Managing Grief in AIDS Organizations
Kitsy Schoen, LCSW

After more than a decade, cumulative losses have saturated the private and work lives of HIV service providers. Consequently, grief, traditionally thought of as a personal matter, must become a concern of organizations. Many workplaces, however, are largely unprepared for coping with multiple loss and are suffering from complications associated with grief. The strategies outlined in this article suggest ways organizations can cope with chronic loss and minimize the destructive consequences of grief.

Sources of Grief

Grief and loss are not new issues, especially in human service and health care settings. Yet in AIDS organizations, a combination of factors contribute to the exceptional role of grief and its intensity. First, the exponential growth in the numbers of cases of HIV infection and deaths and the routes of HIV transmission have both resulted in the concentration of losses within families, friendship networks, and communities. Second, the high numbers of organizational staff—and their friends—and volunteers who have HIV disease is unusual among health care agencies focusing on specific diseases, such as cancer or heart disease. Third, staff members often rely heavily on co-worker support to counteract the stresses of HIV caregiving, and the illness or death of a co-worker becomes a source of additional grief. All of these conditions combine to create chronic traumatic stresses, and HIV organizations of all sizes—from large agencies to private mental health and medical practices with small staffs—are in effect, “grieving organizations.”

Why have so few HIV service organizations addressed grief related stress? A large part of the answer lies in the cultural relationship to grief in the United States. The grieving process is poorly understood, largely invisible, and its impact minimized. There is little precedent in the workplace for addressing personal issues, especially ones as profoundly personal as grief. Some managers have feared that, if they addressed grief directly, they would be opening a Pandora’s box of uncontrolable emotions and the expectation that they will provide employees support for other personal issues. They have also been concerned that grief support would require unreasonable amounts of time, money, and other resources. Finally, many HIV service organizations have been in the early stages of development and have only now been able to attend to the pressures of constant loss.

The Dynamics of Loss Saturation

Organizations experience the effects of grief at all levels: among individuals, within groups, and pervasively throughout the organization. The symptoms of loss saturation in organizations closely parallel the impact of grief on individuals. Most can be attributed to the emotionally and physically draining nature of grief, the lack of acknowledgment and support for the grieving process, and feelings of helplessness, rage, and survivor guilt.

Responses to loss—anticipatory grief, bereavement, and trauma—are all complex experiences that change over time. Sometimes their impact is obvious, immediate, and compelling. At other times, they are like an undertow, exerting a powerful but invisible influence. A wide range of sometimes conflicting feelings are a normal part of the grieving process. They include:
Editorial: Enduring Grief

Robert Marks, Editor

Grief is so much a fact of life for those of us working in the midst of the epidemic that we hardly ever consider it. It is like the chemicals in the air we breathe. Almost imperceptible most of the time, on those odd days when atmospheric conditions are right we notice the grime and odor just long enough to feel slightly queasy. The typical response to smog, as to grief, is to hold your breath for a moment, perhaps duck inside, and acclimate. Before you know it, it’s gone. Well, not really—just hidden by better weather and denial.

Like smog, grief continues to take its toll, causing anxiety, depression, and burnout among HIV workers whether or not we notice it. But in these times of deficit spending, many of us—staff and employers—perceive emotional needs as a luxury easily sacrificed to the pressure of the burgeoning epidemic. The irony is inescapable. It is the fundamental premise of HIV-related work that, especially in times of crisis, the emotional response deserves as much attention as the physical reality. In order to continue to serve clients and patients effectively, HIV workers and organizations must respond to grief.

Acknowledgment

It is no wonder that Kitsy Schoen emphasizes the importance of acknowledgment in responding to grief and its hidden effects. Jerry Santek and Michael Kuller prove Schoen’s point in descriptions of their organizations’ responses to grief among staff: a plan that acknowledges grief and provides practitioners with support reduces burnout and turnover. And an item in this month’s Recent Reports section examining a proposal for an AIDS organization staff plan suggests that responding to burnout may make good economic sense.

There is no lack of sympathy for organizations—from large service agencies to the small offices of private practitioners—struggling to deliver care in an environment of scarcity. But how long can it all last when organizations passionately work to make up for the lack of resources by making staff a supernatural resource, when they seek to rise above scarcity by becoming abundance itself?

The most effective response to grief is not in doing more work, but, clearly, in stepping outside of work. In order to make the extraordinary efforts the epidemic requires, individuals, communities, and, perhaps chiefly, organizations must respond to grief and burnout. This response must be ongoing and prophylactic—attending to past and present grief and anticipating future loss. In the end, grief, not death, is the most enduring aspect of the epidemic: unattended, it is like smog, eventually choking you or forcing you to move on.

sadness, despair, relief, loneliness, anger, elation, emptiness, guilt, meaninglessness and meaningfulness. Three concepts are particularly important in characterizing loss saturation: unresolved grief, survivor guilt, and post-traumatic stress. Unresolved grief often plays a substantial and hidden role in organizational problems such as reduced productivity, low morale, increased conflict, absenteeism, increased turnover, difficulty setting limits, and inadequate attention to positive feedback and informal support. These problems become more deeply entrenched when employees believe it is unsafe or unprofessional to mention the hard-to-manage feelings associated with grief.2

Survivor guilt is another powerful but largely invisible phenomenon. For most people, it is difficult to reconcile personal well being with the dire circumstances others face. HIV disease, because it is so serious and, in some areas, so pervasive, evokes a particularly stark contrast between those who are infected and those who are not. The urge to create a more equitable balance between the poles makes it difficult for some individuals and work groups to set limits or take adequate care of themselves, causing them, for example, to overwork. The result is a state of sympathetic “dis-ease.” It is also typical for loss saturated organizations to focus less and less on the positive aspects of work, including positive feedback and acknowledgment, celebration of life events, and activities that nurture staff members.

The post-traumatic stress model is helpful in understanding another common dynamic experienced in loss saturated work environments. According to this theory, individual reactions to trauma swing between adaptive numbing and a flooding of feelings. In the workplace, this frequently leads to tension between those at opposing ends of the spectrum and to accusations that some are “over involved,” and others are “jaded and burned out.” This dynamic is often reflected in conflicts between new and old staff, direct
and indirect service providers, and sero-positive and seronegative staff, or along social divisions of gender, class, and race.

Planning a Response

To respond to these pressures, organizations must create a culture that openly acknowledges the presence of grief and gives permission to staff to express a range of reactions to loss. This is most effectively accomplished through a planning process that seeks to develop ongoing and easily maintained strategies aimed at both day-to-day operations and formal structures, policies, and benefits.

The main hurdle to achieving these goals is gaining recognition that grief-related issues are appropriate and important for an organization to address. Once this is accomplished, a straightforward planning process—in itself an intervention, since it acts as a formal acknowledgment that grief has an impact on work—can be employed to develop strategies tailored to the specific needs of the work site.

An assessment is the first step of the planning process. The assessment seeks to: define the problem; identify confounding organizational issues, such as changes in structure; begin to clarify staff expectations of the organization; and provide baseline data for evaluation purposes. In defining the problem, it is helpful to note trends related to demographics, departments, or job classifications. For example, direct service providers may be particularly vulnerable to distress, or there may be departments where staff—responding to personal or workplace losses—may be more subject to loss saturation.

Developing a training program, the second step, can lay the groundwork for understanding and discussing grief in the workplace. The primary objective of training is to impart an appreciation of the range of “normal” responses to loss and experiences of grief, and to explain why people react differently. Sometimes it is helpful to offer training to supervisors first because of their central role in creating a supportive environment. Ultimately, an all-staff training is necessary, because it serves as a collective acknowledgment of loss and creates a common framework for discussion and strategy development.

Strategies for Addressing Grief

The training process sets the stage for developing strategies in four categories: identifying ongoing ways to acknowledge losses; providing support for a range of grieving experiences and needs; making changes in policies and benefits; and creating mechanisms to acknowledge appreciation of staff. Strategies need to address all levels of the organization and should take place in many arenas, including during all-staff meetings, within individual departments, and through committees of staff representatives.

Acknowledge Loss. The ongoing acknowledgment of loss reminds staff that there are external sources of psychological distress and minimizes the tendency of staff to blame themselves, others, or the organization for this distress.

Support strategies seek to create opportunities for “debriefing,” that is, expressing emotions associated with loss and illness. Different coping styles require different support strategies. While informal support may occur spontaneously among employees—especially...
when loss is frequently acknowledged in the workplace—many employers will have to develop more formal strategies.

“Support groups” are useful when carefully facilitated and focused on the content of work and its relation to grief, and not on other organizational issues. They must also allow for various styles of participation. When only a portion of the staff is involved in support groups, the workplace may become divided between those attending and those not attending. A monthly “team building” session, including all staff members, is an effective alternative to support groups. Some work sites offer a paid hour off each week for staff to pursue their own forms of support—ranging from individual therapy and 12 step programs to exercise routines. Others sponsor on-site stress management, grief support, and relaxation programs to meet a range of staff interests and needs.

Assess Personnel Policies and Benefits. Changes in personnel policies and benefits are important not only for their tangible outcomes, but also because they incorporate an employer’s acknowledgment of grief into the culture of the workplace. This commitment helps sustain the changes initiated by the planning process.

Design specific personnel polices to offer support and to accommodate the acute and chronic stresses of grief. Redefine bereavement leave and dependent care leave policies to be inclusive of non-traditional family members and friends, or to be used at the discretion of employees. “Planned sick leave” or “mental health days” give staff an opportunity to take time off when feeling overwhelmed, and allow employers time to plan for staffing. “Flex time” not only helps grieving employees adjust their work schedules, but also gives them more control over the conditions of work, a critical factor in minimizing burnout.

Formalize Staff Appreciation. Individuals and organizations need to balance the constant strain of loss by deliberately creating opportunities for positive interactions among staff. Identifying times for staff members to come together informally during lunches and outings, for instance, helps build trust and good will. Staff also need regular opportunities to talk about their accomplishments and goals and to receive feedback from supervisors and co-workers. Without such efforts, the interpersonal life of an organization can become bleak.

Once it is developed, distribute a description of grief-related strategies to new staff during orientation and to old staff at yearly personnel reviews. Continually evaluate the strategies, first at three to four months after implementation, and then at regular intervals, either semi-annually or yearly. Periodic evaluations help sustain grief interventions and adjust them to changing needs of staff members and the organization.

Conclusion

It may be surprising that such a simple approach can really help organizations cope with grief and loss. While this process cannot change the magnitude of grief within AIDS organizations, acknowledgment of loss and support of employees makes the difference between a well-functioning organization and one diminished in effectiveness. By bringing difficult feelings into the open and implementing concrete solutions, employers and staff can understand the appropriate place of grief in AIDS work and get beyond the barriers of unacknowledged emotion.

References

1. Many of the concepts discussed here were first presented in Macks J, Bidgood R, Schoen K. Managing grief and loss in the Workplace. VI International Conference on AIDS, San Francisco, June 1990.


Authors

Kitsy Schoen is a therapist in private practice and a partner with JKRAssociates, specialists in managing grief and loss in the workplace. Ms. Schoen has worked in HIV, hospice, and bereavement care since 1984.

Clearinghouse: Organizational Grief

This Clearinghouse reflects the fact that little has been published on HIV-related grief among mental health and health care professionals.

References


Macks J. Sustaining professional AIDS caregivers and their organizations. In Land H, ed. AIDS Interventions and Response from the Human Services.


Scott CD, Jaffe DT. Managing occupational stress associated with HIV
Organizations Respond to Grief

Theory and practice may be difficult to reconcile. To balance Kitsy Schoen’s theoretical article with examples of practical experience, we have asked two AIDS workers—one from a non-profit agency and the other from a for-profit company—to describe how their organizations have responded to grief among employees.

SF AIDS Foundation
Jerry Santek

The San Francisco AIDS Foundation was among the first agencies established in response to the AIDS pandemic. It has 58 paid staff, a volunteer base of 350, and focuses its efforts on direct client services, education, and public policy. When it became clear that the deaths of clients, volunteers, colleagues, and friends was affecting staff productivity, morale, and retention, the foundation empowered a staff committee to examine the effects of grief and loss in the workplace.

The committee found that staff consistently responded to the illness or death of a colleague by taking on increased responsibilities, failing to set limits, working longer hours, and only reluctantly taking time off. As work load increased, so did stress. When stress levels peaked, staff members often blamed managers, coworkers, and clients. This contributed to discord among staff, heightened conflict with managers, prompted staff turnover, and diminished morale.

Staff Recommendations
In response to their findings, the committee recommended that the entire staff meet to discuss issues of grief and loss so that they can learn from their experiences and develop appropriate coping skills. There was some reluctance to participate among staff who believed their work was not affected by grief or who felt that the issue was a personal one. However, the meeting was deemed mandatory.

During the meeting, staff assessed the impact of grief on the agency, agency departments, and individuals, and proposed steps the agency as a whole and staff members as individuals should take to manage grief. Suggested agency steps included increasing leave time, creating a staff lounge, and instituting monthly staff socials; individual steps included setting work limits, allowing for quiet time during the day, and bringing flowers to the office.

Interventions included increasing leave time, creating a staff lounge, and instituting monthly staff socials.

Implementation
Of the top 10 suggestions made at the staff meeting, most have been implemented. Suggestions that required foundation action—such as increased vacation and mental health leave—have all been implemented. However, suggestions that required individual staff initiative and commitment—such as creation of a memorial board or scrapbook—have not been implemented. This result is particularly

See also references cited in articles in this issue.


Contacts
CareGivers Project, 88 First Street, Suite 502, San Francisco, CA 94105, (415) 243-8520. Provides a special four-day “Caregivers Renewal Course” directed at volunteers and professional caregivers to promote healing from burnout. Although located in the Bay Area, the project has presented the course throughout the U.S. and in other countries.
Gay Men’s Health Crisis, 129 West 20th Street, New York, NY 10011, (212) 807-6664. Conducts grief and healing workshops for caregivers as well as open-ended therapy groups.
JKRAssociates: Specialists in Managing Grief and Loss in the Workplace (Judy Macks, Kitsy Schoen, Rick Bidgood, Alan Emery), 2261 Market Street, Suite 284, San Francisco, CA 94114, (415) 621-1898.
Kairos House, 114 Douglas Street, San Francisco, CA 94114, (415) 861-0877. An organization that focuses on care for professional AIDS caregivers. Sponsors a group called “Pacing Ourselves” that lasts eight weeks, and offers on-site presentations and assistance in planning and facilitating staff retreats to alleviate burnout.
interesting because staff identified individual steps as “personal priorities.”

A year after the initial staff meeting, the committee surveyed reaction to the changes that had taken place. Of the 41 staff members who responded, 35 felt that an appropriate amount of money was allocated to these interventions. The majority felt supported by the agency in addressing grief and loss in the workplace, and reported better working relationships, increased productivity, fewer incidents of worker burnout, and improved staff morale.

In pursuing next steps, the agency will address department-specific mechanisms for coping with loss. To accomplish this, directors will evaluate strategies for managing issues that are unique to their departments.

Critical Care America
Michael Kuller

Critical Care America is a for-profit health care company that offers an alternative to hospitalization by providing home-based infusion therapies to patients, particularly those with HIV disease. During infusion, specially trained intravenous (I.V.) nurses provide assistance and support to patients receiving nutrition, drugs, or fluids.

Critical Care America (CCA) designed its HIV Care Program with the special needs of HIV-infected patients and their caregivers in mind. Both patients and caregivers face a stigmatized, life-threatening disease with an array of treatments that enhance quality of life but do not forestall death. In this context, CCA caregivers often experience grief and its associated stresses after losing patients whom they have come to know well. In 1989, CCA responded to this situation by making psychosocial support for patients an integral part of the HIV Care Program, and extended this support to caregivers to help reduce burnout and turnover.

Organizational Stresses

In the Bay Area, psychosocial support for the staff was provided through a facilitated biweekly support group. Although attendance was voluntary, most of the nursing staff chose to participate and found it to be valuable. In early 1991, two events changed this situation: the group facilitator left and CCA merged with two former competitors.

In response to these events, CCA's full-time social worker—who works with the company’s patients—suggested that we contract with a consultant who had expertise facilitating staff support groups and experience with grief in the workplace. The new facilitator began by assessing employee concerns using a confidential questionnaire. The facilitator found that many employees had strong feelings about the merger and that these were becoming confused with grief related to patient care. In addition, many of staff members were found to be experiencing significant changes in their personal lives, including dealing with sick and dying friends and family members. These seemingly unrelated issues were intermingled and created additional stress that was affecting productivity.

Providing Support

Through a series of meetings and workshops, the facilitator addressed the issues concerning staff members. Using these sessions as a springboard, the facilitator then established ongoing biweekly staff support group meetings. The meetings—held on company time in the morning before regular work hours—have been well attended by clinical and office staff.

The comments of one nurse illustrate the value of this type of support. In her busy day, running from patient to patient, she is not able to take time to deal with the grief she experiences. To her, the support group is an acknowledgement by the company that it is difficult to provide care to sick and dying patients. It offers her an opportunity to express her feelings in a supportive environment, and a chance to improve communication with her co-workers. Were these benefits not available, she feels, she would not be able to continue this type of job.

Comments and Submissions

We invite readers to send letters responding to articles published in FOCUS or dealing with current AIDS research and counseling issues. We also encourage readers to submit article proposals, including a summary of the idea and a detailed outline of the article. Send correspondence to:

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Normal and Abnormal Grief
Fawzy FI, Fawzy NW, Pasnau RO. Bereavement in AIDS. Psychiatric Medicine. 1991; 9(3): 469-482. (UCLA School of Medicine.)

The stigma associated with AIDS has led to the compromise of social support and effective rituals for those grieving the deaths of people with HIV disease, according to a comprehensive review of bereavement theory and HIV-related grief. The result is that this group of people—including people with HIV disease, and their friends, partners, family, and health care workers—is at greater risk for abnormal or complicated bereavement behaviors.

Normal bereavement reactions tend to move in stages and have been described by several theorists. Lindemann, noting that grief is a syndrome with psychological and physical symptoms, included among these stages a preoccupation with thoughts about the deceased, feelings of guilt, anger, and hostility, and changes in customary social interactions. Bowlby defined the primary task of bereavement as emotional withdrawal from the person who has died so that new relationships can be formed. This is achieved by expressing anger at those who seem to be responsible for the loss. According to Engel, shock and disbelief, are followed by a growing awareness of the loss, and restitution and recovery, a process that takes at least six months.

Abnormal bereavement reactions are maladaptive exaggerations of normal grief behaviors. Unresolved grief has at least nine manifestations, including intensified psychophysiologic reactions, changes in social interactions, detrimental activities affecting social and economic realities, intense hostility, repression of hostility resulting in a "wooden or formal" manner, assuming the symptoms of the deceased person's last illness, and deep depression.

Health care workers who treat patients with HIV disease are at particular risk for abnormal bereavement. A terminal prognosis forces caregivers to confront their own death anxieties. The ongoing loss associated with HIV disease may result in emotional exhaustion, and the lack of effective treatment and palliative procedures may lead to a loss of self-esteem among caregivers. This may be exacerbated by guilt about irrational fears of HIV transmission if caregivers believe they have failed to provide the same care they have provided to other terminal patients.

Worden's 10 principles of grief counseling can be adapted for use with AIDS-related bereavement. Key elements of this model are expression and acceptance of all the feelings associated with loss, aiding the survivor to let go and live well without the deceased, and provision of ongoing support for positive coping mechanisms.

The Cost of Burnout
Soos J. Caring for the AIDS caregiver: An evaluation of staff burnout at Shanti Project and a benefit-cost analysis of the "Staff Care Plan." Master's thesis. University of California, Berkeley, 1991. [To request a copy: write or call James Soos, 4611 18th Street, #1, San Francisco, CA 94114; 415-861-8729.]

A cost-benefit analysis of a "Staff Care Plan" for a San Francisco-based AIDS service organization found that the plan is likely to meet its objectives of reducing burnout and being cost-effective, despite a projected cost of as much as $157,000. The Shanti Project is a volunteer-based agency with a staff of 61 that provides emotional and practical support to people with AIDS and their loved ones. In 1990, the agency considered a Staff Care Plan to reduce the costs of occupational burnout. Burnout affects health care professionals in particular because their jobs involve emotional involvement with clients, lack of adequate time to grieve losses, and large case loads. In addition, for AIDS caregivers, strong identification with clients blur the distinction between patient and caregiver.

The cost of occupational burnout to the Shanti Project is projected to be in a range of $39,234 to $157,357. This estimate was derived by measuring absenteeism, workers' compensation premiums, job turnover rates and the resulting replacement costs, and productivity losses. In 1990, absentee rates were 3.2 to 3.6 days in excess of the national average. Job turnover was 25 percent in 1989 and 34 percent in 1990, 6 to 15 percent higher than nurses, the closest comparison group. Since Shanti's salaries and benefits compare favorably with other non-profit organizations in the area, low remuneration was not a factor in burnout. In such cases, management...
styles and organizational structure are among factors that may need to be examined as possible contributors to burnout.

A telephone survey of seven other large AIDS service organizations determined that liberal leave and vacation policies, employee support groups, and management training ameliorated the staff burnout problem. The Staff Care Plan incorporates these elements and others including: an optional four-day, 40-hour work week; encouragement to use full vacation time each year; support groups and grief circles; in-house publication of death notices; staff retreats; breaktime walking groups; and staff meetings to discuss burnout prevention.

The plan’s costs—estimated to be between $27,354 and $180,045—suggest that it would be cost-effective, and as measured against theoretical literature regarding burnout interventions, likely to meet its objectives.

**Stresses and Rewards of AIDS Volunteering**


Australian researchers developed scales to measure levels of stress and reward experienced by HIV support volunteers, and many items in the scales may be relevant to professionals caring for people with HIV disease. Stress and reward levels were positively correlated to each other, suggesting that a high level of emotional involvement may lead to both responses.

Volunteers from several Australian AIDS organizations compiled lists of stresses and rewards they derived from the volunteer experience. Volunteers rated each item in terms of importance, and researchers evaluated the final scales for consistency. To assess consistency with established measures of stress and coping, 72 HIV volunteers responded to three instruments: the new scale, the Maslach Burnout Inventory (MBI), and the General Health Questionnaire (GHQ), which measures psychological and social health.

Thirty-one of the scale’s items were grouped under four major areas of stress: emotional overload, client problems, lack of support, and lack of training. Respondents rated the emotional overload factor as the most stressful and the three other factors as significantly less stressful. Several psychosocial factors predicted high stress levels, including the lack of a support network, the coexistence of other sources of stress, the length of volunteer service, and, especially, the number of client deaths experienced.

Thirty-six of the scale’s items were grouped under four major areas of reward: personal effectiveness, emotional support, social support, and empathy/self-knowing. Respondents rated personal effectiveness highest. Being seropositive, and having support, particularly group support, were predictors of higher reward scores. The surprising positive correlation of stress and reward scores suggests that organizations should consider the level of positive, as well as negative, response when evaluating support and relaxation needs of caregivers.

There was a low, but positive, correlation between the stressor scale and both the GHQ and the MBI. In addition, there was a relatively high internal consistency among the 31 stressor items. These results taken together suggest that the scale measures components of stress experienced by AIDS volunteers, but that these components are not adequately measured by the GHQ and the MBI.
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