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5 HR. BEREAVEMENT AFTERCARE: ISSUES FOR THE CLIENT AND THE DEATH CARE PROFESSIONAL

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SEGMENT 1: RATIONALE FOR A MULTIDISCIPLINARY SUPPORT SYSTEM

SEGMENT OUTLINE:

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SEGMENT OBJECTIVES:

Upon the completion of this segment of the course you will be able to:

1. Identify social and psychological factors that demonstrate the need for aftercare.
2. Develop an understanding of the purpose of Bereavement Programs, Aftercare Opportunities, and ancillary resources
3. Breakdown general categories which define the role of death care professionals.
4. Discuss and analyze the use of self-help and support groups, hospice programs, and funeral home grief aftercare programs.
5. Identify issues associated with effective aftercare.

NARRATIVE SUMMARY

It's always a challenge to know how to best help your client families in the days, weeks, and months after the loss of their loved one. Most people in this country have access to a 911 phone number for emergencies, as well as opportunities to learn first aid and CPR. Yet how convenient or widely available are classes to deal with the grief and loss experienced by the roughly eight million (through death alone) newly bereaved members of our society each year? It seems as if we have professionals trained and equipped to deal with everything: marriage counselors, substance abuse, childhood development, financial advisers: except the one area that touches us all: death and dying. There appears to be no general agreement on whose job this is.

The concepts of aftercare and grief counseling are relatively new and have become specialized fields of attention only in the past fifteen to twenty years as understanding and recognition of "normal" grief processes have been studied and written about. This section will attempt to establish a framework for examining the broad range of aftercare delivery mechanisms and the roles of various professionals within those systems.

Specifically, these final parts of the course will address models of bereavement aftercare, present counseling techniques for helping the bereaved, discuss the unique, contemporary issues facing death care professionals in the area of aftercare, and recommend coping strategies to reduce stress and prevent burnout among those who regularly deal with grieving people. This section of the course serves as an overview introducing concepts and constructs that are discussed in more detail later. In addition, it offers suggested actions that professionals may take who wish to improve the death education and bereavement aftercare in their communities.

NEED FOR AFTERCARE

Dictionary definitions of "aftercare" offer a medical model, explaining the term as the treatment of a convalescent patient, such as would be utilized following surgery. While at first glance this implies the existence of an abnormal or pathological condition, upon reflection there is a valid metaphor: something has been "cut out" of a griever's life, and the griever most certainly does require special handling. Where the metaphor stops, of course, would be in the suggestion that grief itself is abnormal or pathological.
In the death and dying profession, "aftercare" is defined as any post death or post funeral program of survivor rehabilitation designed to help the individual through the grief process and successfully readjust to his or her environment. Although the term "rehabilitation" continues to imply pathology, its purest meaning involves restoring or learning new habits that promote a useful and healthful life. Indeed, as we will see, the best aftercare programs utilize the research that has occurred over the last few decades and approach the common problems bereaved people face with a systematic appreciation of the difficult emotional struggles they face.

SOCILOGICAL FACTORS

The need for grief aftercare is peculiar to twentieth-century Western culture. In preindustrial societies, higher death rates meant that many people died at what we would consider relatively young ages, interrupting their role in society. Their deaths took place within the circle of the family and the community, and Blauner (1966) suggests that death was viewed as a social process with an immediate effect on society.

With industrialization, death rates were lowered, resulting in death occurring largely among elderly adults who have completed their societal role. Indeed, Rubin (1990) offers that the impact of those deaths do not affect the society as a whole and are only minor footnotes in the cycle of societal events.

But we now live in a postindustrial society, and Morgan (1995) attributes the need for aftercare to the technological advances that have changed our "normal" experiences. Longer life expectancies, higher degrees of mobility and resulting familial separations, plus the "removal" of death to institutions all mean that we have "unlearned" the concept of death as a natural part of the life cycle:

Today, at least 75% of persons die in hospitals. The consequence of this is that dying is now seen by fewer people than it previously was. We do not have the mass deaths that once were viewed on streets, and we do not have persons dying at home.

We scarcely even see the aged. Few of us live within 500 miles of our place of birth. Consequently, we and our children do not see the aging process taking place. The elderly live in senior homes or retirement villages where they are seen only by other elderly or professionals. Consequently, death seems not to be a gradual process but a telephone call in the night... As a result we have no role models either for our own dying process or for expressing grief at the time of another's death. P. 37

The absence of familiarity with—let alone a cohesive structure for—experiencing the grief process leaves untold numbers of people in our society "at loose ends" with their painful feelings. While much more assistance to the bereaved is available today than even ten years ago, the supply of aftercare is nowhere near sufficient to meet the "demand."
John W. James and Frank Cherry, founders of the Grief Recovery Institute, an internationally respected educational and outreach program based in Los Angeles, comment on this situation in the introduction to their Grief Recovery Handbook (1988):

No matter how hard or how long we worked, no matter how many professionals we trained, no matter how many support groups were started, it didn’t seem that we were doing enough. The number of people still in pain years after a loss is staggering. Our purpose [in publishing the handbook] was, first, to help individual recover from their grief, and then, ultimately to change the way each of us responds to those suffering from loss. We published five thousand copies of the book ourselves [thinking] that five thousand would last us a long time—within eight weeks we were out of books. (P. XII)

While many mental health professionals, funeral industry leaders, medical personnel, caregivers, volunteers, and even enlightened employers know the recognition of the need for aftercare, there exists no standard “blueprint” for the organization and operation of aftercare services or intervention strategies in our society. The efforts, advances, and roles of these (and other) helping individuals will be looked at later in this part of the course.

**PSYCHOLOGICAL FACTORS**

As discussed earlier, numerous, variable factors determine the psychological context of each individual’s unique grief experience. In a very real way, our knowledge of the grief process and its “influences” has outstripped our ability to provide customized or even adequate aftercare. For example, is it advisable to form a support group that includes grievers who have lost close loved ones when the circumstances range from long illness to murder to a plane crash? What is the best way to meet the needs of grieving children? Flow do we help “disenfranchised” grievers—those whose feelings aren’t recognized by society—with their unique problems? These bereaved may include friends, coworkers, AIDS survivors, a partner in an illicit love affair, or people who deeply feel the loss of a dear neighbor, mentor, aunt, or parent “surrogate.” What of grievers who are mourning different types of losses—a longtime job, divorce, a pet, childbearing functions, a limb?

While there are themes and threads that run universally through the grief process, it is important that aftercare advocates, providers, and helpers be sensitive to the significant psychological variations that may be at work among grieving populations. It is not by accident that organizations with both educational and support functions have grown up around particular grief circumstances.

We are already aware of Compassionate Friends (an aftercare organization for parents who have lost a young child), Mothers Against Drunk Driving, and the Widowed Person’s Service of the American Association of Retired Persons (AARP). By way of further examples, there are groups that specifically help parents whose babies died from sudden infant death syndrome (SIDS), as well as groups for survivors of violent death (including suicide). And in today’s world, it is not surprising to learn that families of victims of natural disasters (hurricanes, fires, floods) or other forms of tragedy (such as terrorism) form self-help groups on their own to target and cope with the unique psychological impact such deaths leave in their wake. Collectively, these groups recognize intellectually and/or intuitively that they face special needs regarding the psychological factors of timeliness, preventability, fulfillment of the deceased’s life, context of the death, and secondary losses. It is simply a fact that most communities are not presently equipped to serve even the range
of contingencies mentioned here, and that, to a great extent, the bereaved themselves have perhaps been the most impressive pioneers in efforts to identify and meet their own needs.

PURPOSE OF AFTERCARE

This text has presented various models of grief characteristics, stages of grief, and tasks of grief work. Regardless of which models are preferred, the goal of any aftercare program is to facilitate the process through reassurance, education, and permission to express thoughts and feelings, and social support within a nonjudgmental framework.

Before examining methods by which this goal can be achieved, it is important to first make the distinction between grief counseling and grief therapy. No one has clarified this issue better than Worden (1984), which summarized the differences in an article for the newsletter of the Association for Death Education and Counseling (ADEC):

Grief counseling involves those interventions which help persons experiencing normal grief to deal with the tasks of mourning in order to complete these within a reasonable time frame. The focus is on recent loss, within the past year or so, and on normal grief, which is uncomplicated and which moves toward satisfactory completion.

Grief therapy, on the other hand, has a different goal and focus. In grief therapy the goal is to help identify and resolve the conflicts of separation which preclude the completion of mourning tasks in persons whose grief is either absent, excessive, delayed, or prolonged. These aberrations of the grief process are what the Diagnostic Manual of the American Psychiatric Association categorizes as “complicated bereavement.” (Pp. 1-2)

Worden (1984) determines that it is not so much who does the intervention or where it is done that is important, but the focus and goals of the treatment. What is also critical is that both counselors and therapists (whether volunteers or professionals) have grieved and resolved their own losses and are aware of their own competencies and limitations. Counselors and therapists need to have “the grace to refer a client who is grieving a loss with which [they] have difficulty dealing” (pp. 1-2).

REQUIREMENTS OF A BEREAVEMENT PROGRAM

Perhaps the “square-one” question should be answered first: Does intervention really help grievers?

In a study that followed 194 widows for thirteen months, Raphael (1977) conducted extensive initial interviews, assessing various psychological factors, and grouped the widows into two categories: those whose grief outcome was predicted to be “good,” and those whose outcome was predicted to be “bad.”

Those with favorable predictions received no counseling, and at the end of the study 80 percent indeed showed a good outcome. Of the widows predicted to have unfavorable grief outcomes, half were given regular counseling and half were not. At the end of thirteen months, those who received
counseling were twice as likely to have achieved a “good” outcome as those who received no counseling.

As reported by Bowlby (1980):

Widows in the counseled group showed a lower incidence of depression, anxiety, excessive alcohol intake and certain psychosomatic symptoms than did widows in the non-counseled group. The conclusion that counseling is in some degree effective is strongly supported by internal evidence derived from a detailed study . . .[in which] it was found that those who made best use of the counseling sessions had a significantly better outcome than those of the group who did not. (P. 198)

Because we have “unlearned” that death is a natural part of the life cycle, it becomes necessary to “unlearn” the responses to it we have been taught by our parents or by society. All the information now available clearly shows that burying feelings, keeping busy, expecting “time” by itself to create healing, or rushing to “replace” a loss will not promote authentic recovery from pain and permit a healthy foundation for life without the loved one.

Rando (1995) delineates seven steps to facilitate uncomplicated grief and mourning. They can serve as an excellent cornerstone for any comprehensive bereavement aftercare program:

1. Make contact and assess.
2. Maintain a therapeutic and realistic perspective.
3. Encourage expression of feelings and recollection of the deceased.
4. Help the mourner identify and work through secondary losses and unfinished business.
5. Support the mourner in coping with the mourning process.
6. Help the mourner accommodate to the loss.
7. Work with the mourner to reinvest in the new life.

In addition, an aftercare program must have the ability to identify complicated and/or pathological grief responses and offer appropriate treatment or referral to a professional competent in the area of abnormal grief responses. Comprehensive aftercare programs that meet all these requirements are rare in our society, but many programs exist that meet some or most of them.

The Grief Recovery Handbook (1988) developed by the Grief Recovery Institute (GRI) lays out five requirements for resolution of normal grief and guides readers through a program of activities and exercises that move them through the following “stages”:

1. Gaining awareness that an incomplete emotional relationship exists
2. Accepting responsibility that in part you are the cause of its existence
3. Identifying recovery communications that you have not delivered
4. Taking actions to communicate them
5. Moving beyond loss through sharing with others

The GRI's recently developed companion workbook facilitates an individualized approach to grief recovery, presented in a commonsense; "plain-talk” style that dispels myths about death while offering comfort and practical advice to the user.
Although aftercare resources and services are “out there,” often they are fragmented, inadequately publicized or coordinated, and may fall short of meeting the continuing needs of bereaved people as they work through the various stages of their grief. Furthermore, two factors affect the actual utilization of available assistance. First, the lack of general knowledge about the normalcy of grief and its symptoms may leave bereaved people feeling stigmatized and incapable of reaching out, and may inhibit loved ones from suggesting aftercare program participation; second, the bereaved may be too overwhelmed by or mired in grief to even recognize a need for these services. Until our societal attitudes and understanding of death and grief change on a widespread basis, it is incumbent upon those various professionals and “enlightened” caregivers to identify and reach out to bereaved people with information and encouragement to make use of appropriate aftercare opportunities.

AFTERCARE OPPORTUNITIES

While the roles of various professionals and institutions in aftercare delivery will be covered more thoroughly in later sections of the course, it is logical here to give a brief description of the aftercare formats and media that are most available in communities today. These grief and bereavement “services” are not in any way mutually exclusive, and they may be offered by a variety of agencies—public, private, for-profit, not-for-profit, voluntary, or religion-based. Opportunity categories include

1. Print and video materials
2. Interpersonal activities
3. Individualized intervention

A wide range of helpful information is available to grieving people in the form of books, booklets, magazines, and videos. Published with “laymen” in mind, many current titles exist that discuss “good grief,” living with loss, and warning signs that may indicate a need for professional assistance. Another category is books that take the form of a personal memoir or “diary” recounting the writer’s specific, meaningful loss. These books may be extremely valuable to grievers who have suffered a similar or parallel loss.

Public libraries and bookstores are likely to offer at least a sampling of such books, and various denominational publishers may have a selection of titles that approach death and mourning from a particular spiritual point of view. These materials might be found in a church or synagogue library or a religious bookstore.

Thanatos is a quarterly journal that mixes a variety of articles (essays, educational pieces, poetry, recent research, book reviews) that address the emotional, psychological, and practical issues surrounding dying, death, and grief. In addition, there are publications aimed at people experiencing specific types of losses, for example, death of a spouse, parents suffering from stillbirths or neonatal deaths, and survivors of loved ones who died violently.

Educational filmmakers have also addressed the subjects of grief and bereavement with (typically) generic programs to help children and teenagers understand death and the grief process. Public libraries, school districts, and/or counseling organizations may have catalogs available for purchase or rental of these programs.
Interpersonal opportunities for aftercare might include workshops, lectures, grief support groups, telephone “hot lines,” or even formal education in bereavement and its resolution. These platforms encompass a broad range of activities with varying formats and goals. A quick list of examples could include the following:

1. An afternoon or evening seminar on “Getting through the Holidays” following a death
2. Regular support group meetings for families and loved ones of AIDS-related deaths
3. A “drop-in” support group for the recently widowed, perhaps with an educational and social orientation
4. A “closed-end” (specified duration) series of professionally supervised meetings for teens who have lost a sibling or close friend
5. One-day seminars on “Understanding Loss” or “Coping with Grief”
6. A grief-facilitative class for adults using techniques of art and poetry therapy
7. A workshop on developing effective rituals to help heal grief
8. Employee assistance programs (EAP) on managing or working with bereaved employees
9. A concrete “coping skills” course for widowers with young children
10. A lecture on common legal and financial issues following a loved one’s death
11. Crisis care teams or “task forces” of professionals and/or volunteers who assemble to help grievers in emergency situations
12. Supervised groups for young children to facilitate grief expression through “play” activities

Readers of this text should remember that any one, some, or all of these examples might be sponsored or “driven by” a funeral home, a hospital, a church, a community-based counseling organization, a hospice, a college or adult education program, or a freestanding bereavement center. Depending on the format and the audience, these activities may be conducted or led by a social worker, a psychologist, a member of the clergy, a medical professional, a bereavement educator, a trained volunteer, an academic expert, or “someone who’s been there.” There is almost no end to the creative, interpersonal opportunities that can be developed in communities when enlightened individuals and institutions come together to afford grieving people a place to meet, interact, talk, and learn from each other.

Individualized intervention can also take a number of forms, the most obvious of which is private sessions with an experienced psychologist or psychotherapist. Such attention is usually required in situations we have described as complicated bereavement, that is, the manifestation of excessive, delayed, prolonged, or absent grief. Not surprisingly, the “standards” by which these symptoms are defined are a source of constant discussion and debate among mental health (and related) professionals. Returning briefly to Rando’s list of psychological factors influencing grief, we can speculate that other candidates for individualized intervention might include those who are experiencing additional stressors, such as concurrent or multiple losses.

As noted by Parkes (1972),

It should be emphasized . . . that care of the bereaved is a communal responsibility, and family members and others should not withdraw their support simply because a person has been referred to a psychiatrist. The powers of the psychiatrist are strictly limited and what [he or she] can do is not, in essence, different from what can be done by any sensitive empathic person. (P. 180)
There is also the personality factor to consider in individual intervention—the reality that some people are, by nature, “loners” and not comfortable in-group settings. Some community bereavement programs, as well as churches and senior centers, offer what is known as “peer counseling.” In general, these services provide one-on-one emotional support with a trained volunteer who has experienced a similar loss. The challenge, of course, is identifying individuals who might accept and benefit from such aftercare activity, since they are unlikely to seek or expect assistance with their grief. Outreach, then, becomes an especially important function of such aftercare operations.

ANCILLARY RESOURCES

Very recently, a variety of services have appeared that afford dying people and bereaved people “nontraditional” opportunities to cope or find help with grief and its healing. Grief Net is a system on the Internet that lists resources and provides communications for professionals and bereaved persons dealing with dying, bereavement, and major loss in any way. It uses the systems known as gopher server and a web homepage, offering aftercare providers a bulletin board with listings of upcoming conferences, workshops, and seminars around the world as well as other useful Internet sites.

The Bereaved Persons Resource Center is Grief Net’s giant “information house,” with doors leading users to specific resources under a range of subjects including adoption loss, children’s and adolescent resources, caregivers’ resources, information on natural and human disasters, general bereavement resources, hospice information, chronic illness, widow and widower resources, among others.

Founder and editor Cendra Lynn of Ann Arbor, Michigan, reports that Grief Net, launched in the spring of 1994, is accessed more than four thousand times a week from more than six hundred sites around the world.

Death Net, the world’s first website to specialize in end-of-life issues, was created by the Right to Die Society of Canada and the National Hemlock Society. It claims to offer the largest collection of right-to-die materials and services on the Internet.

Endeavors that may or may not prove popular with dying people and their loved ones are services to assist in creating “a remembrance archive”—a message or series of messages created by the dying person for grievers prior to death. Using video, audio, or print media, these messages, whether sentimental, philosophical, or personal, can be personalized and designated for delivery upon death, anniversaries, special occasions, or milestones in the survivors’ life. Whether such activities, in general, promote comfort, support, closure, and healing is a matter for further study and debate.

ROLE OF DEATH CARE PROFESSIONALS

Depending on the circumstances of a death, families and loved ones may have contact with a variety of professionals whose attitudes, behavior, and interventions can influence the grief process. Typically, these professionals might include medical personnel, clergy, mental health professionals, hospice staff, and funeral service providers. Each group can offer unique assistance to grievers, in subtle or very direct ways.
MEDICAL PERSONNEL

The “problem” with physicians is that they are trained to regard death as an enemy to be conquered and the loss of a patient as failure. Physicians who regularly deal with terminal patients may, to protect their own emotional well-being, detach themselves from patients (“The transplant in Room 213 . . .”), or speak “about” them to family members as if they were not present. The effect is one of “killing” the patient socially before he or she has died. This can be extremely disturbing to both patients and their loved ones.

Nurses are more likely to be trained in the grief process and generally have more contact with patients and their families. Nurses can play an important part in allowing the terminally ill and family members to express their fears and concerns simply by listening and validating their feelings, and fully explaining what is being done for the patient. In the normal course of their duties, nurses may also become aware of situations within families that might benefit from contact with a hospital social worker or chaplain. Nurses should be familiar with hospital services in these areas and should feel empowered to make referrals.

It should be remembered that both doctors and nurses grieve when a patient does die, particularly if the relationship or the treatment has been a long one. It has been noted that a letter of condolence signed by the physician or attendance at the funeral can be of immense importance to the family, reassuring them that their loved one received personal care and attention.

CLERGY

While religious affiliations and spiritual beliefs will vary in both content and relative importance from one grieving person to another, the clergy play an important role in bereavement, as it is generally assumed they “understand” these matters better than the average person. As leaders or representatives of “helping” organizations who theoretically have both academic and practical experience with dying people and their families, members of the clergy are in a unique position to comfort, educate, follow up, and facilitate “good” grief, both in the funeral setting and afterward. As in all professions, however, there are differing levels of talent and skill, and it is physically (as well as practically) impossible for even the most well-meaning minister to give bereaved people the full complement of guidance they need. Manning (1985) suggests:
There is no set pattern for ministering to those in grief. Each minister must design his or her own method. The method must fit the personality of the minister and be suited to the time allotted. We are people with different gifts and different callings. Some of us will be more comfortable with this type of ministry than others.

… This does not excuse us from dealing with people in grief, but it should relieve us of guilt and pressure…. Some ministers will need to concentrate on training others. Some will need to delegate the responsibility to staff members. Some will enjoy the work and find it to be a natural part of their lives. (P. 56)

He cautions that some clergy are prone to make the same mistakes as other would- be supporters, attempting to “explain” or intellectualize the death, rush the griever through his or her feelings, or even avoid the subject altogether.

Manning believes that, particularly where survivors are linked to a religious institution, clergy can facilitate a family’s recognition of their mutual need to share their grief, to be honest with one another, and to help them arrive at a sense of significance of the deceased’s life. In deaths where the clergy does not know the family well, he offers a more general role for the clergy to play during and after a funeral, which includes “being there,” helping friends express their sympathies in comforting ways, and giving the grievers “permission” to feel their feelings. In Manning’s opinion, the most important part of ministering to the bereaved is to listen to them. He refers to this as the “laying on of ears.”

MENTAL HEALTH PROFESSIONALS

The role of mental health professionals in grief and bereavement work has been referred to throughout this text. Indeed, the majority of research resulting in what is known in this arena today has come from experts in the fields of psychology and psychiatry. In terms of aftercare, this section will address specific counseling techniques and facilitative interventions.

For our purposes here, let us simply note that mental health professionals are often the providers as well as the recipients of death education and training programs (discussed later in this course), and quickly review some of the common “forums” that afford mental health professionals and grievers the opportunity to make contact with each other:

1. Telephone “hotlines” offering comfort and/or advice
2. Hospital bereavement programs and/or social work departments
3. Hospice programs
4. Public school systems (counseling departments); colleges and universities (counseling centers)
5. Community bereavement programs (independent or through public agencies)
6. Private clinics or individual professional practices
7. Funeral service providers
8. Church or senior center support group programs
9. Primary physician and/or legal referrals
10. Voluntary "helping" organizations, such as the National SIDS Foundation and the American Red Cross

All death care professionals should be aware that not every mental health worker is knowledgeable or equipped to deal with issues of death and grief. Many have not been trained in this area and are uncomfortable when it is presented, often because they have not come to terms with and resolved losses in their own lives.

Returning to Worden (1984):

If such losses are not adequately resolved in the counselor's life, they can be an impediment to a meaningful and helpful intervention. On the other hand the counselor who has experienced his own loss and adequately worked it through can be a superb resource to the person experiencing a recent loss of a similar kind. Again the key is knowing one's own limitations. (Pp. 1-2)

It is necessary first to appreciate that hospice is not a place but a concept of caring that provides comfort and support both to people in the final stages of a terminal illness and to their families. Hospice services are often delivered in a patient's home, but they can also take place in hospitals, nursing homes, or residential facilities. Hospice care emphasizes the quality, not the length, of life, and generally takes a "team approach" involving medical personnel, clergy, social workers, volunteers, and counselors, among others.

There is validity to the opinion of some that the growing hospice movement is becoming the "warehouse" of bereavement information and aftercare sensitivity, since it includes involvement with families prior to deaths of many kinds. The National Hospice Organization is a nonprofit organization with more than fifteen hundred member hospice programs. It maintains an 800-number telephone Helpline for information to members and the public. It would be unfair, however, to regard hospice professionals and programs as the ultimate source for delivering aftercare services, since their primary mission is to provide humane, patient-centered care and patient-centered decision-making. As a model and resource, for the development of multidisciplinary approaches to aftercare, however, hospice is becoming an increasingly visible and valuable force in American society's ability to look at and deal with death.

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FUNERAL SERVICE PROVIDERS

In the contemporary funeral industry, aftercare is a word still searching for a definition. To some providers it may be a card to the bereaved family; to others it may be a series of timed mailings of helpful newsletters or commercially published booklets on coping with grief; to others it may be a program of support groups and/or public lectures on various aspects of loss; to others it may include follow-up phone calls to families and referrals to counselors or community resources.
As professionals who should be concerned with promoting a more comprehensive awareness of grief and loss, it is interesting that there is division within the funeral industry regarding its role in providing aftercare. One president of a mortuary science college recalls being told as a student not to become too close to families—to "just be available." The concern seemed to be in "overstepping boundaries" or "crossing a line" that belongs to therapists.

If funeral service is to be regarded as a social service, then it must offer society more than cars and caskets. Rosemary Hillman, of Grief Support Services in Des Moines, Iowa, has been quoted as saying, "Aftercare is not grief counseling. But funeral directors and cemetery professionals should make the bereaved aware of resources in their communities." She encourages death care facility professionals to know about, encourage, and direct survivors to information and support systems that are available after the funeral; she further believes they have a role in promoting general education in their communities on topics relating to death, dying, and funerals.

Grief Net’s Cendra Lynn maintains the opinion that availability of aftercare services (whether provided directly or through referrals) not only is the wave of the future but also will ultimately become "a competitive factor" among funeral service providers. In a recent interview a respected member and spokesperson of the National Funeral Directors Association "looks to the day" when funeral homes keep full-time social workers or psychologists and attorneys on staff to serve their clients’ array of ongoing emotional and pragmatic needs.

ISSUES IN AFTERCARE

To a great degree, this entire section of the course has raised many issues regarding aftercare:

- Whose job is it?
- What are its goals and purposes?
- What form does it take?
- How is it delivered?
- How do grievers find it, or how does “it” find them?

It should be clear by now that there are no hard-and-fast answers to these questions and that one very important key to building widespread, comprehensive aftercare programs is death education. We will use this term in a completely separate and distinct manner from the "education" of the bereaved that results from aftercare. Here, death education refers to any formalized curriculum or recognized institutional program designed to inform or train any “level” of student in the general or specific aspects of death, dying, or grief and its resolution.

DEATH EDUCATION

The availability of education in death-related issues in America is widely scattered. What’s more, death-related issues may also be covered in certain courses offered by departments of
anthropology, gerontology, religious/pastoral studies, and nursing. Naturally, each of these academic fields will address death and grief in the context of that particular discipline. It is perhaps only when one “graduates” into a chosen career or profession that further, cross-disciplinary opportunities for education and understanding of death and grief become available and important for ongoing competence and professional skill development.

Although we have already mentioned the Grief Recovery Institute (GRI) and the National Hospice Organization (NHO), it should be added that the GRI provides accredited programs in grief education at the university level for continuing education to interested licensed or nonlicensed professionals; it has also developed programs for dealing with loss that have been implemented in junior and senior high school throughout the United States and trained the schools’ administrators, counselors, and/or teachers in their operation. It also provides speakers or delivers education, training, and/or consulting services to professional groups and associations such as nurses, alcohol and drug abuse counselors, highway patrolmen, fire department members, physicians, cemetery professionals, and even veterinarians.

The NHO holds conferences that, each year, target particular aspects or themes of hospice work, such as pastoral care, voluntarism, or psychosocial aspects of dying and grief, including multiculturalism and AIDS-specific hospice issues. These conferences, which attract experts and academics as well as hands-on professionals, are open to the public as well as to NHO members.

Additionally, death care education is fostered by the Hospice Foundation, a nonprofit organization that advocates the hospice concept of care by conducting programs of education and information for physicians and hospital staff, sponsoring research, serving as a philanthropic presence within the national hospice community, participating in public policy initiatives, and working for the inclusion of hospice principles in the American health care system. It has organized and sponsored several national teleconferences on grief and bereavement and has established a Pastoral Intern Program, which trains divinity students in principles of hospice.

No overview of death education would be complete without an introduction to the Association of Death Education and Counseling (ADEC), an international, multidisciplinary organization dedicated to improving the quality of death education and death-related counseling and caregiving. The ADEC was formed in 1976, and its members include, among others, educators, funeral directors, social workers, psychologists, nurses, nuns, rabbis, physicians, hospital volunteers, and hospice personnel.

Headquartered in Hartford, Connecticut, ADEC promotes the interchange of related theory and research among its members and provides support to them and all those studying and working in death-related fields. It aims to enhance the ability of professionals and laypeople to better meet the needs of those with whom they work in death education and grief counseling.

The ADEC takes an active role in educating the public on death-related issues and sponsors an annual conference with leading professionals and researchers. The organization also offers courses and workshops, and has established standards required for certification in death education and death counseling.
Death care professionals, or those whose jobs only occasionally bring them into contact with grieving populations, may have been exposed to commercially published death education and aftercare materials, curricula, and training programs. While it is not the purpose of this text to endorse or condemn any of these resources, given the current fragmentation of aftercare delivery, it is incumbent upon those attempting to provide quality programs and care to examine the credentials, philosophies, and references of organizations offering such materials or programs before committing their own (or their clients') time and money.

### FRAGMENTATION VERSUS COORDINATION

The absence of clear areas of responsibility or frameworks for aftercare delivery can have different results in different communities: (1) Programs and opportunities are fragmented, perhaps serving only particular types of grievers; (2) programs and opportunities are scattered and/or inadequate; or (3) programs and opportunities are coordinated utilizing resources and skills from throughout the community to assist a wide variety of grievers facing a wide variety of loss. An example of the third possibility is the Centre for Living with Dying in Santa Clara, California. This facility, utilizing both professionals and volunteers, provides emotional support to individuals and families facing life-threatening illness or the trauma of having a loved one die. It also provides a broad-based educational program to the community on the subjects of grief and loss and how they impact the world around us.

Established in 1976, the Centre has developed specialized services to meet a wide range of needs. Senior citizens who have an ill spouse, have lost a loved one, or are experiencing loss of health or their home can receive group or one-on-one support. Grieving children and adolescents are served through peer support groups and one-on-one emotional support. Crisis intervention is available to schools that are experiencing death of a student or teacher, including needs assessment, classroom visits, faculty support, consultation on memorials or tributes, and follow-up support and referral.

The Centre also sponsors and coordinates groups for bereaved victims of violent crime, suicide survivors, a siblings grief group, widows and widowers, parents, people living with HIV, as well as their families and loved ones. It operates a corporate outreach program to address issues of loss and change in the workplace (whether through serious illness, death, or disaster), and it sponsors a Critical Incident Stress Debriefing team to deal with events that provoke unusually strong emotional reactions, such as those facing emergency workers in life- and death situations. This type of coordinated, comprehensive care is unusual in the United States, but it shows what can be accomplished on a day-to-day basis when caring, committed people from a variety of disciplines pool their time and abilities.

At the national level, various organizations have developed emergency and disaster preparedness plans that take into account the grief and psychological consequences to both victims and workers when natural or man-made disasters of major proportions strike. Generally administered through state or local directors, coordinated response in times of intense crisis and stress might occur among groups such as the American Red Cross, the National Funeral Directors Association, the American Psychological Association, and the Salvation Army.

An important development in coordination of aftercare efforts involved the 1995 meeting between board members of the National Hospice Organization and the National Funeral Directors
Association (NFDA). Although for years the NFDA has had representation on the NHO’s Council of Hospice Professionals, this “first-time,” three-day conclave for top-level discussion and identification of areas of mutual interest and cooperation is a promising signpost on the road toward multidisciplinary delivery of comprehensive aftercare.

It should be apparent by now that death care professionals do not—and cannot—work in a vacuum. The universal nature of loss and grief demands that professionals become familiar with all available local resources, identify areas of need and deficiency, and work together to create programs and delivery mechanisms that answer the requirements of their particular community.

This section of the course defines aftercare as any program that provides help to bereaved people throughout the grief process. Noting the contributing sociological and psychological factors, the need for aftercare was discussed for both the “normally” bereaved and those grieving specific types of loss. We made the distinction between grief counseling and grief therapy, and offered several models of “goals” for after-care efforts and programs. Various types of aftercare opportunities, formats, and media were presented to give readers some broad examples of program and activity possibilities, on both interpersonal and individual levels.

The unique roles of various death care professionals were reviewed, including medical personnel, clergy, mental health professionals, hospice workers, and funeral service providers. This led to exploration of two major issues in improving aftercare services: death education and fragmentation versus coordination.

REFERENCES

10. Lynn, C., of Rivendell Resources. 1995. Interview, August.

SEGMENT 2: COUNSELING TECHNIQUES FOR HELPING THE BEREAVED
SEGMENT OUTLINE

1. Nonverbal Skills
   a. Proxemics
   b. Facial Expression
   c. Paralanguage
   d. Eye Contact
   e. Personal Attire
   f. Hand Gestures
   g. Body Position
   h. Physical Environment
   i. Posture
   j. Head Movement

2. Listening Skills
   a. Barriers
      i. Defensiveness
      ii. Attitudes or Biases
      iii. Personal Inner Struggles
      iv. Interruption
      v. Overload
      vi. Timing
vii. Physical Exhaustion
viii. Filtered Listening

b. Guidelines
   i. Listen Actively
   ii. Listen with Empathy
   iii. Listen with Openness
   iv. Listen with Awareness
   v. Resist External Distractions
   vi. Hold Rebuttals
   vii. Analyze Nonverbal Messages

3. Verbal Skills
   a. Types of Questions
      i. To Gain Facts
      ii. To Reveal Facts or Feelings
      iii. To Clarify Facts or Feelings
      iv. To Stimulate Thought
      v. To Summarize Discussion
   b. Types of Comments
      i. A Reflective Comment
      ii. A Challenging Comment
      iii. A Restatement Comment
      iv. An Encouraging Comment
      v. An Assessment Comment
      vi. A Permission Comment
      vii. A Controlling Comment

4. Summary

SEGMENT OBJECTIVES:

Upon the completion of this segment of your course, you will be able to:

1. Summarize the effective use of verbal and non-verbal skills when helping the bereaved.
2. Construct methods for using such nonverbal skills as proxemics, facial expressions, paralanguage, eye contact, personal attire, hand gestures, body position, physical environment, posture, and head movement.
3. Demonstrate effective use of listening skills barriers and guidelines.
4. Compile a system for using effective verbal skills to gain facts, reveal facts, clarify facts or feelings, stimulate thought, and summarize discussions.
5. Diagram reflective, restatement, encouraging, assessment, permission, and controlling comment statements used when counseling the bereaved.

NARRATIVE SUMMARY
Susan, Tom’s widow, walks slowly into the funeral home. You notice her red, swollen eyes. Tears often accompany grief, but you cannot help questioning, “Is there something more?” Tom’s death was unexpected. The heart attack that took his life at forty-seven did appear premature. Since Susan wants to talk, you listen. She explains, “Tom really was a good man even though we frequently fought. Could these heated arguments have shortened his life?” she asks in a shaky voice. Your eyes meet hers and you wonder, “What do I say? What should I not say? How can I help her in this grieving?”

What counseling techniques are appropriate in the grief context? This part of the course seeks to answer this question, with special attention focused on those who help in funeral services. We will examine the nonverbal, listening, and verbal skills a funeral helper should exhibit when serving those suffering from grief.

**NONVERBAL SKILLS**

Nonverbal communication accounts for about two-thirds of our communication (Harrison 1965, p. 161). When we examine the emotional part of our relationships the proportion skyrockets to 93 percent (Mehrabian 1971, p. 77). In the grief context, recognition of nonverbal cues becomes essential in helping those who are grieving.

Nonverbal communication functions in four specific areas: (1) it can strengthen the words used. “I am so sorry for all I did wrong with . . .” may be accompanied by a tear-saturated voice. (2) It can contradict the verbal message. “I’m okay, I’m okay” said when the person is struggling for composure indicates she or he is not okay. (3) The nonverbal can replace any verbal communication. When you put your hand on a shoulder to steady a mourner or pick up a small child who doesn’t understand, you may not be using words, but the message speaks volumes. (4) Nonverbal messages can say more than verbal ones. Posture, facial expression, and eye contact give you far more data about how the person feels than just the words spoken.

Ten areas surface when we consider nonverbal communication (Wolfelt 1990, pp. 51-57). Your awareness of these areas will enhance your relationship with those you serve.

**PROXEMICS**

Proxemics examines the use of space or distance between people. The more we desire a person, the closer we try to be to that person. Death creates distance, which the bereaved does not want. A loved one has died, and the separation makes any intimacy impossible. This creates frustration for those who once enjoyed an intimacy with the person who died.

In a time of crisis intimacy develops faster. Brothers or sisters who have not communicated may now want to be near to each other. Conversely, where strong dislike resides, distance will be present. A relative may attend the funeral but attempt to keep a distance from either family members or the deceased. An awareness of space usage will give you insights not obtainable by verbal means.
FACIAL EXPRESSION

Our face serves as the canvas where we paint our nonverbal messages. "We send more nonverbal messages with our faces than any other means, and the face usually reveals the highest accuracy of all nonverbal messages" (Gangel and Canine 1992, p. 88). At times we sense these messages without clear consciousness of where they originate. Our faces have a difficult time lying. They communicate our feelings in the vulnerable time of coping with death. A person may try to mask true grief feelings, but usually people see beyond the mask. The face shows the intensity of grief an individual experiences.

PARALANGUAGE

Paralanguage examines the tonal areas of the verbal message. We constantly search for congruence between the tone and content of any message. As you relate to the bereaved, listen to how she speaks, not just to what she says. If a person says, "I will be all right," only to demonstrate he is anything but all right, we believe the nonverbal. We learn more about the relationship when we listen to the tone as well as the meaning of the messages we receive.

EYE CONTACT

Eye contact can tell us much about self-image. Guilt or inferiority sometimes surfaces because of a failure to connect with the eyes. The eyes serve as power brokers. In times of bereavement, power seems missing, and this can show up through the eyes. The deeply felt hurt accompanying death will frequently emerge from the eyes. The eyes of children require your special attention as they do not hide what the inner self feels.

PERSONAL ATTIRE

How we dress makes a constant statement about each of us. Our clothes, jewelry, and shoes send messages about who we are. While more casual attire seems increasingly popular, some still demonstrate their respect by wearing a suit and tie or best clothes to a funeral. The clothing people choose to wear can reveal their station in life, their values, and their opinions of the funeral occasion. This may take the form of ostentation or abject poverty, but some message will be sent via this channel.

HAND GESTURES

A person’s hand gestures may serve as an indicator of anxiety during crisis. The grieving person can exaggerate or accelerate hand motions as he or she seeks to make sense of the situation. A person’s background and culture should also influence your assessment of this nonverbal behavior. Some
groups communicate more with the hands than others. As a general rule, you should watch for abnormal motion and confirm what you see with what you hear.

**BODY POSITION**

Body position presents us with a subtle but powerful way to observe nonverbal messages. At times you can almost see the burden a person carries by the bend of the body. We include or exclude others by how we position the body. We best read nonverbal communication when we sit in an “L” position, which allows each person to pick up the body messages from the other. When we sit directly across from one another, we are in a competitive stance. A side-by-side arrangement distorts the accuracy of nonverbal messages. You will enhance your relationship possibilities if you arrange the environment for a ninety-degree or “L” sitting configuration.

**PHYSICAL ENVIRONMENT**

The physical environment and its control can either encourage or discourage maximum communication. Bright colors, flowers, good ventilation, good lighting, quality furniture—all help produce a better environment. Spacious surroundings foster better communication and help build a relationship atmosphere. An effective physical environment allows for intimacy or distance as the need dictates. A spirit of informality and warmth can be enhanced or hindered by the physical surroundings. An excellent question we might periodically ask is, “If I were walking into this room for the first time, how would it affect me?”

**POSTURE**

Our posture reveals the deeper feelings we have in any relationship. The hurt felt within surfaces through a person’s body long before it does through speech. The numbing fatigue so often felt by the bereaved can appear as a weight on the shoulders that drags a person down. Ask yourself, “Does he seem overburdened in how he carries the body?” Do you notice a slowness of step and a slouch in the person you seek to serve?

**HEAD MOVEMENT**

A person’s head movement reveals a more immediate relationship message. When the head moves up and down, we sense conscious agreement. If movement is from side to side, we immediately register it as negative feedback or disagreement. In grief, mixed messages can occur. A side-to-side motion may be used to attempt to deny reality. This usually will be accompanied by poor eye contact and facial expression that struggles to accept what has happened. At times, a person may transmit disconfirmation by turning away from you. A person may send the message “If I look away, you will not actually be present.” Head movement or the lack of it continually communicates where we are in a given relationship.

**LISTENING SKILLS**

**BARRIERS**
Unfortunately, listening is something everyone can do and do poorly. At least eight obstacles block our effective listening. In the grief process, listening becomes more complicated because it is a time of personal and emotional crisis. Be attuned to these obstacles either in your experience or in the lives of those you seek to help.

### DEFENSIVENESS

This often stems from preoccupation with our own self. A defensive person reaches a premature conclusion. Statements like “I know what you are going to say...” or “It has been our normal experience that...” can preface this behavior. We read into the other person’s words our own expectations. Prejudices, or judgments before the facts are understood, characterize this defensive behavior. You may find yourself rehearsing specific responses. You mentally script out what you will say and what the other person will say. The problem arises when the real situation does not follow the planned one. Avoid trying to script ahead at the expense of listening. Certain words or phrases serve to ignite conflict in each of us. If a grieving relative resents the cost of the funeral, he or she may voice derogatory remarks about you. Watch out for emotionally laden words that may be triggers for defensive behavior.

### ATTITUDES OR BiASES

A bias-free person probably does not exist. Even so, more prejudice resides in each of us than we are willing to admit. Consider a man arriving at your funeral home in an old beat-up dirty pickup to make funeral arrangements for his wife. He enters wearing bib overalls, which have obviously been worn more days than anyone else would dare. You look at his unshaven, unruly countenance and wonder who this man can be. Prejudice could easily enter the picture as you see a poverty-ridden man who could never afford a decent burial for his wife. But what if this same man was actually an eccentric multimillionaire? All of his outward signs and your own bias against him made you ready to reject him before you clearly grasped the facts. Your prejudice would initially hinder your ability to listen. Our prejudice influences early listening far more than we realize.

### PERSONAL INNER STRUGGLES

When we are emotionally crippled by our own difficulties, we listen to others less effectively. Intrapersonal conflict can create a battleground within that reduces our listening skills. We can only give our energy to focus on one perspective at a time. If we are consumed by our own set of difficulties, we will not listen well to those we attempt to help. It is like standing so close to one tree that we cannot see other trees, not to mention the rest of the forest.

The more you inherently dislike an individual, the more difficult it will be to listen to him or her. Keep in mind that some individuals going through the grief process may be juggling so much guilt they cannot hear you clearly. This demands patience and simplicity in communication for those robbed of good listening skills by grief.

### INTERRUPTION
This malady appears to be increasing in our society. You may find your mind moving much faster than the speaker's tongue. The grief-ridden individual often labors to express thoughts that normally would be easily uttered. Be careful about rushing in with your own words until you have heard the hurting person. Since our society seems dedicated to reducing all social graces, interrupting has become a way of life for many. We further compound the interruption problem by the fact that we listen about five to six times faster than we talk. This gives the listener time on his or her hands. Will we use it to pick up the nonverbal cues? Or will we cut off the speaker because we are ready to talk? Relationships are better built when we learn to not interrupt.

OVERLOAD

In this information age an overabundance of data plagues us in staggering proportions. In the mid-1980s the average individual processed about five hundred verbal messages a day. Just ten years later we find ourselves bombarded by over two thousand messages a day. We are not overloaded with data; we are drowning in it! Some solve this dilemma by tuning out or blocking the listening process. Filtering or blocking information greatly curtails what we actually process in listening.

TIMING

We are increasingly aware of time's value. Many now view time as more valuable than money. Since time is fast becoming a scarce resource, many prize it highly. “I don’t have time to listen to you. “I must run. “Can we talk about this later? . . .”—these are everyday experiences for nearly everyone. For you to give your time to listen to the grieving person may be your finest statement of relationship importance.

PHYSICAL EXHAUSTION

Since listening requires stronger concentration and effort, fatigue reduces our intake ability. When we experience loss of sleep, abnormal stress may sometimes be unavoidable. Even so, listening will suffer when these things are present. A lack of rest affects your entire personality. Fatigue distorts the thinking and the listening process, causing relationships to suffer. Fortunately, most physical exhaustion is only a temporary problem. Be alert to the short-term negative effect arising from the barrier of fatigue.

FILTERED LISTENING

We often hear what we want to hear or what fits into our mind-set. If we have a positive predisposition, we will listen for the good. If we program our minds negatively, we listen for the bad. The more we reduce the extremes in filtering, the better we will listen. We need to hear things as they are without the superimposed filters that distort our listening and the reality around us.

GUIDELINES

The following seven guidelines should help improve our listening skills and help us to productively counsel those who are grieving.
LISTEN ACTIVELY

Little effort is required to speak, but we expend major energy when we listen. We depend on another person when we listen. We must lock into what that individual is saying, how they are saying it, why they are saying these words, and what they are not saying. Developing your skill in this area will take time. Don’t be discouraged if progress is slow at the beginning. Listening is like any habit: repetition, review, recalling, memory, indexing—all must function well if maximum listening is to occur.

LISTEN WITH EMPATHY

Empathy puts the spotlight on the mourner (Wolfelt 1988, p. 160). This is more sensed than planned. If you genuinely care for hurting people, it will show. To empathize causes you to go into partnership with the grieving person. You assure him or her of your caring and compassion. Your actions will always reveal this better than your words. Do your eyes convey your concern? Familiarity may breed not contempt but rather monotony. As in any vocation, things can become routine. You must guard against a negative attitude that sends the message “This is just a job.” Do you easily reach out to people in their distress and grief? Empathy relates to the measure of your reach as you seek to help those trying to cope with death.

LISTEN WITH OPENNESS

We do this best when we reduce defensive behavior and filtered listening. Make every attempt to focus on the facts, not the inferences we so often make from the facts. To reduce our ever-present blind spots, the other person needs a sense of permission to give us criticism or negative feedback. If we are perceived as arrogant, this problem will continue until someone feels secure enough in the relationship to help us see how we are perceived.

At times, we hide our own lives too much. When we listen well, we share appropriate information with the listener. Each person going through the grief process longs to know if other humans have this problem. Usually, a discreet confession of your own humanity will generate more openness from the grieving party.

LISTEN WITH AWARENESS

Watch for agreement between what a person says and how he or she says it. Consistency is the goal of our awareness. We achieve greater accuracy when we listen with our eyes and ears. Work toward mastering more than just the content of someone’s words. Why is she saying this? What is he not saying? Why is she saying these words with this intonation? What nonverbal cues agree or disagree with what he is saying? These types of questions will sharpen your awareness as you serve those who are hurting.

RESIST EXTERNAL DISTRACTIONS

Give the person your complete attention. This could mean physically repositioning yourself to more easily see the speaker. In some instances you will need to improve your ability to concentrate. Work on your ability to focus on what is said.

HOLD REBUTTALS

Normally, this will not be a problem, but someone will eventually test your ability to be gracious. It may be something said or done that undercuts your reputation or credibility. Exercise extreme care
when someone hits your hot button. You can win a battle and lose a war with just your words. Usually unjust criticism reflects primarily on the sender, and time equalizes when we are patient.

**ANALYZE NONVERBAL MESSAGES**

Most emotional messages come via the nonverbal channel. In the grief process the mourner writes volumes. To what extent are tears appropriate? What proactive steps can be taken in managing grief? When is it time to stop or start physical movement during a funeral? Nonverbal messages normally answer these questions and others like them.

These guidelines, while not exhaustive, should assist the funeral helper in sharpening his or her listening skills. We best learn listening, like swimming, by doing it. Begin today to sharpen your ability to listen.

**VERBAL SKILLS**

**TYPES OF QUESTIONS**

The following five major types of questions are helpful for the funeral helpers.

**TO GAIN FACTS**

Here we focus on such details as family facts, occupational data, religious background, and type of funeral service.

**TO REVEAL FACTS OR FEELINGS**

Support as much as possible, set individuals at ease, assure your presence to help, and empathize with their grief (e.g., “What would you like in the way of music?”).

**TO CLARIFY FACTS OR FEELINGS**

Beware of ambiguity. Clarifying helps focus any discussion. Ask for more response in a loving and graceful way. When you clarify, you better determine areas of difference or agreement. Frequently, a clarifying question leads to more questions (e.g., “Would you prefer the family viewing on Friday night or Saturday morning?”).

**TO STIMULATE THOUGHT**

This serves to probe beneath the surface. You are requesting their opinions. This type of question often is open-ended. You may use a “why” question when attempting to stimulate thought. A question like this helps grievers see issues for themselves (e.g., “Why do you think he wanted the funeral in a church?”).

**TO SUMMARIZE DISCUSSION**

You attempt to help the grievers see where they are in the discussion. It might be an internal summary. This question can serve as a prelude to their decision making (e.g., “We have talked about when the funeral should be, now who will you want to officiate in the funeral?”).
TYPES OF COMMENTS

The following types of comments will assist you as you seek to maximize the help you offer to each grieving person. Take care to focus on each individual as unique and to structure your comments from your heart as well as your head.

A REFLECTIVE COMMENT

Emotional diversity marks the work of a funeral helper. Everything from strong weeping to stoic coldness can occur. Therefore, you need to help a person reflect as to where he or she is and wants to be. When we cultivate this ability, we build more effective relationships between the funeral helper and the grieving person. Wolfelt (1990, p. 98) made five astute observations about the nature of feelings you will encounter:

- Feelings are neither good nor bad, they just are.
- Everyone has a right to his or her feelings.
- Feelings always make sense when considered in context.
- Feelings are not dangerous (actions can potentially be dangerous).
- Denying a feeling does not make it go away.

With these thoughts in mind, master the art of helping by using statements like “You seem especially quiet today and that’s okay.” “You are absolutely right; good memories stay with us forever.”

A CHALLENGING COMMENT

The appropriateness of this comment surfaces when barriers keep the mourner from a sense of well being. Bathed in compassion, a loving, challenging comment may assist the grieving person. Great care should mark this type of comment. Usually the mourner exhibits dysfunctional behavior before we give this comment. The comment normally focuses on the future. You do not challenge the person’s past or present grief but attempt to help him or her see that tomorrow will dawn and there will be a way to cope. Again, make this a positive comment about the person’s ability to go forward with his or her life. For example, a statement such as “I suspect you will want to finish that course at the local college you are taking” can help the person refocus and see an ongoing life.

A RESTATEMENT COMMENT

You are not repeating the other person’s words but restating the concept. The mourner might say, “I just don’t think I can go on without her.” You might reply, “I know you will miss her tremendously.” Develop the skill of restatement. This is an ability to put the same concept in different words. A comment like this slows down the communication process and allows the grieving person to move at a slower rate. When feelings are keenly experienced, a slower rate of data processing becomes highly appropriate.

AN ENCOURAGING COMMENT

Look for something linked to the mourner that you can give a sincere compliment. Your words usually have either a building effect or a destructive effect. To establish a strong relationship, you want to use constructive words. Thanking the person for his or her cooperation during the funeral process may be one form of encouragement. A statement such as “In every area we have talked
about you have provided us with just the right information, and I want to thank you for your splendid cooperation." Sincerity must mark your comments when you attempt to encourage the mourner.

AN ASSESSMENT COMMENT

This statement tries to help the person evaluate an area calling for a decision. In times of grief, decision making becomes difficult or almost impossible. "I understand this is what you think would be best here" might be an assessment-related comment. You are giving the person feedback so she can affirm or disconfirm a decision she must make.

A PERMISSION COMMENT

When the tears flow, a person will often apologize for them. Assure the individual that tears are normal in the grieving process (Wolfelt 1988, pp. 127-28). Sometimes a person needs to ventilate anger at life, at circumstances, or even at the deceased. This comment tells her it is okay to feel as she feels.

A CONTROLLING COMMENT

At times emotions may run wild. The cathartic effect has passed and dysfunctional behavior prevails. A comment that takes charge can be appropriate. Wisdom should dictate the use of such statements. For example, a common "Let me help you ..." and then taking the person's arm and assisting in whatever is needed can be appreciated. However, be careful never to rush appropriate grief expression.

SUMMARY

When you build a relationship with a bereaved person, you help that individual at one of life's critical moments. Since emotional expression marks this mourning time, the awareness of and response to nonverbal messages enhance the relationship-building process. Sharpening listening skills gives you tools to enhance your counseling ability. Your skill in asking questions and making comments renders help in one of life's most difficult times. Always remember that the bereaved person will remember who you were long after he or she has forgotten what you said and did.

REFERENCES


SEGMENT 3: MODELS OF BEREAVEMENT AFTERCARE

SEGMENT OUTLINE:

1. The Need for Bereavement Aftercare
2. Bereavement Aftercare Programs
a. Professional Services  
b. Self-Help and Support Groups  
c. Hospice Programs  

3. Models of Bereavement Aftercare  
a. Hospital-Based Support Programs  
   i. Henry Ford Medical Center  
   ii. Mercy Medical Center  
b. Funeral Home Grief Aftercare Programs  
c. ACCORD  
   i. Booklets  
   ii. Newsletters  
   iii. Pamphlets  
d. Maximum Living Bereavement Services  

4. Models from Hospices and Other Groups  
a. Hospital Services of Santa Barbara  
b. Grief Education Institute  

5. Are Aftercare Programs Effective?  

6. Summary  

SEGMENT OBJECTIVES:

Upon the completion of this section of the course, you will be able to:  

1. Identify the specific needs for bereavement aftercare.  
2. Label bereavement aftercare programs in the categories of professional services, self-help, support groups, and hospice programs.  
3. Review models of Bereavement Aftercare.  
4. Recall models from Hospices and other groups involved in grief education.  
5. Determine the effectiveness of Aftercare Programs.  

NARRATIVE SUMMARY

This part of the course describes the various kinds of support—known as “aftercare”—available to the bereaved as they move through the grieving process after the death of a loved one. Aftercare can take different forms, including bereavement programs sponsored by funeral homes, state-regulated hospice bereavement programs, support groups, and self-help groups. The material covered will also discuss contemporary issues that have given rise to newer bereavement programs, such as support groups for survivors of suicide or for those bereaved by acquired immune deficiency syndrome (AIDS) or by sudden infant death syndrome (SIDS). Finally, specific programs from various geographic locations are discussed.  

THE NEED FOR BEREAVEMENT AFTERCARE
Making the transition—from a world with the deceased in it, regardless of what that means or how it manifested, to a world without the deceased—is the ultimate goal of mourning. The overall transition can be viewed as a series of smaller transitions—from wife to widow, from parent of four to parent of three, from best friend to just being by oneself. Because we are human, we often resist making these painful, yet necessary, transitions. The bereaved may stall at a particular stage of mourning, unwilling or unable to move through grief basic tasks. Everyone who experiences bereavement requires comfort and consolation. Most often—and ideally—comfort and consolation come from strongly sympathetic and supportive family members and friends who are willing to be available for weeks and months after the death has occurred.

Raphael (1983) has written, “The pain and suffering of grief has been known to human society for a long, long time. Just as it has been suggested that this distress may have evolutionary significance for the human group, it might also be hypothesized that the comfort and consolation human beings offer to each other are powerful influencers of the bonds so essential for family and community life. Much of the meaning of bereavement takes place in the warmth of family life and friendship” (p. 352). Traditional means for facilitating grief include family, church, funeral rituals, and social customs. Unfortunately, not every family is warm, loving, and supportive. Some are too fractured by dysfunction; others may be widely scattered by geography. And the bereaved’s extra familial support network may be less than ideal as well, unable to provide the level of support the bereaved requires, or unaware of the importance of ongoing support once the immediate shock has worn off and funerary rites are over. Often friends return to the routines of their lives before the death, unmindful of the long and difficult road ahead for the bereaved.

Societal norms once provided clear, well-defined, and accepted “rules” regarding bereavement such as dress, demeanor, and duration. These norms have changed, weakening and even erasing those rules and often leaving the bereaved feeling (and in fact being) quite alone within weeks or even days after the death. American society encourages the quick fix, exhorting those who suffer a loss to “put it behind you and get on with your life.” Such attitudes discount the bereaved’s very real grief, and can contribute to a sense of isolation.

There can also be difficulty resolving grief when the bereaved chooses to participate in few, if any, of the rites and/or rituals commonly associated with death. Some bereaved has the deceased cremated and have no religious funeral or any kind of memorial service by which to mark the occasion and facilitate the process of accepting the loss. The absence of any sort of funerary service may also result in the bereaved receiving limited social support from those who would otherwise have been present. Absence of any sort of rite of detachment can leave family members and friends sufficiently uncertain regarding the bereaved’s situation that they do little, if anything, by way of offering support to the bereaved.

The importance of ongoing support in bereavement should not be minimized. The nature and strength of the bereaved’s social support network has already been identified as a key factor in predicting bereavement outcome. The stronger and more supportive the network, the better the outcome. Individuals who have what they perceive as non-supportive or nonexistent social support networks are most likely to have poorer bereavement outcomes (Raphael 1983, p. 372).

According to Rando (1984), “What the griever needs most is acceptance and nonjudgmental listening, which will facilitate the expression of emotions and the necessary review of the
relationship with the lost loved one. He will then require assistance in integrating the past with the new present that exists” (p. 79). This view is supported by Jacobs et al. (1994), who wrote “widows report that active coping, social supports, and social involvement were most effective for them for coping with bereavement” (p. 557).

**BEREAVEMENT AFTERCARE PROGRAMS**

The absence of ideal support configurations has given rise to the development of other resources for bereavement aftercare. These resources can be used in concert with the bereaved's support network, or they may constitute the only support the bereaved has available in resolving the grief. The goal of grief counseling, writes Worden (1982), is “helping people facilitate uncomplicated, or normal, grief to a healthy completion of the tasks of grieving within a reasonable time frame” (p. 35).

Parkes (1987) identified three major categories of bereavement aftercare: (1) professional, (2) self-help and/or support groups, and (3) hospice (a combination of professional and trained volunteers). “The care offered usually ranges from individual counseling in the bereaved person’s home, to group meetings, which may be ‘social groups’ or ‘therapy groups.’ The latter are usually led by a professional” (Parkes 1987, p. 259).

According to Raphael (1983), “Professional and professionally supported services and self-help services are capable of reducing the risk of post bereavement morbidity. . . . The goals for effective programs are: the encouragement of grief and the promotion of mourning. Not only may the bereaved person be comforted and consoled, but he may, sensitively and appropriately, be assisted in the resolution of his loss” (p. 372).

Writes Worden (1982) regarding the overall goals of grief counseling:

The overall goal of grief counseling is to help the survivor complete any unfinished business with the deceased and to be able to say a final good-bye. Specific goals correspond to the basic tasks of grieving:

1. To increase the reality of the loss;
2. To help the counselee deal with both expressed and latent grief;
3. To help the counselee overcome various impediments to readjustment after the loss;
4. To encourage the counselee to make a healthy emotional withdrawal from the deceased and to feel comfortable reinvesting that emotion in another relationship. (P. 36)

Worden's aftercare model is similar to Parkes's, but is more detailed:

1. Professional services by trained doctors, nurses, psychologists, or social workers who can support a person who has sustained a significant loss (individual or group setting)
2. Volunteers selected and trained by professionals (i.e., Widow-to-Widow program)
3. Self-help groups (i.e., Compassionate Friends)
It is useful at this point to distinguish between "support groups" and "self-help groups," as they are often considered synonymous. While their goals may be the same—the effective, healthy resolution of grief—their processes are in fact quite different. Support groups are generally run by a combination of professionals (i.e., doctors or social workers) and volunteers who are trained by those professionals. Support groups "have predetermined outcomes and a strong separation between helpers and supporters" (Klass 1985, p. 354).

Self-help groups, on the other hand, are made up of members who share a common condition, situation, heritage, symptom or experience. They are largely self-governing and self-regulating, emphasizing peer solidarity rather than hierarchical governance. As such, they prefer controls built upon consensus rather than coercion. . . . They advocate self-reliance and require equally intense commitment and responsibility to other members, actual or potential. They often provide an identifiable code of precepts, beliefs and practices that include rules for conducting group meetings, entrance requirements for new members and techniques for dealing with "backsliders. . . ." They generally offer a face-to-face or phone-to-phone fellowship network usually available and accessible without charge. Groups tend to be self-supporting, occur mostly outside the aegis of institutions or agencies, and thrive largely on donations from members and friends. (Klass 1985, p. 354)

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**PROFESSIONAL SERVICES**

Professional services are generally those provided by a psychiatrist, psychologist, licensed professional counselor, or social worker who is specially trained in working with the bereaved. Typically, professional services entail a one-on-one relationship between the professional and the bereaved. Sessions may take place in the bereaved's home or at the professional's office. Session length and duration vary based on the bereaved's need, as evaluated by the professional (and likely agreed to by the bereaved). Professional services can be quite costly, depending upon individual practitioners’ fee schedules.

The goal of professional grief counseling is to facilitate the accomplishment of the basic tasks of grief within a reasonable, albeit indeterminate, time frame.

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**SELF-HELP AND SUPPORT GROUPS**

Self-help groups tend to be programs of attraction. That is, members join out of a perceived need or desire to share their experience with others who have gone down the same path before them. One example of a bereavement self-help group is the Com-passionate Friends, an organization founded in England in 1969 for parents who have experienced the death of a child. According to Klass (1985), "A central tenet of the TCF process is that only those who have lost a child can understand" (p. 355).
The process of joining a self-help group is the same as that followed by parents who decide to join TCF. There are three steps: (1) deciding to attend a meeting; (2) deciding to affiliate (forming bonds with other members); and (3) deciding to help others (Klass 1985, pp. 356-67). As the healing progresses, members gradually move from a “taking” mode typical of newcomers to a “giving” mode, in which they have gained the knowledge, experience, strength, and hope required to begin to help others.

Support groups are typically run by professionals with the help of specially trained volunteers. There are support groups for a variety of bereaved individuals. One is a group called Widow-to-Widow, in which widows support each other during the mourning process. “In adult support groups there is typically a common problem or concern among the members and an emphasis on peer help. These groups can be viewed as surrogate systems of help to be used by people for whom such systems are inadequate or absent. Support groups differ from traditional psychotherapy or counseling groups because they do not aim to ameliorate intrapsychic or interpersonal difficulties, even though this may occur as a result of participating in the group” (Zambelli, Grace, DeRosa 1992, p. 484).

But adults are not the only ones who can benefit from support group participation. Recently, increasing awareness has led to the formation of support groups for bereaved children. “The goal of most children’s support groups is to help children cope with the death of a parent. Typically, the groups are short-term and utilize the following techniques: art making, game play, therapeutic stories, role play, and discussion” (Zambelli, Grace, DeRosa 1992, p. 484).

The overall goals of child bereavement groups vary somewhat from those for adults because children often have widely differing views on death from those held by adults. Schilling et al. (1992, p. 406) identified three goals for child bereavement support groups:

1. Normalize the loss process.
2. Provide peer support.
3. Create a safe, nonthreatening environment in which to express fears, fantasies, and ambivalent feelings about death. (P. 406)

HOSPICE PROGRAMS

Hospices are commonly and mistakenly believed to be organizations that focus only on caring for dying patients and supporting their families prior to the time of death. While this is true, hospice guidelines generally include recommendations for counseling and support of the bereaved. According to Worden (1982), “Comprehensive care includes work with the bereaved family. Most hospice programs use some combination of professionals and volunteers to do the counseling” (p. 37). In fact, the National Hospice Organization’s own standards state, “Family needs continue after the death of one of their members” (Rando 1984, p. 293).

Hospices are regulated by federal and state standards that are designed to ensure a baseline quality of care for the terminally ill and their families. Federal standards, which fall under the auspices of the Health Care Financing Administration (HCFA) of the Department of Health and Human Services, mandate the following:

Counseling services must be available to both the individual and the family. Counseling includes bereavement counseling, provided after the patient’s death as well as dietary, spiritual and any
other counseling services for the individual and family provided when the individual is enrolled in the hospice.

(a) Standard: Bereavement counseling. There must be an organized program for the provision of bereavement services under the supervision of a qualified professional. The plan of care for these services should reflect family needs, as well as a clear delineation of services to be provided and the frequency of service delivery (up to one year following the death of the patient). (42 CFR Ch. IV, 10-1-90 edition)

One model of a comprehensive bereavement aftercare program is that of the Michigan Hospice Organization, which has a five-pronged approach to aftercare. This program reflects the standards outlined previously and includes the following, as described in the organization's manual:

1. A bereavement correspondence program, consisting of regular monthly mailings (for a maximum of fourteen months). Each mailing contains information on grief and another selected topic, such as insomnia, journaling, children and death, depression, anger, and readjustments. In addition, mailings provide information about other bereavement services that are available.

2. A grief recovery program, a five-week support program.

3. A support group “to promote and encompass healthy grief through better understanding and information of the grief process and to allow the bereaved to move through their grief in a mutually supportive environment.”

4. A getting through the holidays seminar, which is held before Thanksgiving and consists of information and exercises, including a guided meditation, designed to help the bereaved during the Thanksgiving-Christmas-New Year's holiday season.

5. Memorial services, scheduled periodically for the bereaved and for hospice staff members.

The Michigan model stresses that bereavement services begin prior to death and are available twenty-four hours per day, 365 days per year. Introductory letters explain the services that are available. At the time of death, a bereavement counselor sends a note to the bereaved. Two weeks after the death, the counselor contacts the bereaved again. Four to six weeks after the death, the counselor schedules a home visit for a bereavement assessment. If the bereaved declines a visit, the counselor sends a packet of information about available services and support, information about natural responses to grief, inspirational materials, such as poems, and a service evaluation questionnaire (information courtesy of Michigan Hospice Organization, 900 3rd Street, Suite 101C, Muskegon, MI 49440; 616-722-2257).
The Henry Ford Medical Center (HFMC), in Dearborn, Michigan, provides a bereavement support group, which is facilitated by a social worker and a priest with a degree in sociology or psychology. The stated purpose of the support group is “to provide an opportunity to share experiences and concerns with others who are grieving, following the loss of a loved one. It is normal to feel uncertain or to deny one’s emotions. Let us help you gain support during this time.” The HFMC bereavement support group meets every third Tuesday, during the early evening, making the time convenient for most people. HFMC also provides listings of other local area bereavement support groups and listings of area grief counselors, all with contact information.

Supplementary information includes a pamphlet entitled “Grief after Suicide” (a publication of the Mental Health Association in Waukesha County, Inc., Waukesha, Wisconsin); a handout explaining normal grief reactions, complete with recommendations for further information; and copies of articles relating to the value of tears and recommendations for telling children about death.

The bereavement support group at HFMC Fairlane is sponsored by the Henry Ford Hospice. The flyer provides contact information for those seeking details about the program (information courtesy of Henry Ford Medical Center, Health Education Center, Dearborn, Michigan).

MERCY MEDICAL CENTER

In their mission statement, Mercy Medical Center makes this pledge to the bereaved: “We are committed to helping people accept death as a part of life; to receive support and comfort during their experience with death; and to grow in the understanding of loss and grief.”

Mercy Pastoral Care provides bereavement classes, “offering information, support and education for adults who are grieving the loss of a loved one.” A separate program is available for bereaved children. Mercy’s adult program has four key components:

1. A bereavement information and support group—Offers professional support; is a “safe,” confidential place to share thoughts and feelings; is free of charge; and meets bimonthly.
2. Bereavement library—Books and other reading materials on bereavement may be borrowed by program participants or others for up to two weeks.
3. Bereavement education series—Offers a five-week program providing organized education program about grief issues; is free of charge; and is presented quarterly.
4. Pastoral counseling—By appointment for individuals and/or families.

Mercy’s children’s program brochure has two purposes. First, it provides the parent or caregiver with a basic education regarding ways in which children experience death. The brochure outlines the factors that influence the child’s reaction, such as age, personality, and relationship to the deceased, and provides basic principles for helping children deal with their bereavement. Second, the brochure provides information about the bereavement support group for children and adolescents, aged three to eighteen. The group meets every other week and requires preregistration (information courtesy of Mercy Medical Center, Roseburg, Oregon).

FUNERAL HOME GRIEF AFTERCARE PROGRAMS

Aftercare service provided by funeral homes is a relatively new concept, and while not all funeral homes support the idea, increasing numbers do. According to Louis L. Lawson, “One of the simplest things a funeral home can do is to establish itself as a referral service for community members. One
of the few places people can and do talk about death is in the funeral home. So it seems natural for someone in the funeral home to have done the legwork and provide a list of support groups to give their families” (“Emerging Trends in Aftercare,” by Louis L. Lawson. Originally published in AFD Today Magazine. Reprint courtesy of ACCORD, Inc).

“Post funeral programs range from simply making referrals to a therapist or a local self-help group, to providing written material and/or a newsletter, to establishing a full bereavement follow-up program. They can be performed by the funeral director, a paraprofessional, or a mental health professional. They can be extensive or minimal” (“Post Funeral Care Programs Help Clients, Funeral Homes,” by Margaret H. Gerner, MSW. Reprint courtesy of ACCORD, Inc).

ACCORD

Writes ACCORD president Sherry L. Gibson about her organization, “At AC-CORD we have a philosophy that aftercare is a continuum of care. . . . ACCORD’S main focus is teaching funeral directors how to develop follow-up and grief-counseling services.” ("Aftercare/Preneed Represent a Continuum of Care," by Sherry L. Gibson. Courtesy of ACCORD, Inc.) ACCORD provides extensive written materials to its client funeral homes, including booklets, pamphlets, and newsletters. It also provides the following types of materials directly as well as indirectly (through the funeral home) to bereaved families:

**Booklets.** ACCORD publishes an untitled, fourteen-page booklet that contains three main sections: What Will I Be Feeling? How Can I Cope?, and Where Can I Find Support? The booklet provides, in a question-and-answer format, the definition and explanation of grief, some practical questions, and an emphasis on a wide range of feelings that the bereaved experience, while stressing the need for the bereaved to “experience your feelings.” The booklet discusses rest, nutrition, exercise, and journaling as important coping strategies.

**Newsletters.** Newsletters come under two titles. One, “In Accord,” comes directly from ACCORD via funeral directors, while the others bear the logo of the individual funeral home. Each newsletter generally contains three articles (the first is typically authored by ACCORD’S founder, Dr. Sandra Graves), perhaps a question-and-answer page, and some practical, everyday hints in a column lightheartedly entitled “How to Boil Water.”

**Pamphlets.** ACCORD has pamphlets specific to various losses, including widowhood; loss of a parent, grandparent, sibling, baby, son or daughter, or “someone special”; or loss of a loved one who died from AIDS, suicide, and death by trauma. There are also pamphlets geared to bereavement by age group, such as “How to Help Children Cope with Death” and “Teen Grief” (information courtesy of ACCORD, Inc., 1930 Bishop Lane, Suite 947, Louisville, KY 40218-1937).

**MAXIMUM LIVING BEREAVEMENT SERVICES**

Maximum Living Consultants, Inc., in Birmingham, Michigan, under the direction of Dr. John D. Canine, provides funeral homes with two levels of aftercare service. According to Dr. Canine, the goal of both levels is identical: “To improve the quality of life by examining the facts and psychological theories associated with the bereavement process and then, relate these facts and theories concerning death, dying, and bereavement to an individual’s personal feelings, values, and
priorities.” Funeral homes can choose aftercare service that provides information about bereavement (general information on grief, a list of counselors, and a list of support groups) that is sent directly to the bereaved, as well as follow-up survey services regarding customer participation and quality of service. If the funeral home wishes to provide more comprehensive aftercare services, it can choose services that include greater personal contact with the bereaved, including one-on-one counseling, designated house calls, and organized monthly support groups.

The Maximum Living program uses two books, written by Canine, as core resources. The Challenge of Living (1983) walks the reader through a basic education about death, including societal attitudes that help us avoid confronting our own deaths. Canine (1983) believes that death awareness is central to living a healthy life:

The whole point of death awareness is to make a person so aware of his own death that a “new” individual emerges, an individual who sees life from a more meaningful perspective. Because this person’s sense of value has changed or deepened, his new view of life makes him “creative beyond any expectations,” and he experiences a fuller existence. Death acceptance is the key to coping effectively with your emotions about death. To fear death is to keep it locked in the closet. To accept death is to bring it into the open thus removing your fear. It is the purpose of death awareness to unlock the doors of communication allowing people to share with each other their thoughts and feelings about death.

Death awareness helps you deal with these emotions through learning and sharing in an unthreatening environment. This is where the healing process begins, and then you are on your way to effectively coping with your personal loss. (Pp. 21-22)

Canine then takes the bereaved through what can be expected emotionally, and ways in which the bereaved can help him- or herself heal over time.

Canine’s I Can, I Will (1990) is a support group guide, written for support group leaders as well as the bereaved. Central to this handbook is Canine’s list of “Seven Steps to Assist Those Who Are Grieving.” Those steps are

1. Actualize the crisis.
2. Help identify and express feelings.
3. Assist in living without the deceased and ease emotional withdrawal.
4. Alert yourself to time.
5. Interpret normal behaviors.
6. Allow for individual differences.
7. Give continued support. (Pp. 39-43)

Canine’s program emphasizes the universality of the grieving process while acknowledging the unique nature and aspects of each mourner’s experience. The handbook contains exercises to be performed by individuals or support group members that will assist them in tracking and evaluating their personal grieving process. The culmination is a short questionnaire—entitled “How Do I Know I Am Better?”—in which the bereaved can document the progress or the completion of the grieving process (information courtesy of Maximum Living Consultants, Inc., 640 N. Woodward Avenue, Birmingham, MI 48009).
**MODELS FROM HOSPICES AND OTHER GROUPS**

**HOSPICE SERVICES OF SANTA BARBARA**

Hospice Services of Santa Barbara, California, provides an extensive package of written materials, designed for hospice volunteers and support group participants that gives information about the grieving process and the support group process.

Materials include the following:

1. “Grief Work Is Love Work” contains quotations about personal views of grief and asks two questions “For Reflection” based on those quotes.

2. “Participating in a Support Group” summarizes the group’s purpose and goals, and explains the overall format (“nonconfronting, small group”). It is followed by a list of guidelines that stress listening, sharing experiences, not seeking/giving advice, respecting group member confidentiality, and non-judgmental respect for and acceptance of others’ experiences and opinions.

3. “Typical Responses during Grief” (reprinted from Hospice of Schenectady) lists expected/normal reactions to grief, including physical sensations, thoughts, psychological, spiritual, behaviors, and feelings.

4. “The Tasks of Mourning” lists five tasks, similar but not identical to those posed by Worden and Rando: accepting the reality of the loss; experiencing and expressing feelings; beginning to put our lives back in order; placing the loss in a wider context of meaning; and reaching out to others. Below the list of tasks are four questions for group members, for example, which tasks seem hardest, and where do members feel progress is being made?

5. “Reminders for the Journey” is a list that stresses self-awareness and self-acceptance: the importance of experiencing our own feelings; the need to accept whatever it is we are feeling; the importance of expressing what we are feeling; the need to go at our own pace; and the need to be aware of movement and shifts within our lives. (Information provided courtesy of Hospice Services of Santa Barbara, 22 East Canon Perdido, Santa Barbara, CA 93101.)

**GRIEF EDUCATION INSTITUTE**

The Grief Education Institute (GEI), in Denver, Colorado, is a nonprofit corporation, formed “for the purpose of promoting the successful resolution of grief resulting from death.” GEI provides six services, including the grief line (a telephone hot line); educational experiences for the public; support groups (for adolescents and adults, led by a facilitator, which meet for ten weeks); facilitator training (for support group leaders); a lending library and The Journal (a quarterly newsletter); and a leadership manual for leading support groups (a manual that describes in detail all of the issues covered in facilitator training) (information courtesy of the Grief Education Institute, 4596 Iliff Avenue, Denver, CO 80222).
This has provided a small sampling of the myriad bereavement programs available nationwide; most hospitals and communities, as well as an increasing number of funeral homes, offer bereavement aftercare programs.

**ARE AFTERCARE PROGRAMS EFFECTIVE?**

Some skepticism about the effectiveness of bereavement aftercare programs still exists; academics disagree on whether or not bereavement outcomes are significantly affected by post-death intervention because few empirical studies have been conducted. My own experience and that of others involved in aftercare, however, has been that aftercare programs are most valuable to the bereaved, particularly when there are unusual circumstances surrounding the death of the loved one that could result in prolonged or unresolved grief.

It is widely believed that bereavement aftercare can assist the bereaved in making an ultimately healthy adjustment to the loss of a loved one. Longman’s (1993) study on hospice aftercare program effectiveness concluded: “That the hospice bereavement programs were perceived as beneficial to the participants was evident in their comments and attendance at the programs. Perhaps the contribution to nursing is the knowledge that such programs are available and can assist interested individuals in their bereavement” (Longman 1993, p. 173).

Schilling et al. (1992) voice tentative support for the benefits of bereavement groups for children, writing, “Clinical observations . . . suggest that early intervention can facilitate mourning and promote better adjustment to environmental changes following the death. . . . [Intervention studies across many other risk domains have demonstrated that children learn to cope with stress and challenges by watching, listening to, and interacting with their peers” p. 407).

More recently, Schneiderman et al. (1994) concluded that there is little sound evidence either in favor of or against bereavement programs.

It is entirely likely that social class, pre-morbid family functioning, social supports, the age of the dead family member and of the survivors as well as the nature of the death (sudden, expected, suicide, etc.) have as much to do with individual and family functioning during the bereavement period as any intervention we might provide. . . . [I]t is entirely possible that bereavement programs may work for some families under certain conditions. (Pp. 216-17)

Effectiveness of bereavement aftercare programs is typically judged, to some extent, on their widespread use, and the fact that their attendance is continuously high. Practitioners believe that if participants were not deriving some benefit from the programs they would stop attending. More research, which quantifies program results rather than merely providing descriptions of programs and participants, is needed.

This part of the course looks at the various bereavement aftercare programs that are available in most communities today. It also discussed the reasons why aftercare programs have come into being and have endured, such as the fragmentation of the family, the lack of social support, and the absence of clear social norms to guide the bereaved through the grieving process. Hospitals, funeral homes, social service agencies, and private practitioners have filled the void once occupied by family and friends. Professional counseling services, support and/or self-help groups, and hospice organizations all are available to provide bereavement aftercare. Some services are costly; many are free of charge to participants.
This part of the course briefly looked at a variety of aftercare programs from across the United States, demonstrating the principles of most, if not all, programs were similar in nature, with the emphasis on helping the bereaved move through the tasks of grief to a healthy conclusion of the mourning process. Some organizations provide literature only, while others provide literature and services, such as one-on-one counseling or participation in a facilitator-led support group. Finally, the section of the course briefly examined the effectiveness of bereavement aftercare programs.

REFERENCES


SEGMENT 4: CONTEMPORARY ISSUES INFLUENCING BEREAVEMENT AFTERCARE
SEGMENT OUTLINE

1) Acquired Immune Deficiency Syndrome
   I. Family and Friends’ Grief Issues
   II. Societal Attitudes toward AIDS
   III. Aftercare Issues for the Bereaved

2) Sudden Infant Death Syndrome
   I. Family and Friends’ Grief Issues
   II. Aftercare Issues for the Bereaved

3) Alzheimer’s
   I. Family and Friends’ Grief Issues
   II. Aftercare Issues for the Bereaved

4) Suicide
   I. Family and Friends’ Grief Issues
   II. Aftercare Issues for the Bereaved

5) Homicide
   I. Family and Friends’ Grief Issues
   II. Aftercare Issues for the Bereaved
   III. Aftercare Issues for Children

6) Miscarriage or Abortion
   I. Family and Friends’ Grief Issues
   II. Aftercare Issues for the Bereaved

7) Summary

SEGMENT OBJECTIVES:

Upon the completion of this segment of the course, you will be able to:
1. Illustrate the issues that AIDS introduces on the grief process.
2. Identify factors affecting the grief process for those bereaved by Sudden Infant Death Syndrome.
3. Review aftercare issues for the bereaved when Alzheimer’s is involved.
4. Identify grief issues whenever suicide is the cause of death.
5. Recall the effects of homicide, miscarriage or abortion on the grieving process.

NARRATIVE SUMMARY

When we speak of “modern” death, what we are actually talking about is the late-twentieth-century reaction to and means of coping with death in all its aspects. Some ways of dying are more socially “acceptable” than others. While we view a disease like acquired immune deficiency syndrome (AIDS) as terrifying and unique, it should be remembered that many other cultures in many other times have experienced diseases far more devastating than AIDS. One example is the bubonic plague, nicknamed “Black Death,” which killed between one-quarter and one-third of the entire population of Europe in a two-year period, from 1348 to 1350, striking particularly hard in congested cities and towns.

Other deadly killers have stalked humans before and since, including smallpox, diphtheria, and malaria. Modern-day scourges such as the epidemic of inner-city murder are also not new. Throughout history, particularly in Western Europe, war and murder were frequent causes of death; 80 percent of all newborns in medieval Europe died prior to their fifth birthday. For many centuries, life was hard and short.

As a result, it is incorrect to view certain kinds of deaths in the 1990s as “new.” Rather, these “new” causes of death, such as AIDS, Alzheimer’s, murder, have been known since time out of mind, albeit sometimes in different guises. What is new is the way in which people in late-twentieth-century America live (family configuration), where they live (extended families living long distances from one another), and the blurring and subsequent dissolution of many societal norms and traditions surrounding death and mourning. Each factor has contributed to an overall lessening of social support for those grieving the death of a loved one.

Late-twentieth-century America is a nation in which fully 50 percent of all marriages end in divorce; once-stable families disintegrate with frightening regularity. The mores that once kept couples together, and families intact, no longer exist. Shattered families can, and often do, become blended families, but the bottom line is that the primary family structure, in many cases, has broken down, taking with it the traditional sources of support in times of bereavement.

Another facet of the problem is geography. Many families—intact and otherwise—are physically located great distances from other family members. In the event of a death in the family, the members all converge for funeral home visiting hours, the wake, and the funeral, but often are en route to their respective homes in a matter of days, leaving those who are most deeply affected by the death to manage alone. The hundreds or even thousands of miles dilute, if not destroy much-needed ongoing support for the bereaved.
At this moment in history, Western cultures appear to have forgotten or abandoned the time-honored notion that the prescribed period of mourning is at minimum one year. Denying death at every opportunity, we now see the immediate mourning period—defined as the time from the death through the funeral, and perhaps a month or two afterward—as ample for completing the basic tasks of mourning. As such, social support is withdrawn from the bereaved at a time when it may be most needed. The clarion call to "get on with your life" denies and discounts the need to complete the grieving process in a nonspecific time frame.

These societal pressures are exacerbated when combined with "nonstandard" means of death. Some deaths, such as those from AIDS, suicide, elective abortion, sudden infant death syndrome (SIDS), or murder, fall sufficiently so far outside of the mainstream that they inspire anxiety in all of us, and often fall into the category Worden identified as "unspeakable." As a result, beyond the immediate time of death and funerary ritual completion, these deaths are often ignored because of the extreme discomfort they generate in those surrounding the bereaved. Discomfort appears to produce a sort of social paralysis, one in which people who would ordinarily be supportive of the bereaved decline to take on their support roles and instead fade into the background. Not knowing what to say or do, they say and do nothing.

It should be understood that no matter what the cause of death, the bereaved must do their grief work and move through the basic tasks of grief if they are to successfully heal. No death cause is more “significant” or more worthy of grief than any other. No bereaved person can be said to be more bereaved than another; the mother who loses a son to AIDS hurts no more or no less than the mother whose son is killed in a car wreck. The common denominator in “nonstandard” death causes, which distinguishes these mourners from others, is the sense of isolation they feel because of other peoples’ reactions to the mode of death.

This part of the course explores six types of “nonstandard” deaths: AIDS, SIDS, Alzheimer’s, suicide, murder, and miscarriage and/or abortion. It discusses the issues that complicate the grieving process, and suggests ways in which the bereaved can be helped with their grief work.

ACQUIRED IMMUNE DEFICIENCY SYNDROME AFTERCARE IMPACT

FAMILY AND FRIENDS’ GRIEF ISSUES

Family and friends of people killed by AIDS are burdened by three factors, in addition to the pain of their loss. First, many AIDS victims’ survivors often feel shame because AIDS is often (but by no means always) a sexually transmitted disease. AIDS is particularly frightening because it is highly communicable and always fatal. Because the earliest victims of the ongoing AIDS epidemic were homosexual males, there has been widespread condemnation of AIDS victims for certain behaviors that are seen by some as perverted and self-destructive.

In addition to ordinary citizens who are frightened by the specter of a fatal disease for which there is no cure, some politicians and even some religious leaders have called for the identification and quarantine of those who are HIV-positive and those suffering from full-blown AIDS. It has even been suggested that funding for further AIDS research should be abandoned because one way of contracting AIDS is via homosexual contact. The media have been rife with reports of emergency medical technicians, doctors, and other health care providers refusing to assist or treat AIDS patients. Many AIDS victims are abandoned by their own families when the cause of their illness is...
revealed. And the stigma associated with AIDS remains so great that even obituary notices frequently list fictitious, more socially acceptable causes of death such as cancer or pneumonia rather than AIDS.

It is into this environment that the bereaved are thrown after losing a loved one to AIDS. The second factor facing them is social isolation. That the bereaved experience a sense of isolation under these circumstances is unsurprising. Traditional sources of support are often missing, particularly when families deny that AIDS was the cause of death.

Gregory and Longman (1992) detail the experiences of several women who lost sons to AIDS. One woman, named Anne, was forbidden by her employer from telling her coworkers that her son was dying of AIDS. Still more cruelly, the employer asked Anne’s fellow employees not to attend the funeral; for fear of creating panic among the employees should they find out the real cause of death. “Anne experienced discrimination and stigmatization in the workplace. As a result, her public discourse on the death of her son was silenced. Also denied were opportunities for sharing her suffering with her friends and co-workers…. Restrained in sharing her suffering, Anne became a speaker for an AIDS project…. This activity helped Anne work through her suffering” (pp. 339-40).

Such experiences are common. Social condemnation contributes to social isolation, which results in the mourning process being stymied. With little or no social support in their grief, the bereaved walk a long, lonely road toward healing.

Their road is further complicated by a third factor—the fear of becoming infected themselves. This fear is not limited to sexual partners of AIDS victims but includes caregiving family members as well. Such fear can cause the bereaved to distance themselves from the person who is dying, which can produce enormous guilt in the bereaved once death comes. Thus, the grief process is complicated even further.

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**SOCIETAL ATTITUDES TOWARD AIDS**

AIDS, despite heroic efforts to educate the public to the contrary, remains a socially unacceptable way to die. Hand in hand with fear go disgust and disapproval—directed at those who contracted HIV and AIDS through homosexual activities or intravenous drug use. Some sliver of societal compassion remains for those perceived as contracting AIDS “innocently,” such as babies infected in utero, people infected by blood transfusions with tainted blood, and perhaps those who became infected through heterosexual sexual contact.

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**AFTERCARE ISSUES FOR THE BEREAVED**

Social stigmatization results in shame, isolation, and concomitant withdrawal or absence of social support precisely when it is most needed—during the death and subsequent grieving for a loved one who died from AIDS. As mentioned earlier, while the grief of the person bereaved by AIDS is no greater or less than the grief of anyone else who has lost a loved one, the circumstances and cause of death are different and, in the eyes of some, less worthy of grief than other losses from other causes.

It has been well documented in the literature that perhaps the single most critical component in producing an uncomplicated bereavement outcome is the presence of strong, continuing social
support. When that support is limited or nonexistent, what resources are available to those bereaved by AIDS that will facilitate the healing process? Two come to mind.

As documented by Gregory and Longman (1992) in their study on mothers whose sons died of AIDS, active participation in AIDS awareness and prevention activities helped mothers to heal. One resource was the creation by one mother of an AIDS quilt panel that she designed to depict the progress of her son’s life. These mothers, in their search for meaning in the midst of their grief, crafted highly individual solutions and helped themselves to heal by breaking out of the shame, silence, and isolation imposed by a society frightened by AIDS. In so doing, they memorialized their sons by helping stem the epidemic’s spread.

The second avenue the bereaved can choose is less public and less vocal, but it can be valuable in the grieving process—becoming a member of an AIDS bereavement support group. Membership in any support group immediately bestows upon participants the valuable gift of co-membership; no longer need they be isolated. Membership bestows the knowledge that participants are not alone in their situation or their grief.

A support group can provide a safe place in which to express or explore feelings, share experiences, and ultimately assist others. Amelio (1993) writes of one AIDS bereavement support group, which was open to anyone bereaved by AIDS:

By encouraging parents, wives, gay and straight lovers, adult children, and siblings to talk about their grief with one another, the concept of AIDS as a ‘gay disease’ has dissipated and the isolation experienced by so many of the members in their lives outside of the group is diminished.... The group has been an outlet for all members to express their fears, mourn their losses, and share their rage. Through mutual support and non-evaluative listening these issues can seem less overwhelming and isolating. (Pp. 48-51)

SUDDEN INFANT DEATH SYNDROME

FAMILY AND FRIENDS’ GRIEF ISSUES

“Sudden Infant Death Syndrome (SIDS) is the sudden unexpected death of a previously healthy infant that remains unexplained after investigation. SIDS is the leading cause of death in the United States among infants one week to one year of age. The suddenness and absence of definitive cause make a SIDS loss one of the most severe crises that can occur in a family” (Carroll and Shaefer 1994, p. 273).

SIDS strikes suddenly, without warning, and because it remains poorly understood, the family in which a baby has died of SIDS has special grief issues with which it must deal. In particular is parental guilt for not having adequately cared for the baby. This guilt can be exacerbated by a lack of support from family and friends. According to May and Breme (1983), "Because the etiology of SIDS remains unknown, relatives and persons outside the family may state or imply that the parents were neglectful or even abusive to the child, thereby isolating the family in their grief" (p. 65). Further, they assert that SIDS deaths precipitate family crises of gigantic proportions: "Because
of the sudden and unexpected nature of SIDS and the unknown etiology of the child’s death, families almost universally experience a feeling of ultimate responsibility which represents the primary way in which SIDS deaths differ from other losses. This responsibility is occasionally projected onto another (i.e., physician or sibling), but is typically personalized in the form of guilt” (p. 61).

Another issue with SIDS, frequently overlooked, is the impact that the baby’s death has on its siblings. Not only do siblings grieve the loss of the dead baby, often experiencing unwarranted guilt about the death themselves, but they must also deal with their parents' grief over the loss. Further, SIDS siblings experience more anger than might be anticipated. Anger is a normal response to the loss of a loved one. With SIDS, however, sibling anger can be part of the overall family grief dynamic. Hutton and Bradley (1994) report that “anger may occur with two foci: as directed at the parents for allowing the death to happen, or for being over-protective after the death; or as directed at the dead baby for causing the grief, or for terminating the eagerly-awaited "big sister" or "big brother" role” (p. 725).

Legal ramifications in the aftermath of an SIDS death can be profound, as law enforcement agencies may be called in by medical service providers to investigate when the cause of death is uncertain. Dealing with the police in the aftermath of a baby's death from SIDS can make an already difficult situation—one filled with the shock and numbness associated with sudden, unexpected deaths—more stressful for the families of the SIDS victims.

AFTERCARE ISSUES FOR THE BEREAVED

SIDs deaths often leave a grieving family to wonder exactly what happened to the dead baby, and why. May and Breme (1983) write that:

Early crisis intervention including an explanation of the nature of SIDS to parents and the performance of an autopsy can help to prevent subsequent emotional problems in the family. . . . [A] Diagnosis of SIDS should be made as soon as possible where the gross autopsy reveals no other cause for death. To learn from the physician, nurse, pathologist or other emergency room personnel that the infant's death was not their fault can prevent the establishment of erroneously based patterns of guilt and blame, and can provide enormous relief to families. (P. 65)

In the event that the information has not already been provided, another important factor in aftercare is stressing that the death could not have been prevented. The funeral home director and/or clergy are uniquely positioned to provide SIDS information to surviving family members, as well as to note the presence or potential for complicated grief reactions and make the appropriate referrals (May and Breme 1982, p. 71).

May and Breme (1983) suggest that professionals working with SIDS families exercise caution when the couple expresses a desire to quickly have another child in an apparent effort to “replace” the dead baby. As it is impossible to replace a dead child, and being such a “replacement” baby may be damaging to the subsequent child, “the decision to have subsequent children should be made in a rational fashion after the emotional resolution of grief has been accomplished” (p. 67).
According to Carroll and Shaefer (1994), support groups, which require grieving parents to reach for help outside the family unit, were attended by less than 50 percent of the couples they studied. “The use of seeking help outside the family remained the least used of all the coping patterns for participants. Communication and spousal support were the predominant coping methods” (p. 280). Considering these findings, those involved in aftercare with an SIDS family would do well to advise and if possible facilitate maximum open communication and sharing of feelings, not only of the parents but also of surviving siblings.

ALZHEIMER’S

FAMILY AND FRIENDS’ GRIEF ISSUES

Alzheimer’s is a disease of the brain that produces progressive dementia and, ultimately, death. Because Alzheimer’s kills its victims slowly, often over many years, families (generally adult children or spouses) are frequently cast in caregiving roles for extended periods of time. Depression is common among Alzheimer’s caregivers, as is increasing isolation from sources of social support as the disease progresses and demands on the caregiver increase.

While it might be assumed that once death occurs caregivers’ experience, along with their grief, a sense of relief that the caregiving responsibilities are finally over, this is not necessarily the case. Bodnar and Kiecolt-Glaser (1994) report on three studies which indicate that “feelings of guilt also increased, reflecting continued caregiver distress postloss. . . . One key mechanism related to continued vulnerability appears to be the persistence of thoughts or recollections about the stressful experience” (pp. 372-73). Further, they found that while the caregiver presumptively has more time for social contacts and social activities after the death has occurred and caregiving duties have ended, social contacts in fact decreased. One cause may be growing older, but another may be that “the multiple sacrifices made during caregiving (job, finances, social activities, gratifying activities, etc.) may be difficult to redress when caregiving ends and may effectively accelerate diminution of some facets of their social networks” (p. 378).

AFTERCARE ISSUES FOR THE BEREAVED

As with anyone else grieving the loss of a loved one, the Alzheimer’s caregiver’s grief work can be significantly helped by the presence of strong, ongoing social support during bereavement. Continued rumination about the caregiving experience is associated with continued caregiver distress and depression. In such situations, social contacts are likely to assist in dispelling such distress. One way in which Alzheimer’s caregivers may differ from others grieving a loss is that they are likely to be people who are in either their middle years (as in the case of adult child caregivers) or their later years (surviving spouse). Everyone who has experienced a loss needs social support in the form of someone who will listen to them as they relate their experiences. Particularly with respect to elderly Alzheimer’s survivors, social isolation may be exacerbated by a lack of mobility,
either physical (due to illness or disability) or in transportation (due to an inability to drive or own a car, or perhaps to drive after dark, etc). In such circumstances those who would provide social support—family, friends, clergy, funeral home director—may need to travel to or facilitate transportation for the bereaved in order for the bereaved to have access to that and other forms of support throughout the grieving process.

SUICIDE

FAMILY AND FRIENDS’ GRIEF ISSUES

People whose loved ones die by taking their own lives are known as “survivors of suicide.” Such individuals are left with the by now familiar tasks of grief experienced by anyone who loses a loved one. But survivors of suicide have other, extremely complex issues to resolve as part of their grief work.

Wagner and Calhoun (1991-92) report: “Studies examining societal responses to survivors of suicide list potential negative behaviors that survivors are likely to encounter: blame, rejection, lack of understanding, inability of others to understand the survivor’s sadness, continued and stylized behavior, negative attitudes about the deceased, and pressure to stop grieving” (pp. 61-62). It may be that no other cause of death produces such a large gap between the bereaved and those from whom they would like to receive support.

Although the survivor may experience a strong need for support, the support system’s ability to fulfill this need adequately may be adversely affected by the suicide. In addition to the more negative social perception, the social context is further confused by the lack of prescriptive social rules to guide the behavior of potential comforters, creating awkwardness and social discomfort: it is easier to avoid the bereaved than to make social mistakes. (P. 62)

Wagner and Calhoun further report that participants, who were survivors of suicide, reported feelings of anger, abandonment, hurt, loneliness, depression and hopelessness. Most also reported feeling guilty and having a strong need to know why the suicide occurred in order to make sense of the death.

Allen et al. (1994), in a study on the effect of the cause of death on responses to the bereaved, found that “survivors of suicide are perceived to be different from individuals grieving deaths from other causes. The individual bereaved by a suicidal death was viewed as more psychologically disturbed, more ashamed, and more able to prevent the death than were survivors of accidental or natural deaths” (p. 44).

This negative and judgmental view can create or contribute to the isolation felt by the bereaved. Wagner and Calhoun (1991-92) found that of the twelve survivors of suicide studied, eleven
reported experiencing “negative” support (inadequate, inappropriate, hurtful). Those who would provide support under different circumstances often withdraw, thereby providing little support, or negative support, because of their own feelings about suicide, and their uncertainty about and discomfort in dealing with someone bereaved by suicide.

In the main, Western society condemns suicide, except in extreme cases, such as physician-assisted suicide of a chronically or terminally ill person. Social support networks in an effort to make sense of a suicide search—often angrily—for someone to blame. When a person chooses to die, survivors cast about for explanations, rationalizations, and people, circumstances, or organizations to hold accountable. Recently a young Episcopalian priest aptly pegged suicide as “a very terrible weapon,” which deeply wounds survivors (personal communication).

AFTERCARE ISSUES FOR THE BEREAVED

In Wagner and Calhoun’s (1991-92) study, all survivors of suicide indicate that they felt they had received “helpful support” from others, but “seven [of the twelve] survivors sought ‘outside’ help, expressing the feeling that suicide requires a special type of support. ... it was support from other suicide survivors that gave these survivors what they wanted most” (p. 66). More than one survivor stated that only those who have experienced surviving the suicide of a loved one could truly understand, empathize, and give the support they required. There is a strong belief that the needs of suicide survivors are significantly different from those of people bereaved in other ways, and thus that only other suicide survivors can understand them.

Again, it is a post bereavement support group that likely will provide the supplementary social support suicide survivors require. Like the AIDS bereavement support group mentioned earlier, a suicide support group can provide the kind of safe, nonjudgmental environment suicide survivors need for working through their feelings of grief, guilt, and anger. It appears that, to a greater degree than other bereaved individuals, suicide survivors have a need to make sense of why their loved one chose to end his or her life, in order to fully heal and move forward.

Those who would give support to suicide survivors are advised by Wagner and Calhoun’s study to provide lots of attentive listening, so that survivors can verbalize their thoughts and feelings, and in so doing move toward a successful bereavement outcome.

HOMICIDE

FAMILY AND FRIENDS’ GRIEF ISSUES

A glance at the headlines of any major city newspaper, or a few minutes spent listening to local or network newscasts on any given day, confirms the worst fears of many citizens—that Americans are killing each other in increasingly large numbers. Causes often cited include, but are by no means limited to, illegal drug trafficking, domestic violence, and gang activities. While murder is hardly limited to any one segment of society—witness the 1994 murders of Nicole Brown Simpson and Ronald Goldman, as well as the 1994 drowning murders of young Michael and Alex Smith by their mother, Susan Smith—murder is a major cause of death for young African-American males in urban areas. In many cases, children are killing other children.
Bereavement following the murder of a loved one, according to Parkes (1993, p. 49) is “surely . . . one of the most traumatic types of loss experienced,” and he lists seven factors in murder that can contribute to the development of problems in the bereavement process. They are

1. Sudden, unexpected deaths
2. Untimely deaths
3. Witnessing of horrific circumstances
4. Threat to the life of the survivor or other loss of personal security
5. Guilt at having survived
6. Intense anger or ambivalence
7. Deaths by human agency, particularly when compensation is involved

Among the typical reactions of people bereaved by murder are numbness, rage against the person who committed the murder, guilt for not having protected the victim or in cases where the killer was a relative, and fear, particularly when the killer has not yet been apprehended. According to Parkes (1993),

People who have suffered major bereavements commonly lose the sense of invulnerability that enables most of us to move about the world without undue anxiety.

It is hardly surprising that some of those bereaved by murder experienced chronic fear, shut themselves up at home, avoided people and places associated with the loss, and were unable to go to work.

Many of the symptoms reported by bereaved people in the wake of murder or manslaughter can be seen as those of a post-traumatic stress disorder (PTSD). Thus, haunting memories sometimes associated with nightmares of the murder and leading to fear and hyper alertness were common. Reminders of the murder (e.g., by the press) would evoke severe distress, and often led to avoidant behavior. (P.51)

Burman and Allen-Meares (1994) also report that reactions among children who witness the murder of one parent by the other parent resemble the symptoms of post-traumatic stress disorder:

The symptoms manifested by a violent catastrophe of this magnitude have been likened to those of posttraumatic stress disorder. These symptoms include recurrent intrusive thoughts, images and sounds of the incident; nightmares; feelings of emotional detachment coupled with anxious attachment; a wish to avoid all feelings and reminders of the incident; a chronic fear of recurrence; and poor concentration and performance. (P. 28)

Children, in addition to losing both parents (one to death, the other to the penal system), must also cope with the uncertainty about their futures that such a murder inevitably produces. Where and with whom will they live? Will they have to change schools? Will they be together, or will they be separated? Their grieving process is further complicated by the presence of conflicting loyalties—to the dead parent as well as to the parent who committed the murder.
Bereavement from murder, considering the issues listed above, is unlike any other bereavement; the circumstances of the death set into motion a daisy chain of events from which it is difficult to extricate oneself. According to Parkes (1993), the overwhelming nature of bereavement by murder affects the grieving process in several ways:

(a) By inducing post-traumatic stress—a kind of emotional shock which generates anxiety, depressive avoidance, and vivid mental imagery; (b) by evoking intense rage towards the offender and all associated with him at a time when there may be little opportunity to vent that rage effectively; (c) by undermining trust in others, including the family, the police, the legal system, and God; (d) by evoking guilt at having survived and at failing to protect the deceased. . . . The bereaved people in this clinic saw themselves as in a rut from which they could not escape. (Pp. 52-53)

It seems likely, considering the nature of bereavement following murder, that professional help may be necessary if the grief process is to proceed normally. The goals of such professional help should include the following components: reassurance; recovery of a sense of control over one’s life; find out what happened; strong support from family members; creation of memorials (Parkes, 1993, p. 52). In addition, self-help groups, such as Parents of Murdered Children, can give the bereaved a place to share their grief and rage among others who have experienced similarly traumatic losses. It also provides the opportunity, ultimately, to assist others as they work their way through their grief.

AFTERCARE ISSUES FOR CHILDREN

Children traumatized by the murder of a loved one experience emotions similar to those of adults—feelings of rage, depression, and guilt are common—but do not have the same abilities to articulate those feelings. The aftercare techniques that work for adults are generally not suitable for helping young children, which necessitates development of age-appropriate and developmentally appropriate therapies.

Burman and Allen-Meares (1994) report on two young boys who witnessed their father murder their mother, and describe the activities that helped the boys to resolve their grief and confront the other issues the murder created. Regarding these two particular children, they write: “Early and ongoing environmental supports were shown to mitigate some of the profound effects of these traumas. Inter-generational family strengths and values (embodied in the aunt who often acted as surrogate parent, as well as positive church and school influences) were the foundation of the rehabilitative process” (p. 30).

Any person, who has experienced the loss of a loved one, needs to be able to talk about the experience and the feelings it produced. According to Burman and Allen-Meares (1994), this is especially true for children:

Therapy with the children centered around . . . through symbolic play, fantasy, art, and storytelling. . . . Through the use of storytelling, clay, hand puppets, and photographs, representations of the past were relived. Painful feelings were expressed through the
puppets. . . . Photographs of their mother abetted the grieving process by displaying happier images and memories, detracting from their last horror-filled moments with her.

Through months of re-experiencing and confronting the past, they moved toward the future. . . . [B]y sharing, validating, reflecting, and reframing events and responses in a supportive environment, the process of coping more realistically and adaptively was developed. (Pp. 31-32)

Support groups for children bereaved by murder also can be useful, particularly in light of the fact that children traumatized by violence often grow up to be adults who use violence themselves. About the two boys in their study, Burman and Allen-Meares (1994) write: “Children’s groups, using role plays, behavior rehearsals, and direct communication and feedback, dealt with anger and conflict resolution; feelings about specific traumatic events; and the improvement of self-esteem, communication, and social skills. The children realized that others experienced similar traumas, thus lessening the isolation and stigma involved with parental murder” (p. 32).

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**MISCELLANEOUS**

**FAMILY AND FRIENDS GRIEF ISSUES**

Only in recent years has there been any significant level of awareness regarding bereavement following a miscarriage (or spontaneous abortion) or an elective abortion. Previously, it was believed that, particularly in the case of a miscarriage occurring in the earliest weeks of pregnancy, the parents either did not grieve or had no real need or reason to grieve, since the pregnancy was so short. Today, however, there is growing awareness of the very real grieving that parents, and particularly mothers, experience when a wanted pregnancy ends in miscarriage.

Grief issues with respect to miscarriage appear to center around the degree to which the developing baby was perceived as “real” by its parents, particularly its mother. The more real the baby, the greater the sense of loss when the pregnancy terminates. For parents to whom the baby is not yet real, there may be little or no grief.

In the case of elective abortion of a wanted baby because of a fetal abnormality, the grief issues become increasingly complex. Not only is the baby dead, but, according to Kolker and Burke (1993), “unlike other perinatal losses, in this case the parents must take active steps to bring about the death of their baby; they ‘play God.’ Experience indicates that the parents’ response to abortion after CVS [chorionic villus sampling, a first trimester genetic test] is similar to that of abortion after amniocentesis. The critical factor is wontedness, not gestational age” (p. 520).

In addition to experiencing grief over their choice to terminate a wanted pregnancy and thereby bringing about the death of the developing fetus, parents commonly experience guilt, as described by Kolker and Burke (1993): “Regardless of how strongly they believe their decision was right, the bereaved parents worry about being criticized for ‘killing’ their baby. They may avoid telling acquaintances, co-workers, or relatives who might tell them they should not have had the abortion...
or, in the case of parents who are known carriers of serious genetic abnormalities such as Duchene’s muscular dystrophy, that they should not have gotten pregnant” (p. 521).

Unlike other kinds of deaths, our culture generally bypasses any rituals involving babies who die in utero or shortly after being born. In these cases the babies are neither named nor baptized, much less given funerals. This absence of ritual can complicate parental grieving for the dead baby; there is no baby to hold, and no baby to name, but the fact of the baby is grieved nonetheless. “Parents who did not have a chance during the abortion to see and hold the baby and who have neither memories nor mementos such as a photograph, may find it more difficult to let go” (Kolker and Burke 1993, p. 522). There is, however, a growing awareness of the need for rituals that acknowledge the loss and assist with grieving and closure, and such awareness has spawned a response from the funeral home industry. For example, the Detroit-area R. G. and G. R. Harris Funeral Homes provide free funerals for the parents of such babies.

As a result of this absence of closure and letting-go activities, recovery can take years. “Paradoxically, a factor that facilitates healing is parental bonding with the baby, the perception that the loss is one of a real son or of a real daughter rather than of a vaguely acknowledged fetus” (Kolker and Burke 1993, p. 522).

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### AFTERCARE ISSUES FOR THE BEREAVED

It appears that one of the keys to a successful grief recovery after the abortion of a wanted but abnormal fetus is the acceptance of the dead baby as real. A major part of bereavement aftercare in such circumstances is preparing the parents for unanticipated emotions and reactions to the abortion before the termination. Kolker and Burke (1993) offer guidance to aftercare givers and those who would support the grieving parents:

We wish to emphasize merely that genetic counselors, medical staff, and members of the bereaved couple’s informal networks need to be more aware of the repercussions of this experience so they can offer the couple more support. Couples undergoing prenatal diagnosis deserve more complete information about the consequences of the alternative procedures so they can make truly informed decisions. Women having an abortion must be given candid information about the abortion process and encouraged to bond with the baby before they let go. Finally, in the aftermath of the termination, the couple must be treated by society as the bereaved parents they are and allowed to mourn the death of their baby. (P. 524)

This view is supported by lies and Gath (1993) in their study of women who terminated their pregnancies because of fetal abnormality:

Grief counseling can play a part in the management of these women. Before the termination, the women and their families can be advised about the likely emotional reaction to the termination. After the termination, they can be provided with support. Sensitive and informed enquiry should be used to encourage the women to describe their symptoms. The women also need to be advised that they may experience a worsening or recurrence of their symptoms both at the expected date of the baby’s birth and at the anniversary of the termination. (P. 413)
SUMMARY

Those who are bereaved for any reason are in particular need of support from their traditional social network because, as mentioned in earlier parts of the course, the most important component in a successful, uncomplicated bereavement outcome is strong, ongoing social support. This kind of support is often precisely what is lacking in “nontraditional” deaths. The social support network, through disapproval and/or discomfort, is unavailable to provide necessary help. The subsequent feelings of isolation can prolong and complicate the bereaved’s grief work process.

With the exception of those bereaved by SIDS, who preferred not to seek help outside their immediate family, subjects in the studies discussed found solace and a sense of belonging by participating in specialized bereavement support groups. People in each category—AIDS, suicide, and murder—reported feeling less isolated when they became support group members. They were comforted by the fact that they were no longer alone in their experience or in their grief.

AIDS survivors found outlets for their grief by participating in AIDS awareness projects and in creating a panel for the national AIDS quilt. Both activities were a type of memorial to the deceased. Similar memorial creation was seen to be useful for those bereaved by murder.

Survivors of suicide appear to have the strongest need for outside support, particularly from others who have also lost a loved one to suicide. The experience of having a loved one take his or her own life is sufficiently traumatic and unique that survivors report that only other survivors can understand their feelings.

The parents of babies being aborted due to fetal abnormalities are in a singularly unique bereavement situation. Not only do they know the death will occur, they take deliberate action to have the death take place; they make the decision to terminate the pregnancy. In this situation, counseling prior to the abortion can mitigate the bereavement process by alerting the parents to the kind of emotions they may experience after the termination.

REFERENCES


SEGMENT 5: ISSUES FOR THE DEATH CARE PROFESSIONAL

SEGMENT OUTLINE

1. Risks for Death Care Professionals
   a. Definitions of Burnout
   b. Expectations of Caregivers
   c. Organizational Hazards
2. Examining Stress and Burnout
   a. Stages of Burnout
   b. A Professional Model for Caring for the Dying
3. Managing Burnout
   a. A Holistic Approach
   b. Meaning and Mourning
4. Summary
SEGMENT OBJECTIVES:

Upon the completion of this segment of the course, you will be able to:

1. Recognize the definition of professional burnout and its use in the Death Care Profession.
2. Recall expectations of caregivers.
3. Identify the stages of burnout.
4. Comprehend professional models for caring for the dying.
5. Apply techniques to help with burnout.

NARRATIVE SUMMARY

We know that the separation of the aged, the ill, and the dying in our society creates problems for loved ones in processing their grief. But it is not widely recognized that those professionals and volunteers to whom the care and ministry of dying people fall need to grieve as well. This population might include doctors, nurses, hospice workers, counselors, funeral directors, emergency workers, clergy, social workers—anyone whose job entails working with individuals and families facing death.

The investment death care professionals make is one of emotion as well as time and skill. It requires regularly confronting their own mortality, and when bonds are formed between caregiver and client, the death will provoke a grief response that must be acknowledged and processed.

This section of the course will discuss the factors that place death care professionals at risk for stress and burnout, offer a model for recognizing burnout stages, and address techniques that can be adopted on an individual as well as an organizational basis to manage and prevent this debilitation of caregivers and reduction of their performance on the job.

RISKS FOR DEATH CARE PROFESSIONALS

Stress takes a toll on people—physically, mentally, emotionally and spiritually—and when stressors are assigned “value,” as on the Social Readjustment Rating Scale, death is rated as the highest stressor of all. People whose jobs bring them into contact with pain, chronic illness, death, disaster, and dying are particularly susceptible to the phenomenon known as burnout.

Canine (1994) states, “Burnout is rooted in an individual's desire for meaningfulness. We want our lives to be significant. And each of us determines what that meaning is—and isn’t—that allows us to feel fulfilled ... in harmony with ourselves.” When we are thwarted, either by external or internal circumstances, from realizing our meaningful, “ideal” selves, we no longer feel good and may begin to experience bouts of anxiety, depression, guilt, and disillusionment. The consequences of burnout may include loss of health and well-being as well as a decline in professional performance.

DEFINITIONS OF BURNOUt

...
There are several excellent definitions of burnout, alternately characterizing it as a syndrome, a condition, a loss, and a state:

1. A debilitating psychological condition brought about by unrelieved work stress, which results in depleted energy reserves, lowered resistance to illness, increased dissatisfaction and pessimism, increased absenteeism and inefficiency at work (The Work Stress Connection: How to Cope with Job Burnout, by Robert Veninga and James Spradley).

2. A progressive loss of idealism, energy, and purpose experienced by people in the helping professions as a result of the conditions of their work (Burnout, by Jerry Edelwich with Archie Brodsky).

3. A state of physical, emotional, and mental exhaustion caused by long-term involvement in situations that are emotionally demanding (Career Burnout Causes and Cures,” by Ayala Pines and Elliot Aronson).

Indeed, a variety of research studies have demonstrated higher-than-average stress levels among funeral directors, palliative care unit nurses, and emergency workers with experience in incidents of critical stress. The potential for burnout increases as stress—for this discussion, death—occurs in serial or consecutive fashion with little or no time to grieve one loss before the next one happens.

Dr. Ronald Barrett, a psychologist at Loyola Marymount University who gives seminars to health care workers treating and attending persons with AIDS, has coined the term “bereavement burnout”—a situation that develops when there is such an accumulation of unresolved, compounded grief that an individual may simply grow numb.

Regardless of how we choose to think about burnout, or what form it might take in each of us, burnout tends to be progressive—indicating that there are steps and activities we can undertake to prevent the serious damage it can inflict on our ability to be compassionate to ourselves and others.

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**EXPECTATIONS OF CAREGIVERS**

Rando (1984) offers some thoughts on death care professionals’ vulnerability to burnout that are distinct from the external issues inherent in such work:
Many caregivers enter their respective professions because they are “rescuers” who want to save people from distress. Being a rescuer may set a caregiver up for the unrealistic goal of rescuing the dying patient, when there needs to be acceptance of the inevitability of death and of the fact that it ultimately vanquishes us all. In some cases caregivers will pay lip service to the goal of palliation, but continue to be task-oriented, searching for a cure. It is important for both patients and caregivers that the rescue fantasy be relinquished. Otherwise patients lose the emotional support they need from caregivers, and caregivers continually frustrate themselves by trying to accomplish tasks that can’t be done. (P. 433)

Barrett (1993) suggests that professional caregivers often begin their careers with naive enthusiasm, which may include the expectation of making a difference, a dent in the problems facing their clientele. While a new social worker, for example, may indeed offer significant comfort or facilitate communication between dying people and their families, she may soon become overwhelmed by the sheer volume and urgency of need she confronts on a daily basis.

It is not unusual for visiting nurses or home hospice workers to become deeply emotionally invested in the families they serve; when a death occurs, the isolated nature of their work often leaves them bereft of opportunities to interact with colleagues and process feelings. In addition, these individuals are constantly adjusting to diverse settings as they move from patient to patient, creating even more stress.

ORGANIZATIONAL HAZARDS

Also contributing to burnout potential are the factors of systemic design and organizational procedures under which many death care professionals work. Rando (1984) observes: “Since the care of the terminally ill is different than traditional medical care, there are often unclear expectations for those who are working with the dying. [This] lack of clarity . . . makes caregivers more open to stress because they are unable to ascertain the criteria against which they will be assessed” (p. 437). Further, mechanisms to reduce stress, manage threat of burnout, and process grief are frequently all too absent from an organization’s perhaps already overtaxed resources. A lowering of morale, a sense of being “alone” with one’s feelings, reduction in job satisfaction, and negative interpersonal dynamics may result.

While some hospitals and hospice groups offer regular “debriefing” and even ritualized opportunities for staff members to deal with specific deaths, many do not. Communication channels between and among levels of caregivers may be informal, logistically problematic, or even discouraged. And since caregivers often believe they are supposed to be “strong” and not ask for help themselves, when an institution does not foster opportunities to share information and/or feelings, it is easy for professionals to become caught in a repeated cycle of attachment and loss, attachment and loss, attachment and loss—until emotional disinvestment seems to be the only option to survive on the job. At this point, all their resources are devoted to simply coping.

EXAMINING STRESS AND BURNOUT

The serious threat burnout poses for a decrease in physical, social and professional effectiveness requires an awareness of both its symptoms and its stages. Among the symptoms of burnout that have been identified are exhaustion, despair, powerlessness, apathy, alienation, depression, loss of
self-esteem, irritability, loss of energy, cynicism, poor concentration, nightmares, loss of creativity, and negative attitudes. These can be reflected in behavioral changes that not only affect coworkers and quality of client care but may seriously affect an individual’s personal relationships.

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**STAGES OF BURNOUT**

The stages of burnout (see Figure 22-1) are marked by five progressive “points” that have accompanying mental, emotional, and physical ramifications.

The first stage is characterized by the initial stimulation of a new job and the enthusiasm and desire to succeed and prove oneself. This is the positive, if perhaps unrealistic, time when a death care worker feels ready, willing, and able to “do it all.”

The second stage is reached when stress has started to build and fatigue and job disappointment set in. The professional may come to believe (correctly or incorrectly) that the organization, agency, or society of which he or she is a part doesn’t share the same level of commitment to the work and its urgency. This is particularly the case with health and human services personnel serving the AIDS community, who can become further burdened with stress by the homophobia, ignorance, and social stigmas they may encounter as part of their work. An interesting footnote is that there are support groups for HIV-negative caregivers, due to stages of burnout.
The belief of some factions within the HIV-positive community is that those without the virus cannot really understand or be effective with those who are so afflicted.

Chronic exhaustion, the third stage of burnout, brings a higher intensity of emotion and possible physical symptoms. Anger, depression, proneness to accidents, and conscious or unconscious guilt may come into play. The individual may become less communicative and begin to withdraw socially. Use of addictive coping mechanisms such as caffeine, alcohol, nicotine, or other drugs may increase substantially during this stage.

The fourth stage is that of emergency, or the crisis point. If no intervention has taken place, the death care professional is at risk for opportunistic illness and is likely to demonstrate aversive behavior on the job, such as coming in late, leaving early, taking longer breaks, becoming angry when demands are made, and treating clients impersonally. Simultaneously, the professional is experiencing feelings of failure and pessimism, and may obsess over his or her disappointments and loss of values that were held so brightly in the first stage.

The fifth stage is the crossroads between help or hopelessness. It should be a goal of every death care professional and their managers to prevent a “stage five” situation from happening. A relevant sidelight to a study of funeral directors suffering symptoms of critical incident stress revealed that
those in the group reporting increased symptomatology (those thirty to thirty-nine years of age) were also most likely to “drop out” of the funeral business.

Although no direct cause-and-effect relationship can be drawn from the data, it should suggest to institutions and employers that if vulnerable groups can be identified, there should be programs or mechanisms or techniques in place to help them before burnout claims more sorely needed death care professionals.

A PROFESSIONAL MODEL FOR CARING FOR THE DYING

It has been noted that the increased “kinship” between terminally ill patients and their network of caregivers results in death care professionals becoming “surrogate grievers.” This notion may soon be disabused as it becomes more widely recognized that caregivers’ grief is neither a substitute nor a replacement for a faraway family’s grief but an authentic response to loss—particularly if the person was in some way special or memorable in the professional’s life.

Reynolds (1993) observed:

The number of mortalities the average care hospital experiences is staggering when one considers the major service areas of neonatology, cardiology, oncology, AIDS, and “med/surg.” To become intimately involved with patient/families during the crisis of an acute episode and then to precipitously end our helping efforts at the time of death is a travesty and breach of the individual and institutional helping contract. . . . We need to explore the development of comprehensive bereavement support and outreach programs within the context of the acute care hospital. (P. 10)

And it must be comprehensive enough to extend to the caregiving staff.

Fortunately, there is a model that follows the adaptation process that health care professionals must go through in order to work with patients who are facing death. In 1977 Harper developed the Schematic Growth and Development Scale in Coping with Professional Anxieties in Terminal Illness. This “charting” of normative stages reflects the understanding and conflict-resolution ability caregivers must develop so they can care humanely for dying people, build their capacity to help, and enjoy freedom from the incapacitating effects of burnout. Readers should appreciate that this scale is not a guideline for burnout prevention but instead presents issues and objectives that prevention programs may wish to take into consideration.

The maturing of the professional who copes with stress in caring for the dying is likely to encompass the following stages:

1. Intellectualization: knowledge and anxiety—Caregivers are uncomfortable with death and manage anxiety by focusing on professional knowledge and factual issues of policies and procedures. Conversations with the patient are not personal.

2. Emotional survival: trauma—The caregiver feels death on an emotional level and grieves his or her own mortality. This is accompanied by pity for patients whose death is unavoidable, guilt at their own health, and trauma at the reality of death.
3. Depression: pain, mourning, grieving—This is the “grow or go” stage where caregivers must accept the fact that death does exist and is painful. Mastery of self is a challenge; if the reality of death is not accepted, workers may leave the field.

4. Emotional arrival: moderation, mitigation, and accommodation—No longer preoccupied with their own death or incapacitated by depression, caregivers’ emotional responses are appropriate. They are sensitive enough to grieve and resilient enough to recover.

5. Deep compassion: self-realization, self-awareness, and self-actualization—Caregivers are able to relate compassionately to the dying patient, in full acceptance of the impending death. Behavior and performance are enhanced by the dignity and self-respect they afford themselves, enabling them to give dignity and respect to the dying patient.

Although a model for managing burnout will be presented shortly, the ability to “work through” Harper’s five stages implies that caregivers are noting and managing their stress along the way. Barrett (1993) suggests some “prescriptions” that death care professionals might wish to practice to keep their stress levels within reasonable bounds:

1. Be reality-oriented: accept the “givens” of a system.
2. Develop reinforcement alternatives; look for different ways to “validate” your success.
3. Use time management techniques.
4. Conduct routine attitude tests or assessments.
5. Seek information that might make the job easier.
6. Establish and maintain support systems.
7. Take time out.
8. Monitor diet and physical fitness.
9. Learn to delegate.

MANAGING BURNOUT

In a very real way, managing burnout is parallel to leading a well-balanced, harmonious life. The difficulty for death care professionals, of course, is that their emotional, physical, and mental resources are often stretched beyond “normal” limits due to the trauma, pain and suffering, serial losses, and compounded grief they deal with on a regular basis.

A HOLISTIC APPROACH
Canine’s model illustrating management of burnout identifies five major arenas of life that death care professionals must attend to in order to minimize their potential or likelihood for burnout. The model is intentionally circular, as it is meant to resemble a wheel, since “a wheel goes somewhere.” As Canine told an audience at the 1994 conference of the National Funeral Directors Association, “If one area of the wheel is flat, the wheel doesn’t go anywhere. We must care for the whole person. At the center you see a diamond shape. A diamond is a gem. This is the spiritual center from which you design your destiny.”

The significance of this “core” does not require religious affiliation. What is referred to here is the unique world perspective, or philosophy of life, that filters each experience an individual has and how he or she responds to it. For example, a person riding a crowded bus who believes someone is carelessly poking him with an umbrella may turn to discover a blind person fumbling with his white cane. Anger turns to acceptance, for he is now filtering his experience through a philosophy that values understanding and compassion for the blind.

Death care professionals need to be cognizant and aware of their spiritual filter, their purpose in life, and how to best exercise their spiritual muscles—whether through prayer, meditation, journal writing, communing with nature, self-examination and reflection, or practicing the tenets of a particular religious faith.
One outer “section” of the wheel involves the mind: What is the mental state of the person at risk of losing balance and tumbling into burnout? Does the nurse appreciate herself and her abilities? Is the minister at war with himself over a real or imagined flaw in his character? Are the funeral director’s behavior and attitude congruent (“in sync”) with his values and beliefs? Is the doctor forever putting herself down?

This mental arena for burnout management relates to self-image, self-esteem, and self-criticism. In order to feel good and maintain harmony within, it is necessary to appreciate and honor one’s talents and accomplishments (large and small), keep one’s “actual” self as close as possible to one’s “ideal” self (living as much as possible according to one’s personal moral and/or ethical code), and not being afraid to answer our inner critic when it has something to say. This could mean reaffirming how worthwhile we are when we’re feeling “down,” or it may require listening carefully to what the inner critic is telling us we need to change by modifying our behavior, taking a sharper look at our idealized self, or both.

Another arc on the holistic wheel is the caregiver’s emotional life. This addresses the good feelings that result when emotions are identified and expressed. Canine (1994) observes, “We learn so much when we communicate. The identification and expression of feelings has the potential to remove conflict in our thinking—to remove cognitive distortion.”

He eschews the “strong, silent” macho stereotype that American men are taught to emulate, and recommends that emotions (particularly negative ones) not be allowed to “free-float” where they may land on scapegoats or innocent victims. Emotions should be identified, expressed, and locked onto the appropriate object. For example, if a funeral director is genuinely disturbed when burying a child, his emotional well-being is better served by sharing the truth of his feelings with a colleague than by going home and kicking the cat.

The goal is to grow better, not bitter.

Two very strong emotions that plague caregivers (and others) are anxiety and anger. In burnout management, it is important for individuals to recognize that these feelings are generally triggered by a lack of understanding or a lack of control. When faced with anxiety and/or anger, it is crucial to ask yourself (and possibly check in with others) what it is you don’t understand or what it is you can’t control that may be creating these uncomfortable emotions.

The final component of the holistic wheel’s emotional quadrant is the need in life to embrace forgiveness. Canine believes it is impossible to live a meaningful life without forgiveness, so if burnout is rooted in the desire for meaningfulness, every caregiver should remain aware of Joan Borysenko’s (1987) definition of forgiveness: “Accepting the core of every human being as the same as yourself, and giving them the gift of not judging them” (pp. 41-42).

A third area on the burnout management wheel is the physical condition of the at-risk professional. It is common sense that no one embark on a regimen of exercise without first consulting a physician. But once achieved, physical well-being can be maintained with approximately twenty minutes of exercise four times a week. The particular form of activity is not as important as the heart rate at which the workout is performed. An accepted formula is to start with the number 225, from which one subtracts one’s age and then calculates 75 percent of the remainder figure. This is the maximum heart rate that should be targeted for the exercise period.
Concurrent with regular exercise, people wishing to avoid burnout should avoid alcohol, drugs, tobacco, and caffeine, and should monitor a careful level of fat and sodium intake in their diet. Overall nutrition should incorporate recommended percentages of protein, carbohydrates, vitamins, minerals, and fibers.

The fourth quadrant on a wheel of life that’s “going somewhere” is the social arena. This includes the primary relationships—personal and professional—as well as the casual ones in a caregiver’s life. Those who find fulfillment in communicating with others, and who maintain satisfying hobbies and/or social activities are unlikely to experience burnout.

The ability to communicate and to respond to others’ needs in a dependable fashion creates bonds and trust. Reaching out to others socially throughout life affords an opportunity to build sustaining bridges with others that are rewarding and meaningful.

MEANING AND MOURNING

Death care professionals play a special role in our society. Their willingness to assist in what are often the most difficult moments in people’s lives places unusual demands on their energies and can be depleting and draining, particularly when many deaths are experienced in a short period of time.

Barrett (1993) warns that people in these fields often neglect their own need to get emotionally “caught up” and that unresolved grief becomes "excess baggage" that may lead to mental health complications, physical distress, and problems with interpersonal relationships. “Life moves so quickly,” he says, “we don’t have an opportunity to remember the significance of a person, or their specialness.

We need to ask: What happened here? How do I feel about this? What does this mean to me? How am I challenged by this?”

When losses aren’t acknowledged, the accumulated grief can wear us down, burn us out, literally make us sick. Death care professionals must develop a regular coping system and mourning mechanism to put each death into context.

Barrett (1993) believes that individuals, as well as institutions dealing with death, must develop mechanisms or rituals to grieve their losses. These can take a variety of forms and may include some type of tribute to the dead person. One method might be to simply write down the person’s name and concentrate on that person. Who was she? What was special about him that you will miss? What was her impact on your life or his gift to you? If you could convey a message to him, what would it be? How would you bring closure to the relationship? What gesture might you make? Is forgiveness, of yourself or the other person, needed so that you can go on from here?

He suggests that we take a moment to grieve every day.

Delayed and unresolved grief will not stay swept under the rug indefinitely, and those most at risk for burnout are those who “care too much.” The answer is not to “pull back” and become
emotionally unavailable to support your clients but instead to recognize and accept that caring and hurting go hand in hand.

**SUMMARY**

Issues for death care professionals addressed in this part of the course involve the dangers of stress and burnout and the need for organizational and individual mechanisms for coping, communicating, and grieving. The progressive stages of burnout were examined, along with a professional model that caregivers who wish to mature may consider in “charting” their own emotional progress.

A holistic approach to managing burnout was presented, taking into account the full spiritual, mental, emotional, physical, and social requirements for a harmonious, well-balanced life. The relationship between meaning and mourning, and its importance in burnout prevention was offered as a concept death care professionals must integrate into their lives.

**REFERENCES**

PART 1: RATIONALE FOR A MULTIDISCIPLINARY SUPPORT SYSTEM

1. The concepts of aftercare and grief counseling are relatively new and have become specialized fields of attention only in the past fifteen to twenty years as understanding and recognition of "normal" grief processes have been studied and written about.
   True _____ False _____

2. Dictionary definitions of "aftercare" offer a medical model, explaining the term as the treatment of a convalescent patient, such as would be utilized following surgery.
   True _____ False _____

3. In the death and dying profession, "aftercare" is defined as any post death or post funeral program of survivor rehabilitation designed to help the individual through the grief process and successfully readjust to his or her environment.
   True ___ False ___

4. Although the term "rehabilitation" continues to imply pathology, its purest meaning involves restoring or learning new habits that promote a useful and healthful life.
   True ___ False ___

5. In preindustrial societies, higher death rates meant that many people died at what we would consider relatively young ages, interrupting their role in society.
   True ___ False ___

6. Grief counseling involves those interventions which help persons experiencing normal grief to deal with the tasks of mourning in order to complete these within a reasonable time frame.
   True ___ False ___
7. While religious affiliations and spiritual beliefs will vary in both content and relative importance from one grieving person to another, the clergy play an important role in bereavement, as it is generally assumed they “understand” these matters better than the average person.
   True ___ False ___

8. The ADEC takes an active role in educating the public on death-related issues and sponsors an annual conference with leading professionals and researchers.
   True ___ False ___

9. The ADEC was formed in 1976, and its members include, among others, educators, funeral directors, social workers, psychologists, nurses, nuns, rabbis, physicians, hospital volunteers, and hospice personnel. True ___ False ___

10. Given the current fragmentation of aftercare delivery, it is incumbent upon those attempting to provide quality programs and care to examine the credentials, philosophies, and references of organizations offering such materials or programs before committing their own (or their clients’) time and money.
   True ___ False ___

PART 2: COUNSELING TECHNIQUES FOR HELPING THE BEREAVED

1. Nonverbal communication accounts for about two-thirds of our communication.
   True ___ False ___

2. Proxemics examines the use of space or distance between people.
   True ___ False ___

3. We send more nonverbal messages with our faces than any other means, and the face usually reveals the highest accuracy of all nonverbal messages.
   True ___ False ___
4. Paralanguage examines the tonal areas of the verbal message.
   True ___ False ___

5. In times of bereavement, power seems missing, and this can show up through the eyes.
   True ___ False ___

6. The clothing people choose to wear can reveal their station in life, their values, and their opinions of the funeral occasion.
   True ___ False ___

7. A person's hand gestures may serve as an indicator of anxiety during crisis.
   True ___ False ___

8. Body position presents us with a subtle but powerful way to observe nonverbal messages. At times you can almost see the burden a person carries by the bend of the body.
   True ___ False ___

9. A defensive person reaches a premature conclusion. Statements like “I know what you are going to say ...” or “It has been our normal experience that ...” can preface this behavior.
   True ___ False ___

10. Your words usually have either a building effect or a destructive effect. To establish a strong relationship, you want to use constructive words.
    True ___ False ___
PART 3: MODELS OF BEREAVEMENT AFTERCARE

1. Making the transition—from a world with the deceased in it, regardless of what that means or how it manifested, to a world without the deceased—is the ultimate goal of mourning.

   True ___ False ___

2. Aftercare can take different forms, including bereavement programs sponsored by funeral homes, state-regulated hospice bereavement programs, support groups, and self-help groups.

   True ___ False ___

3. American society encourages the quick fix, exhorting those who suffer a loss to “put it behind you and get on with your life.” Such attitudes discount the bereaved’s very real grief, and can contribute to a sense of isolation.

   True ___ False ___

4. Parkes (1987) identified three major categories of bereavement aftercare: (1) professional, (2) self-help and/or support groups, and (3) hospice (a combination of professional and trained volunteers).

   True ___ False ___

5. Support groups “have predetermined outcomes and a strong separation between helpers and supporters” (Klass 1985, p. 354).

   True ___ False ___

6. Self-help groups are largely self-governing and self-regulating, emphasizing peer solidarity rather than hierarchical governance.

   True ___ False ___

7. Professional services are generally those provided by a psychiatrist, psychologist, licensed professional counselor, or social worker who is specially trained in working with the bereaved.

   True ___ False ___

8. Hospices are regulated by federal and state standards that are designed to ensure a baseline quality of care for the terminally ill and their families.

   True ___ False ___
9. Post funeral programs range from simply making referrals to a therapist or a local self-help group, to providing written material and/or a newsletter, to establishing a full bereavement follow-up program. They can be performed by the funeral director, a paraprofessional, or a mental health professional. They can be extensive or minimal.

True ___ False ___

10. Effectiveness of bereavement aftercare programs is typically judged, to some extent, on their widespread use, and the fact that their attendance is continuously high.

True ___ False ___

PART 4: CONTEMPORARY ISSUES INFLUENCING BEREAVEMENT AFTERCARE

1. When we speak of “modern” death, what we are actually talking about is the late-twentieth-century reaction to and means of coping with death in all its aspects. Some ways of dying are more socially “acceptable” than others.

True ___ False ___

2. Some deaths, such as those from AIDS, suicide, elective abortion, sudden infant death syndrome (SIDS), or murder, fall sufficiently so far outside of the mainstream that they inspire anxiety in all of us, and often fall into the category Worden identified as “unspeakable.”

True ___ False ___

3. No death cause is more “significant” or more worthy of grief than any other.

True ___ False ___

4. The stigma associated with AIDS remains so great that even obituary notices frequently list fictitious, more socially acceptable causes of death such as cancer or pneumonia rather than AIDS.

True ___ False ___

5. May and Breme (1983) suggest that professionals working with SIDS families exercise caution when the couple expresses a desire to quickly have another child in an apparent effort to “replace” the dead baby. As it is impossible to replace a dead child, and being such a “replacement” baby may be damaging to the subsequent child, “the decision to have subsequent children should be made in a rational fashion after the emotional resolution of grief has been accomplished”.


6. Particularly with respect to elderly Alzheimer’s survivors, social isolation may be exacerbated by a lack of mobility, either physical (due to illness or disability) or in transportation (due to an inability to drive or own a car, or perhaps to drive after dark, etc.). In such circumstances those who would provide social support—family, friends, clergy, funeral home director—may need to travel to or facilitate transportation for the bereaved in order for the bereaved to have access to that and other forms of support throughout the grieving process.

7. It appears that, to a greater degree than other bereaved individuals, suicide survivors have a need to make sense of why their loved one chose to end his or her life, in order to fully heal and move forward.

8. Many of the symptoms reported by bereaved people in the wake of murder or manslaughter can be seen as those of a post-traumatic stress disorder (PTSD).

9. Grief issues with respect to miscarriage appear to center around the degree to which the developing baby was perceived as “real” by its parents, particularly its mother. The more real the baby, the greater the sense of loss when the pregnancy terminates. For parents to whom the baby is not yet real, there may be little or no grief.

10. The most important component in a successful, uncomplicated bereavement outcome is strong, ongoing social support. This kind of support is often precisely what is lacking in “nontraditional” deaths.

PART 5: ISSUES FOR THE DEATH CARE PROFESSIONAL

1. It is not widely recognized that those professionals and volunteers to whom the care and ministry of dying people fall need to grieve as well.

2. The investment death care professionals make is one of emotion as well as time and skill. It requires regularly confronting their own mortality, and when bonds are formed between caregiver and client, the death will provoke a grief response that must be acknowledged and
3. People whose jobs bring them into contact with pain, chronic illness, death, disaster, and dying are particularly susceptible to the phenomenon known as burnout.

True ___  False ___


True ___  False ___

5. The consequences of burnout may include loss of health and well-being as well as a decline in professional performance.

True ___  False ___

6. Dr. Ronald Barrett, a psychologist at Loyola Marymount University who gives seminars to health care workers treating and attending persons with AIDS, has coined the term “bereavement burnout”—a situation that develops when there is such an accumulation of unresolved, compounded grief that an individual may simply grow numb.

True ___  False ___

7. Canine’s model illustrating management of burnout identifies five major arenas of life that death care professionals must attend to in order to minimize their potential or likelihood for burnout.

True ___  False ___

8. Death care professionals need to be cognizant and aware of their spiritual filter, their purpose in life, and how to best exercise their spiritual muscles—whether through prayer, meditation, journal writing, communing with nature, self-examination and reflection, or practicing the tenets of a particular religious faith.

True ___  False ___

9. Two very strong emotions that plague caregivers (and others) are anxiety and anger. In burnout management, it is important for individuals to recognize that these feelings are generally triggered by a lack of understanding or a lack of control.

True ___  False ___
10. Delayed and unresolved grief will not stay swept under the rug indefinitely, and those most at risk for burnout are those who “care too much.” The answer is not to “pull back” and become emotionally unavailable to support your clients but instead to recognize and accept that caring and hurting go hand in hand.

True ___ False ___