

FOCUS A GUIDE TO AIDS RESEARCH

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The Impact of AIDS-Related Deaths and Illnesses on Gay Men in New York City

John L. Martin, PhD, MPH

The catastrophic experience of being sick with AIDS cannot be underestimated. Physical, emotional, and social hardships wrought by this disease are tremendous and taxing. But in addition to those actually sick with AIDS, a much larger group is experiencing severe stressors associated with the epidemic, namely those people who know and are close to those with AIDS. While not physically ill, the social network of persons with AIDS is experiencing actual losses (due to death) and potential losses (due to illness) which may generate severe emotional reactions and promote physical health problems.

Results from studies of the phenomenon of anticipatory grief and bereavement suggest that the stress associated with helping a loved one through the course of illness and death may be particularly potent as a cause of mental distress and physical illness. Given the high rate of increase in the number of AIDS cases, the segment of the population experiencing social losses due to AIDS is expanding rapidly. Thus, health problems generated by actual losses, potential losses, and hardships due to AIDS may become a serious, albeit ancillary, public health concern associated with the epidemic.

Nowhere is this problem more evident than in gay male social networks. Because of the perceived vulnerability to AIDS shared by almost all gay men, bereavement and illness among gay friends of gay men generate particularly powerful reactions. The subjective sense of threat associated with AIDS stems largely from the lack of clear answers about why one person becomes sick while another does not. While the disease is known to be associated with increased levels of sexual activity, low levels of sexual activity or reductions in sexual activity have not assured future health.

In addition to the intense personal threat experienced by many gay men regarding AIDS, an additional feature of the epidemic which makes bereavement and illness due to AIDS particularly distressing is that the sequence of illness and death often occurs more than once in a brief time period. It is not unusual to encounter reports of entire gay social networks that have been decimated due to AIDS. Such a pattern is in contrast to the biological family of a gay man who gets AIDS. While members of that family may indeed undergo severe distress over the illness and loss, this experience tends to occur only once. Grief can then run its natural time course toward resolution.

However, when one death after another occurs in sequence, the grieving process may be disrupted while the actual grief is compounded. Since many gay men live within social networks that serve as surrogate families in which close emotional ties are maintained, losses within this group cannot be considered insignificant. Thus, gay men who have experienced multiple instances of sickness and death due to AIDS may be at especially increased risk of mental and physical health problems associated with bereavement and anticipated bereavement.

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Study in New York

This report addresses two questions about AIDS-related losses. First, who in the gay community is most likely to have lost someone close due to AIDS? Second, what are the mental health effects associated with AIDS-related losses for gay men? Answers to these questions are important in order to know (a) the particular segments of the gay community most likely to need support services around bereavement and loss, and (b) the types of distress symptoms most likely to arise from bereavement and loss.

Methods

The data come from a study of 745 New York City gay men who were recruited in 1985 as part of a longitudinal evaluation of the psychosocial impact of the AIDS epidemic on the gay community. At the time of that first interview none of the men had a diagnosis of AIDS, most were college-educated (75%), most were white (86%), and the average age was 36. Half of the sample subsequently enrolled in a serologic study; 36% were HIV-seropositive. All psychosocial data were collected in face-to-face structured interviews which covered a variety of domains including demographic characteristics of each respondent, his parents, and his lover (if he had one); experience with anti-gay violence; sexual behavior history; psychological distress; drug use; alcohol use and alcoholism; HIV antibody testing experience and attitudes; coping strategies around AIDS; AIDS-related beliefs, knowledge, and attitudes; social network structure; social support; involvements with persons with AIDS; grief reactions; medical history; medication use; health service use; stressful life events; and a variety of personality characteristics.

In order to determine the extent to which respondents had experienced losses or had men with AIDS in their social

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AIDS-Related Deaths. . .

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networks, each man was asked to name the men he knew who were ill with AIDS and who had died of AIDS. By asking for names (first names or initials only) it was possible to limit the tendency to exaggerate or over-report losses, a phenomenon which tends to occur during phases of AIDS-anxiety, depression, and preoccupation. From these lists of names two variables were derived and used in this analysis. The first was a count of the number of men that each respondent knew who had AIDS and was alive at the time of the interview (average number of men known = 1.37, SD = 1.62). The second was a count of the number of men that each respondent knew who had died of AIDS during the course of the epidemic (average number of known deaths = 2.46, SD = 2.31). Overall, the average man in this sample knew four men who either had died of AIDS or were ill with AIDS as of mid-1985. These numbers have increased dramatically since then, resulting in a secondary epidemic of bereavement growing at a logarithmic rate in the gay population.

Results

Before examining the relationships between the loss variables and distress variables, a number of tests were conducted in order to determine who in the gay community was most likely to have lost someone close. These analyses revealed that gay men who were HIV-antibody positive and men who had one or more symptoms of ARC were also more likely to report a loss, and they reported the greatest number of losses. This doesn't mean that HIV-negative men, and men who have no ARC symptoms, have not been bereaved. Indeed, bereavement and loss are being experienced by increasing numbers of people everywhere. But what it does mean is that there is a core segment of the gay community who, in addition to having health problems related to AIDS, are also experiencing bereavement more frequently than anyone else.

Turning to the question of the psychological consequences of AIDS-related deaths, a number of important correlates were found. The strongest psychological symptoms found to be associated with losses were those indicative of demoralization, sleep disturbance, and traumatic stress responses (such as panic attacks, nightmares, numbing, etc., specific to fears about AIDS). In addition, increases in sleeping pill use, average number of medical consultations, and use of psychological services due to concern over AIDS were also strongly associated with increasing numbers of losses.

A somewhat different picture emerged when the analysis was shifted to the number of men known to be ill, but alive, with AIDS. As with actual loss, a direct relationship was found between the number of those known to be ill with AIDS and scores on demoralization, traumatic stress response, sleeping pill use, and medical consultations. However, there were also significantly high rates of suicidal ideation as a function of increased numbers of men ill with AIDS in the social network.

Conclusion

It is clear from these results that being a survivor of this epidemic carries a toll in the form of significant psychological symptomatology. In addition, the finding that those most likely to be bereaved are themselves at highest risk for AIDS and its related disorders underscores the complex clinical problem facing mental health providers who treat gay men in their practices. Not only is the problem of grief and bereavement complicated by the occurrence of multiple losses, but the issues are compounded by the high likelihood that the patient or client is himself facing the devastating health problem of AIDS.

To the extent that social and personal resources can effectively buffer the impact of these kinds of stressors, prevention efforts can be developed and aimed at bolstering

these defenses. Because of the extensive number of areas of functioning that are potentially and adversely affected by bereavement due to AIDS, targeting specific areas for prevention efforts is crucial, especially in light of the fact that the concentration of AIDS cases has more than doubled since the data presented here were collected.

John L. Martin, PhD is the director of the AIDS Research Unit at the Columbia University of Public Health. A full report on these results will be published in an upcoming issue of the Journal of Consulting and Clinical Psychology.

Diagnosis/Treatment/Prevention

AIDS and Bereavement

**Kitsy Schoen, LCSW and
Ellie Schindelman, MPH**

As the AIDS epidemic has grown, the needs of the bereaved have become more apparent and professional support is now recognized as an essential response. Individuals who are grieving in isolation or experiencing multiple losses prompt particular concern.

People often underestimate the profound and encompassing effects of grief. The loss of a loved one is a significant marker in our lives. It is a time of crisis that can precipitate deep and positive changes. However, if the loss is not grieved fully, physical symptoms or illness may develop, and emotional disturbances can become evident immediately, or even years later after another crisis or loss.

This article will discuss some of the specific ways the loss of someone to AIDS or ARC can affect bereavement. It will also provide information on the grief process, describe some of the more serious problems which can develop, and discuss how caregivers can help the bereaved.

For a bereaved gay partner, the lack of support and recognition of gay relationships can have many consequences The partner may be denied his rightful place in rituals such as funerals and memorial services.

AIDS and Grief

The social context in which AIDS occurs can make the bereavement process more difficult. Many of those bereaved are afraid to disclose the actual cause of death because they fear discrimination or rejection; they may choose not to disclose the diagnosis and may find they avoid conversations about their loved one. Pain often becomes intensified or prolonged as sorrow is kept inside. The silence may also feel like a betrayal of their loved one, and lead to feelings of worry and guilt. On the other hand, those who are open about the cause of death may find that providers of bereavement support are not always AIDS-sensitive and may not offer a sympathetic and safe environment for sharing grief.

Homophobia plays a large role in the stigma associated with AIDS, and many of the bereaved are affected by our culture's deep-seated prejudice against gay people. Parents, women partners, and children of bisexual men may have first learned about their loved one's homosexuality at his diagnosis. Although they may initially push aside their reactions in their

overriding concern for his well-being, more negative feelings may surface later. Parents may feel responsible for their child's homosexuality, and ultimately for his death. Wives may be confused, hurt, and angry about their husband's secret life, and may be unable to understand and accept this part of him. When there is extensive guilt or ambivalence, the grieving process can be quite difficult.

For a bereaved gay partner, the lack of support and recognition of gay relationships can have many consequences. Frequently, the gay relationship is minimized. The partner may be denied his rightful place in rituals such as funerals and memorial services. There may be disputes over wills and life insurance. Even for the most positively gay-identified survivor, the invalidation of the relationship can re-ignite internalized homophobia, which often appears as low self-esteem and depression. Creating rituals and remembrances at birthdays, anniversaries, and holidays can help the bereaved partner continue to recognize the significance of the relationship and the loss, and allow the natural grieving process to unfold.

Tragically, many of the bereaved themselves may also be at risk of developing AIDS. Survivors may already be diagnosed with AIDS or ARC, or they may know they are antibody-positive, which may add to feelings of loss, anxiety, and confusion brought on by bereavement. For partners, concerns about their own health may become more acute in bereavement because they are no longer focusing on their lover's illness. Many express concern that no one will be there to care for them; they are angry at the deceased for abandoning them. In addition, they may feel it is unnecessary to attempt to separate emotionally from the deceased if their own death is just around the corner.

Some of the first signs of grief can be hauntingly like the classic early symptoms of AIDS: tightness in the chest, difficulty breathing, weight loss, fatigue, inability to concentrate, and forgetfulness. Losing someone close increases one's vulnerability to illness. Seeing a physician soon after the loss will help clarify the sources of symptoms.

Additionally, because of the epidemic proportions of AIDS, it is not uncommon for people to be grieving or anticipating the loss of more than one person to AIDS, even within the same family. Some, especially AIDS caregivers, face many losses. As of yet, there are no simple guidelines on how to cope in these circumstances.

Grieving the loss of someone who was an IV drug user can be complex. The bereaved may be angry, confused, hurt, or struggling to understand the addiction. Parents may be saddened over years of estrangement. The grieving process often forces the bereaved to recognize and cope with their own co-dependency or drug use. As in all AIDS services, bereavement counselors should be knowledgeable about chemical dependency and co-dependency.

The Normal Experience of Grief

Grief is a natural, healthy and dynamic response to loss. Although there are significant individual and cultural differences in how grief is approached and expressed, the bereaved share some universal experiences. The effect of a loved one's death is so immense that the bereaved can be numb and in shock for the first days or weeks. Often the bereaved are relieved by this numbness, thinking that the loss won't hurt as much as they expected. Later they feel that they are "going crazy" or "falling apart" when the pain of mourning breaks through. The symptoms of grief are often disturbing if the bereaved does not know what to expect. The mixture of feelings may include sorrow, anguish, regret, guilt, longing, loneliness, anger, anxiety, depression, confusion, hopelessness, fear and relief; and physical symptoms like lethargy, weepiness, or anxiety. Generally, it takes at least six months, and commonly two years, to grieve a close death.

Dr. William Worden, an expert in grief counseling, suggests there are four tasks the survivor must complete to resolve the grieving process: accept the reality of the loss, experience the

pain of mourning, adjust to life without the deceased, and reinvest the energy devoted previously to the deceased in other relationships and endeavors.

Complicated Bereavement

When has normal bereavement developed into something more serious? The length of time someone has been grieving is not the best indicator of complicated bereavement. Someone will need additional help if anxiety has developed into phobic responses, if addictive behaviors have developed, or if the emotional lows of grieving have turned into a clinical depression.

People who are grieving often long to join their loved one. Some have explicitly suicidal ideations. While this is quite normal, it is important to do a standard risk assessment and determine if the person has a plan and the means. Often these feelings are subconscious and are acted out in self-destructive behaviors.

Bereavement Support

Increasingly, mental health professionals will be called on to provide support to those bereaved by AIDS. The loss of a loved one in the context of an epidemic and a highly stigmatized illness is very stressful. We do not yet know what "normal" grief is under these circumstances. Often, bereavement support will be necessary beyond the time immediately following the death, not only because the grieving process will extend beyond that initial period, but because the process may well be complicated by multiple losses. General guidelines for this support include:

- (1) Provide information. Information helps to normalize the experience and gives the person permission to grieve;
- (2) Encourage talk about feelings. Many bereaved falsely assume that people do not want them to talk about their loss; and
- (3) Encourage peer support.

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BRIEFS

An Excerpt

Borrowed Time: An AIDS Memoir. Copyright © 1988 by Paul Monette. Reprinted by permission of Harcourt Brace Jovanovich, Inc.

I don't know if I will live to finish this. Doubtless there's a streak of self-importance in such an assertion, but who's counting? Maybe it's just that I've watched too many sicken in a month and die by Christmas, so that a fatal sort of realism comforts me more than magic. All I know is this: The virus ticks in me. And it doesn't care a whit about our categories No one has solved the puzzle of its timing. I take my drug from Tijuana twice a day. The very friends who tell me how vigorous I look, how well I seem, are the first to assure me of the imminent medical breakthrough. What they don't seem to understand is, I used up all my optimism keeping my friend alive. Now that he's gone, the cup of my own health is neither half-full nor half-empty. Just half.

Equally difficult, of course, is knowing where to start. The world around me is defined now by its endings and its closures — the date on the grave that follows the hyphen. Roger
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BRIEFS

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Horwitz, my beloved friend, died of complications of AIDS on October 22, 1986, nineteen months and ten days after his diagnosis. That is the only real date anymore, casting its ice shadow over all the secular holidays lovers mark their calendars by. Until that long night in October, it didn't seem possible that any day could supplant the brute equinox of March 12 — the day of Roger's diagnosis in 1985, the day we began to live on the moon.

The fact is, no one knows where to start with AIDS. Now, in the seventh year of the calamity, my friends in L.A. can hardly recall what it felt like any longer, the time before the sickness. Yet we all watched the toll mount in New York, then in San Francisco, for years before it ever touched us here. It comes like a slowly dawning horror. At first you are equipped with a hundred different amulets to keep it far away. Then someone you know goes into the hospital, and suddenly you are at high noon in full battle gear. They have neglected to tell you that you will be issued no weapons of any sort. So you cobble together a weapon out of anything that lies at hand, like a prisoner honing a spoon handle into a stiletto. You fight tough, you fight dirty, but you cannot fight tougher than it [can].

Paul Monette is a novelist and poet. *Borrowed Time* will be released this month.

Recent Reports

Grief is an Individual Journey, According to UC-San Francisco Study. People who still feel emptiness and pain long after the death of a loved one are not alone, according to researchers at the University of California, San Francisco. Writing in the September 1987 issue of *Death Studies*, Ida Martinson concluded that grief is not always resolved or completed within a year or two, as some studies have indicated. Rather, while some people may get over their grief quickly, others may feel pain for many years, even when they seem to have successfully adapted their lives to the loss.

The UCSF study involved interviews with 49 families who had experienced the death of a child from cancer seven to nine years before. These same families had been involved in an earlier study which had followed their grief process for the first two years after their loss.

Three patterns emerged from the study. In the first, researchers found that after seven to nine years, some family members had resolved their grief in the traditional sense of "getting over it." For these people, time had erased the pain, and they felt a desire to get on with their lives. They did not view themselves as significantly changed by the death and made a conscious effort to put the experiences of the child's life and death behind them.

The second group dealt with their loss by attempting to fill the emptiness — keeping busy or substituting other problems or situations to take their minds off their grief. Most of these people reported a lessening of their grief through their other involvements.

But for those in the third and largest group, grief was still a continuing everyday presence in their lives, even after seven to nine years. The pain of their loss had gradually diminished, but they viewed it as a part of themselves, a special relationship which was permanent and irreplaceable. Despite these feelings, most of these people described their daily lives as very rich and meaningful. Time had lessened the pain until it became a comfortable feeling filled with cherished memories.

Grieving people cannot be expected to follow time limits or a specific path. Instead, understanding that people respond differently to grief may facilitate family communication and mutual support. Most importantly, the study concludes, people who continue to feel emptiness and pain long after the loss of a loved one can be assured that they are not alone.

Revised AIDS Case Definition. Scientists reported the results of their study of the impact of the revised, expanded case definition of AIDS on the reporting of AIDS cases in San Francisco (*Lancet*, April 16, 1988). The revised definition, published by the CDC, went into effect on September 1, 1987. Using the new and old definitions, Rutherford et al compared the numbers of AIDS cases reported to the San Francisco Department of Public Health during the three month period after the revision.

Of the 336 cases of AIDS which were reported after September 1, 1987; 283 (84%) met the old case definition, while 53 (16%) fit only the new definition. Most of the new diagnoses included the symptoms of HIV encephalopathy, presumptive toxoplasmosis, and presumptive *Pneumocystis carinii*.

Rutherford concluded by saying 16% may underestimate the number of cases which fit the new definition of AIDS, due to an expected lag between publication of the new definition and its widespread use. Further studies will need to be conducted to adequately assess the impact of the new definition on projections of future AIDS incidence.

Editor's Note: It should be noted that the 16% increase in the number of AIDS cases may also be an overestimate and may possibly reflect a surge in the reporting of cases which had accumulated in physician's caseloads, but which had not yet qualified as AIDS.

Next Month

Clinical manifestations of AIDS and other conditions secondary to infection with HIV often include disorders that affect the nervous system. In the July issue of **FOCUS**, **James W. Dilley, MD** will present the most common of these disorders with particular attention to those which affect the brain. Emphasis will be placed on the clinical presentations of these disorders, and a discussion of the role of the mental health provider in identifying symptoms of neurological involvement will follow. James Dilley is the Director of the AIDS Health Project.

Also in the July issue, **Alicia Boccellari, PhD**, Director of the Neuropsychology Service at San Francisco General Hospital, will discuss the neuropsychological assessment and management of people with HIV infection.

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The amount of research information now appearing in the medical and lay press staggers most AIDS health care and service providers. The goal of **FOCUS** is to place the data and medical reports in a context that is meaningful and useful to its readers.

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