AIDS mourners, and those who seek to assist them, face an ever-changing landscape of cultural and individual meanings related to the nature and social implications of HIV disease and the losses associated with the epidemic. These meanings profoundly affect an individual’s response to loss and the success with which he or she resolves grief. The process of finding meaning in AIDS grief is facilitated by a well-grounded, comprehensive view of AIDS bereavement, a perspective that takes into account the historical and cultural contexts of AIDS bereavement and the individual psychological processes affecting AIDS mourning and grief. The Integrative Model of AIDS Bereavement proposed by this article provides such a perspective and is a useful basis for AIDS bereavement education, counseling, and psychotherapy.

The Integrative Model is based on empirical research, theory, and clinical observation related to both AIDS and general bereavement. This model is designed to help clinicians evaluate the type and level of bereavement distress experienced by an AIDS mourner. Based on this assessment, there are a range of bereavement activities and interventions that can be matched to the particular manifestation of AIDS bereavement for each mourner. Finally, the integrative model proposes a psychotherapeutic approach—Integrative AIDS Bereavement Therapy—that combines psychodynamic and cognitive behavioral therapy.

The Grief Process: Phases and Tasks

Several psychodynamically oriented authors have described grief as a process that can be understood in terms of phases or tasks. While these models are helpful in educating mourners as to what to expect during the process of grief and in identifying those mourners who are somehow blocked in resolving their grief, several cautions apply to these findings. First, Stephen Shuchter and Sidney Zisook admonish, "Grief is not a linear process with concrete boundaries, but rather a composite of overlapping, fluid phases that vary from person to person." Second, Camille Wortman’s research indicates that a sizable minority of mourners is able to manage the course of grief with little or no bereavement distress.

John Bowlby developed a comprehensive theory of the process of attachment formation and the psychological reaction to separation and loss. Bowlby suggested that over the course of weeks and months, bereaved individuals typically move through a succession of four phases: shock and numbing; yearning and searching; disorganization and despair; and greater or lesser degrees of reorganization. These phases overlap and individuals may oscillate back and forth between any two. The duration of these phases of grief is dictated largely by personal values and cultural norms. Bowlby believed that “complicated grief” is best understood as an exaggeration or distortion of the normal process of grieving. Bowlby discussed two particularly relevant variants of complicated grief: “absent grief” and “chronic grief.” In his view, the absence of grief often indicates an impeded mourning process, usually stemming from conscious or unconscious psychological defenses. Chronic grief involves the undesired persistence of grief reactions, including shock, yearning, searching, disorganization, and despair. In the most severe form of chronic grief, painful memories and thoughts intrude into consciousness and interrupt occupational and social functioning.

J. William Worden—basing his theories
Editorial: The Normalizing of Grief
Robert Marks, Editor

My first inclination as I sit here is to tell you that people are still dying and that understanding grief and loss is crucial to understanding AIDS. It’s a little strange that after 20 years of death, we as a community find ourselves in an optimistic rush: four years of plunging death rates. Leaves you wondering what’s to mourn. But you don’t need to fear the worst about antiviral treatment—that its success won’t last over time and that many are now facing treatment failure and severe side effects—to understand that people continue to die or that grief can be forever.

Last week, at the AIDS Health Project staff meeting, the mood was more somber than usual. One social worker told the story of a group he facilitates, the youngest member of which is the most seriously ill. All I could think of was this man’s decline and the sadness and anger of his peers who feel marginalized in a world that seems to have closed the book on AIDS (how much more despairing must people in Africa feel upon hearing news reports on the epidemic from richer countries?). Perhaps the saddest thing is that for most of the epidemic, we shared our grief; it was a community experience, even for a while, a national one. Now, at a time when we might mix joy into the sorrow, we find that the experience of living in the epidemic is no longer unified and we can share neither.

Back at the staff meeting, someone announced that a former staff member was in the hospital battling lymphoma. At the end of the meeting, one of our trainers got up and presented a 50-foot paper timeline that agency staff had created in 1997 showing the course of the epidemic and which was annotated with memories from staff members and training participants who had added to it over the past two years. Grief is our history and grief is our future.

But as Peter Goldblum and Sarah Erickson suggest in this issue of FOCUS, for most people, the process of grief follows a “normal” course toward resolution or at least accommodation. Based on their recently published AIDS Health Project Monograph, Working with AIDS Bereavement, their contribution is a conceptualization of what factors threaten this normal process and how mental health providers can anticipate complicated grief and help clients respond to it.

There is no denying the hope that one day the history of AIDS death will dim (although perhaps only in time to be restimulated by the normal endings of old age). The optimism is tantalizing and worth grasping, for it is based on the undeniable reality of renewed health for many people. But it cannot erase the facts that people continue to die today and that their lineage is the equally compelling reality of multiple and unending loss.

References

Psychological Mediation of Grief

Mardi Horowitz proposes a phase model of grief in which certain processes must occur to facilitate assimilation, accommodation, and healthy resumption of living in the aftermath of a stressful life event. Horowitz suggests that in order to cope adequately with an extreme stressor, an individual must resolve the personal meaning of the traumatic event. For the individual to return to pre-traumatic levels of functioning, this resolution must include coming to terms with the implications it has for interpersonal relationships, self-image, and behavior. According to Horowitz, when individuals experience a death of a loved one, they are forced to revise their “core models” of themselves, their role relationships, and their future plans. This reorganization process takes time, and according to Horowitz, is related to some of the disorientation of mourning.

on Bowlby’s work—proposes four tasks of mourning that he suggests must be accomplished before mourning is complete. The notion of tasks of grief has an advantage over the idea of phases, because tasks offer active guidance toward behavioral change and emphasize intentional actions on the part of the mourner to complete the process of grief. Having a positive focus and direction for managing grief can be enormously comforting to mourners.

Worden’s tasks are: to accept the reality of the loss; to experience the pain of grief; to adjust to an environment in which the deceased is missing; and to withdraw emotional energy from the deceased and reinvest it in another relationship. Because Worden’s model is based on his work with bereaved spouses, the fourth task is not appropriate for all mourners, for example, family members. In such cases, the fourth task might be better conceptualized as “beginning or returning to avenues for personal growth and expression.” Consonant with the view of grief as a process, the Integrative Model defines “normal” or “uncomplicated” grief as the adequate management of the grief process, in which mourners successfully move through the phases and tasks of mourning consistent with their own values and cultural norms.
Horowitz also made observations and explanations of a typical pattern for mourners: that is, the vacillation between times of cognitive and emotional intrusion and times of psychological suppression of these disturbing thoughts and emotions. The extent to which a person allows thoughts, memories, or emotions to emerge into consciousness depends on the nature and effectiveness of internal control mechanisms. In healthy responses to bereavement, the mourner is able more or less to accommodate both states of emotional arousal and emotional withdrawal until grief is “worked through.” In grief that has gone awry, the modulation of these states is faulty, characterized by either emotional overwhelm or extreme avoidance, sometimes referred to as psychic numbing.

Coping with the Stress of Grief

Susan Folkman applies cognitive psychology theories of stress and coping to the understanding of both general and HIV-related bereavement. Folkman’s framework views the loss of a loved one as a stressful event, that is, “one that involves a relationship between the individual and the environment that is appraised by the individual as personally meaningful and as taxing to personal resources.” In this view, loss causes stress when an individual perceives that the demands placed upon him or her by the loss outweigh the resources that he or she has to cope with the situation.

A key concept in stress and coping theory is appraisal. Appraisal refers to the cognitive evaluative process that imbues a situation or event with meaning in terms of an individual’s well-being. Appraisal can be separated into those perceptions that concern the recognition of jeopardy —evaluating whether a danger is irrelevant, threatening, or as having already occurred—and those that concern the availability of resources for managing potential or actual harm. A second core concept in Folkman’s model is coping. Coping is a process by which the individual changes cognitive or behavioral responses to manage the specific demands that are appraised as stressful. Coping has two major functions: to manage or change the problem that is causing the distress (problem-focused coping) and to regulate emotional responses to the problem (emotion-focused coping).

The Integrative Model and Assessment

The Integrative Model of AIDS Bereavement synthesizes and applies these psychological theories in the context of three other factors: the history of the epidemic, including the forces of stigma and isolation and the sheer numbers of deaths that have accumulated over time; the role of culture and custom in determining individual responses to death, mourning, and bereavement; and the philosophical phenomena—secular and spiritual conceptions of life and death—that operate as clients strive to find meaning and cope with loss. A central tenet of the Integrative Model is that bereavement distress is not a single entity. Therefore, effective treatment requires precise assessment in order to define and address a mourner’s particular concerns.

To apply the Integrative Model, the clinician first considers whether a client is currently experiencing uncomplicated grief or complicated grief with or without co-existing clinical disorders. To make a diagnosis of complicated grief, clinicians apply the criteria articulated within the Integrative Model: that is, that the mourner is experiencing an atypical intensity (overly numbed or overly intrusive) or duration (absent or chronic) of grief symptoms (shock, numbness, yearning, searching, disorganization, despair), that has led to an unacceptable level of functional impairment in critical areas of work and relations.

Next, clinicians must distinguish AIDS grief from other forms of mental disorder. While grief reactions—both complicated and uncomplicated—share symptoms with a variety of mental disorders (for example, affective disorders, post-traumatic disorders, and other anxiety disorders), recent clinical studies indicate that these disorders can be reliably distinguished by using a criteria-based definition for complicated and uncomplicated grief and standard psychiatric diagnostic procedures. It is important to keep in mind, however, that grief reactions may co-exist with psychiatric disorders.

Finally, the clinician reviews bereavement risk factors to determine the likelihood of a mourner developing bereavement complications in the future or—in a case where complicated grief already exists—exacerbating current bereavement distress. The identification of specific risk factors for AIDS bereavement distress both signals the need for bereavement interventions and directs the clinician toward the appropriate type and focus of intervention.

Risk analysis in the Integrative Model for AIDS Bereavement divides risk factors into two categories: “bereavement burdens” and personal impediments to coping.
Bereavement burdens include: being HIV infected; being a caregiver, primary partner or spouse, or parent; perceiving interpersonal conflict or a lack of social support; experiencing accumulated stressors (including multiple loss); being young, and experiencing difficulty resolving a relationship with the deceased. Personal impediments to coping include: the tendency to engage in ineffective and avoidance coping; the tendency to over-engage in self-focused attention; the tendency to experience guilt and lowered self-esteem; the tendency toward negative thinking; and current substance abuse or dependency.

In interpreting the diagnostic value of any of these risk factors, it is important to note that single factors typically do not predict specific negative bereavement outcomes. Concern should be heightened by both the magnitude of each risk factor and the number of risk factors identified. It is also important to understand how risk factors relate to each other. This is especially true in terms of the overall relationship between bereavement burdens and personal impediments to coping.

Based on the information gathered in AIDS bereavement assessment, the clinician can categorize individual mourners into four levels of bereavement distress: uncomplicated grief; uncomplicated grief with risk factors; complicated grief without clinical disorder; and complicated grief with clinical disorder. Understanding these levels and their defining criteria prepares clinicians to provide the types of interventions that will be most helpful to clients.

While in most cases of AIDS bereavement individuals are able to manage the emotional and physical impact of grief with the support of their friends, family, and community, clinicians may be called upon to assist people at every level of bereavement distress. The Integrative Model identifies four bereavement activities that may be applied differentially to specific levels of bereavement distress: bereavement education and support, bereavement risk reduction counseling, grief therapy, and psychiatric treatment.

Educational Support and Risk Counseling
Bereavement education and support is helpful to mourners at all levels of bereavement distress and may be delivered in a variety of venues. Through written material, conversations with friends, one-on-one counseling, or support groups, AIDS mourners learn about the universal nature of bereavement and the unique aspects of AIDS bereavement. They also learn about the signs of bereavement distress, the definitions of effective coping strategies, and ways to find bereavement activities and services in their community. A variety of AIDS bereavement support group formats—professional and self-help; time-limited and open-ended—may assist AIDS mourners.

Bereavement risk reduction counseling—both individual and group—focuses on mitigating factors that place mourners at risk for bereavement distress. Risk reduction counseling needs to take into consideration the two types of AIDS bereavement risk factors: bereavement burdens and personal impediments to coping. Once a clinician identifies a mourner as being at risk for bereavement distress, he or she should teach specific coping-oriented strategies to mitigate the relevant risk factor.

Individuals come to the tasks of grieving with different levels of personal coping competency and personal problems. An individual's pre-existing ability to cope with stress is the best predictor of bereavement outcome. For example, one study

References
Nolen-Hoeksema S, McBride A, Larson J. Rumination and psychological dis-
correlated success with the ability to maintain a fighting spirit, to reframe stress in terms of personal growth, to sustain social support, and to plan a course of action.6

In an intervention called Coping Effectiveness Training, developed by Susan Folkman and her colleagues at the UCSF Coping Project, group facilitators focus on two processes to mediate stress: appraisal and coping. Clinicians teach participants to fit the coping strategy to the characteristics of the stressful situation. For example, if a mourner has a solvable problem, such as financial difficulties, clinicians encourage “problem-oriented coping” strategies. For clients responding emotionally to situations outside of their control, clinicians teach “emotion-focused coping,” for example, relaxation techniques.10

Psychotherapy and Psychiatric Interventions

There are two major variations of grief-related psychotherapy: problem-oriented approaches and psychodynamic approaches. Problem-oriented approaches emphasize specific behavioral changes to relieve the pain of complicated grief. Psychodynamic approaches view complicated grief as blocked or unresolved grief and assist the client in understanding and resolving underlying reasons for the blockage.

Time-limited, problem-oriented psychotherapy—focused on facilitating the tasks of grieving and on mitigating any risk factors—may be helpful to clients experiencing complicated grief, with or without co-existing mental disorders. Shuchter and Zisook suggest that rather than viewing the goal of bereavement therapy as the resolution of psychological attachment to the deceased, which may take several years, grief therapy should address specific grief-related problems with the understanding that the client can return if additional problems arise in the later stages of bereavement.11 One problem-oriented strategy is the therapeutic use of rituals, a formal activity that provides a structure—a time and a place—to honor important losses.

The primary goal of psychodynamic grief therapy is symptom reduction.12 This is accomplished through the mitigation of an individual’s need for psychological defenses against awareness of ideas and images that lead to stress and intolerable emotional states. Therapy accomplishes this goal by helping mourners consciously connect their thoughts and memories of the stressful event with their associated emotional responses. For clients who tend to “over-control” their awareness of their inner life, thus experiencing emotional numbing, the therapeutic task is to encourage a re-experiencing of grief; for those who experience intrusive-repetitive thoughts or affects, the task is to promote avoidance or the working through of these painful phenomena.

Although it is important to encourage mourners to experience grief, some people may become emotionally overwhelmed and may need assistance to tolerate intense grief. Whenever possible, clinicians should apply nonpharmacological interventions such as general relaxation exercises to reduce stress or behavioral approaches to reduce insomnia. When these approaches are not sufficient, judicious use of anti-anxiety agents and sleeping medications may be indicated.13 There are two circumstances when psychopharmacologic interventions should be considered to actually manage bereavement: to treat co-morbid psychiatric conditions and to modify affects that are unique to the grief experience.13

Integrative Therapy for AIDS Bereavement

By harnessing the aspects of bereavement support and education and...
psychotherapy and risk reduction counseling, Integrative AIDS Bereavement Therapy assists mourners to move successfully through the phases and tasks of mourning in a manner that is consistent with their personal and cultural values. The integrated approach undertakes four tasks: establishing rapport and validating loss; developing an integrative and dynamic understanding; working through psychodynamic blocks and facilitating cognitive and behavioral change; and reinforcing positive changes and terminating the therapy.

Task I. Establishing Rapport and Validating the Loss. As is true for most effective therapeutic approaches, the first task of Integrative AIDS Bereavement Therapy is to listen carefully to the client's story. A sympathetic review of details of the client's relationships and the events that led up to and followed the death establishes rapport and helps the client understand the meaning of the death for him or her.

Task II. Developing an Integrative and Dynamic Understanding. The second task is to determine the type and level of bereavement distress and the psychological factors that affect the mourning process. The clinician and the client review the client's progress through the phases and tasks of grief, the intensity and duration of grief symptoms, the nature of grief symptoms, and the level of functional disruption. If the client is suffering complicated grief, the clinician and client explore the possibility of conscious or unconscious conflicts and mechanisms that may be blocking the mourning process, and review mental and physical symptoms and history. The clinician then assesses bereavement burdens and personal impediments to coping to determine whether specific cognitive or behavioral changes will improve coping.

Task III. Working Through Psychodynamic Blocks and Facilitating Behavioral Change. Based on the assessment in Task II, the clinician and client establish specific therapeutic goals and strategies to meet those goals. These strategies may include: using bereavement education to support and educate the client and to reduce his or her alienation; analyzing further and working through psychodynamic blocks to grief resolution; and setting cognitive or behavioral goals and programs to reduce bereavement burden and increase coping skills.

Task IV. Reinforcing Positive Changes and Terminating Therapy. At the end of therapy, a brief termination period provides time for the client and clinician to review lessons learned and to reinforce any cognitive and behavioral changes. Successful mourning is dependent on a range of individual factors, and its achievement may require the mourner to return to therapy for further assistance and reinforcement after the termination of initial therapy.

Conclusion

The overall goal of the Integrative Model of AIDS Bereavement is to help mourners adequately manage the mourning process and resolve their grief. The model seeks to be broad enough to manage the universal aspects of bereavement, yet specific enough to address the uniqueness of individual AIDS mourners. Placed within a social, cultural, and historical context, the model guides efforts to provide knowledgeable and compassionate care to all who suffer the loss of a loved one to AIDS.
Recent Reports

Psychosocial Resources among Caregivers
Park CL, Folkman S. Stability and change in psychosocial resources during caregiving and bereavement in partners of men with AIDS. Journal of Personality. 1997; 65(2): 421-447. (University of California San Francisco.)

A study of male partners of men living with AIDS suggested that their psychosocial resources—those characteristics upon which people draw in order to cope with the stress—remained stable during caregiving and bereavement periods.

Researchers at the University of California San Francisco Coping Project recruited participants through advertisements and referrals, and compiled data on this topic between 1990 and 1994. The 314 participants fell into one of the following groups: seropositive caregivers of seropositive partners; seronegative caregivers of seropositive partners; or seropositive partners of seronegative individuals. At entry, the average age of participants was 38 years, and the average length of each partnership was seven years.

Participants in the HIV seropositive groups tended to identify as non-Caucasian, to be less educated, and to have lower incomes compared to individuals in the seronegative groups.

Researchers sought to assess the effects of caregiving on caregivers’ psychological and social resources, and to determine whether these effects were related to the imminence of death of the partner, whether the death of the partner affects resources, and whether HIV serostatus influences caregivers’ ability to care for and grieve for their partners.

Assessment included bimonthly questionnaires and interviews and lasted seven months.

The results support the “personality hypothesis,” which states that psychosocial resources remain stable if an individual’s personality is stable in terms of aspects such as religious beliefs, optimism, and perceived social support. However, the study also found support for the “wear and tear hypothesis,” which states that the chronic stress of caregiving and bereavement diminishes resources. The study also found that HIV seropositive caregivers were not at greater risk for resource depletion.

Telephone Support for Bereaved Mothers
Wiener LS. Telephone support groups for HIV-positive mothers whose children have died of AIDS. Social Work. 1998; 43(3): 279-285. (National Institutes of Health.)

A telephone support group for HIV-infected mothers grieving the HIV-related death of a child resulted in an increased sense of support and normality, some release of regrets and guilt, and a better ability to take care of themselves, according to a description of the group process.

Facilitated by a social worker, the year-long support group applied a novel method: a monthly telephone conference call. During the first session, the group leader outlined the goals of the group, and each participant introduced herself by sharing details about the days and moments before and after her child’s death. The following sessions covered a variety of topics ranging from maladaptive coping to future hopes.

All participants had lost a child who was treated for HIV disease at the National Institutes of Health up to four months prior to the first group meeting. The group consisted of five women between the ages of 25 and 42 whose children—ranging in age from 3 years old to 10 years old—had passed away. Three of the mothers had become infected with HIV through sexual contact, and the other two had become infected as a result of needle sharing.

Participants reported that the 12-session group helped them to overcome feelings of social isolation and gain insight, self-understanding, and a sense of belonging that helped them grow through their grief. Group members exchanged phone numbers, began to make connections, and allowed themselves to remember and feel. Both individually and as a group, participants struggled with guilt and regrets while trying to maintain and regain some sense of inner integration. Each woman left the group knowing that grief is an evolving process and that she had more work to do to make sense of her loss and to establish a new relationship with her deceased child.

Group Therapy for Multiple Loss
Maasen T. Counselling gay men with multiple loss and survival problems: The bereavement group as a transitional object. AIDS Care. 1998; 10(Supp. 1): S57-S63. (SAD-Schorer Foundation, Amsterdam.)
ABOUT UCSF AIDS HEALTH PROJECT PUBLICATIONS

The AIDS Health Project produces periodicals and books that blend research and practice to help front-line mental health and health care providers deliver the highest quality HIV-related counseling and mental health care. For more information about this program, visit http://ucsf-ahp.org/HTML2/services_providers_publications.html.