Survive a Plague, most of whom had lived with AIDS at least since 1990. Its most recent footage of him was filmed less than two years ago.

Witty, incisive and often warm, Cox was also prescient. Seven years ago he proposed to start an enterprise called the Medius Institute for Gay Men's Health. It was dedicated to improving the health, well-being and longevity of gay men in mid-life (generously defined as 35 to 65). The goal was to look in a cross-disciplinary way at all the factors affecting the physical, mental and emotional health of a set of men who had lived through the AIDS epidemic, come out the other side and were too often doing startling, illogical and very dangerous things.

We hear a lot about "wounded warriors" with regard to American military battles overseas, and and justifiably so. It's devastating for young men and women to watch as trusted comrades are grievously hurt or killed at their side. It's equally devastating to return to a society that honors veterans for a day, then expects them to act "normal" and resume life as the same people they were before the war. While the life-long disabilities they suffer may be politely overlooked, it's clear that they're expected to shield the memories, losses and fears brought back from the battlefield.

But for military veterans, there's a $140-billion Veteran's Administration to thank them, care for

them and minister to their needs. The veterans of our own war here at home aren't so lucky.

There are the hundreds of thousands of men and women who survived the worst of the AIDS epidemic during the 1980s and 1990s. They are the wounded warriors of our fight. And they have no such support -- especially those who've lived with HIV for 15 years or more. Whether HIV-positive or negative, many of them suffer what would likely be defined as post-traumatic stress disorder (PTSD). Their rates of dysthymia and depression are higher, they may engage in unsafe sex, and a few of those with HIV inexplicably stop taking the lifesaving anti-retroviral medications that saved their lives 15 years ago. Men who know the rules of safe sex may test positive after staying negative for three decades.

With the enthusiastic support of a small group of tenured activists, Spencer Cox laid out proposals for studies of this kind of post-traumatic stress, reached out to his network of contacts within HIV research and medicine and read copiously. But what we learned in the 12 short months of Medius was that no one really cared. Medius had little luck finding institutional funding. It wasn't a service organization but essentially a think tank and research group, trying to bring together researchers across disciplines to gather data that could support design of programs that would meet the needs of gay men in midlife. "Too wonky," we heard. "Such an obscure niche," we heard. "Find a wealthy patron," we heard. But we learned that wealthy, middle-aged gay men, even those with friends quietly succumbing to all manner of ills, didn't want to hear it. Depression, drug addiction and destructive behaviors weren't to be discussed, though all had a friend or two who'd vanished from polite life. And the professional AIDS establishment, with a few notable exceptions, was worse. The basic attitude was that if the personnel of ACT UP had problems, well, we were probably college-educated gay white men, and we undoubtedly had the money and resources to solve our own damn problems.

Meanwhile, Cox himself was grappling personally with the very problems Medius sought to study. The institute never got off the ground, and he began to drift further away from longtime friends and colleagues. In his later years he grappled with what was likely depression, suffered several hospitalizations, used meth and degenerated mentally and physically. In the months before his death, he had apparently stopped taking the antiviral medications he helped to get approved 15 years before.

Medius today lives on solely in a pair of incisive white papers written by Cox in 2006 and 2007: The Legacy of the Past: Gay Men in Mid-Life and the Impact of HIV/AIDS (2006) and Living on the Edge: Gay Men, Depression and Risk-Taking Behaviors (2007). In retrospect, we can read those papers "and break the private code written between the lines," writer Mark S. King suggested last week. "It spells out 'HELP ME'."

And the need for that research remains as urgent as the mental anguish suffered by Cox and the other veterans of the AIDS wars. I've been told that LGBTQ activists in their 20s find the term "war" too confrontational and militaristic. "Look how far we've come," I hear. "We'll have marriage equality in the next decade, and we'll be just like everyone else!" That may be. But realistically, our society doesn't expect the veterans of the wars in Iraq and Afghanistan and Vietnam to be "just like everyone else." It grapples, however imperfectly, to understand their wounds and provide for their needs.

In that light, perhaps now is the time to resuscitate the research that Medius advocated for. If we really want to honor the life and work of Spencer Cox, we will do the scientific work to understand why people like him die too early. We'll fund the studies, set up the programs and hold out our hands to bring suffering AIDS veterans into the light. Otherwise, the Jan. 20 memorial service for Cox will offer one day of feel-good sympathy and remembrance, and then more wounded warriors from our battle will continue to suffer and die before their time.

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