

Grief and Bereavement Care

With sufficient support, grief and bereavement can be transformative.

By Kathleen A. Egan, MA, RN, CHPN,
and Robert L. Arnold, EdD

Just as no two deaths are alike, so it is with grief and bereavement.

Dying patients face momentous losses: of physical control and function, of independence, of relationships, of possibilities, and ultimately of life itself. To family members and friends, the loss of a loved one causes great stress, temporarily impairing concentration, decision making, and work performance. Without adequate support, grief and bereavement may affect health. But with sufficient support, grief and bereavement can enhance the personal growth of all involved, helping them to find greater meaning in life.

Bereavement, encompassing grief and mourning, denotes the emotions and behavior of a person who has suffered a loss, especially the death of another. A person who outlives another (a “survivor”) may be

said to go through a “bereavement period,” the time it takes to grieve the loss and adjust to life without the other. Bereavement is thus specific to survivors.

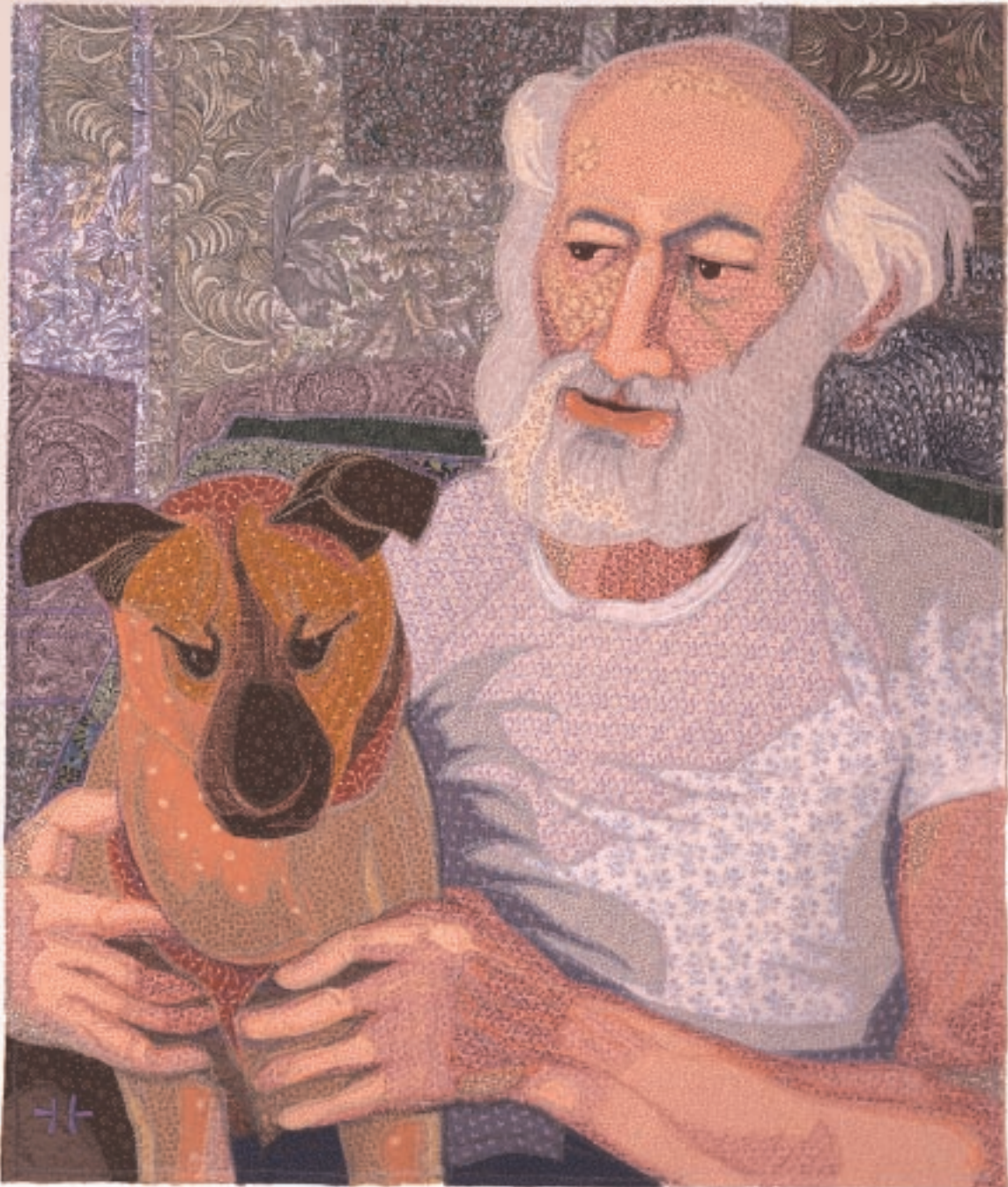
Grief signifies the emotional responses (especially distress) caused by any loss, including an approaching death and the death itself. Mourning refers to actions customarily associated with grief (such as wailing). Dying patients and their families and friends all go through grief. All nurses should be familiar with the various ways of supporting patients and families at such a time. The following case illustrates grief and bereavement care.

A CASE OF GRIEF AND BEREAVEMENT

Sara Polk, a 58-year-old retired bank teller, has advanced chronic obstructive pulmonary disease (COPD). Until two weeks ago, when she began to exhibit greater weakness, fatigue, and dyspnea, she was living at home with help. On hospital admission at that time, she presented as cognitively alert and competent. Ms. Polk, who is divorced, has two adult children: Patrick, a 40-year-old single attorney who lives in a different state, and Christina, a 37-year-old teacher who lives nearby with her hus-

Kathleen A. Egan is vice president and Robert L. Arnold is professional development coordinator at the Hospice Institute of the Florida Suncoast, Largo, FL. Contact author: Kathleen A. Egan, the Hospice Institute of the Florida Suncoast, 300 East Bay Drive, Largo, FL 33770; kathyegan@thehospice.org. This article is the ninth in a series on palliative nursing that is supported in part by a grant from the Robert Wood Johnson Foundation. Betty R. Ferrell, PhD, RN, FAAN (bferrell@cob.org), and Nessa Coyle, PhD, NP, FAAN (coylen@mskcc.org), are the series editors.

Palliative Nursing



▲
Sienna, by Deidre Scherer, fabric and thread, 22" × 19", 1992;
photo by Jeff Baird.

The artist's father swore off any more pets after the loss of his 14-year-old dog. But several months later, Sienna caught his eye and became his companion for the next 14 years.

For more on the artist and her work, go to www.dscherer.com.

Normal Grief: Expected Changes

Physical	Functional	Interpersonal	Intrapersonal	Spiritual
Appetite	Activities of daily living	Relationships	Mood	Beliefs
Sleeping patterns	Economic status	Family roles	Stress level	The search for understanding
Energy level	Productivity at work or school	Social status	Concentration	The search for purpose and meaning
Sexual function		Social skills	Thoughts of dying, death, life, living	The need to ask the "big" questions
Blood pressure			Focus on health	
Digestive processes			Sense of self, identity	
General health				

band and five-year-old twins. No other family members live in the area. Patrick has not visited his mother for a long time but calls on holidays; he pays for much of her care. Christina calls daily and visits after work whenever she can arrange childcare.

Ms. Polk reports that although she's physically comfortable, she feels anxious, frustrated, and helpless, adding, "I know I'm dying, but there's so much to do. I have a lot to apologize for—things left undone or unsaid." The nurse inquires, "Would you like to talk about it?" By listening to Ms. Polk, the nurse begins to identify her end-of-life goals. "I want to apologize to Patrick for making him grow up too fast," she says. "I want to clear things up so that Patrick and Christina don't fight over my things after I'm gone." She'd like to see them become close again, she says. She adds although she's not afraid to die, she is afraid of physical pain and of leaving her affairs "in a mess." The nurse reassures her that the physical pain will be controlled, then asks, "How else can we help?" and agrees to return the next day.

The next morning Ms. Polk seems more relaxed. On her previous hospital admission, a social worker inquired about establishing an advance directive, a designated health care surrogate, and a do-not-resuscitate (DNR) order, and raised the issues of estate planning and hospice care. At the time, Ms. Polk didn't want to discuss these matters, but now she asks the nurse to schedule a meeting with the social worker. She also says that her children will have a difficult time with her dying, and she needs some suggestions in how she can help them through it. The nurse explains that knowing what to expect as death approaches often helps, as does being involved in a loved one's care. Further, she discusses bereavement education and counseling and pro-

vides literature on such services. Ms. Polk asks the nurse whether she would be willing to talk to her children, and she agrees to do so.

During Christina's next visit, the nurse encourages her to ask about her mother's care and the dying process, and realizes that Christina knows neither what to expect nor how she can help. The nurse describes the various changes likely to occur as death approaches, and when Christina declares that she feels helpless and guilty for being unable to care for her mother at home, the nurse replies, "Many family members feel as you do. But I notice that you're very attentive to your mother and that when you're here she's more relaxed, her breathing is less labored, and she seems more peaceful." Christina seems relieved to hear it.

During the next several days, Ms. Polk completes several "life closure" tasks, including establishing an advance directive, naming Christina as her health care surrogate, and signing a DNR order, after which she appears calmer. The nurse schedules 15-minute daily visits with Ms. Polk, giving her the chance to talk about what's most important to her. During one visit, Ms. Polk says how much she misses her son and wants to speak with him. With her permission, the nurse calls Patrick and encourages him to call, which he begins to do every night. Although he still feels hesitant to visit his mother, the two have several substantive discussions, and Ms. Polk says she feels forgiven.

During the next visit, Ms. Polk talks about wanting to make peace with God. The nurse asks if she'd like a clergyman or a counselor to visit, and Ms. Polk says that she would. The nurse contacts a local hospice, and a hospice chaplain and counselor are brought in. The chaplain visits several times, hears Ms. Polk's confessions, and performs the Sacrament

for the Sick. The hospice counselor talks with Christina and Patrick also, giving them additional emotional support.

One evening, as Ms. Polk's death becomes imminent, she asks to see the sunset, and the nurse and Christina take her outside after supper. Mother and daughter talk quietly, expressing their love for each other and their mutual gratitude. As she returns to her room, Ms. Polk thanks the nurse for making possible this special time. In anticipation of the patient's death, the nurse proposes that Christina stay in her mother's room that night. A cot is brought in and she sleeps near her mother, holding her hand. Ms. Polk dies in her sleep early the next morning. The hospice counselor helps with funeral arrangements and later calls Christina and Patrick to offer emotional support.

The nurse attends the memorial service. Afterward, Patrick tells her that he's feeling shock, disbelief, sadness, and guilt, and that he believes his mother has "gone to a better place." The nurse talks with him about grief and bereavement care, promises to send him educational materials, and suggests he consider attending a support program offered by a hospice. She also encourages him and Christina to be mindful of their needs for sleep, hydration, and nutrition and to avoid alcohol, sugar, and caffeine. Later, she tells them, "Your mother was extremely proud of the people you've become. She told me that she believed she would live on through your accomplishments."

On the first anniversary of Ms. Polk's death, the nurse receives a card from Christina and Patrick, thanking her for the good care their mother received. They have found comfort in their communities, Patrick through volunteer work with the American Lung Association and Christina through participation in a hospice bereavement group.

THE EXPERIENCE MODEL OF CARE

The nurse caring for Ms. Polk and her family had an understanding of the Experience Model of Care (also known as the Patient and Family Value-Directed Model of Care),^{1, 2} developed at the Hospice of the Florida Suncoast and incorporating Cassel's theory of "personhood" and Byock's developmental "tasks" approach with 25 years of hospice experience. The model's aims include helping all involved to understand the experiences of dying and death and being both preventive (in terms of grief and bereavement) and proactive.

The Experience Model of Care views grief and bereavement in the following ways:

When Goals Conflict, Consider Intent

A patient and family favor different approaches to care. What then?

A dying patient and family members and friends may not share the same "life closure" goals. When there are differences, it's important to look past wishes expressed to determine the underlying needs. In many cases, different goals stem from the same intent or desire, such as wanting the best treatment, doing all that is possible, or wanting comfort and dignity, yet they conflict because one or both parties aren't fully informed of the benefits and drawbacks of a treatment, or because of a difficulty in communication.

For example, a dying patient who feels prepared for death may decide that she doesn't want further life-prolonging procedures; she wants to die naturally. But her daughter insists that providers do everything possible, unaware that such measures will only prolong her mother's suffering. The nurse realizes that she must determine the underlying basis of each woman's beliefs. She asks the daughter, "Why do you think it's important to do 'everything'? How do you think these interventions would benefit your mother?" She asks the patient, "Can you say why you don't want life-prolonging measures?" Once dialogue begins, it becomes clear to the nurse that both women want the same thing: a comfortable, dignified death for the patient. The nurse explains to the daughter that her mother will not be "abandoned" and that pain relief will continue.

In some cases, family members may never agree on the patient's end-of-life goals; when this happens, the patient's wishes must prevail with continued support for the family. If the patient is cognitively impaired or otherwise unable to make her wishes known, the patient's health care proxy makes determinations according to the patient's known or probable wishes. (For more information, see "Ethical Concerns in End-of-Life Care," *AJN*, January 2003.)

- **It accepts grief and bereavement as normal**, not pathologic.
- **It guides patients and families through "life closure and completion" tasks** that imbue emotional strength and impart greater meaning.
- **It employs preventive as well as standard interventions**, with the goal of providing bereavement care to family and friends *before* the death of a loved one, thereby averting the development of complicated grief.
- **It focuses on the survivor** as the most important person in the provision of care.
- **It challenges providers to think "interdimensionally"** and to address all aspects of the survivor's bereavement. It is particularly sensitive to how changes in one dimension (or area of life) influence changes in all others.

Words aren't
always necessary.
Gentle touch
and silence
can convey
understanding
when words
cannot.

BEREAVEMENT AND TYPES OF GRIEF

Several types of grief have been identified, and it's important that nurses recognize and distinguish among them. Previous or concurrent losses—regardless of whether and how acknowledged or supported—can determine the types of grief patients and families experience. And how well grief resolves depends largely on the support available to survivors.

Anticipatory grief occurs before a death, usually at the time of diagnosis. A patient may anticipate loss of good health (and in some cases a body part), independence, financial stability, cognitive ability, autonomy, and life itself. Family members, friends, and caregivers may grieve for the patient's losses as well as for their own.

Anticipatory grief may have some benefit, but it doesn't necessarily lessen a survivor's grief. It can provide time to acknowledge that the patient is dying, to prepare for the death, to adapt to changes that will occur as the patient loses function, to par-

ticipate in a review of life, to tend to matters left unsettled, and to resolve conflicts. Family members and friends can begin to prepare for life without the patient by adjusting to new responsibilities (or the absence of them) and developing new skills. After a death, an aunt may become her niece's guardian, or a widow or widower may need to learn to drive or cook, for example. Assessment of the needs of family and friends in bereavement care should begin *before* the patient's death, ideally, from the time of diagnosis and throughout the illness. When families are prepared and support services are used before the death, healthy adaptation during bereavement is more likely to occur.

Normal grief is said to occur when a person's emotional and behavioral responses to a loss are expected ones, according to the individual's experience, culture, social status, and relationship to that which has been lost (see *Normal Grief: Expected Changes*, page 44). Exactly how these responses manifest themselves varies, and it's therefore essential to know what's normal in each case in terms of coping strategies, affective expressions, and behavior. It's especially important to assess a person's history of loss—including losses sustained not only in death but also in separation, divorce, or estrangement—and resources such as emotional support systems and short- and long-term coping skills.

It's important to remember that changes in one area of life effect changes in all. Fear and worry are typical *intrapersonal* (emotional and cognitive) responses to the death of a life partner, for example, and something as commonplace as balancing a household account (or another such *functional* challenge) might elicit them. *Physical* responses include elevated blood pressure and sleeplessness. Fear might be manifested socially in extreme shyness or rudeness, affecting *interpersonal* relations. The survivor may wonder why God has deserted him (a *spiritual* consideration). Similarly, an intervention undertaken in one area of life (such as teaching an elderly widow to balance the checkbook) can favorably affect the others.

Bereavement care must entail respect for the survivors' wishes and their ways of coping with loss. Listening attentively and responding to survivors' identified needs are ways of demonstrating respect. Examples of the latter include remaining fully present when a person expresses grief, even if the form or intensity of expression is disconcerting, and facilitating the performance of rituals that differ from those of one's own background.

Complicated grief occurs when a survivor's

Mercy in the Room

Author Stephen Levine instructs caregivers in working with 'unattended sorrow.'

With his wife, Ondrea, author and spiritual teacher Stephen Levine has counseled dying people and their families for more than 30 years. A former codirector of the Hanuman Foundation Dying Project in Santa Fe, NM, he has worked with Elisabeth Kübler-Ross, Ram Dass, and the Dalai Lama, among others. His books include *Who Dies? An Investigation of Conscious Living and Conscious Dying* and *A Year to Live: How to Live This Year as if It Were Your Last*. From his home in northern New Mexico he recently spoke with *AJN* senior editor Sylvia Foley about grief.

Sylvia Foley: You seem to have an extraordinary ability to accept death and to be "in the moment" with people who are confronting it.

Stephen Levine: I think of it as opening our hearts in hell. Let me tell you a story. There once was a patient dying in a hospital I worked in who said that two kinds of people came into her room. She said that one kind could hardly sit still in their chairs. They could hardly touch her, or be present, and there was very little eye contact. She said that another kind could merely sit with her, without having something to say, having even to reassure her. Their presence, their acceptance of her situation, was reassurance enough. She said, "Their fingers might just lay gently on my forearm; they didn't have to grasp me, they could touch me with love."

That's what's difficult for nurses—working with the situation as it is. They've been trained to do something about it.

At one hospital, one nurse on the burn unit had an incredible presence. We asked her, "Would you like to come work with us on the cancer ward?" And she said, "Not really, because I would feel helpless there. But for people who are burned, as horrifying as that can be, I can do something."

SF: Why did she feel that she couldn't have that same presence with the patients on the cancer ward?

SL: Because she wanted to change their circumstances. And if you're a nurse providing palliative care, you're not really trying to do that; you're trying to help people accept their situations. She found death more difficult than horrific pain. And I can understand that, perfectly.

One of the difficulties in nursing—the reason why so many nurses drop out of the profession—is that there isn't the time to do the work you'd like to do. You don't have time to sit quietly with a patient. The workloads are being increased, and nursing staffs are being decreased.

I know nurses who have known each other 20 years, working in the same hospital ward with the same patients, who've never really talked to each other about them. That's because that has never been encouraged. What's encouraged is to "Keep a stiff upper lip." And they're so glad to get away from the feeling of helplessness that they don't talk to each other.

Nothing dispels helplessness like talking about it. Everyone feels helpless. Nurses are so busy helping others that often they ignore themselves.

SF: What are some of the techniques you teach?

SL: There's one I call "softening the belly." We hold grief in our bellies. Remind yourself to let go. Push your belly out a little, let the breath drop down into the abdomen, and take a few soft breaths. I don't know any simpler method of opening to the moment. What happens is that you start to notice that the

hardness in the belly is the same as the armor over the heart. Have mercy on yourself so that there's mercy in the room.

I remember a woman who was in pain; she had a cancer that was fulminating. She'd been a difficult person all her life. The people who worked for her disliked her intensely and she had few friends. In fact, nobody came to her bedside while she was going through this; she received no visitors. And she threw things at the nurses and called them names.

That patient's pain grew to be so great that one day she couldn't bear it anymore. There was no resistance left in her. She later said that she was like somebody drowning in a pond who suddenly threw her arms up in the air and let herself sink. And as she sank down through the pain, she experienced something beyond anything she had experienced before—a moment of love of herself.

After that, her room became a place that nurses loved. There the patient was with the son she hadn't seen in decades and the granddaughter she had never met—a two-year-old child with curly red hair, playing with the rings on her grandmother's fingers. The mercy in the room was remarkable because, perhaps for the first time in her life, this woman *had* to surrender. I think that's what we're talking about, nurses doing the same thing: surrendering, trusting the patient's pain, and meeting it with mercy instead of with panic. The fear of death is really the fear of pain. And when nurses are taught how to soften around their own pain, they can start softening around their patients' pain.

SF: What techniques are useful for nurses, specifically?

SL: I've taught nurses the "Ah" breath [a deep relaxation technique], which involves taking on another person's breath [by matching the rhythm of the other's breathing with one's own breath]. We'd pair them off. One participant—playing the patient—would lie down and the other—acting as the nurse—would sit beside him on the floor, watching his belly, taking on his breath. And after 10 coordinated breaths, the person sitting up would start making the sound "Ah" on each exhale. Then the partners would switch roles. [When you use this technique,] you can see the patient's respiration rate drop, indicating that physical pain is decreasing.

SF: What are you working on now?

SL: I'm working on a book entitled "A Book of Loss." It's not only about the loss of a loved one, but about the loss of certainty in our lives, the loss of expectations. I've heard so many relatives of patients say, "Can you take their denial away?" And I've responded, "No, why would you want to do that?" I like the term "unattended sorrow" better than the word "grief." People attend to it at their own pace. Those are things that a dying person has to deal with, but they're also what all of us have to deal with every morning. I think most people wake up frightened, with some element of apprehension in facing the day. So working with loss is the work of us all.

I see death as just a change in lifestyle, in a sense. And I know that death and dying are not the same. Dying is very difficult. Death may be, *may be*, the high of a lifetime. The fear of dying is not an irrational one. I have confidence in dying. Which doesn't mean that I'm not going to be afraid on my deathbed. It's what I will do with that fear that's important.



Stephen Levine

responses are overwhelming to him, maladaptive, or unusually prolonged.³ Complicated grief can result if

- a loved one's death is sudden (as in cases of suicide, homicide, or accident).
- the survivor and the deceased were estranged or relations were strained.
- a child dies.
- the survivor has had more than one loss.
- the survivor has unresolved grief from previous losses.
- a loved one suffered greatly at the end of life.
- the survivor lacks adequate support.
- the survivor's grief is so intense that he cannot function as he would normally or accept that the relationship has ended, or both.

Complicated grief can manifest as one or more of the following: extreme isolation, severe or prolonged depression, violent behavior, suicidal ideation, or "workaholic" or other addictive behavior. Other indicators include swift "replacement" of the lost relationship and avoidance of any reminder or imitation of the deceased. People with these symptoms usually require assessment and intervention by mental health professionals. The following gives an overview of the five types of complicated grief: chronic, delayed, exaggerated, masked, and disenfranchised.³

Chronic grief begins as normal grief, but instead of subsiding continues for an excessively long period of time. What's excessive in one person may not be in another, and determination should be based on knowledge of the survivor (gained by listening to his account of past losses and how he has adjusted to them). Some people may begin to define themselves by their losses (a man might refer to himself at all times as "Samantha's widower," for example), contributing to the development of chronic grief. In general, if a survivor is troubled daily by strong and static thoughts and feelings for an unusually long time, additional intervention may be required. Discuss your observations with a mental health professional to determine whether referral is necessary.

Delayed grief, in which a survivor consciously or unconsciously represses his feelings in order to circumvent pain,³ may involve avoiding discussion of the deceased, working too much, or becoming overly concerned with others' problems. The survivor may begin to grieve the loss only when he has had time for reflection. At that point some form of bereavement care may be helpful, such as a peer support group.

Exaggerated grief manifests in self-destructive

behavior,³ in which the survivor attempts to ease emotional and spiritual pain through potentially harmful coping strategies. It's important to assess for substance abuse, unsafe sexual practices, suicidal ideation, and suicide attempts, all symptomatic of this form of grief. It's best to ask direct questions—for example, "Are you using drugs or alcohol to ease pain?" and "Are you having or have you had suicidal thoughts?" Exaggerated grief often results from the severe stress caused by significant loss; if present, it's important to seek referral to a mental health professional to ensure the survivor's safety.

In *masked grief*, the survivor is unaware that his response to a loss is interfering with his ability to function.³ He may appear fiercely independent and reject help, often because he fears further loss. For example, a survivor might avoid relationships or sabotage existing ones. Indicators of masked grief include keeping physical distance, withholding affection, and making critical and hurtful comments. In contrast, some survivors become overly dependent on others, feeling helpless and fearing isolation or separation from loved ones. Either extreme can strain relationships and result in rejection by others or excessive reliance on them.

Disenfranchised grief occurs when a survivor can't fully or publicly acknowledge the loss of a loved one because the relationship is culturally unacceptable or marginalized.⁴ Those at risk include gay and lesbian partners, former spouses or friends, former or illicit lovers, and coworkers. Disenfranchised grief commonly manifests as anger, sadness, and isolation. It may be compounded by geographic separation from family, friends, and community; estrangement; and financial barriers such as high cost of travel to a funeral.

A PREVENTIVE APPROACH

Early and ongoing bereavement assessment—beginning with diagnosis and continuing throughout the illness and after death—and a collaborative process are essential components of a preventive approach to bereavement care.

Preventive interventions include grief and bereavement education, bereavement counseling, and help with what Byock has called "developmental landmarks and tasks for the end of life."⁵ Byock saw dying as a stage of human development characterized by striving toward certain goals. He intended these to serve not as a set of requirements but rather as "diagnostic tools enabling clinicians to anticipate issues with which patients may struggle and from

'Looking for Signs of What Is Killing Them'

Why do nurses write so often about death and dying?

which suffering may arise."⁵ Tasks include

- a sense of completion of worldly affairs (fiscal, legal, and social).
- a sense of completion in relationships to community, family, and friends.
- a sense of the meaning of one's life.
- the experience of self-love.
- the experience of being loved by others.
- the acceptance of the end of one's existence.
- the willingness to embrace the unknown and let go.

To these ends, nurses can help in several ways, such as fostering communication among patients and families and friends and helping them to understand what they're going through. Also, families and friends can be encouraged to participate in caregiving. For example, to help the patient with "completion in relationships to friends and family," the nurse might ask, "Is there anyone you would like to see or talk to?" If the patient says yes, the nurse can help him contact them by telephone, mail, e-mail, or gatherings. Such opportunities may benefit not only the patient but also those he contacts, preventing complicated grief.

There's evidence that involvement in caregiving benefits survivors. In a recent study, 129 spouse caregivers were asked to rate their levels of caregiving, according to the spouse's need for assistance with activities of daily living, and the associated mental, emotional, and physical stresses they underwent.⁶ The risk of developing complicated grief was assessed according to several indicators, including the use of antidepressive medication, weight change, and the incidence of unhealthful coping behavior. Those with little or no involvement in the care of a terminally ill spouse (n = 40) were found to be at higher risk for complicated grief than were those with greater involvement (n = 89). This was the case regardless of how stressful spouses found caregiving.

If a patient's family members are unable to act as caregivers (because of age or infirmity, for example) or have limited access to support (because they live in a rural area, for example), greater advocacy efforts and team involvement may be required of nurses. An assessment of resources available—in community support and bereavement care—may be warranted.

Survivors who have acted as caregivers may develop exceptional inner strength as a result, yet this strength is often overlooked. Nurses working with patients and families in long-term, custodial, and acute care settings should be especially sensitive to this possibility. Speaking of caregiving only in terms

I've known many nurses who have a special kind of vision, a combination of expertise and insight I call the "clinical gaze." They identify the signs and symptoms of many diseases, they know how death approaches, and when it arrives, they don't turn away from it. Writing can be a way for them to let go of what they've seen and, at the same time, to celebrate the significance of their work. And, in writing, they may realize something else—that the clinical gaze can't be turned off as though it were a light switch.

In the foreword to *Intensive Care: More Poetry and Prose by Nurses*, I noted that "nurses write about birth and, more often, about death. Perhaps the specter of death lurks in everything we do. While this may dismay some readers . . . others might find comfort in the details of nurses' attentiveness, our proximity to the mysteries of life's beginnings and endings . . . [and] in knowing that [our] moments alone with the newly born and the dying are recognized here for what they are: privileged, frightening, rewarding, blessed."

In Amy Haddad's "Ten Items or Less," a poem taken from that anthology, a nurse brings the clinical gaze into a grocery store.

I can spot them
even in the checkout line.
Putting the rubber stick
between their oranges and my bread,
I see hands
marked with purple, green,
and yellow bruises.
I know where they have been,
the needle sticks just the start of it.

The bruise tattoos,
each prick leaving its history.
I match the hand to the face
looking for signs of what is killing them
as they sort coupons
for cereal or canned tomatoes.

As the narrator waits in the checkout line, someone places a rubber divider between "their oranges and my bread." On the stranger's hand, she immediately recognizes the purple, green, and yellow bruises left by needles. Yes, a reader might think. *I've seen this too.*

But there's a further dimension to this clinical gaze. "I know where they have been," the narrator tells us, "the needle sticks just the start of it." In my discussions with Haddad, I learned that she, too, underwent chemotherapy, and her experience of it informs the poem. Not only does she recognize signs of illness in others, she envisions the future of illness, too, the suffering that "just the start of it" implies, the effects of chemotherapy, the waiting for test results—in the way that a nurse who's had these experiences might relate to patients with renewed empathy.

In the last stanza, the narrator scans the shoppers' faces "for signs of what is killing them." The brutality of the word "killing" stands in stark contrast to the unremarkable chore of shopping for groceries, an activity that presupposes that there is an appetite, a meal to prepare, a future. Such is the power of the imagination and of good poetry.
—Cortney Davis, NP, RNC, nurse practitioner at Danbury Hospital in Danbury, CT

Haddad A. Ten items or less. In: Davis C, Schaefer J, editors. *Intensive Care: More Poetry and Prose by Nurses*. Iowa City, IA: University of Iowa Press. 2003. p. 102. Reprinted by permission of the poet.

Efforts to
remove
emotional pain
can hinder the
grieving
process; pain
is a necessary
component of
grief.

of hardship (“stress” and “burden”) can hinder grieving, but when it’s spoken of in terms of gains (in “courage” and “skills developed”), it can help survivors to find meaning in the care they’ve given.

Long-term support is sometimes warranted for survivors. (Hospices usually provide such support for at least a year, and sometimes longer.) In addition to bereavement counseling and peer support groups, survivors may benefit from nursing support available by e-mail, mail, and telephone, as well as from educational literature.

STANDARD APPROACHES

Helping survivors through bereavement can entail normalizing their grief, encouraging them to identify and express feelings, helping them acclimate to life without the deceased, allowing or creating rituals, providing education, and distinguishing complicated grief from normal grief. Remember that a person’s response to death will be shaped by culture, experience, personality, and coping skills.

Normalizing grief. Many survivors fear that they will never be free of the pain of loss and that their responses to it are abnormal. For example, a woman who loses her partner to breast cancer might report

trouble sleeping and find herself unable to concentrate on her work. Hearing from the nurse that such responses are to be expected will help her to understand that her grief is normal, as will hearing that there is no single “right” way to grieve.

Encouraging expression. By actively listening and conveying respect and compassion through tone of voice and body language, a nurse can encourage survivors to identify and express their feelings. This can alleviate stress and, in some cases, allow for thoughtful problem solving.

Offering comfort. Although the desire to comfort others is natural, knowing how to do so is an acquired skill. No two people, not even two survivors with similar experiences, will grieve in exactly the same way. It’s important not to compare a survivor’s experience of loss to your own or to those of others. Avoid such comments as “I know how you feel.” Open-ended engagement that invites response, such as “Tell me how you feel,” is best.

Nurses often want to “fix” situations and eliminate pain. Although these desires are common, it’s impossible for a nurse (or any health care professional) to fulfill them. In fact, efforts to remove emotional pain can hinder the grieving process; pain is a necessary component of grief.

Still, there *are* ways nurses can help. Sometimes the simplest interventions are the most effective. For example, attentive listening, using gestures such as eye contact and stillness, can convey acceptance of someone’s grief. Also, storytelling helps people to understand and accept what they’ve undergone, is cathartic, and disseminates a historical record; for these reasons it’s often used by bereavement counselors.⁷ But words aren’t always necessary. Gentle touch and silence can convey understanding when words cannot. If you’re uncertain whether to speak or remain silent, observe the survivor’s body language for clues or gently inquire, “Do you want to talk or just sit quietly?”

Helping survivors to acclimate. Encouraging survivors to talk about life without a loved one serves at least two purposes: helping them begin to accept the loss emotionally and planning for and responding to changes in social or financial status.

Survivors often ask “big” questions, such as, “Why did this happen?” “What is the meaning of life?” “What purpose does my loss serve?” and “What is God’s role in this?” There are no simple answers. It’s not unusual for survivors to embrace, confront, or reject their spiritual beliefs, question their lifestyles, and express intense emotions that can range from unbridled exuberance to utter hope-

lessness. Often, the nurse is most helpful by listening actively, but ultimately, each person must grapple with these questions on his own.

Rituals and traditions. These can serve to acknowledge a loved one's death and may take the form of funeral and memorial services. Later, more private rituals may include visiting the grave, planting a tree in remembrance, and observing moments of silence. In some hospitals, staff members have created "memorial books" in which they record their memories of deceased patients and comment on their relationships to them.

Providing grief education. Grief can take months or years to resolve, and some people may never complete the process. Explain to survivors that grief and grief-related symptoms may resurface or become more intense on holidays, birthdays, the anniversary of the death, and any other dates that hold significance.

Referral to supportive resources. Although nurses should know how to assess for grief and implement preventive and supportive care, it's equally important to know when to refer to specialists. Many communities provide bereavement care that is readily accessible and of high quality to people anticipating or surviving a death. Hospice organizations may be helpful in either providing these services or offering referrals to them. Bereavement services include

- individual, family, or group counseling.
- specialty counseling (directed toward children or survivors of homicide or suicide, for example).
- education (through Web sites, printed material, and community forums).
- retreats.
- community memorial services.

Addressing complicated grief. If a survivor's grief is complicated or isn't resolving as expected, referral for further services may be warranted. In addition to those named above, these may include visits to a physician or a psychiatrist, or both.

In a survivor with symptoms of exaggerated grief, the initial focus will be on ensuring his safety, and the plan of care may include close or constant supervision, inpatient or outpatient psychiatric care, and treatment for substance abuse. In survivors with masked grief, bereavement care aims to promote healthy interdependence and independence, for example, by teaching them how to set "boundaries" with others. For example, if a survivor whose spouse had done all the driving becomes overly dependent on a family member for transportation, teaching him how to use public transportation will decrease his dependence.

In people with disenfranchised grief, bereavement care may entail acknowledging the relationship and the loss, as well as providing opportunities to honor the memory of the loved one. It's important for nurses to acknowledge and address social stigmas and legal barriers. For example, the nurse might say to a gay man whose partner has died, "I know you expected to grow old with him." In the case of a survivor estranged from the rest of his family and therefore excluded from funeral and memorial services, the nurse might help create a ritual that honors the survivor's relationship to the deceased.

SELF-CARE OF PROFESSIONALS

Though death is a daily occurrence in many health care settings, nurses and other providers may find the deaths of certain patients emotionally wrenching. And when a nurse is exposed to death frequently, it can be even more difficult to resolve grief; she may not have finished grieving for one patient before another dies. This may be trying to new nurses.

It's important to find ways of supporting yourself. Your colleagues and peers may be able to help you adapt to repeated loss. If they can't, look for other sources of support, such as a mentor, a friend, or a community leader. In some cases, when losses accumulate, a nurse may show symptoms of post-traumatic stress disorder, the treatment of which requires mental health consultation. Most work settings offer access to such professionals through an employee assistance program.

In a recent study, Evans and colleagues explored strategies used by providers to cope with patients' deaths.⁸ Ten residential hospices that employed a total of 199 caregivers were included. Participants were asked to consider a recent (within six months) death of a patient that was particularly stressful to them and to describe the patient, their own coping strategies, and their satisfaction with the experience. They also were asked to complete the Ways of Coping Questionnaire, a 66-item tool developed by Folkman and Lazarus⁹ used to evaluate the coping process as related to a specific event.

Sixty-nine caregivers employed at seven of the 10 hospices responded; one-third identified themselves as RNs, one-third as certified nursing assistants, and one-third as "other." "Positive reappraisal" (reinterpreting an event in a favorable light) was the coping strategy most frequently used; 85% of respondents said they used prayer, suggesting that for many hospice workers the death of others is seen as an opportunity for spiritual growth. Employees dissatisfied with their end-of-life experi-

ences reported using confrontational coping styles, tended to accept greater responsibility for patient outcomes (suggesting a greater need to exercise control), and used escape and avoidance strategies to deal with the stress of caring for dying patients. Strategies that attempt to control the dying patient's circumstance are incongruous with best practice, and they also cause greater stress. Evans and colleagues' findings suggest that among nurses, chronic stress can result in burnout, poor health, and poor patient outcomes. They also suggest that professional caregivers such as nurses may benefit from support offered through inservice training and environmental interventions (the creation of quiet areas where staff members can congregate informally, for example). ▼



Complete the CE test for this article by using the mail-in form available in this issue or by going to Online CE at www.ajnonline.com.

REFERENCES

1. Egan K, Labyak M. Hospice care: a model for quality end-of-life care. In: Ferrel B, Coyle N, editors. *Textbook of palliative nursing*. New York: Oxford University Press; 2001. p. 7-22.
2. Labyak M. The experience model: transforming the end-of-life experience. *Hospice and Palliative Care Insights* 2002(2):9-14.
3. Worden JW. Chapter 4. In: *Grief counseling and grief therapy: a handbook for the mental health practitioner*. 2nd ed. New York: Springer Pub. Co.; 1991. p. 83-99.
4. Doka KJ. Chapter 1. In: *Disenfranchised grief: recognizing hidden sorrow*. Lexington, MA: Lexington Books; 1989. p. 3-11.
5. Byock IR. The nature of suffering and the nature of opportunity at the end of life. *Clin Geriatr Med* 1996;12(2):237-52.
6. Schulz R, et al. Involvement in caregiving and adjustment to death of a spouse: findings from the caregiver health effects study. *JAMA* 2001;285(24):3123-9.
7. Arnold R. Introduction to clinical bereavement group work: tools and techniques discussion slides. In: Arnold R, editor. *A guide for bereavement professionals. Manual one*. Largo, FL: The Hospice Institute of the Florida Suncoast; 2002. p. 15-44.
8. Evans WM, et al. Coping strategies used in residential hospice settings: findings from a national study. *Am J Hosp Palliat Care* 2001;18(2):102-10.
9. Folkman R, Lazarus L. *Ways of coping questionnaire*. Redwood City, CA: MindSpring; 1988.

CE² HOURS

Continuing Education

GENERAL PURPOSE: To present registered professional nurses with a thorough discussion of grief and bereavement using a case study to illustrate the process and its resolution.

LEARNING OBJECTIVES: After reading this article and taking the test on the next page, you will be able to

- discuss bereavement, various manifestations of and approaches to it, and existing research that expands understanding of the grieving process.
- describe the different types of grief.
- plan appropriate interventions, both preventive and after a death.

To earn continuing education (CE) credit, follow these instructions:

1. After reading this article, darken the appropriate boxes (numbers 1–16) on the answer card between pages 48 and 49 (or a photocopy). Each question has only one correct answer.

2. Complete the registration information (Box A) and help us evaluate this offering (Box C).*

3. Send the card with your registration fee to: Continuing Education Department, Lippincott Williams & Wilkins, 345 Hudson Street, New York, NY 10014.

4. Your registration fee for this offering is \$13.95. If you take two or more tests in any nursing journal published by Lippincott Williams & Wilkins and send in your answers to all tests together, you may deduct \$0.75 from the price of each test.

Within six weeks after Lippincott Williams & Wilkins receives your answer card, you'll be notified of your test results. A passing score for this test is 12 correct answers (75%). If you pass, Lippincott Williams & Wilkins will send you a CE certificate indicating the number of contact hours you've earned. If you fail, Lippincott Williams & Wilkins gives you the option of taking the test again at no additional cost. **All answer cards for this test on *Grief and Bereavement Care* must be received by September 30, 2005.**

This continuing education activity for 2 contact hours is provided by Lippincott Williams & Wilkins, which is accredited as a provider of continuing nursing education (CNE) by the American Nurses Credentialing Center's Commission on Accreditation and by the American Association of Critical-Care Nurses (AACN 11696, category A). This activity is also provider approved by the California Board of Registered Nursing, provider number CEP11749 for 2 contact hours. Lippincott Williams & Wilkins is also an approved provider of CNE in Alabama, Florida, and Iowa, and holds the following provider numbers: AL #ABNP0114, FL #FBN2454, IA #75. All of its home study activities are classified for Texas nursing continuing education requirements as Type 1.

*In accordance with Iowa Board of Nursing administrative rules governing grievances, a copy of your evaluation of this CNE offering may be submitted to the Iowa Board of Nursing.