

“A Grief Observed”: The Experience of HIV-Related Illness and Death Among Women in a Clinic-Based Sample in New Haven, Connecticut

Jeannette R. Ickovics
Yale University School of Medicine and Yale University

Jennifer A. Druley, Allison C. Morrill,
Elena Grigorenko, and Judith Rodin
Yale University

This study examined how women in a clinic-based sample in New Haven, Connecticut, ($N = 168$), have been affected by the AIDS epidemic. The aims of this study were to (a) document the proportion of women who knew individuals who were HIV positive, who were symptomatic with AIDS, or who had died from AIDS; (b) compare the demographics of women who knew someone infected with HIV with those of women who did not know anyone infected with HIV; and (c) examine prospectively the effects of the number of AIDS-related losses on women's mental health. Many women have been deeply affected by the AIDS epidemic: Nearly 3/4 of the women in this study knew at least 1 person who had died of AIDS. Women who experienced multiple AIDS-related losses over the course of the study were significantly more anxious than those who experienced no loss or 1 loss. Implications for clinical interventions are discussed.

From the beginning of the AIDS epidemic through December 1997, the Centers for Disease Control and Prevention (CDC; 1998) reported that 390,692 people in the United States have died of AIDS-related illness. AIDS is one of the top three leading causes of death among young women and men aged 25–44 years in the United States (CDC, 1998). As the AIDS epidemic persists, individuals will continue to be faced with the psychological challenge of the deaths of one or more members of their social network, including family members, lovers, friends, and acquaintances. Some will be faced with those newly diagnosed with HIV or symptomatic with AIDS-related illness—foreshadowing losses and bereavement to come.

Bereavement has long been associated with psychological dis-

stress, including increased depression (e.g., Clayton, 1979; Clayton, Halikas, & Maurice, 1972; Harlow, Goldberg, & Comstock, 1991; Parkes & Brown, 1972) and anxiety (Jacobs et al., 1990; Parkes & Weiss, 1983; Zisook, Schneider, & Shuchter, 1990). However, these reactions are not universal (Lindemann, 1944; Stroebe & Stroebe, 1983; Wortman & Silver, 1989). For example, in studies of reaction to conjugal loss, rates of depression have ranged from 12% to 88% (Clayton et al., 1972; Glick, Weiss, & Parkes, 1974; Lund et al., 1986; Vachon et al., 1982). In studies examining parents' reactions to the death of a child, more consistent adverse emotional responses have been reported (Lehman, Wortman, & Williams, 1987; Littlefield & Rushton, 1986; Radestad, Steineck, Nordin, & Sjogren, 1996; Vance, Boyle, Najman, & Thearle, 1995).

Until recently, bereavement research has focused almost exclusively on the mental health consequences of loss of a spouse or child; research to determine the mental health consequences of the deaths of other members of one's social network has been limited. Since the beginning of the AIDS epidemic, several studies have examined the psychological consequences and bereavement associated with AIDS-related losses among gay and bisexual men. In one longitudinal study, men who experienced an AIDS-related death of a lover or close friend reported increased depression and other symptoms of psychological distress compared with those who reported no such loss (Martin, 1988). Moreover, there was a “dose response” relationship between the number of AIDS-related losses and the extent of depression-related symptoms, such as demoralization, sleep problems, and recreational drug use. In later years of the study, significant main effects for bereavement were found in each year after controlling for potential confounding variables; however, the psychological impact of AIDS-related deaths diminished in intensity and duration over the follow-up period (Martin & Dean, 1993).

In other studies including men who have sex with men, the experience of any AIDS-related loss (Kemeny et al., 1994) or

Jeannette R. Ickovics, Department of Epidemiology and Public Health, Yale University School of Medicine, and Department of Psychology, Yale University; Jennifer A. Druley, Allison C. Morrill, Elena Grigorenko, and Judith Rodin, Department of Psychology, Yale University.

Jennifer A. Druley is now at the Department of Psychology, Cleveland State University; Allison C. Morrill is now at the New England Research Institutes, Watertown, Massachusetts; and Judith Rodin is now at the Office of the President, University of Pennsylvania.

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Correspondence concerning this article should be addressed to Jeannette R. Ickovics, Department of Epidemiology and Public Health, Yale University School of Medicine, 60 College Street, Suite 415, P.O. Box 208034, New Haven, Connecticut 06520-8034. Electronic mail may be sent to Jeannette.Ickovics@yale.edu.

Procedure

Study participants were recruited sequentially at each site. After a clinic appointment that included either HIV counseling and testing or other clinic services, the women were given basic information about the study and invited to participate. Approximately 80% of the eligible women agreed to participate. A total of five structured interviews were conducted at the clinic: following the initial appointment (baseline or Interview 1); 2 weeks later, after tested participants received their results and posttest counseling (Interview 2); and again approximately 3, 12, and 18–24 months later (Interviews 3, 4, and 5, respectively). Recruitment and the baseline interviews were conducted between May 1991 and September 1992; the final follow-up interviews were completed 18–24 months postenrollment (1993–1994). Participants were paid for each interview—a total of \$150 if they completed all interviews.

The initial interview was conducted after HIV counseling or other medical procedures were completed. All procedures were approved by a university human investigations committee, as well as by institutional review boards at each clinic (e.g., board of directors). Participation was completely voluntary and noncoercive. Respondents were told that their decision to participate in this research study would not affect their receipt of health care in any way. Interviews were conducted by trained interviewers who had at least a master's degree in psychology. In over 90% of the cases, the same interviewer conducted all five interviews.

Instruments

Data were collected through structured interviews. On the basis of pilot testing, measures were simplified to enhance comprehension. Interviews were conducted in Spanish for women whose primary language was Spanish. Demographic information was collected and included age, race or ethnicity, income, employment status, and history of drug use.

Knowledge of persons infected. At baseline, respondents were asked to indicate whether they knew anyone since the beginning of the AIDS epidemic who (a) died of AIDS, (b) had been sick with AIDS, or (c) was HIV positive but not sick with AIDS. At each follow-up interview, the women were asked whether they knew anyone else since the previous interview in these three categories. These questions were asked hierarchically, such that if an individual was reported as having died of AIDS, that same individual was not included in either of the other two categories. Interviewers verified that each death had not been reported at a previous interview.

Each respondent was asked how many individuals she knew in each category; for the three persons closest to her, she was asked to specify her relationship to the person(s) infected. The type of relationship was coded into one of six categories: husband or primary partner, immediate family member (e.g., sister), extended family member (e.g., uncle), close friends, acquaintance, or an individual from a community or social organization (e.g., church member or colleague from work). These were dichotomized as close relationships (husband or primary partner, immediate family member, and close friends) or casual relationships (extended family member, acquaintance, and individual from a community or social organization) for the multivariate analyses. If multiple losses occurred (two or more individuals known who died of AIDS-related illness) and a woman had lost someone representing both types of relationships (e.g., a close relationship as well as a casual relationship), the type of loss was categorized hierarchically as close.

There were only 27 women who experienced two or more losses during the study period. Each of these cases was reviewed to verify that each death had not been reported at a previous interview. These data were collected with sufficient detail to determine relationship status to the deceased if the loss was of a family member or primary partner (i.e., husband or boyfriend). For those who reported losses of two or more persons from one of the general categories (e.g., close friends or those

known from a community or social organization), multiple losses were reported during a single interview for each respondent ($n = 9$).

Mental health. To assess mental health, we used the short version of the Hopkins Symptom Checklist to measure depression (15 items) and anxiety (10 items; Derogatis, Lipman, Rickels, Uhlenhuth, & Covi, 1974). Respondents rated how often they experienced various feelings during the past month using a scale ranging from 1 (*not at all*) to 4 (*often*). Considering all five interviews, we found that the mean scores for depression ranged from 1.08 to 1.29 ($SD = 0.60$ – 0.68) and that the mean scores for anxiety ranged from 0.87 to 1.00 ($SD = 0.60$ – 0.68). For the Anxiety subscale, 1 item (headaches) was dropped to increase the internal consistency; Cronbach's alphas were .88–.91 for the Depression subscale and .85–.88 for the revised Anxiety subscale.

Statistical Analyses

Descriptive statistics are presented to document the proportion of women who knew individuals with HIV, symptomatic with AIDS, or who had died of AIDS-related illness, including the number of individuals known and the nature of these relationships. Bivariate analyses included chi-square analyses and *t* tests to describe differences in the social and demographic backgrounds of women who knew someone infected with HIV versus those who did not know anyone infected with HIV.

We conducted prospective, longitudinal analyses using analyses of covariance (ANCOVAs) to predict the consequences of AIDS-related losses on the women's levels of depression and anxiety. An ANCOVA permits the examination of association between variables of interest (in this case, number of AIDS-related losses and mental health) while controlling for potential confounding factors (e.g., demographics and prior or preloss level of mental health; Wildt & Ahtola, 1978). Additional strengths of this analytic approach include the ability to eliminate systematic bias and to reduce error variance as a function of naturally occurring group differences (Stevens, 1992). Moreover, prospective analyses permit stronger inferences to be made about the cause-and-effect relationship between AIDS-related loss and mental health.

To assess changes in mental health as a function of multiple loss, we compared women who had two or more losses during a study period with those who had one loss and with those who had no loss. For those with no loss, mental health assessed at the first interview was used as the baseline control. The mental health outcome for the no loss group was defined as an average score of mental health assessed at Interviews 2–5. Outcome mental health scores were averaged for this group to obtain the most representative measure of well-being following baseline; this operationalization is least sensitive to random fluctuations and includes all of the outcome measures that were used for the one loss and multiple loss groups.

For those with one loss during the study period, baseline mental health was assessed at the interview immediately prior to the loss, and the response to loss was assessed at the interview immediately following the loss. For those with multiple losses during a study period, mental health prior to the time interval in which the first instance of loss occurred was used as the baseline indicator of mental health, and the response to loss was assessed at the interview immediately following multiple loss. This was a conservative approach, maximizing the opportunity to evaluate the effects of loss prospectively (i.e., mental health was measured within a fixed time interval pre- and postloss) while minimizing the potential risk of confounding influences on depression and anxiety.

We began broadly by considering all HIV-related illness and death reported since the beginning of the epidemic. We then restricted our focus to deaths that occurred during the study period and the impact of these deaths.

should be interpreted with caution, these data indicate that most of the women in this study knew many people living with or dying from HIV or AIDS.

As a group, the women in this study knew 778 individuals who had died of AIDS throughout the AIDS epidemic, including 488 deaths reported at baseline and 290 deaths during the study period. Among those who had experienced any AIDS-related loss, the vast majority knew nine or fewer persons. Only 10 women reported 10 or more deaths: 7 of these women were current or former drug users and reported many losses of drug-using friends and partners; 1 woman's husband was a former drug user, and she had experienced his death as well as the death of many of his drug-using friends; and 2 women were health care providers who had experienced the deaths of many of their patients to HIV-related disease.

The goal in Tables 1 and 2 was to describe broadly how many women in this study were touched by the AIDS epidemic because they knew individuals with HIV and AIDS. Table 3 provides more information by clarifying the nature of these relationships. Although acquaintances account for a large proportion of losses, many of the relationships the women shared with the individual(s) with HIV/AIDS were close relationships. As shown in Table 3, nearly one half of the individuals the women knew were either spouses or partners, immediate family members, or close friends.

We compared the background characteristics of the women who knew someone infected with those of the women who did not know anyone infected using chi-square analyses and *t* tests. Table 4 shows the results of the chi-square analyses and presents the percentages of women with various background characteristics who said that they knew someone who was HIV positive, had experienced symptoms of AIDS, or had died of AIDS. Women of color were significantly more likely than Caucasian

women to know someone who was HIV positive, had experienced symptoms of AIDS, or had died of AIDS. Two of the three social class indicators were related to whether the women knew someone affected by HIV or AIDS: Women with less education and those not employed at the initial interview were more likely to know someone who had died of AIDS, and those not employed were more likely to know someone symptomatic with AIDS. Annual income was not related to knowing someone with HIV or AIDS. Women who had a history of drug use (heroin, cocaine, or both) were more likely than women without such a history to know someone infected with HIV or symptomatic with AIDS. The *t* tests revealed that older women were more likely than younger women to know someone who was symptomatic, $t(167) = -2.24, p < .05$, or who had died of AIDS, $t(167) = -2.96, p < .01$.

Prospective Analyses of the Mental Health Effects of Loss Due to AIDS

For the prospective analyses, two sets of analysis of covariance were conducted: One used depression and the other used anxiety as the dependent measure of mental health. To assess change in mental health as a function of loss, we statistically controlled mental health prior to the first instance of loss during the study period and made comparisons on depression and anxiety postloss. Five women who tested positive for HIV antibodies were not included in these prospective analyses because depression and anxiety associated with one's own diagnosis could influence the experience of AIDS-specific loss; none of the women reported the presence of any other life-threatening illness.

We considered including only those who had experienced no loss prior to the study period; however, because less than one

Table 4
Sociodemographic Characteristics of the Women Who Knew Individuals Who Were Infected With HIV, Were AIDS Symptomatic, or Had Died From AIDS

Sociodemographic characteristic	Value (n)	HIV positive			AIDS symptomatic			Died from AIDS		
		%	n	χ^2	%	n	χ^2	%	n	χ^2
Race				5.00*			14.16***			14.60***
Caucasian	89	46	41		39	35		60	53	
Of color	79	63	50		68	54		86	68	
Education				0.70			4.93			10.30*
<high school	30	60	18		67	20		90	27	
High school graduate	45	51	23		58	26		78	35	
Some college	45	56	25		42	45		58	26	
College degree	48	52	25		50	24		69	33	
Employed				1.12			6.81**			4.34*
No	86	58	50		63	54		79	68	
Yes	82	50	41		43	35		65	53	
Income				0.33			1.78			0.16
<\$6,000	53	51	27		60	32		74	39	
\$6,000–12,000	58	55	32		48	28		72	42	
>\$12,000	57	56	32		51	29		70	40	
Have used heroin or cocaine				7.38**			7.24**			2.76
No	90	44	40		43	39		67	60	
Yes	78	65	51		64	50		78	61	

* $p < .05$. ** $p < .01$. *** $p < .001$.

and women who were older were more likely to know someone with HIV or AIDS. These demographic characteristics reflect the epidemiology of AIDS—indicating similarities between those affected by the AIDS epidemic and those individuals most likely to become infected.

The personal documentation of C. S. Lewis's experience of bereavement in his book *A Grief Observed* may well describe the grief experienced by the women in our study following AIDS-related loss: "No one ever told me that grief felt so much like fear. I am not afraid, but the sensation is like being afraid" (1961, p. 1). The women in our study experienced heightened anxiety following multiple loss due to AIDS. Our findings are consistent with prior research indicating that anxiety is associated with the loss of social relationships (Baumeister & Leary, 1995; Zisook et al., 1990). That women with multiple losses experienced the greatest increase in anxiety following loss suggests that this type of grief reaction may become even more pronounced as the number of losses increases. This is consistent with the conservation of resources model of the adverse impact of loss spirals (Hobfoll et al., 1995). Cumulative losses in short time intervals may not provide the opportunity to resolve anxiety of a given loss before having to face another loss.

The scope, severity, and complexity of AIDS-related bereavement may indicate a need to reconceptualize grief in the context of the AIDS epidemic (Schwartzberg, 1992). In addition to the anxiety surrounding the loss of personal relationships, anxiety with regard to one's own HIV status may have contributed to the increased distress that followed AIDS-related loss. Also, features of HIV disease, such as the infectiousness of HIV, lack of a cure, and stigma associated with HIV, may have contributed to the heightened anxiety the women experienced following loss. Finally, those who are more anxiety prone may have been more likely to recall AIDS-related deaths, especially those not particularly close to the respondent (i.e., recall bias).

Studies of bereavement have documented the co-occurrence of mild or moderate anxiety and depression (Brier, Charney, & Heninger, 1985; Jacobs et al., 1990; Parkes & Weiss, 1983; Zisook & DeVaul, 1983). Although the women in our study experienced heightened anxiety following loss, they either had no persistent depressive response to AIDS-related losses or had resolved any such feelings of depression. Similar to the gay men in studies of AIDS-related loss (Kemeny et al., 1994; Martin & Dean, 1993; Neugebauer et al., 1992), it may be that the women in this study had adapted to AIDS-related loss on some level. It would be psychologically adaptive to inoculate against the effects of loss in some way, which may account for the limited effects of AIDS-related losses on depression.

Several alternative explanations are also possible. Anticipatory grief or anticipatory relief may also influence the mental health responses to AIDS-related deaths; the fact that AIDS-related losses are preceded by prolonged and debilitating illness may permit anticipatory acceptance of the loss. Although we could not address this issue directly, we did compare baseline depression scores with depression scores immediately preceding the first instance of loss and did not find these scores elevated. In addition, there was no difference in depression scores between individuals who had experienced AIDS-related losses prior to the study and those who did not. Measurement insensitivity may have contributed to this null finding; some investigators have

indicated that studies of bereavement should differentiate between grief and depression (Kemeny & Dean, 1995). Also, failure to statistically control for prior losses may have contributed to the lack of an effect of AIDS-related losses on depression. Finally, both depression and anxiety are influenced by many factors not measured in this study, including prior experiences with death; knowing others with HIV or AIDS, whether or not one was in the caregiver role; personality; coping styles; and social support.

This study was limited by the moderate sample size and our inability to restrict the type of loss to only close others (e.g., partner, close friend, or family member), as has been done in previous studies of men who have sex with men (e.g., Martin & Dean, 1993; Neugebauer et al., 1992). Nonetheless, type of relationship (close vs. casual) was included as a potential moderator in the examination of the effects of loss on both depression and anxiety and was not statistically significant. Moreover, the interaction between type of relationship and the number of losses was tested post hoc, and this interaction term also failed to reach statistical significance for predicting either depression or anxiety. That there was no difference in the emotional impact between close versus casual losses is important to note and may reflect the depth of reaction for individuals experiencing any AIDS-related loss (e.g., often someone similar with regard to age, race or ethnicity, and geographic proximity). By including all losses and analyzing the data prospectively, we took a conservative approach; if mental health effects were identified (as with anxiety), then this likely reflects a true emotional response to AIDS-related loss.

It must be reiterated that two thirds of the women in the study were recruited because they had sought HIV counseling and testing. Although HIV counseling and testing was statistically controlled in all analyses, this experience may have had an effect on the high rates of AIDS-related losses reported by the study participants and potentially on their emotional states.

There was no way to verify whether the individuals referred to as HIV positive early in the study period were also recategorized as being symptomatic with AIDS or dying later during the study period. Therefore, the specific numbers given for knowing people with HIV or AIDS should be interpreted with caution. Overall, at least one half of the study participants reported knowing someone living with HIV or AIDS, foreshadowing the future impact of the AIDS epidemic on the mental health and well-being of communities hard hit by the epidemic. Nearly three quarters reported knowing at least one person who had died from AIDS-related illness. All of the deaths reported by each respondent were verified to ensure that they were referring to unique individuals; this was most critical because the prospective mental health analyses were based on reported deaths due to AIDS.

In contrast to these potential limitations, this study had some notable strengths. The primary strength of this study was its longitudinal design, enabling the prospective evaluation of the mental health impact of AIDS-related losses. The cohort analyses provided the ability to examine the mental health impact of AIDS-related losses within a specific time frame by examining pre- and postloss values of depression and anxiety. This study extends previous research by including a diverse, community-based sample of women. As a group, the women in the study

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