Ensuring Competency in End-of-Life Care
Communication and Relational Skills

Charles F. von Gunten, MD, PhD
Frank D. Ferris, MD
Linda L. Emanuel, MD, PhD

Physician competence in end-of-life care requires skill in communication, decision making, and building relationships, yet these skills were not taught to the majority of physicians during their training. This article presents a 7-step approach for physicians for structuring communication regarding care at the end of life. Physicians should prepare for discussions by confirming medical facts and establishing an appropriate environment; establish what the patient (and family) knows by using open-ended questions; determine how information is to be handled at the beginning of the patient-physician relationship; deliver the information in a sensitive but straightforward manner; respond to emotions of the patients, parents, and families; establish goals for care and treatment priorities when possible; and establish an overall plan. These 7 steps can be used in situations such as breaking bad news, setting treatment goals, advance care planning, withholding or withdrawing therapy, making decisions in sudden life-threatening illness, resolving conflict around medical futility, responding to a request for physician-assisted suicide, and guiding patients and families through the last hours of living and early stages after death. Effective application as part of core end-of-life care competencies is likely to improve patients' and families' experiences of care. It may also enhance physicians' professional fulfillment from satisfactory relationships with their patients and patients' families.

JAMA. 2000;284:3051-3057 www.jama.com

PHYSICIAN COMPETENCE IN END-OF-life care requires skill in communication, decision making, and building relationships. Physician ability in this area correlates directly with patients feeling satisfied with their medical care and adhering to medical advice, as well as indirectly with liability litigation.[1-3] It may also substantially enhance physicians' own experiences of providing care. Yet, these skills were not taught to the majority of physicians in practice during their training.

We present a 7-step approach for structuring the communication of important information. It expands on the approaches described by Buckman[4] for the communication of "bad" news to include setting treatment goals, advance care planning, withholding or withdrawing therapy, making decisions in sudden life-threatening illness, resolving conflict around medical futility, responding to a request for physician-assisted suicide, and guiding patients and families through the last hours of living and early stages after death. A review of the literature supports this overall approach to structuring such conversations.[5]

A 7-Step Communication Tool

The first 3 of the 7 steps prepare the patient, caregivers, and physician for discussing important information. After delivering the news, the last 3 steps permit the physician to respond to the patient's reactions and establish a plan. The steps' discrete and sequenced presentation is only a model to guide practice and the acquisition of proficiency (TABLE). In clinical practice, steps will be accomplished in different ways and with varying intervals, or even sequence.

Step 1 is preparing for the discussion. To prepare, physicians should confirm the medical facts of the case, establish an appropriate environment, make sure that enough time is available to communicate the information effectively, and ensure that everyone the patient would like to have present is able to attend. Step 2 is establishing what the patient (and family) knows. Beginning with open-ended questions establishes what the patient and/or family know about the patient's situation. Step 3 is determining how information is to be handled. More than 90% of US residents would rather know the truth about their illness, especially if it is one that will be fatal.[6] However, because people handle information differently, it is important for physicians to first determine how each patient wants to have information shared. Patients have the right to decline to receive information. Physicians should not assume that an individual's preferences track with ethnic, cultural, or religious norms.

To minimize the risk of communication errors, step 3 might best be accomplished at the beginning of the patient-physician relationship before specific news needs to be given. Some-

Author Affiliations: Center for Palliative Studies, San Diego Hospice, San Diego, Calif (Drs von Gunten and Ferris); the Education for Physicians on End-of-Life Care (EPEC) Project, the Interdisciplinary Program on Professionalism and Human Rights, Northwestern University Medical School, Chicago, Ill (Dr Emanuel).
Corresponding Author and Reprints: Linda L. Emanuel, MD, PhD, Interdisciplinary Program on Professionalism and Human Rights, 750 N Lake Shore Dr, Suite 601, Chicago, IL 60611-2611 (e-mail: lemanuel@epec.net).
The Patient-Physician Relationship Section Editor: Richard M. Glass, MD, Deputy Editor.

©2000 American Medical Association. All rights reserved.

Downloaded from jama.ama-assn.org at Karolinska Institutet University Library on February 11, 2011

Table. Seven-Step Approach to Communication

1. Prepare for the discussion
2. Establish what the patient (and family) knows
3. Determine how information is to be handled
4. Deliver the information
5. Respond to emotions
6. Establish goals for care and treatment priorities
7. Establish a plan

times family members ask the physician not to tell the patient the diagnosis or other important information. While it is the physician's legal obligation to obtain informed consent from the patient or proxy, an effective therapeutic relationship is enhanced by a congenial alliance with the family. Such requests should prompt an open-ended question to find out why the family doesn't want the patient to be told. After the physician has listened attentively to the family, a suggestion to go to the patient together may result in a discussion that leads to a mutually satisfactory plan for information sharing.

Similarly, when the patient is a child, the parents may want to protect the child from distressing information. Yet, most children will perceive that there is a serious health problem and may develop distrust if information is withheld. It may be better to communicate important medical information to the child at an age-appropriate level. A similar family discussion may allow for such an approach to occur harmoniously.

Step 4 is delivering the information in a sensitive but straightforward manner. Language should be clear and neither overstate nor understate the implications of the news, or the precision of knowledge conveyed by the information, whether diagnostic or prognostic. Frequent pauses are important to check for understanding and to allow time for everyone to absorb the information.

Step 5 is responding to emotions. Patients, parents, and families will have a wide range of emotional reactions to important news. They will need time to react, and the physician should listen quietly and attentively. Many reactions are short-lived. Once the emotion is expressed, people tend to move on more easily. Attention to this step conveys respect and support, and strengthens the patient-physician relationship.

Step 6 is establishing goals for care and treatment priorities. This step is discussed in greater detail in the next section. It may be less relevant when delivering new or serious information. If goals cannot be discussed after delivering news, this step can be addressed at a subsequent meeting.

Step 7 is establishing a plan. Additional information should be gathered and further tests that may be appropriate should be discussed. The overall care plan, including treatment of current symptoms and sources of ongoing emotional and practical support, should be developed. This 7-step approach to communication can provide guidance in several types of encounters in end-of-life care. Before examining each in turn, we will further examine step 6.

Setting Goals for Care

Numerous legitimate goals for medical treatment exist, including cure of disease, prolongation of life, avoidance of premature death, maintenance or improvement in function, relief of suffering, improvement of quality of life, preservation of control, achievement of a good death, and support for families and loved ones. Although goals may seem to stretch along a continuum in a linear fashion, multiple goals may apply simultaneously, and some may seem to be contradictory. Sound clinical decisions routinely require prioritization among potentially contradictory goals.

After establishing the patient's current medical situation, and before settling on specific medical treatments (ie, before step 7), additional open-ended questions should be asked. Questions to ask may include, "What's important to you now?" or "What are you hoping for?" These help to establish the patient's and family's view of the future. With an understanding of patient's and family's needs and expectations, the clinician can better propose realistic goals and how they can be achieved. It is often appropriate to identify those things that cannot be done, either because they will not help achieve the identified goals or because they are not possible.

There is a historical medical convention that clinicians should express hope for full recovery, even if it is not a realistic hope.[7] The principle has been taken so far as to administer treatments that are known to be ineffective, all in the service of maintaining hope. However, perpetuating false hope may prevent the patient and family from finding meaning and value in the time remaining to them. At a time when people most need emotional closeness, collusion to persist in unrealistic goals may prevent reconciliation, emotional growth, final gift giving, and closure. Some physicians find it useful to frame discussions using phrases like, "We can hope for the best, but we also need to plan for the worst."

In discussing goals of care, inept phrasing, even if well-intentioned, may have unintended consequences. For example, a comment of "It's time we talk about pulling back" can imply abandonment. To prevent unintended consequences, it is useful to develop facility with language that reinforces the goals of appropriate medical care. An example would be "I want to give the best care possible until the day you die."

Advance Care Planning

Advance care planning is a form of settling on goals for care. It is intended to guide future medical care in the event that the patient is unable to make his/her own decisions. Most patients believe that it is the physician's responsibility to start advance care planning and will wait for the physician's initiative.[8-10] Once introduced, the patient, proxy, and family can do most of the work on their own. Another member of the health care team (eg, a nurse, social worker, chaplain) can also help.

An advance care planning discussion should begin by asking how familiar the patient is with the concept, and whether he/she is prepared to engage in the discussion. Some patients may already have advance directives in the form of a living will or health care proxy. Others have had experiences with fam-

©2000 American Medical Association. All rights reserved.

Downloaded from jama.ama-assn.org at Karolinska Institutet University Library on February 11, 2011

ily members or friends who were too ill to make decisions for themselves.

After eliciting their understanding and willingness to discuss the subject, the clinician should explain the goals and the process he/she recommends. Even if the patient is able to make decisions, the patient's decision maker should be included in the discussions from the outset. Advance care planning often focuses only on resuscitation decisions. It is more useful to engage in a structured approach that includes the types of clinical scenarios that might arise, and the decisions that patients and proxies most commonly face.

Validated worksheets covering a range of clinical scenarios may facilitate face-to-face discussions between the physician and the patient.[11-13] They also may be used to capture the key points made by the patient. Once the discussion is complete, these worksheets may be used to summarize the conversation so that the patient's final choices can be entered directly into the medical record.

While many physicians believe that advance care planning is time consuming and inadequately reimbursed, the time that the physician takes to counsel and provide information about advance care planning may be incorporated into the coding of the complexity of each patient encounter.[14]

Any statement of a patient's wishes, written or oral, that can be considered a valid statement should be binding, but a formal written document signed by the patient helps to avoid ambiguity. Patients should be encouraged to complete 1 or more documents (eg, a living will or durable power-of-attorney for health care) that comply with the relevant state statutes where the physician practices. Physicians can inquire about these documents at their hospital, state attorney general's office, or local medical society.

Finally, the patient's advance directives need to be available when decisions are being made. Copies of the documents should be distributed to all relevant parties. The patient may want to carry a wallet card or wear a medical bracelet that specifies the whereabouts of these documents.[15]

Withholding/Withdrawing Therapy

Goals of care can change and it may become necessary to discuss withholding or withdrawing 1 or more therapies.[16] Often these discussions involve the proxy or family and can draw on the trust and common understanding of prior communication and planning. Two examples that illustrate such discussions follow.

Example 1: Artificial Feeding and Hydration. Food and water are widely held symbols of caring. Suggestions that artificial nutrition and hydration be withheld may be misperceived by the patient, family, or other caregivers (professional and volunteer) as neglect if the context for the discussion is unclear. To establish the context, the medical condition of the patient should be discussed and overall goals of care reaffirmed. Next, the physician should address whether artificial hydration and nutrition will achieve those goals.

In many cases, artificial nutrition and hydration will neither reverse the underlying pathology nor make the patient feel better. For example, if the goals are improved energy, weight, and strength in a patient with far-advanced cancer, artificial fluid and nutrition are unlikely to be helpful.[17-19] In fact, such interventions may make edema, ascites, pulmonary secretions, and dyspnea worse, particularly if there is significant hypoalbuminemia. While many believe that the patient must be hydrated until death, a state of relative dehydration in a patient who is bedbound and imminently dying may have some benefits. Pulmonary secretions, vomiting, and urinary incontinence may be diminished, and dehydration may actually stimulate the production of endorphins and other endogenous anesthetic compounds that contribute to the patient's sense of a peaceful, comfortable death.[20-22]

The clinician should listen for misperceptions when asking the patient and/or family what they understand about the current situation. They may believe that lack of appetite and diminished oral intake of fluids are causing the patient's level of disability. They may assume that if the patient could get more fluids and nutrition, the patient would be stronger. Clear, simple language should help them understand the real causes of the situation. The family may also need help to recognize their emotional need to care. Then, with the help of other professionals, the family can find other ways to express their need.

Example 2: Discussing Do-Not-Resuscitate (DNR) Status. Getting a DNR order should never be the sole motive for a discussion with a patient or family. Rather, a DNR order best emerges naturally from a discussion of the approaches and interventions that will be taken to achieve their overall goals for care. Engaging in isolated discussions about cardiopulmonary resuscitation (CPR) and DNR status may leave the patient or proxy confused and anxious about the future, and may be perceived as pending abandonment.[23]

Most patients (and some physicians) are unaware that CPR was developed for and remains most appropriate for unexpected events, such as an intraoperative event or cardiac arrest in an otherwise healthy patient.[22] It was not developed and is not indicated for the reversal of the final stages of an otherwise irreversible disease.[24,25] Once the patient's goals for care have been reviewed, whether CPR would be likely to achieve those goals should be considered. The answer is usually no.

During the discussion of CPR, clinicians should avoid 2 unfortunate linguistic conventions. First, language such as "starting or shocking the heart" or "putting on a breathing machine" can imply a false sense of reversibility and independence of organ function. These phrases suggest that heart and lung functions are isolated problems. In the setting of advanced illness, circulation and breathing usually stop because of the relentless progression of the disease. Second, the convention of describing CPR as "doing everything" has the implication that not doing CPR is "doing nothing." Clinicians should not suggest aban-

©2000 American Medical Association. All rights reserved.

Downloaded from jama.ama-assn.org at Karolinska Institutet University Library on February 11, 2011

donment when there is much that can be done for all patients until death.

The discussion should be completed with a proactive care plan (step 7) for the patient. For some patients, full medical intervention is appropriate to achieve their goals for care, even with a DNR order in place.

Sudden Critical Illness

Situations of sudden life-threatening illness usually involve prognostic uncertainty and the need for rapid and frequent decisions. Multiple physicians and numerous other members of the health care team may be working simultaneously to save the patient's life. Managing symptoms and preparing the patient and/or family for the possibility of death or incomplete recovery may be given a lower priority than is desirable.[26-28] In addition to the basic approaches for interacting with patients discussed previously, the following points deserve emphasis in these rapidly changing situations in which tensions are often high.

Regular times should be scheduled for 1 person from the family and 1 from the health care team to meet to discuss the patient's situation. Regular communication is likely to reduce confusion and avoid misunderstandings. In these situations, emotions tend to be prominent, fragile, and sometimes so powerful that rational understanding is difficult.

During these conversations, overall goals of care should be discussed and confirmed frequently, particularly as new information becomes available or the patient's condition changes. The range of possible outcomes should be communicated fully to help the patient (or parents if the patient is a child) and family make informed choices. The clinician should try to be realistic about the possible degrees of recovery and identify decision points in the future when additional information will be available that will help with decision making. Symptom management should be addressed in the initial plan of care.

Even if the prognosis is uncertain and information is limited, it is counterproductive to wait to communicate until substantive new information is available. Frequent updates of even incremental information give the patient and family time to prepare.

An initial plan that includes symptom management will allow the care intended to comfort the patient to continue even when life-sustaining treatments are discontinued. This will minimize the risk that the family will feel that the patient is being abandoned as therapies are withdrawn.

Conflicts About Futility

Resolving conflicts over medical treatment requires particular skill in communication. When applying the 7-step approach to communication, elucidating the patient's and family's understanding of the situation (step 2) is critically important.[29-35] In probing for that understanding, insight into the causes of conflict can help to facilitate resolution.

Conflicts about futility are usually the result of misunderstandings, lack of attention to the family's (or physician's) emotional reaction to the patient's dying, or a conflict in values, rather than a disagreement about the medical facts.

Misunderstandings and/or emotional reactions such as distrust, grief, and guilt can manifest themselves as a conflict over futility. Descriptions of how other physicians were wrong, the previous hospital was not good, the patient's previous physician was only interested in money, the nurses never answered the call lights or administered the wrong treatments, racial or ethnic prejudice was suspected, etc, should trigger the question of trust. It is often helpful to address this gently but directly. Emphasizing what is being done for the patient and offering to facilitate a second opinion or find other individuals whom the patient and family are more likely to trust may help to restore trust. An explicit statement that everyone wants the best care for the patient and reinforcing the goal of working together to achieve the best possible care also may help. The clinician can affirm that accurate and complete information will be shared based on mutual trust and respect.

Conflict over issues of futility may be an extension of anticipatory grief. Social work, chaplaincy, nursing, and other disciplines can help the physician offer support. In making decisions, the family needs help distinguishing between what the patient would want and what the family wants in response to their grief.

Two powerful motivators for human behavior are guilt and unfinished personal business. The archetypal, not-so-subtle situation for either of these is the arrival of the long-estranged or distanced relative at the bedside saying, "You must do everything; you can't let her die." Elucidating these tensions requires skillful interviewing and the willingness to assess the situation using a broad perspective. Because guilt is sometimes associated with a sense of shame, and unfinished business is often painfully private, families may not readily reveal these issues to the physician. Active listening and involvement of multiple team members over time are usually essential. Conflicted relationships are rarely resolved and the resultant guilt is rarely eliminated. However, understanding that this conflict exists may illuminate behavior that previously seemed inexplicable. With time and carefully planned discussion, a resolution may be achievable.

Family dynamics that manifest themselves as conflicts over futility may not be initially apparent to the physician, particularly if the physician does not see the entire family as a group. A family meeting at which the physician is present and in which all parties get together to hear information and make decisions can be an excellent way to both acknowledge intrafamily issues and come to a decision with which everyone can agree.

Many people have a firm religious foundation for their lives and the decisions they make. This may extend to decisions about medical treatments and life-sustaining therapies. The physician should explore how religious issues influence the patient and his/her family in decision making. Physicians may need to overcome the social con-

©2000 American Medical Association. All rights reserved.

Downloaded from jama.ama-assn.org at Karolinska Institutet University Library on February 11, 2011

vention of avoiding religious topics to have this discussion. Relying on chaplains, or perhaps the family's own spiritual leader, to help discuss and elucidate the patient's or family's religious framework can be helpful. The physician can clarify what is in the physician's power to influence, and what is not. Miracles are, by definition, rare. Such conversations need to be scrupulously attentive to accuracy and appropriateness.

Sometimes the relative value of life is a source of conflict. To resolve this tension in a practical way, it may be helpful for the physician to focus on the patient's point of view, including his/her goals for care and wishes expressed previously in advance directives, either formally or informally.

Requests for Hastened Death

Many physicians are likely to receive a request for hastened death at some point in their careers.[36-45] It is quite common for patients with a life-threatening illness to think about suicide, if only in passing. Some will approach the physician with the intent of "thinking out loud."

All requests should prompt the physician to assess the reasons for the request using a broad conceptual framework for suffering that includes all of the issues related to the physical, psychological, social, spiritual, and practical dimensions of life.

To elicit specific information about the type of request that is being made and the underlying causes for it, the physician should ask open-ended questions in a nonjudgmental manner.[40] While some fear that talking about suicide or hastened death will increase the likelihood that the patient will act, this fear has not been substantiated.[42] Particular consideration should be given to the possibility of clinical depression or anxiety; these conditions are associated with requests for hastened death.[38] When evaluating psychological and social issues, the patient's fears about his/her future should be explored. Many patients have witnessed suboptimal care in others that fuels their fears of losing control, being abandoned, being a burden, or being undignified.[42]

The physician should make a commitment to help find solutions to those concerns, both current and anticipated, reinforcing that he/she wants to continue to be the patient's physician until the end. Options to allay immediate concerns and fears should be explored.

Patients may not be aware of the legal alternatives available to them. Patients should understand that they have the right to consent to or decline any treatment or setting of care if any of them seem too burdensome, including the voluntary cessation of fluid and nutrition, either enterally or parenterally.[22]

For the rare patient who has unbearable and unmanageable pain, or other intractable symptoms after maximal palliative care, and is approaching the last hours or days of his/her life, the induction and maintenance of a state of sedation may be an option.[42] Sedation in the imminently dying that is intended and managed to produce a level of obtundation sufficient to relieve suffering without hastening death has a firm ethical basis.[39] This can be achieved safely using appropriate medications (eg, benzodiazepines, barbiturates, or anesthetic agents) and accepted dosing guidelines.[46] Medications that are poor sedatives (eg, opioids) are not appropriate for this purpose. If a patient with intractable symptoms is sedated, it is the intended effect that is important. If the patient dies while receiving sedation, the death should be attributed to the underlying illnesses, not the sedation.

As requests for hastened death and sedation for intractable suffering may have considerable personal, ethical, and legal ramifications, they should not be dealt with in isolation, but rather with the input of trusted colleagues and/or expert advisors. Clinical experience suggests that most requests for hastened death will resolve if unmet needs are addressed.[42] It also remains a fact that, as of October 2000, in all the United States except Oregon, physician-assisted suicide is illegal. When physician-assisted suicide requests are declined, full comfort care should continue and health care professionals should continue to work closely in partnership with the patient and family to minimize their suffering and optimize their opportunity for meaningful and valued time together.

When Death Occurs

No matter how well families and professional caregivers are prepared, the time of death can be challenging. Physicians can help families by preparing them with information about what to expect, and what to do when death occurs.[47] Families, including children, and caregivers may have specific questions for the physician. Basic information about death may be appropriate (eg, the heart stops beating; breathing stops; pupils become fixed; body color becomes pale and waxen as blood settles; body temperature drops; muscles and sphincters relax, so urine and stool may be released; eyes may remain open; the jaw can fall open; and observers may hear the trickling of fluids internally).[47,48]

When a physician lets family know about the death, the steps for communicating bad news should be followed. Physicians should avoid breaking unexpected news by telephone.[4] Communicating in person provides much greater opportunity for assessment and support. As visitors arrive, the physician should spend a few moments to prepare them for what they are likely to see.

When expected death occurs, the focus of care shifts from the patient to the family, and those who provided care. Many experts assert that the time spent with the body immediately after the death will help people cope with their acute sense of loss.[49-51] Those present, including caregivers, may need the physician's permission to spend the time they need to come to terms with the event and say their good-byes. Even in the hospital, there is no need to rush. Those who need to touch, hold, or even kiss the person's body should be encouraged to do so in the way they feel most comfortable (while maintaining universal body fluid precautions). As a visually peaceful and accessible environment may facilitate the acute grieving process, the patient's body should be prepared for the family, with

©2000 American Medical Association. All rights reserved.

Downloaded from jama.ama-assn.org at Karolinska Institutet University Library on February 11, 2011

any lines and machinery disconnected, catheters removed, and any mess cleaned up to allow the family closer access to the patient's body with greater comfort.[52,53]

The physician, spiritual advisors, or other interdisciplinary team members, particularly nurses, may be instrumental in orchestrating events to facilitate the immediate experience of those present. Those who were not present for the death may benefit from a recounting of how things went leading up to the death and afterward. Grief reactions beyond each individual's cultural norms suggest a risk of significant ongoing or delayed grief reactions.[54] Desired religious rites and rituals should not be overlooked.

Once family members have had the time they need to deal with their acute grief reactions and observe their customs and traditions, preparations for funeral or memorial service(s), and burial or cremation can begin. Some family members may find it therapeutic to help bathe and prepare the person's body for transfer to the funeral home or the hospital morgue. For many, such rituals will be their final act of direct caring.

Depending on local regulations and arrangements, some funeral directors will insist on the completed death certificate being present before they pick up the body. All will require a completed death certificate to proceed with any body preparation and registration of the death. To avoid delaying the process, the physician who will complete the certificate should have ample warning that one will be required.

For many, moving the body is a major confrontation with the reality of the death. Some family members will want to witness the removal. Others will find it too difficult and will prefer to be elsewhere. Once the body has been removed and family members are settled, professional caregivers may offer to assist them with some of their immediate tasks. They may offer to notify other physicians and caregivers that the death has occurred so that services can be stopped, equipment removed, and wastes disposed of. Local regulations governing the handling of medications and waste disposal after a death vary.

When family members are ready, professional caregivers can let the family know how to reach them, then leave them to have some privacy together. A bereavement card from the physician, attendance at the patient's funeral, and follow-up telephone calls or visits to see how everyone is coping may be appropriate.[55]

Loss and Grief

To be effective in end-of-life care, physicians need to be able to recognize grief and assist with appropriate interventions for patients, their family caregivers, and themselves. Grief is the emotional response every person has to loss.[56] Throughout the course of a life-threatening illness, patients and families confront many different anticipated, if not actual, losses (eg, loss of functional capabilities, control, independence, body image, dignity, relationships, sense of future, etc). Depending on the perceived importance of the loss, their grief reactions may be pronounced.[56-58] Physicians should have a basic understanding of grief reactions for those patients who seek help.

Normal grief reactions include a range of physical, emotional, and cognitive behaviors that may or may not follow cultural norms.[59-61] Some people will make a conscious effort to deal with the loss. Others will deny what is happening and avoid dealing with the loss. Some coping strategies (eg, increased smoking, alcohol, or medication intake; overwork; or suicidal ideation) may accelerate and even become destructive, especially in the face of seemingly insurmountable loss. Patients experiencing grief may seek assistance from their physicians for these symptoms. The 7-step approach can be used to elicit the cause for the grief reaction and its perceived importance. If grief is not recognized by the physician, misleading or useless diagnostic studies or prescribing of medications may occur.

When grief reactions occur over long periods, are intense, or interfere with the survivor's physical or emotional well-being, they become symptoms of complicated grief.[54,61] There are 4 categories of complicated grief reactions. Chronic grief is characterized by normal grief reactions that do not subside and continue over long periods (normal grief lasts 6-12 months). Delayed grief is characterized by normal grief reactions that are suppressed or postponed. In exaggerated grief, the survivor may resort to self-destructive behaviors such as suicide. Finally, in masked grief, the survivor is not aware that the behaviors that interfere with normal functioning are a result of the loss.

The physician needs to be attuned to behaviors that might indicate complicated grief, especially if these continue beyond 6 to 12 months.[61] The survivor may not be able to speak of the deceased without experiencing intense sadness. Themes of loss may continue to occur in every topic during a clinical interview. Minor events may unexpectedly trigger intense grief and sadness. The survivor may be unwilling to move possessions belonging to the deceased. Sometimes the survivor will develop symptoms similar to those of the deceased.[54] When complicated grief is suspected, referral for specialized help is warranted.

After a major loss, there are typically 4 tasks to complete before the bereaved will effectively deal with their loss.[55] These tasks apply to the many losses that precede the death, as well as to the death itself. While the tasks are interdependent, they are not necessarily completed in sequence. First, the bereaved must realize and accept that the loss or death has actually occurred. Second, they need to experience the pain caused by the loss. As this can be distressing, many who are bereaved try to avoid the pain, and physicians may try to blunt it with medication. If a minor tranquilizer is used, such as a benzodiazepine, it should only be for a brief period.[54] Third, they need to recognize the significance of their losses and the changes to their lives. Finally, as grief proceeds, the bereaved need to reinvest their energy into new activities and relationships.

If grief reactions and coping strategies appear to be inappropriate or ineffective and/or they have the potential to cause harm (eg, destructive behaviors or

©2000 American Medical Association. All rights reserved.

Downloaded from jama.ama-assn.org at Karolinska Institutet University Library on February 11, 2011

suicide), they will need to be assessed and managed quickly. The physician should consult someone, such as a social worker, chaplain, bereavement counselor, psychologist, or psychiatrist, who is skilled in problematic loss, grief, and bereavement care so that therapy can be instigated quickly to reduce the risk of harmful/destructive activities.

Summary

A single clinical 7-step approach to communication can provide a helpful framework for approaching many of the tasks that physicians find challenging in end-of-life care. Effective application, as part of core end-of-life care competencies,[62] is likely to improve patients' experiences of care. It may also enhance physicians' professional fulfillment from satisfactory relationships of care.

Funding/Support: This work is based on the Education for Physicians on End-of-Life Care (EPEC) Project and was supported by the American Medical Association with a generous grant from The Robert Wood Johnson Foundation.

Acknowledgment: We owe our thanks to numerous experts and staff who contributed to curriculum and implementation of the EPEC Project.

REFERENCES

1. Cousins N. How patients appraise physicians. *N Engl J Med*. 1985;313:1422-1424.
2. Laine C, Davidoff F, Lewis C, et al. Important elements of outpatient care. *Ann Intern Med.* 1996; 125:640-645.
3. Gutheil TG, Bursztajn H, Brodsky A. Malpractice prevention through the sharing of uncertainty. *N Engl J Med.* 1984;311:49-51.
4. Buckman R. *How to Break Bad News: A Guide for Health Care Professionals.* Baltimore, Md: Johns Hopkins University Press; 1992:65-97:chap 4.
5. Ptacek JT, Eberhardt TL. Breaking bad news: a review of the literature. *JAMA.* 1996;276:496-502.
6. Field MJ, Cassel CK, eds. *Approaching Death: Improving Care at the End of Life.* Washington, DC: National Academy Press; 1997.
7. Hinohara S. Sir William Osler's philosophy on death. *Ann Intern Med.* 1993;118:638-642.
8. Emanuel LL. Advance directives. In: Berger A, Levy MH, Portenoy RK, Weissman DE, eds. *Principles and Practice of Supportive Oncology.* Philadelphia, Pa: Lippincott-Raven; 1998:791-808.
9. Emanuel LL, Danis M, Pearlman RA, Singer PA. Advance care planning as a process: structuring the discussions in practice. *J Am Geriatr Soc.* 1995;43:440-446.
10. Teno JM, Lynn J. Putting advance-care planning into action. *J Clin Ethics.* 1996;7:205-214.
11. Emanuel LL. Advance directives: what have we learned so far? *J Clin Ethics.* 1993;4:8-16.
12. Pearlman R, Starks H, Cain K, Cole W, Rosengren D, Patrick D. *Your Life Your Choices, Planning for Future Medical Decisions: How to Prepare a Personalized Living Will.* Seattle, Wash: Patient Decision Support; 1992.
13. University of Toronto Joint Centre for Bioethics. *The Joint Centre for Bioethics Cancer Living Will Form.* Available at: http://www.utoronto.ca/jcb/canchap5.htm. Accessed October 22, 1999.
14. von Gunten CF, Ferris FD, Kirschner C, Emanuel L. Coding and reimbursement mechanisms for physician services in hospice and palliative care. *J Palliat Med.* 2000;3:157-164.
15. Morrison RS, Olson E, Mertz KR, Meier DE. The inaccessibility of advance directives on transfer from ambulatory to acute care settings. *JAMA.* 1995;274: 478-482.
16. Council on Ethical and Judicial Affairs. Optimal use of orders-not-to-intervene and advance directives. In: *Reports on End-of-Life Care.* Chicago, Ill: American Medical Association; 1998:52-58.
17. Finucane TE, Christmas C, Travis K. Tube feeding in patients with advanced dementia: a review of the evidence. *JAMA.* 1999;282:1365-1370.
18. American College of Physicians. Parenteral nutrition in patients receiving cancer chemotherapy. *Ann Intern Med.* 1989;110:734-735.
19. Roy DJ, MacDonald N. Ethical issues in palliative care. In: Doyle D, Hanks GWC, MacDonald N, eds. *Oxford Textbook of Palliative Medicine.* 2nd ed. New York, NY: Oxford University Press Inc; 1998:112-121.
20. Ellershaw JE, Sutcliffe JM, Saunders CM. Dehydration and the dying patient. *J Pain Symptom Manage.* 1995;10:192-197.
21. Council on Ethical and Judicial Affairs, American Medical Association. Decisions near the end of life. *JAMA.* 1992;267:2229-2233.
22. Council on Ethical and Judicial Affairs. Decisions to forgo life-sustaining treatment for incompetent patients. In: *Council on Ethical and Judicial Affairs Reports on End-of-Life Care.* Chicago, Ill: American Medical Association; 1998:30-40.
23. Tulsky JA, Chesney MA, Lo B. How do medical residents discuss resuscitation with patients? *J Gen Intern Med.* 1995;10:436-442.
24. Council on Ethical and Judicial Affairs, American Medical Association. Guidelines for the appropriate use of do-not-resuscitate orders. *JAMA.* 1991;265:1868-1871.
25. Council on Ethical and Judicial Affairs. Do-not-resuscitate orders. In: *Council on Ethical and Judicial Affairs Reports on End-of-Life Care.* Chicago, Ill: American Medical Association; 1998:1.
26. Greenberg LW, Ochsenschlager D, O'Donell R, Mastraserio J, Cohen GJ. Communing bad news. *Pediatrics.* 1999;103:1210-1217.
27. Vincent JL. Information in the ICU. *Intensive Care Med.* 1998;24:1241-1246.
28. Todres ID, Earle M Jr, Jellinek MS. Enhancing communication. *Pediatr Clin North Am.* 1994;41:1395-1404.
29. Council on Ethical and Judicial Affairs. Medical futility in end-of-life care. In: *Council on Ethical and Judicial Affairs Reports on End-of-Life Care.* Chicago, Ill: American Medical Association; 1998:46-51.
30. Halevy A, Brody B. A multi-institution collaborative policy on medical futility. *JAMA.* 1996;276:571-574.
31. Hudson T. Are futile-care policies the answer? *Hosp Health Netw.* 1994;68:26-30, 32.
32. Teno JM, Murphy D, Lynn J, et al. Prognosis-based futility guidelines: does anyone win? *J Am Geriatr Soc.* 1994;42:1202-1207.
33. Tomlinson T, Brody H. Ethics and communication in do-not-resuscitate orders. *N Engl J Med.* 1988; 318:43-46.
34. Truog R, Brett A, Frader J. Sounding board: the problem with futility. *N Engl J Med.* 1992;326:1560-1564.
35. Youngner S. Futility: saying no is not enough. *J Am Geriatr Soc.* 1994;42:887-889.
36. Back AL, Wallace JI, Starks HE, Pearlman RA. Physician-assisted suicide and euthanasia in Washington State. *JAMA.* 1996;275:919-925.
37. Breitbart W, Jaramillo J, Chochinov HM. Palliative and terminal care. In: Holland J, ed. *Textbook of Psycho-oncology.* New York, NY: Oxford University Press; 1998:437-449.
38. Chochinov HM, Wilson K, Enns M, et al. Desire for death in the terminally ill. *Am J Psychiatry.* 1995; 152:1185-1191.
39. Council on Ethical and Judicial Affairs. Physician-assisted suicide. In: *Council on Ethical and Judicial Affairs Reports on End-of-Life Care.* Chicago, Ill: American Medical Association; 1998:41-45.
40. Emanuel EJ, Fairclough DL, Daniels ER, Clarridge BR. Euthanasia and physician-assisted suicide. *Lancet.* 1996;347:1805-1810.
41. Emanuel LL, ed. *Regulating How We Die: The Ethical, Medical, and Legal Issues Surrounding Physician-Assisted Suicide.* Cambridge, Mass: Harvard University Press; 1998.
42. Emanuel LL. Facing requests for physician-assisted suicide. *JAMA.* 1998;280:643-647.
43. Meier DE, Emmons CA, Wallenstein S, Quill T, Morrison RS, Cassel CK. A national survey of physician-assisted suicide and euthanasia in the United States. *N Engl J Med.* 1998;338:1193-1201.
44. van der Mass PJ, van Delden JJM, Pijnenborg L, et al. Euthanasia and other medical decisions concerning the end of life. *Lancet.* 1991;338:669-674.
45. van der Wal G, van der Maas PJ, Bosma JM, et al. Evaluation of the notification procedure for physician-assisted death in the Netherlands. *N Engl J Med.* 1996;335:1706-1711.
46. Quill TA, Meier D, Block S, Billings JA. The debates over physician-assisted suicide. *Ann Intern Med.* 1998;128:552-558.
47. Aspen Reference Group. *Palliative Care Patient and Family Counseling Manual*. Gaithersburg, Md: Aspen Publishers Inc; 1999.
48. Martinez J, Wagner S. Hospice care. In: Groenwald SL, Frogge M, Goodman M, Yarbro M, Jones CH, eds. *Cancer Nursing: Principles and Practices.* 4th ed. Boston, Mass: Bartlett Publishers; 1997.
49. Sheldon F. Communication. In: Saunders C, Sykes N, eds. *The Management of Terminal Malignant Disease.* New York, NY: Edward Arnold Publisher; 1993:29-31.
50. Hospice Institute of the Florida Suncoast. *Care at the Time of Death: Hospice Training Program.* Largo, Fla: Hospice Institute of the Florida Suncoast; 1996.
51. Doyle D. Domiciliary palliative care. In: Doyle D, Hanks GWC, MacDonald N, eds. *Oxford Textbook of Palliative Medicine.* 2nd ed. New York, NY: Oxford University Press; 1998:957-973.
52. O'Gorman SM. Death and dying in contemporary society. *J Adv Nurs.* 1998;27:1127-1135.
53. Weber M, Ochsmann R, Huber C. Laying out and viewing the body at home: a forgotten tradition? *J Palliat Care.* 1998;14:34-37.
54. Chochivon HM, Holland MD, Katz LY. Bereavement. In: Holland JC, ed. *Psycho-oncology.* New York, NY: Oxford University Press; 1998:1016-1032.
55. Irvine P. The attending at the funeral. *N Engl J Med.* 1985;312:1704-1705.
56. Evans AJ. Anticipatory grief: a theoretical challenge. *Palliat Med.* 1994;8:159-165.
57. Hospice Institute of the Florida Suncoast. *Grief and Bereavement: Hospice Training Program.* Largo, Fla: Hospice Institute of the Florida Suncoast; 1996.
58. Cassem NH. The first three steps beyond the grave. In: Pine VR, Kutscher AH, Peretz D, et al. *Acute Grief and the Funeral.* Springfield, Ill: Thomas Publisher; 1976.
59. Yancy D, Greger HA, Coburn P. Determinants of grief resolution in cancer death. *J Palliat Care.* 1990; 6:24-31.
60. Janson LJ, Sloan JA. Determinants of the grief experience of survivors. *J Palliat Care.* 1991;7:51-56.
61. Vachon ML, Rogers J, Lyall WA, et al. Predictors and correlates of adaptation to conjugal bereavement. *Am J Psychiatry.* 1982;139:998-1032.
62. Emanuel LL, von Gunten CF, Ferris FD, eds. *The EPEC Curriculum: Education for Physicians on End-of-Life Care.* Available at: http://www.EPEC.net. Accessed November 6, 2000.

©2000 American Medical Association. All rights reserved.

Downloaded from jama.ama-assn.org at Karolinska Institutet University Library on February 11, 2011