

Building Ties Between Cancer Centers

by Jeff Lycan, R.N., and Elaine Glass, R.N., M.S., AOCN®

End-of-life care decisions have become a major topic of discussion among cancer care professionals as well as the mainstream media. Studies demonstrate that more than 50 percent of patients dying in hospitals have moderate to severe pain, and 25 percent die with untreated depression and anxiety.^{1,2} This outcome is not acceptable. Although cancer care professionals have access to the tools needed to treat the pain, depression, anxiety, and other symptoms, they often fail to realize the importance of providing this care.

Of the people who die of cancer every year, 60 percent die in hospice. In fact, 50 percent of the hospice population has cancer.³ Furthermore, a recent Gallup Poll reported that 90 percent of Americans say they would like to die at home surrounded by loved ones.⁴ Unfortunately, only 25 percent get their wish; most people die in hospitals or nursing homes. And, as indicated in the Support Study,⁵ hospital staff often don't follow dying patients' wishes; thus, many dying patients' desires for a good death are not fulfilled. These statistics point to the need for cancer centers to broaden their palliative care programs by working more closely with hospice organi-

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zations to improve end-of-life treatment in acute-care settings.

PALLIATIVE CARE AND HOSPICE

In a recent *Annals of Internal Medicine* article, Steihauser⁶ and colleagues describe a "good" death as having six components: pain and symptom management, communication and clear decision-making with a physician, greater preparation for death, completion (including faith issues, life review, resolving conflicts, spending time with family and friends, and saying good-bye), contributing to the well-being of others, and affirmation of the patient as a unique and whole person. According to the authors, these components are not often achieved because physicians tend to focus on biomedical issues to the exclusion of psychosocial and spiritual concerns. The finding raises several questions:

What do health care professionals need so that they are able to provide the most appropriate care to terminally ill patients at the end of life?

Do health care professionals let patients and families know when the end of life is near?

Are health care professionals telling patients about all their choices by discussing the option of hospice care?

Do health care professionals provide patients and families with opportunities that allow them to achieve their hopes and desires for a good death?

Palliative care has exploded onto the health care scene as a means to help cancer centers and other acute-care environments find answers to these questions as they strive to treat chronic and end-of-life needs more comprehensively.

Still, the meaning of palliative care is often misunderstood by health care professionals as well as by patients. Palliative care, as defined by the World Health Organization, "is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount."⁷

Hospice is one component of a comprehensive palliative care strategy that ensures patient access to appropriate palliative intervention from initial diagnosis to, if necessary, terminal illness. Hospice offers a multidisciplinary team of health care professionals who address the psychosocial, spiritual, and bereavement needs of the patient and family, as well as meet the physical comfort needs of the patient. This multifaceted focus on the patient and family is a major difference in the standard of practice of hospice care versus what other health care systems usually provide.

Hospices and hospitals can no longer afford to exist in isolation. For many hospital cancer programs, collaboration with a hospice organization can broaden palliative care or comfort care efforts and provide the structure to facilitate more efficient and cost-effective care. Palliative care is becoming more recognized as a health care specialty, especially after national certification became available for physicians and nurses in the field. However, medical centers experience difficulty with reimbursement for the non-biomedical services involved in palliative care. In medical centers, palliative care services are reimbursed only in select areas based on events or identified "problems," such as pain and symptom management for dyspnea, depression, or anxiety, for example. In these settings, the "terminal

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illness diagnosis" may not be an "identified" treatment need and is not a reimbursable diagnosis. Therefore, the psychosocial and spiritual care needs are often not adequately addressed. In hospice, the event for reimbursement is the terminal illness diagnosis. The hospice multidisciplinary team intervenes to address the medical and physical needs along with the psychosocial, emotional, and spiritual care needs of the patient and family. Hospice then follows the family and provides bereavement support for up to a year after the death of the patient.

COLLABORATION BRINGS BENEFITS

For a cancer center and a hospice organization to work together, they must first identify avenues for improving end-of-life care. A beginning step is to convene a multidisciplinary task force of cancer center and hospice staff to set goals and to identify and implement strategies to improve utilization of hospice services.

The "Goal of Care Assessment Tool" as described by Fins⁸ includes a number of goals and strategies. Among these are the following:

- increase the proportion of comfort care plans for patients who die in the hospital

- make more timely end-of-life decisions so that patients who have do not resuscitate (DNR) orders, are identified as dying, and receive comfort care plans earlier in the hospital course of terminal admissions

- increase the proportion of patients who are appropriately withdrawn from life-sustaining treatments

- provide more coherent comfort plans so that patients do not receive

treatments and procedures that are not intended for, nor likely to promote, comfort

- expand the proportion of terminally ill patients discharged to home and/or hospice.

Hospice staff can help in a variety of ways by:

- identifying patients appropriate for terminal care and holding discussions with patients and families

- working with hospital staff to jointly write patient education materials about making end-of-life care decisions

- increasing visibility and accessibility of hospice- and palliative-certified physicians and nurses to cancer center colleagues

- offering palliative care consultation services and/or negotiate for inpatient hospice beds

- personally notifying cancer center physicians when their patients die in hospice

- providing educational programs on low-tech vs. high-tech methods for pain management

- monitoring and reporting the number of hospice referrals in order to improve negotiations for managed care contracts (hospice care is less costly)

- offering continuing education for all clinicians in end-of-life care
- improving communication between cancer center health care professionals and patients' primary physicians.

For the many cancer centers that have had to cut the number of skilled case managers, social workers, and/or discharge planners, hospice services can provide assessment of when patients may be ready to be referred for hospice care. If hospital staff is too busy or too uncomfortable with discussing terminal care options, they may

find it easier to leave the current care plan in place rather than try to make hospice arrangements. If hospital staff does not become comfortable in discussing changes along the continuum of illness, they will be slow to improve the care of the dying. Hospices can help as a resource for developing and providing educational resources for hospitals in the art and practice of caring for the dying.

Increasingly, third-party payers are demanding more sophisticated outcome data to justify expense. To that end, hospice and hospital staff must set realistic objectives for measuring outcomes such as patient comfort and level of pain at end of life to help programs streamline and standardize end-of-life care. Protocols should be devised and implemented to ensure that pain and other symptoms such as dyspnea, anxiety, and depression are treated consistently and logically. All hospice patients must be evaluated and reevaluated to determine the appropriate care setting. Criteria for admission and continuance in hospice must be established.

COMMUNICATION IS KEY

Physicians and other cancer care staff must be better informed about the importance of palliative care throughout the treatment plan. Such information can help circumvent the larger trend in the country of physicians wanting to (and some patients or loved ones asking them to) aggressively treat cancer just weeks prior to death at the expense of a patient's quality of life. While oncologists might focus more on biomedical treatment issues, hospice focuses more on symptom control and management of comfort needs.

With hospice staff to provide guidance, cancer care professionals must begin discussion much earlier

in the treatment process on the differences between curative and palliative care. The point needs to be made that from the beginning, curative or more aggressive therapy will be a first priority, but if the disease does not respond to therapy, comfort care may become the higher priority to improve quality of life. Patients introduced to the idea of palliative care may be more receptive to it later on. As the terminal phase approaches, these patients may find it easier to transition into the comprehensive palliative care that hospice provides. Thus, patients are better prepared to make more informed choices in determining which venue is emphasized during the course of their illness.

Hospice staff is skilled with presenting information about prognostic indicators for hospice care eligibility and can help train cancer center staff to talk about and deal with end-of-life issues. Many cancer specialists have had little training in how to communicate bad news. A common misperception is that patients do not want to know that "death is close." However, recent studies dispute this. Patients indicate that, if they knew their death was close, they would often choose treatments and supportive care that would allow them to complete end-of-life goals.^{9,10}

Explanations about outcomes of treatment to patients and families by cancer specialists must be clear and thought out beforehand. For example, avoid such a statement: "I can give you a combination of drugs that is 70 percent effective in your type of tumor."

Instead, a clearer explanation, one that minimizes false assumptions about the outcome of the treatment, might be more appropriate: "The tumor you have may not be curable. However, there is a combination of drugs that is about 70 percent effective in controlling this tumor for several months, perhaps a year or so."

Cancer care professionals also need to be clearer in their explanations to patients and families when a tumor has stopped responding to treatment. Avoid euphemisms and communicate clearly about the potential outcomes of experimental treatments. For example, the following explanation may be quite misleading to vulnerable patients

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and families who have received the news that the current treatment is not working: "Now that you have tried all the standard treatments available, you are eligible to take a new drug through a clinical trial that we can give you here. Initial research on this drug has shown great promise against the type of tumor that you have. Would you like to try it?" Although the statement is positive, upbeat, and hopeful, it does not provide patients and families with any options, and it may give a false perception of the potential outcome. Many patients would interpret the explanation to mean they still had a good chance of being cured of their disease.

A less ambiguous way of providing the same information might be: "Your disease has stopped responding to the standard treatments available. I have two options to offer you. One, you may try a research drug that has shown some initial effectiveness against your type of tumor. Because we have given your tumor so many other treatments, it is doubtful that this new drug will cure your tumor. However, it may give you more time. If you choose not to take this new drug, I can talk with you more about the option of hospice care. Hospice will focus on pain and symptom control, comfort, and support your needs in the final stages of life. If you choose hospice, I can see you in my clinic every month or so and we can decide when the time is right for

you to enter hospice. Would you like to speak with one of our nurses who helps patients and families cope with these tough decisions?" (Note that continuing aggressive therapy for the intent of cure is not consistent with the hospice philosophy and the hospice Medicare benefit, which requires that you have a limited life expectancy of less than six months if the disease runs its normal course. Aggressive therapy such as chemotherapy and radiation may be given to hospice patients to manage symptoms, provide comfort, and improve quality of life.)

Although this latter explanation may take a little longer, it provides patients and families with the information they need to make an informed choice that takes into consideration not only their potential length of life, but also their quality of life.¹¹

Timing of the discussion about hospice is often inappropriate and abrupt. "There isn't anything else we can do. Call hospice!" This statement illustrates the deficits in education of nurses, physicians, oncology social workers, and other health care professionals about care of the dying and inadequate communications with the patient.¹²

Hospice discussions are often left to the last few days because health care professionals may not want to take away the patient's hope. Health care professionals fail to realize that hope can be redefined by the patient in these situations, seeking a change from cure to dying comfortably, being around family and friends, and being at home where patients may more easily achieve closure.¹³ Patients not referred to hospice or referred shortly before they die may not have the opportunity to feel they have the ability to make decisions, have control, or realize their hopes to die a good death, as indicated in several recent studies.^{14,15}

In summary, the need for collaboration between cancer centers and hospices is clear, and the opportunities for collaboration are abundant. For Americans to have a chance of dying well, they must be well informed of all their options in a sensitive manner. Cancer is one of the leading causes of death in this country; it makes sense that cancer centers and hospice should work

together to improve the care of the dying in the hope of achieving "a good death." ■

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The Palliative/Curative Intersection

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There comes a point in caring for patients with advanced cancer when the focus shifts from an all-out battle to cure the disease to a focus on quality of life. In today's health care system, this frightful transition from expectation for cure to awareness that life is coming to a close is an abrupt one. All too often the transition is simply the physician saying, "I think it's time for you to go to hospice," or "there's nothing more I can do." Patients may feel abandoned or rejected at this point, as if they have failed their doctor.

Many in the hospice and palliative care community have called for a change to a less abrupt, more gradual transition toward comfort measures and palliative care. Such a transition makes sense from the clinical, psychological, and ethical perspectives. The need for symptom management and comfort measures spans the entire course of cancer treatment.

As difficult as it is for clinicians to bring up the painful possibility that treatment may not succeed, the patient and family benefit greatly from discussion of palliative care and hospice throughout the illness—even at the onset of treatment. Cancer patients often think about dying. Talking about all options can be tremendously reassuring. Some will say that this open dialogue encourages treatment failure, but the evidence suggests otherwise. Cancer patients who are psychologically and emotionally prepared for all possibilities are not likely to live longer or shorter lives; however, they will be much better at coping with their disease, and their families will adjust better when death occurs. Patients are entitled to receive as much information as they wish to help them make appropriate

choices at the end of life.

Dialogue is crucial. Still, words may be misunderstood. We refer to most treatment aimed at modifying the disease as "curative," when at best the treatment leads to remission or perhaps buys a limited amount of time. A 5 percent chance of partial remission may be heard as: "There's a 5 percent chance this treatment will cure you." Of course, the patient expects to be included in that 5 percent.

Although the majority of people dying of cancer are now receiving hospice care, earlier hospice care helps to avoid symptom distress through prevention of problems and allows hospice staff to develop a closer therapeutic rapport with the patient and family.

How can we provide palliative care earlier and move patients into hospice and palliative care months or years rather than days or weeks ahead of death? Some ideas include:

- a relaxation of the hospice six-month prognostic requirement or replacement with more objective disease severity measures
- establishing mechanisms for the provision of palliative care consultation teams to assist in planning for improved symptom management
- systematic efforts to improve the advanced care planning process to identify and have end-of-life conversations with people sooner.

So many times I have seen patients and families reach the point of death unexpectedly. The death is seen as sudden, although the person had a long illness. Family members are often left with many regrets for words not said.

Ultimately as a society, improving care for those facing the end of life will require us all to muster the courage needed to more fully face our own mortality. ■