

# Fallout from the plague years: multiple loss and its impact on gay men



**Ann Silversides**

## In brief

LAST YEAR ANN SILVERSIDES produced a well-received series of programs for CBC Radio dealing with the impact the multiple loss of close friends to AIDS has had on gay men. In this article she updates and transfers her series to the print medium. She reports that little has been done to study the impact of multiple loss, even though the number of deaths has been so high that in many cases gay men are no longer able to respond emotionally to them.

## En bref

L'ANNÉE DERNIÈRE, ANN SILVERSIDES a produit, pour la radio anglaise de Radio-Canada, une série d'émissions qui ont été bien accueillies et traitaient de l'impact des deuils multiples sur les hommes gais. Dans cet article, elle met à jour sa série et l'adapte aux médias écrits. Elle signale qu'on n'a pas fait grand-chose pour étudier l'impact des deuils multiples, même si le nombre de décès dans leur entourage est parfois tellement élevé que dans beaucoup de cas, les hommes gais n'arrivent plus à y réagir émotionnellement.

**F**or years Paul Rapsey, a 48-year-old Toronto lawyer, performed small rituals to remember his friends on the anniversaries of their AIDS-related deaths. When the toll hit 25, he quit doing it. "I stopped in 1994," he explained. "It got to the point where I was beyond it, I was burned out. I found myself not even going to funerals anymore."

Rapsey is a homosexual and the multiple losses that he has experienced are not uncommon among gay men. The losses have changed the landscape of his life — he describes Toronto as a ghost town because almost everywhere he goes he is reminded of events connected with friends who have died.

Many people are aware of the statistics — by last June, 11 046 AIDS deaths had been reported in Canada, representing 73% of reported AIDS cases. And most people know that in North America these deaths have, to date, been concentrated in the relatively small population of gay men.

But the enormity of losses suffered by individual gay men is not well known or acknowledged, nor is the impact on them well understood. "With events like hurricanes, the Oklahoma bombing and the TWA crash, I often hear gay men express resentment about the public attention given to those kinds of events because those levels of death are absolutely routine in gay communities in the United States," said Berkeley, California, clinical psychologist Walt Odets, author of *In the Shadow of the Epidemic: Being HIV Negative in the Age of AIDS*.

## Deaths in the family

In Toronto, for example, 45% of the patients at a downtown HIV psychiatry clinic reported they had personally known more than 10 men who have died of AIDS. Dr. Mark Hallman, director of the HIV psychiatry clinic of the Wellesley Central and St. Michael's hospitals, said the mean age of these patients is 37.

And even triumphs over the disease can cause problems. Dr. Allan Peterkin

## Features

## Chroniques

**Ann Silversides is a freelance writer living in Toronto. Last year she produced *Sex, Death & Grief: the Impact of AIDS Losses among Gay Men*, a 160-minute radio documentary that was broadcast on CBC Radio's *Ideas* program. A packaged version of those 3 programs is available on audio cassette by calling 416 465-6088; [asides@interlog.com](mailto:asides@interlog.com) (email).**

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of the Clinic for HIV-Related Concerns at Toronto's Mount Sinai Hospital says the successes and failures surrounding the use of protease inhibitors have introduced the community to new grief dynamics. On one hand, "some men who were preparing to die now find their health at least temporarily restored. When their own life was jeopardized, they put their own grief on hold. Now that they are feeling better, a well of grief that had been suppressed often starts bubbling up." On the other hand, HIV-positive men who start taking the combination drugs but derive no benefit face yet another defeat in their lives, Peterkin observed.

Of course, gay men aren't the only people to suffer multiple loss. Almost 2 million Canadians served during the 2 world wars and many people have survived mass disasters, and there are some similarities in reactions to multiple loss among all these groups. "Anybody who experiences multiple loss can suffer from survival guilt and melancholy or numbness," said Peterkin. "They may indulge in substance abuse or risky behaviour. There can be an increased sense of fatalism."

## A war without heroes

But AIDS-related multiple loss has some distinguishing characteristics, many of which stem from societal prejudice. "War vets also suffer multiple loss, but often they come home as heroes," said Peterkin. "Gay men still face societal hostility and the situation is ripe for their losses not to be understood."

Because their relationships often go unacknowledged by society or unsupported by families, gay men frequently experience "disfranchised grief" that is not publicly acknowledged or endorsed — similar grief may be shared, for example, by a mistress or an ex-spouse.

At the same time, when their friends die, gay men suffer a "de facto loss of social support, which we know leads to distress," said Hallman. "Having poor social supports is a high predictor of psychological distress."

As well, the loss of friends is especially powerful for gay men, because very often friends *are* their family. "For them it is like losing family members," said Peterkin. "Many of these men are distanced from their biological family and their friends are their family of choice."

Rapsey said his dead friends "are so much a part of my youth that I can't remember my youth without them. We were gay and not part of mainstream society, and in the '70s and '80s we weren't accepted to the same degree as now. So our family was our social group of friends. These were the people we came out with, and went through crises of broken hearts. . . . These were the people whom I really thought and hoped would be aging with me now,

and seeing my temples go grey and watching my hair fall out and my waist expand."

Gay men are often alienated from traditional religions, many of which preach that homosexuality is unnatural and wrong, yet intimate encounters with death naturally raise spiritual issues. That is why membership has increased dramatically at the Metropolitan Community Church, which ministers particularly to the gay and lesbian community and is located in Canada's larger cities.

## Surviving survival

Survival guilt among gay men can cause special problems. "What did I do that was different [from those who got AIDS]?" said Rapsey. "Probably nothing, to tell you the truth. What is it about me that has allowed me to continue to be healthy and active and productive in life? One thing my survival has done is put responsibility on me. OK, you have what these people weren't able to have and so you have to make good. So there is that burden."

Dr. Philip Berger, a Toronto family physician who has treated AIDS patients since the epidemic began, said he treated one closely knit group of friends and now all of them are dead save for a single HIV-negative man. Just before he died, one member of this group told Berger that within several decades there would be no one to remember him and his friends, no living person to tell the stories. "You sort of get a sense of almost nonexistence," Berger observed.

## Education resources available for MDs

Four different items dealing with multiple-loss and other issues related to HIV disease are available to physicians through the Canadian Psychiatric Association. Order forms are available from Francine Knoops, 613 234-2815 x38; [cpa@medical.org](mailto:cpa@medical.org) (use *HIV materials* as the subject line).

- *HIV & psychiatry: a training and resource manual* (160-page reference manual)
- *The consultant mentor directory for HIV disease and psychiatry* (pocket guide listing Canadian psychiatrists who are experts in HIV-related issues)
- *Living with HIV and dementia: a guide for the extended family* (18-page brochure)
- *Learning to care: an introduction to HIV psychiatry* (57-minute video)



There are very few academic articles about the impact of multiple loss on gay men, and even fewer studies. This is probably because most clinicians and researchers have been busy with the more obviously urgent issues surrounding AIDS. The result is that this loss issue is not well understood. Psychologist Odets noted that “people sometimes talk about post-traumatic stress and trauma theory and applying those kind of treatment approaches [to gay men]. But these are all approaches that assume the acute event is over, that the patient is safe, so to speak, that the patient will not be re-exposed to the trauma. And that is not the truth.”

Indeed, many gay men talk about how difficult it can be, after a string of losses, to try to “reconnect” with the world. They may themselves be HIV negative, but if they try to make new gay friends there’s a good chance these men will be HIV positive, meaning the possibility for another loss exists.

Rapsey and his longtime partner are HIV negative. How do they cope? Rapsey still works in Toronto, but home is now a house in the country, 90 minutes west of the city. “We moved in the expectation that we would develop a new life with new people, gay or straight, young or old,” Rapsey said. “And we have done that. But the one thing we haven’t been able to do is run away from AIDS, because it is out there too.”

One expert (Worden JW. *Grief Counselling and Grief Therapy: a Handbook for the Mental Health Practitioner*. New York: Springer; 1991) says the 4 tasks related to mourning are:

- accept the reality of the loss;
- work through the pain of grief;
- adjust to an environment in which the deceased is missing; and
- move on with life.

Yet when the losses keep piling up, these mourning-related tasks can be impossible to complete. Peter Wood, 50, a former set designer and AIDS activist who lives in Halifax, knows more than 50 men who have died of AIDS, and he and his partner both have the disease. “When I learn that another person has died these days, it is [simply] information and that is how I experience it — as information,” Wood said in an interview. “And it bothers me because I feel that maybe I am not grieving, that I’m burnt out, that I can’t absorb any more of that kind of emotion.”

Rycke Pothier, an Ottawa artist who has AIDS, recently experienced 3 deaths in just 6 weeks. “It was overwhelming for me and I didn’t have time to process each death. I’m used to being able to be strong, and when I suddenly became a shambles that in itself was shocking to me.

“I locked the door, pulled the curtains, took the phone off the hook and stayed alone. Wrapped myself up in my little cocoon and stayed alone for as long as it took me to process it.”

Gay men who are grieving, like other people who are bereaved, sometimes engage in risky behaviour: they drink too much, take drugs or engage in unprotected sex. “It is an oversimplification, but there can be a self-destructive component because, for older men, there can be an ambivalence about living,” said Odets. “We are more sympathetic to these feelings in a 90-year-old who has lost all his friends, but today we have 30- and 40-year-old men like that. Still, simply labelling it as self-destructive can be a way of warding off the complexity of the issue.”

Risky behaviour, numbness and withdrawal are familiar reactions to multiple loss for Yvette Perrault, who began working as a counsellor with the AIDS Committee of Toronto in 1985. “The hardest thing about the job was saying ‘Hello, goodbye; Hello, goodbye’ to people who were dying so fast that we hardly got to know them,” she said.

## A relationship with death

This forced Perrault to consider the multiple-loss issue. “My heart was breaking on the job and I knew I had to develop a relationship with death that does not involve distance. The coping strategies that I had were fine — until I had to deal with a death a week. I needed new coping strategies.”

She went on to establish Ontario’s bereavement project, which counsels people who work in the AIDS field and who have to cope with the effects of multiple loss. “I see a whole lot of people living with a level of what I call psychic numbing, just in order to keep on keeping on. And I would never judge that as negative. It is an adaptive coping strategy and incredibly it has tremendous value because it lets people put a foot in front of the other and take care of the business of the day. For people who are not doing their grief work, either you’re numb or you need intensity to break through that numbness, hence the drug and alcohol abuse. You think ‘now is all there is’ and so you want intensity, skin-to-skin contact, forget the condom.

“What I really want is for people to be curious about their grief,” Perrault concluded. “If people can be curious about their grief, their relationship to grief, they can face the difficult things and come out the other side. In multiple loss, it is a long haul. Something in us has died and needs to be transformed.” ?