

# The presence of absence

## Bereavement in long-term survivors of multiple AIDS-related losses



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**Abstract:** AIDS (acquired immunodeficiency syndrome), caused by the human immunodeficiency virus (HIV), has emerged as an enduring and complex medical and social reality. Some communities have experienced tremendous loss of life from this virus. This article examines the bereavement experiences of HIV-infected and HIV-affected people within an AIDS-impacted community in the province of Ontario, Canada. Mourners face the stigma associated with the illness itself and the marginalisation experienced by the communities most affected by HIV. Six dimensions are considered to characterise the experiences of those bereaved by multiple AIDS-related losses. Creative strategies of resiliency and coping are also identified. The study points to a community-based approach as key to addressing AIDS-related loss of this magnitude.

**Keywords:** AIDS, HIV, bereavement, loss, community

‘So how do you move forward when you lose your entire world? It’s not a small thing – it’s not just that I lost hundreds and hundreds of people while the ground I stood on remained solid. The ground’s not there either – the things that helped me cope with ongoing losses began to disappear too, like my Friday night card group, my cat died, my father died, I had to stop working because of my own health ... At some point, I was able to function – then, at some point, it just got too overwhelming because too much was taken away and the bottom went out.’  
(Bart, a 58-year-old gay man with AIDS)

This article describes a study examining the bereavement experiences of HIV-infected and HIV-affected people in AIDS-impacted communities in Ontario, Canada.

Advances in anti-retroviral therapies have resulted in prolonged life for many people infected with HIV. However, with this prolongation of life has come a series of psychological and psychosocial concerns (Brashers *et al*, 1999; Leaver, Perreault & Demetrakopoulos, 2008; Schwartzberg, 1996). These long-term survivors are exploring uncharted territory, including the navigation of new attachment and loss terrain (Cherney & Verhey, 1996; Kvalsund & Spillman, 1996; Nord, 1997).

Accompanying this HIV-positive population is a corresponding group of HIV-negative individuals who have also lived through the deaths of many friends and experienced catastrophic losses in their ‘community of meaning’ (Cox, 2006; Mallinson, 1999; Odets, 1995; Schwartzberg, 1992a).

## The context

An estimated 63,000 people are currently living with HIV/AIDS in Canada (Public Health Agency of Canada, 2007). The province of Ontario has the highest number – over 26,000 – of people living with HIV in the country. Men who have sex with men account for the majority of people with positive HIV tests (66%). Women now account for 28% of HIV-positive diagnoses each year. The proportion of HIV diagnoses among people who have emigrated from HIV-endemic countries to Canada is increasing steadily over time (above 20% since 2001). The AIDS epidemic has already created a sizable population of bereaved individuals, and AIDS-related deaths continue to mount. Nearly 15,000 Canadians have already died of AIDS, and 9472 of those were citizens of Ontario (Remis, Swantee & Liu, 2009). With each AIDS-related death, a network of family, friends, colleagues, neighbours, and health care providers is left behind to grapple with the impact of those losses.

## A community response to loss

Since 1994, the AIDS Bereavement and Resiliency Program of Ontario (ABRPO – previously the AIDS Bereavement Project of Ontario [ABPO]) has been funded by the AIDS Bureau, Ontario Ministry of Health and Long Term Care to respond directly to the personal and organisational impacts of these AIDS-related losses. ABRPO is mandated to develop practical, culturally relevant grief and loss workshops, training modules, resources and support services for the workers in the province's AIDS sector. ABRPO also partners directly with HIV-infected and HIV-affected community members to develop programmes to respond to multiple loss and community devastation (ABPO, 2005; Leaver, 2005).

Conceptualisations of community have shifted from an exclusively geographical focus to including notions such as 'members' sense of significance, solidarity and security' (Sonn & Fisher, 1996). A central but not exclusive example of this notion is that many gays and lesbians in this county experience themselves as part of a larger community-of-meaning. This more broadly conceptualised community has been devastated by the social and political realities of HIV/AIDS. When individuals who were seen as part of a community-of-meaning died of AIDS, others within that community did not need to know them intimately to experience the deaths as significant and personal losses.

## Identities in AIDS-impacted communities

### Sero-status identity

Assuming an identity based on 'disease status' is pervasive in communities hardest hit by AIDS. It is now common in the gay community and in the AIDS movement to identify oneself in relation to the results of an HIV test: that is, either HIV-sero-positive for the virus (HIV-positive) or HIV sero-negative (HIV-negative). This form of social identity appears unique to HIV/

AIDS (Johnston, 1995; Maxwell, 1996, 1998; Odets, 1995; Patton, 1990; Schwartzberg, 1992b).

### Long-term survivor identity

The phenomenon of AIDS long-term survivors is another important consideration (Kvalsund & Spillman, 1996; Leaver, Perrault & Demetrakopoulos, 2008). Long-term survivors are defined in two distinct ways within HIV-affected communities:

- as HIV-positive long-term survivors – people who were diagnosed prior to the breakthroughs in the anti-retroviral combination drug therapies (1996), and therefore expected to die; and
- as HIV-negative long-term survivors – people who do not live with HIV in their bodies but who have experienced the deaths of entire families and friendship networks. Many have also been the community workers who have cared for literally hundreds of people who have died of AIDS.

Both HIV-positive and HIV-negative long-term survivors share the dubious distinction of being AIDS bereaved.

## The study

As the medical, social and political realities of HIV/AIDS evolved, ABRPO needed to understand better the experiences of its own AIDS-bereaved communities, which now included an increasing number of HIV-positive as well as HIV-negative individuals. ABRPO therefore conducted a qualitative study to examine two questions:

- what are the bereavement experiences of HIV-positive and HIV-negative long-term survivors of AIDS-related losses who live in Ontario?
- how does HIV sero-status affect the bereavement experiences of long-term survivors?

Phenomenological research methods were chosen (Palys, 2003) to capture key features of the AIDS bereavement experience and to determine what meaning the bereaved were making of life with loss. A qualitative, participatory approach consistent with the principles of community-based research was used (Canadian Institutes of Health Research, 2010). A mixed HIV sero-status research team was formed to set up the study design, recruit participants, conduct the initial interviews, co-facilitate the dialogue groups, analyse data and shape findings and recommendations. The study was approved by the Research Ethics Board, Royal Roads University, Victoria, British Columbia.

The research team conducted one-to-one, open-ended interviews using a semi-structured format to ensure that concepts related to bereavement were included (number and types of losses, impact of the deaths, impact of HIV-sero-status and coping strategies). Interviews were audio-taped and

transcribed verbatim. Following the interviews, two dialogue groups were held: one for HIV-positive participants and the other for HIV-negative participants. Dialogue groups were chosen as the most appropriate means for participants to explore together their ideas, beliefs and feelings about their loss experiences (Bohm, 1996). The two dialogue groups were audio-taped and transcribed verbatim. To begin analysis, the research team members independently reviewed and coded the interview transcripts. The team then met to develop an initial coding scheme. Data from each dialogue group were then coded independently, and the team met occasionally to reconcile any differences and revise the coding scheme.

A third dialogue group was formed from participants from the two previous dialogue groups to undertake a final review of the themed data with the research team. This mixed sero-status group further discussed the themes from the interviews and groups and participated in the development of the research conclusions and recommendations. This partnership resulted in a moving, powerful dialogue between people who have not traditionally sat together and spoken so openly about their HIV sero-status identities and loss experiences.

## Participants

A total of 27 participants were recruited, 12 HIV-positive and 15 HIV-negative, through an advert placed in *Xtra*, a prominent community newspaper, and through Toronto's HIV clinics, which serve the majority of people living with HIV in Ontario. Of the participants, 30% were women and 87% identified as gay, lesbian or bisexual. Participants ranged in age from 32 to 78 years old (mean age 48), and came from diverse racial and ethnic backgrounds. Three were immigrants. HIV-positive individuals had been living with HIV for an average of 12 years; two men were recently diagnosed as HIV-positive, but had been living in AIDS-impacted communities for much longer. HIV-negative participants had been affected by AIDS for an average of 20 years. For some, this was over half their adult lives. The number of deaths experienced overall averaged 174 per person, and ranged from 'two sons and two close friends' (a mother) to 'over 1000 acquaintances' (a manager of several gay discos). The vast majority (88%) were connected to the HIV community in some way, either as activists, volunteers or workers in the AIDS sector.

The participant stories are rich. Here (right) are excerpts from two interviews, one with DJ, an HIV-negative gay man, and the other with Will, a 52-year-old man living with AIDS for nearly two decades. Their names have been changed.

## AIDS-related bereavement themes

The 27 participants noted experiences of traumatic, multiple loss that resulted in ongoing and often overwhelming bereavement experiences. They described bereavement responses that manifested at all levels of human experience: physical, mental, emotional, spiritual, sexual and social. Their

### DJ's story

'AIDS created a great deal of conflict for me because at a relatively young age (25) I began to experience the loss of my social supports – an experience that even my parents hadn't begun to have. I didn't feel that I could talk about this with my family; I felt a stigma because it was AIDS.

'I do sometimes wish that I could react with tears and just have a good cry, but my emotions are largely clouded by anger. Death doesn't make me sad, it makes me angry; sadness to me suggests some sense of helplessness – which I don't believe is the response that this disease requires.

'What does seem to help my grief is getting involved. Working on the issues gave me a sense of control and made me feel like I was an active participant rather than a passive participant in what would be the single most defining aspect of my life. But obviously, that same involvement that helped me cope also drew me nearer to more, and more frequent, death.'

### Will's story

'My partner Keith and I were both HIV-positive, and I expected to die first. But in 1991 Keith died – I lost the love of my life. After that it was just one death after another. Because it was so painful, parts of me shut down. It's almost like we "left normal". If you have unrealistic expectations that everything is going to be "okay again" you're setting yourself up for a big fall. That means learning to deal with what actually is.

'But I notice now that there's a shift happening inside of me – the possibility that I could live again and love again is beginning to outweigh the fear of anticipatory grief. There is a funny thing that goes on – you know how painfully awful loss is – you can still feel it – but it's not worth closing off everything because you end up losing more by not opening to life and to love again.

'So, despite all the terrible things that could happen – to shut oneself down so much, to deny oneself so much – I think that's a tragedy too. I really think that we have got to risk trying for some happiness.'

bereavement experiences are not conceptualised in a static, linear, one-dimensional manner, but rather as a dynamic, multi-dimensional process of (in Will's words) 'leaving normal'. These survivors' experiences also pointed to creative strategies of resiliency and coping.

Six distinct themes of AIDS bereavement experiences emerged from the data: confrontation with death, loss of the world as one assumed it would be, survivor syndrome, identity and belonging, making meaning, and rebuilding community. The themes were consistent across HIV sero-status distinctions, although there were differences within the themes between HIV-negative and HIV-positive participants. Highlighted across the themes was the notion of community life as it shapes identity and belonging: this featured as an essential component of how AIDS-loss bereaved people create meaning

from traumatic events. Accompanying each theme was a corresponding set of key questions identified by participants (Table 1). An elaboration of the themes follows.

It is important to note that participants could relate to all of these themes and questions in some way, but the importance of each theme varied between participants. Participants did not address these themes in a concurrent or sequential manner and the themes were not experienced or resolved in a linear fashion. The themes were not dealt with separately; participants described an interplay of the experiences and questions that varied in emphasis and significance for each of them.

### Confrontation with death

The numbers, types and impacts of AIDS-related deaths reported by participants revealed enormous reservoirs of grief and traumatic experiences in this group (an average of 174 deaths per person). ‘I’ve lost my entire community and the life I expected to have’ (Andy, 32, the youngest HIV-negative participant). While the participants were making great efforts to move forward in their lives, the study revealed a lack of appreciation of the complexity of their grief and what constituted working through their grief. For many, myths about bereavement persisted: ‘I should be over it by now’

**Table 1:** The experience of being AIDS bereaved

	Key questions	Aspects
Confrontation with death	‘They’re all dying ... What is happening?’	<ul style="list-style-type: none"> <li>■ Current loss triggers old loss</li> <li>■ Traumatic impact of numbers and kinds of deaths</li> <li>■ Disenfranchised grief; stigma</li> <li>■ Grief overload; no time to grieve</li> <li>■ Intense emotional, physical, spiritual, mental reactions</li> </ul>
Loss of the assumptive world	‘So much is lost. My world is dying ... What does that mean for me?’	<ul style="list-style-type: none"> <li>■ Losses are more than the deaths of people</li> <li>■ Losing a community that was</li> <li>■ Mourning a life that never will be</li> <li>■ Sources of support not available as friends/families die</li> <li>■ Stigma and lack of societal support become additional losses</li> </ul>
Survivor syndrome	‘But I’m still here ... Why am I still here?’	<ul style="list-style-type: none"> <li>■ Bewildering randomness of infections and deaths</li> <li>■ More than feelings of guilt – anxiety, rage, confusion</li> <li>■ Lack of language to convey experience</li> <li>■ Lack of entitlement to grieve or to feel joy</li> <li>■ Choices to be made – withdraw or get involved</li> <li>■ AIDS activism as response</li> </ul>
Identity and belonging	‘Who am I now?’ ‘Where do I belong?’	<ul style="list-style-type: none"> <li>■ Role of culture and pre-AIDS community as reference</li> <li>■ Paradox of belonging and becoming involved – sense of control but closer to death and pain</li> <li>■ Identity disruptions caused by HIV/AIDS; distinctions emerge based on HIV sero-status</li> <li>■ Long-term survivor identity emerges</li> </ul>
Making meaning	‘I have to find ways to make sense of the non-sense’ ‘Who am I becoming?’	<ul style="list-style-type: none"> <li>■ Transformation – shaped by death, loss and survival</li> <li>■ Paradox – living with ambiguity</li> <li>■ Anguish of invisibility and meaninglessness</li> <li>■ Values of love, tenderness, compassion</li> <li>■ Common identity – ‘We are all bereaved’</li> <li>■ Legacy work – remembering the past; honouring the dead</li> </ul>
Rebuilding community	‘Is this is the new normal?’ ‘What is left?’ ‘Who else is here with me?’ ‘What now seems possible?’	<ul style="list-style-type: none"> <li>■ Living with uncertainty – AIDS isn’t over</li> <li>■ Concerns for the next generation</li> <li>■ Challenges of attaching and reinvesting</li> <li>■ Deeper resolution of grief contributes to individual and community health</li> <li>■ Work remains on larger social justice issues</li> <li>■ Desire to dismantle the barriers between survivors; find allies and role models</li> <li>■ Both HIV+ and HIV- desire active role in task of rebuilding</li> </ul>





The AIDS Memorial Wall in Toronto, Ontario. The circle of stone records the names of 2800 people who have died of AIDS since 1981. Names are added by family and friends each year at an annual candlelight vigil

(RuH); ‘I was always told to just put the past behind me’ (Uni); ‘I expected my grief to be over when I said goodbye at the funeral’ (Jason).

These manifestations of grief presented, in part, as intense emotional reactions: anger and rage, anxiety, confusion, numbness, overwhelming sorrow, loss of focus and creativity, disorientation, and somatic, or body-based, problems. However, people did not necessarily recognise these legacies of loss as being associated with their grief response: ‘Do you think feeling so numb all the time is about grief?’ (Lara); ‘Isn’t grief about crying?’ (Paula); ‘I’m not sad – I’m mad’ (DJ).

### Loss of the assumptive world

Losses were noted as being more than the deaths of people. Participants grieved a world that was no longer there. ‘I have to mourn the life that was supposed to be for me as a gay man coming out in a liberated time – a time without some terrible disease’ (Edwin). Participants, particularly those who were connected to a marginalised community, described stigma and lack of societal support as additional losses:

‘I never believed I would feel so alone when my son died of AIDS – I thought people in my church would support a mother losing a child, no matter what that child did or died of, but I was wrong.’ (Paula, mother who lost two sons to AIDS)

‘When I came out as a gay man, I left my small home town and built a whole new life for myself in the city ... I really thought we would grow old together. I pictured how one day we’d be sitting in our rocking chairs on the porch of the queer old-folks home ... now that whole circle of friends is dead and I don’t know how to face getting old without those guys.’ (Barrie, 62, HIV-negative man)

### Survivor syndrome

‘Survivor guilt’ is the term usually used to describe this manifestation of traumatic loss (Lifton, 1980). However, in addition to guilt, these study participants described a wide range of behaviours, thoughts, feelings, beliefs, hopes and fears. Therefore, the term ‘survivor syndrome’ is used to encompass this range of responses to the notion of surviving.

Overall, the experience of survivorship was one of bewilderment that HIV and death seem to randomly pick some people and not others. This was true for both HIV-positive and HIV-negative individuals:

‘Overall, I think the biggest issue I deal with is this seemingly random selection of who got to die and who got to live. My grief now comes through a lens of guilt – I am no better a person, no more valuable, my contributions to the planet will be no more significant than those who died. Yet I remain here, hugely grateful and hugely guilty.’ (DJ)

Many participants also identified a paradox. Because so many had suffered and died and they remained alive, the participants felt that they were ‘not entitled to a life with “big joy” or “big happiness”’ (BA). On the other hand, they felt compelled to ‘live and love big in tribute to those who are no longer here, because they would have wanted a joyful life’ (BA).

### Identity and belonging

Participants described the task of recreating a new identity on many levels: in response to the deaths of loved ones, in response to their own illness, as well as in relation to the loss of the community as they had known it. Additionally, they were faced with the task of creating a new identity in relation to HIV/AIDS itself:

'How do I deal with this uninvited guest [AIDS] who showed up at our party and never left?' (Mike)

Participants' identity as a valuable member of a community was also impacted by losses not necessarily due to death:

'It was easier when I was healthy and could work – but now the pain in my legs won't let me even volunteer – and I wonder what use I am in this community?' (TG)

### Making meaning

AIDS forces us to question meaning and worldview (Hall, 2001; Viney *et al*, 1992), as does bereavement (Schwartzberg & Janoff-Bulman, 1991). The participants in this study frequently referred to 'making sense of the whole thing' (Robert). Making meaning for these participants involved confronting the truth of what had happened, of what remained, and what would never be:

'Would I trade this wisdom to have Wilf and Ted back in my life today? Yeah, I would – but they're not here, so in the absence of their physical presence, I feel a responsibility to make something meaningful out of this horrendous thing that's happened to all of us. Otherwise, it's just a horrendous thing that doesn't mean anything and I want their lives and their deaths to stay meaningful.' (BA)

Making meaning from catastrophic loss and community devastation was not seen as an individual act:

'For sure I need to reflect privately, but more important for me is connecting with others who "get it" – they know what I'm talking about because they've lived it too.' (Wayne)

There was also awareness that making meaning is a continuous process, with no fixed destination or end-points:

'I feel how loss has changed me ... and continues to shape the ways I grow into a very different person than the one I'd imagined. I accept that.' (Uni)

Some participants expressed a spiritual dimension to this process of creating meaning and purpose:

'I keep coming back to the common denominator of love ... and the expression of love in my life. For that to occur I need to be willing to accept the dark with the light. And I have to remind myself when I'm in the muck that sadness is as much a part of the universe expressing as is the vibration of love. That's how I've made sense of things so far.' (Mike)

### Rebuilding community

The work of rebuilding a devastated community was taking place in the context of uncertainty and ambiguity: AIDS is not

over. The loss of community generated profound questions for participants:

'How do we grieve something intangible that is supposed to hold us? If our world is permanently ruptured and those connections that shaped us are not there, then who are we, really?' (Mike)

Long-term survivors faced a continual process of transforming, reinvesting, attaching, more loss, making meaning, taking on new challenges, losing again – and the cycle repeating itself:

'There's a whole generation that's missing with these deaths – they would now be 40, 50, 60 – and I think their loss is having a huge impact on the next generation of young gay men. Who do they have left to be role models and to tell our history?' (Bill)

Participants noted that useful bereavement models and grief supports had to encompass these significant aspects of recreating and rebuilding community:

'No one stands on their own. If we don't deal with HIV, communities and cultures die. If we don't rebuild a strong community rooted in strong cultural traditions, there's no self-esteem to prevent AIDS.' (Lola, Aboriginal community leader)

### Accessing grief care

The study noted important distinctions between HIV-positive and HIV-negative bereaved people in the ways in which they recognised and attended to grief overload and accessed structured supports for grief care.

The HIV-positive long-term survivors dealt with their grief backlog primarily by creating and maintaining strong peer networks and peer support groups. This was consistent with their approach to life prior to their diagnosis with HIV: they were active in community-building (MaZ, Mike, Robert, Ruby) and had strong social supports (Wayne, Bart, Bill). Their current peer networks, although not set up as formal bereavement groups, provided all the elements of a truly supportive bereavement group (Ingram, Jones & Smith, 2001; Leaver, Perreault & Demetrakopoulos, 2008; Sikkema *et al*, 2004; Sikkema *et al*, 2005). These gatherings and informal groups offered recognition of loss and attachments. They helped create a language to discuss the meaning of loss, validated a range of grief responses and sustained gentle but firm expectations that people should not 'stay stuck' but should resolve loss and continue to embrace life in some way:

'I think we should be really proud of all that we've been able to do for one another in this community. We rose to the occasion and accomplished something remarkable when we organized to take care of each other.' (Mike)

The HIV-positive participants no longer perceived themselves as the dying, even though many of them were once on their

deathbeds (MaZ, Robert, Will). They had found new roles (TG and BJ), furthered social justice agendas (Billie, MaZ, Mike), formed authentic connections (Bart, Wayne), deepened their spiritual practices (Bill, Ruby), acquired new skills for processing loss (Jason, Robert), strengthened their peer networks (Bart, TG), developed support groups (Will), and honoured the dead (BJ, Robert). Through these activities, the HIV-positive long-term survivors in this study were consciously engaging in a meaningful way with the present and the future while they continued to reflect on the past.

In contrast, the HIV-negative individuals in the study reported greater levels of isolation, distress, anxiety, rage, guilt and meaninglessness:

'I don't think my experience of loss is as real, as important or relevant as those who are HIV-positive.' (Charles)

As the rate of deaths slowed down and HIV-negative people were no longer required to fulfill the role of care providers in a time of crisis, many of the HIV-negative participants seemed to experience a diminishment of the protection afforded by their care-giving role. With this came a corresponding bubbling-up of the backlog of grief connected to decades of insufficiently dealt with losses. The backlog of grief demanded to be acknowledged, but often went unrecognised or unaddressed:

'I never felt there was a place for my grief as an HIV-negative guy' (Edwin).

There were limited places to which the HIV-negative bereaved could go for communal experiences of understanding, managing and transforming their grief. 'It's really tough to make deeper connections – people just don't want to go there' (Hayden). Bereavement needs, if they were recognised at all, might be referred to mental health professionals offering individual attention:

'[My local AIDS agency] had no groups for HIV-negative people – they sent me off to a counsellor, but I didn't want one-to-one therapy, I wanted to find other people with similar experiences.' (SO)

One-to-one support has value, but it does not create the peer networks and social supports that are essential to the validation and integration of loss experiences into a social identity (ABPO, 2005; Borkman, 1999; Sikkema *et al*, 2005).

## Resilience

The participants who described themselves as having a positive attitude and as learning to live again and able to risk loving again were those who still had buddies or who had found one or two people with whom they could 'talk real' (Hayden). Those who were able to transcend their profound loss

experiences were the ones who had a meaningful connection or strong sense of community prior to AIDS. These individuals found a way, despite the devastation, to 'create and often recreate something to land on' (Robert).

The people who described themselves as 'not doing okay with their losses' were those who had been too young to form a solid identity before AIDS hit, or did not have a solid connection to community life:

'I was 12 years old when AIDS hit, and all my life has been with the holes left by AIDS.' (Andy)

'I feel isolated and invisible. When I moved to the city, the gay community was already dying.' (TG)

Regardless of HIV sero-status, the participants who said that they coped well and could identify a wide range of strategies to foster resiliency were those with strong cultural foundations or spiritual beliefs and those with intentional, ongoing rituals for processing death and bereavement. They also found ways to acknowledge their losses:

'I think there is tremendous value in large-scale memorial activities like the AIDS Quilt, the Candlelight Vigil, and the AIDS Memorial. These events are communal and visible and allow us to 'dip in and dip out' of our grief.' (MaZ)

The participants' descriptions of what really mattered to them can be regarded as building-blocks for programmes that foster resiliency and develop healthy, grief-aware communities. They included:

- a sense of belonging
- authentic connections
- access to structured peer supports
- meaningful participation in community life
- being visible and being valued for one's struggles to survive
- putting life experiences to good use in community HIV prevention efforts and advocacy work.

## Conclusion

This study highlights the complexity and multiple dimensions of AIDS-related bereavement experienced by long-term survivors, and the backlog of grief and loss in AIDS-affected communities, particularly for HIV-negative individuals. AIDS bereavement is about much more than a response to individual deaths. The bereavement experiences of this group of people require an approach that recognises AIDS-related multiple loss as complex and community-oriented, and connected dynamically with the broader social context. A more authentic picture of the complexities involved in working with AIDS multiple loss can be captured by expanding the question: 'It's not only "Who has died?" but "What has died?"'



The study findings suggest that community-based bereavement interventions that are capable of meeting the challenge of multiple AIDS-related losses must adopt a multi-dimensional and integrated approach. Bereavement responses appear most effective when they are integrated into community life. The study findings suggest that the emphasis of AIDS bereavement work should expand from personal process to community possibilities in order to attend more fully to the needs of the individual:

'Heal the community by healing the individuals and in this way resurrect the sense of community fundamental to the mental health of the individual.' (Kaal, 1991) ■

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