

# Difficult Conversations

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*Palliative care is an essential service,* and will become increasingly important as the incidence of cancer increases over the next 20 years. If the fundamental responsibility of health care professionals is to ease suffering, then palliative care merits priority status and should not be viewed as an optional extra. When palliative care is holistic and focuses on the physical, emotional, spiritual, and social needs of the patient, it can improve the patient's quality of life and may even enhance the efficacy of physical treatment.

Traditional medical education presents the medical care of the terminal/dying patient as a passive withdrawal of curative treatment. Yet death is not a disease; it is a natural part of the life cycle. Cancer care professionals must be careful not to describe death solely in medical or biological terms. Instead, they should assume an active, positive role in making this aspect of living as meaningful and comfortable as possible.<sup>1</sup>

Today, the “do everything” approach—with little regard for the wishes of the patient or family—is the default position of many medical professionals.<sup>2</sup> We are a “healing hero culture” and believe we must do all we can to keep a patient alive. We may be focusing too much on preventing death, and not knowing when to let go is a key barrier to adequate end-of-life care.<sup>3</sup>

*The British Medical Journal* reported that physicians predicted that their dying patients would live five times longer than they actually did.<sup>4</sup>

This finding suggests that palliative care should probably be introduced earlier in the course of a chronic, ultimately fatal disease than typically occurs today if we want to help patients and their families prepare physically, emotionally, and spiritually for the transition from life to death.<sup>5</sup>

Providers are becoming increasingly aware that many of the most difficult to manage end-of-life needs have their origins early in the disease course. If such needs are addressed at the onset of treatment, they are much more easily dealt with than in the final days of life.

## *Quality of Life and Palliative Care*

A 1990 World Health Organization (WHO) definition of palliative care emphasized its use in patients who did not respond to curative therapy.<sup>6</sup> Although this definition might indicate that palliative care would be appropriate only during the final stages of a disease process, palliative and curative care can occur simulta-

neously. One does not necessarily negate the other.

Since the goal of palliative care is to improve the quality of life for people living with a life-threatening illness, determining what patients consider important in their lives is critical. Generally, patients focus on five areas:<sup>7</sup>

- Their state of being, including physical and cognitive functioning, psychological state, and physical condition
- The quality of palliative care they are receiving, which



affects their feelings of security, self-respect, and spirituality

- Being in the right physical environment, whether that is home, a health care facility, or a place that offers opportunities to enjoy the outdoors and nature
- Their relationships: whether they are receiving adequate support, whether they and their loved ones have clear communication and/or unfinished issues, and

whether their concerns about becoming a burden have been addressed

- Their overall outlook: whether they have a sense of hope, whether they can find some joy and purpose in life, if they have a sense of control, and many other existential and spiritual concerns about facing death.

## A "Good" Death

Interviews with patients have identified six components that constitute a "good" death: 1) good pain and symptom management, 2) being able to participate in care and treatment choices, 3) receiving preparation for death from caregivers and knowing what to expect while dying, 4) a focus on relationships (resolving conflicts, spending time with family and friends, and saying good-bye), 5) feeling that one has made a contribution to others, and 6) life review and affirmation of the whole person.<sup>8</sup>

When patients were asked to rank the components of a good death in order of importance, the top five choices were 1) freedom from pain, 2) being at peace with God, 3) the presence of family, 4) remaining mentally aware, and 5) being able to make treatment choices.<sup>9</sup>

In most studies, patients mentioned pain management as very important, yet oncology patients continue to report inadequate pain control.<sup>10</sup> A 1998 study reported that 95 percent of pain in patients who have terminal illnesses can be lessened with pain medications, but almost one half of terminal patients still die in pain.<sup>11</sup>

## How to Improve Care

Early in the treatment process, the palliative care team should meet with patients and their families to: 1) explore treatment options; 2) discover what the patient and family know about the patient's disease and treatment and answer questions; 3) find a way to alleviate the patient's immediate discomforts; 4) explain current medical risks, including suicide; 5) create a palliative care follow-up plan; and 6) evaluate what hasn't been discussed and make plans to address this information in the future.<sup>12</sup> No matter how uncomfortable these discussions may be, they will minimize the patient's sense of loneliness and isolation.

Telling the patient that no more can be done for them and that they are moving towards death is never a pleasant task. Nevertheless, this conversation can be critical in setting the tone for remaining care. If done well, caregivers can help foster a positive attitude, strengthen the patient-physician relationship, and affirm that the patient is not



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alone.<sup>13</sup> If done poorly, people can be robbed of hope. The best person to speak to the patient at this time is the physician with whom the patient has the most longstanding relationship, and who also has the skills to talk face-to-face about end-of-life issues. No one should conduct this discussion over the phone.

Although the importance and benefit of allowing people to have hope is undisputed, most health care professionals do not understand the role of hope in a seriously ill or terminal patient. For the nonterminally ill, hope means hope for a cure or becoming better. In patients with terminal illnesses, hope often relates to living a meaningful, day-to-day life for the time they have left, relief from pain and suffering, having a peaceful death, or being able to safeguard the future of their family.<sup>14</sup>

The National Coalition of Healthcare and the Institute for Health Improvement developed a list of promises that physicians should make to their dying patients.<sup>13</sup> One of these promises is that the patient will never have to endure overwhelming pain, shortness of breath, or other difficult symptoms. Unfortunately, much evidence indicates that physicians too do not manage pain well, often because of their fear of legal repercussions.

### *Educating Providers About Palliative Care*

Palliative care is receiving increasing attention from national and state organizations. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO), professional organizations such as the American Medical Association, and state legislatures are encouraging educational programs that help health care professionals gain a better understanding of pain management, end-of-life issues, and palliative care.

California mandates physician training in end-of-life issues, and the California Medical Board is beginning to track patient complaints of poor pain management. In fact, a California jury awarded \$1.5 million to a family who said a California physician did not adequately treat their loved one's pain as he was dying.<sup>15</sup>

Other states have also taken action. In January 2002, the New Jersey legislature introduced a bill that would require educational courses in hospice care and end-of-life pain management for all medical students enrolled in a New Jersey medical school. Also in January 2002, Michigan approved a package of 12 end-of-life-related bills.<sup>16</sup> In 2001 the Florida Senate considered a bill requiring certain health care facilities and providers to comply with patient requests for pain management and palliative care or lose their medical licenses. Other states are following these leaders.

Still, the skill of speaking with patients and families about sensitive end-of-life issues is not being adequately taught in medical schools, and studies indicate that medical students are also poorly trained in the care of the dying.<sup>17</sup> Most medical schools include some material about death and dying in their curricula, but only as an elective subject or as part of a broader course. Education about pain management is inadequate and often addresses only postoperative pain issues, not pain management at the end of life. Information about pain medication is frequently covered in courses that do not have a focus on death and dying.

Choice in Dying, a national, not-for-profit organization dedicated to fostering communication about complex



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end-of-life decisions, initiated a five-year project to examine death and dying in more than 11 medical education programs. The project showed that the medical community needed to develop explicit goals and objectives for end-of-life education that encompass the physical, emotional, legal, ethical, social, and spiritual needs of the dying patient. Additionally, education programs should incorporate an interdisciplinary approach to teaching palliative care.

The program showed that end-of-life education must be integrated into both preclinical and clinical training to foster positive feelings about the physician's role in caring for dying patients. Allowing medical students to interact with dying patients and caregiver mentors that model ideal knowledge, skills, and attitudes is an excellent way to enhance the ability of future doctors to communicate with dying patients, their families, and the staff members who care for them.<sup>17</sup>

Medical students should be taught a protocol for breaking bad news. This protocol might include 1) having an appropriate setting that is private and comfortable, 2) finding out how much the patient already knows, 3) determining how much the patient wants to know, 4) sharing information in short segments, not all at once, 5) responding to the patient's feelings, 6) establishing goals and priorities for care and treatment, and 7) discussing a follow-up plan.<sup>18,19</sup>

The American Geriatric Society recommends that all medical students develop core competencies related to end-of-life issues for the geriatric population, including obtaining advance directives, evaluating a patient's decision-making capabilities, euthanasia, assisted suicide, and pain management.<sup>20</sup>

### *A Model Training Program for Medical Students*

Since December 1995, a joint program of the University of South Florida (USF) and LifePath Hospice has helped third-year medical students better understand end-of-life care. Originally funded through a grant from the National Cancer Institute, this program is considered so important and successful that it continues today even without grant funding. Specifically, medical students in the program

learn how to manage the symptoms, communicate with, and support the care choices of homebound patients with terminal illnesses who are near the end of their lives. The program is the only opportunity that University of South Florida medical students have to visit and evaluate an end-of-life patient in the home setting.


All third-year medical students do a four hour-per-week, month-long rotation through the hospice during their internal medicine ambulatory clerkship. During the first week they attend a didactic seminar on end-of-life issues, which covers basic hospice concepts (i.e., pain and symptom management), communication with the terminally ill, and the impact of psychosocial and spiritual issues on patient choices. During the second and third weeks, they visit two homebound patients, one with a nurse case manager and one with a counselor preceptor. During these visits, students conduct a comprehensive physical exam and psychosocial assessment on each patient and interview the patients and their caregivers. During the fourth week, medical students submit written papers describing their emotional reaction to the experience, take a post-test, and make an oral patient presentation to an interdisciplinary team consisting of a physician, hospice nurses, counselors, and the other medical students in their group. Care is discussed from an interdisciplinary prospective.

Currently, USF and LifePath Hospice are jointly conducting a survey of those physicians who participated as students six years ago to determine how they might have changed their behavior and practice when treating patients with terminal illness as a result of this experience during their education.

### Looking to the Future

Although our society has difficulty discussing death, we as medical professionals must learn how to communicate with patients who have terminal illnesses and listen more carefully to what our patients tell us about how they want to spend the last days of their lives.<sup>21</sup> As medical technology advances, patients are facing increasingly complex choices about end-of-life care. Many patients are rejecting the high-tech world of medicine and opting instead for the peace of a quiet but comfortable death at home surrounded by family and friends.

Author and oncologist Roger Cole elected to work exclusively with patients with terminal illnesses to understand the deeply emotional experiences his dying patients were going through. He discovered that talking with them brought comfort to their final days and gave him a sense of enlightenment. He maintains that physicians typically make one of three choices: 1) telling their patients everything, 2) telling their patients nothing, or 3) telling their patients what they think the patient should know.<sup>22</sup> The problem is that these choices are all physician-centered.

Cole believes that his conversations with his patients during their final days, oriented to the patients' needs, were extremely important and brought them comfort. Once these patients were freed of their pain, they began to feel peace, joy, and eventually detachment from worldly worries, realizing that death is not an end, but a passage. 

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### References

- 1 Callahan D. Setting and communicating the limits of biotechnology—biotechnology and ethics: a blueprint for the future. Keynote speaker at the Hastings Center; May 16, 1996; Garrison, NY.
- 2 Hu KK. Fight for a peaceful death: a personal essay. *J Palliative Med.* 2001;4 (2):209.
- 3 Meier DE. Palliative care in hospitals: making the case. CAPC management training seminar; February 2002; Tampa, Fla.
- 4 Christakis N, Lamont E. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. *Br Med J.* February 19, 2000;320:469.
- 5 Schonwetter R, Redmond L, Lowell J, et al. Palliative care. *Clin Cardiol.* 2000;23 (suppl II):21-25.
- 6 World Health Organization. *National Cancer Control Programmes—Policies and Managerial Guidelines.* 2<sup>nd</sup> ed. Geneva: World Health Organization; 2000.
- 7 Cohen SR, Leis A. What determines the quality of life of terminally ill cancer patients from their own perspective? *J Palliative Care.* 2002;18 (1): 48-58.
- 8 Steinhäuser K, Christakis N, Clipp E, et al. Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA.* November 15, 2000; 284:2476.
- 9 Cohen SR, Leis A. What determines the quality of life of terminally ill cancer patients from their own perspective? *J Palliative Care.* 2002;18 (1):48-58.
- 10 Swenson CJ. Ethical issues in pain management. *Oncol Nurs.* May 2002;18 (2):135.
- 11 Jones J, Hall P, Schroeder C, et al. Discussing end-of-life issues with patients: reflections on developing an interviewing template to assist first-year medical students. *J Palliative Care.* 2001;17(4): 254-258.
- 12 Quill TE. *Caring for Patients at the End of Life: Facing an Uncertain Future Together.* New York, NY: Oxford Books; 2001.
- 13 Avery JA. Giving bad news in a good way. *Physician-Related News for Physicians of the Florida Suncoast.* Fall 2001:1.
- 14 Duggleby W. Hope at the end of life. *J Hospice Palliative Nurs.* April-June 2001;3(2):51.
- 15 Pacl DS. California passes law for physician EOL education. *AAHPM Bulletin.* 2002.
- 16 *Last Acts Policy News.* January 2002; 3(1).
- 17 Nelson W, Angoff N, Binder E, et al. Goals and strategies for teaching death and dying in medical schools. *J Palliative Med.* 2000;3(1):7.
- 18 Buckman R. *I Don't Know What to Say...How to Help and Support Someone Who Is Dying.* New York, NY:Vintage Books; 1992.
- 19 Von Guten CF, Ferris FD, Emmanuel LL. Ensuring end-of-life care: communication and relational skills. *JAMA.* 2000;284(23):3051.
- 20 The American Geriatrics Society—Education Committee Writing Group. Core competencies for the care of older patients: Recommendations of the American Geriatrics Society. *Acad Med.* 2000;75(3): 252-255.
- 21 Perron V, Schonwetter R. Hospice and palliative care programs. *Palliative Care.* June 2001;28(2):427.
- 22 Cole R. *Mission of Love—A Physician's Spiritual Journey Toward a Life Beyond.* Berkeley, Calif: Celestial Arts; 2002.