Mr. R.D.R. was a 62-year-old male newly diagnosed with prostate cancer. He had presented with distant metastases. Mr. R.D.R. lived with his elderly mother, didn’t say much, and had an odd sense of humor. The urology oncology study coordinator developed a pleasant and polite working relationship with him. He appeared to be a loner, a man of few words, and always came to visits by himself. As his disease progressed and pain became an issue, the nurse coordinator began to realize that no one knew of his diagnosis or prognosis. The treating medical oncologist asked the nurse coordinator to “talk” to him. The proud and quiet man was stoic as he related that his mother didn’t know he had cancer or that his time was limited. The nurse was speechless at his ability to hide his disease but more so at the lack of his support system. The nurse began the first of many nurse-patient talks about end-of-life care issues. The patient was urged to tell his mother of his diagnosis since she might want the opportunity to reminisce and talk about the past. The nurse told him how sad she would be if she were his mother and didn’t have this chance to say what she needed to say, to say good-bye. He was noncommittal.

Mr. R.D.R.’s next hospital visit was an emergent one. He was in terrible, uncontrolled pain because he had failed to report the pain previously and believed in “biting the bullet.” He was admitted to the inpatient unit and lapsed into a morphine-induced coma. He looked peaceful, but thin and ragged.

He died in the morning hours with his mother at his bedside, but had never awakened to have that last talk with her. The closure that the nurse thought was so important had not happened between this adult child and his mother. When the nurse introduced herself to his mother, she smiled through tears and said her son had often mentioned the nurse’s name. She appeared lost as she commented, “I don’t even know who he wants as pallbearers. What am I going to do?” We sat together for a time. The nurse’s presence and sense of being there were all she could offer this woman as she mourned the loss of her son.

Competent and compassionate end-of-life care is the right of everyone. Nursing and the health care profession are obligated to meet this need for their patients and provide crucial information and support. Continued efforts must be made to increase our knowledge about the normal dying process, symptom management, and the role of the interdisciplinary team in supporting patients in their final wishes for a “good death.”

Definitions

Death is a frightening subject for many people. Some readers will not think this article pertains to them or they may simply feel uncomfortable reading about end of life (EOL). Yet, if you are working with urologic patients and their families, end-of-life care is part of the care package. Death is the final stage of life for all of us. Hospitals market pregnancy and childbirth classes to young couples and yet classes on how to die “well” are not offered. The tide is slowly changing in efforts to better educate health care professionals on EOL issues. While nursing, as a whole, has taken some important steps, much is still left to be done.

In the past, many young women died during childbirth and children died at young ages. Death was often an acute event. Today, the way people live and die is changing. People are living longer and many live with chronic disease. Now death is, often times, a series of set backs and stabilization periods rather than an acute process. There can be a slow decline in health status or
periods with crises and recovery before death.

In our society, the terms hospice, palliative care, and end of life can be confusing. The terms can have a very different meaning or be used interchangeably. It could be viewed that hospice is a concept of care when disease is no longer curable, palliative care is a concept of care aimed at symptom management, and end of life is a time frame.

Ferrell and Coyle (2002, p. 27) define hospice as a “program of care that supports the patient and family through the dying process and the surviving members through bereavement.” Recent information from the Hospice Foundation of America reports that 80% of hospice care is provided in homes and nursing homes (Field & Cassel, 1997). The World Health Organization defines palliative care as “the active total care of patients whose disease is not responsive to curative treatment” (Ferrell & Coyle, 2001, p. 28). The aim of palliative care is to relieve and control symptoms and thus promote one’s quality of life. Palliative care can lead to EOL care but is not always end-of-life care. A patient with a disease such as amyotrophic lateral sclerosis is an example of a patient who may receive palliative care. During a respiratory event that required hospitalization and intubation with ventilatory support, this patient would be treated to relieve the disease symptoms and prevent further decline. The patient and family would be supported through this process with the intent to discharge the patient to the home setting. It is during this time that a goal of the health care team should be to help the patient and family define their goals of care. Ferrell and Coyle (2002, p. 28) state that EOL care refers “explicitly to the final weeks of life when death is imminent.”

Today, the public has found a new interest in EOL care due to several reasons. This is due in part to the aging of the American population, recent media attention to both physician-assisted suicide and euthanasia, and the recent deaths of famous celebrities such as Bob Hope. Betty Ferrell and her team from the City of Hope National Medical Center in Duarte, California, have spearheaded a movement to increase nursing knowledge concerning EOL care. Dr. Ferrell points out that there is a great difference in the way people want to die and the way death usually occurs (Ferrell & Coyle, 2001). If you have taken the time or had the opportunity to talk to patients or personal family members about their thoughts on dying, many people express that they would like to die at home. They would like to be surrounded by their loved ones, be in familiar surroundings, have their pets next to them, or have comforting music in the background. Contrast this to the sterility and unfamiliarity of dying in a hospital where many still live out their final days.

To facilitate the patient’s choice, discussion about EOL issues must be done earlier and more systematically by the health care professional. These discussions are difficult for clinicians to initiate. But according to Quill (2000), normalizing the discussion allows the patient to learn about her/his right to high-quality pain and symptom management and can educate the clinicians about the patient’s values and goals. Quill (2000) suggests key questions to initiate EOL discussion: “What would be left undone if you were to die sooner than later?” “Given the severity of your illness, what is most important to you to achieve?” and “What do you consider your quality of life now?”

Lessons Learned

In the case study presented, I was a nurse dedicated to delivering excellent cancer care. But, I was not as well versed on the topic of death and dying. As a nurse graduating in the 1970s, cancer was hardly discussed, much less the topic of a “good death.” I had no mentors as there were few experts in the field of EOL care at the time. Since the 1970s, I have grown in my comfort and educational levels pertaining to EOL issues. This has been accomplished by formal and informal learning. Health care professionals are fortunate to have an abundance of written material on EOL issues. Continuing education programs offer up-to-date information. The American Association of Colleges of Nursing (AACN) in 1997 published Peaceful Death: Recommended Competencies and Curricular Guidelines of End-of-life Nursing Care. This document describes skills and knowledge needed by nurses to provide quality EOL care. In 2000, Bill Moyers hosted an excellent public television community outreach program series, On Our Own Terms, on EOL care. Membership in specialty nursing organizations can also be beneficial and increase nurses’ knowledge base. I belong to two national nursing organizations (Oncology Nursing Society and the Hospice and Palliative Nurses Association) where EOL care is an important clinical issue and kept in the forefront.

Given my knowledge now, I would handle Mr. R.D.R. differently today. I would have started the EOL discussion earlier. At the first hint of pain and progression of disease, I would have talked to him more directly. I would have enlisted the physician to participate in the discussion with me. I would have asked the patient if he had a clergy member he wanted to involve in the discussion. Unfortunately, the patient did not have a religious affiliation.
He truly was a loner. Sadly, this patient had a very sudden decline in his health and time was against us. But, it is important to point out, that the patient has the right of self-determination. Our plan of care does not always end up being the patient’s plan of care. That can be a very distressing place for a nurse to be — thinking our plan is the best and yet needing to recognize the patient’s rights. While I learned much from this patient, it took me out of my comfort zone in honoring his wishes.

Barriers to End-of-Life Care

There are many barriers to providing quality care at the end of life. One of the major barriers is the lack of adequate educational training for physicians and nurses and other health professionals. This leads to delayed referrals to hospice and palliative care services. Language and cultural issues can also affect discussions on EOL care. Families are often uncomfortable talking about their greatest fear — that of losing a loved one. Spouses often want to protect their loved ones from this sad discussion. In addition, financial issues may cloud the discussion. Unfortunately, insurance and managed care programs may not cover hospice and palliative care (Ferrell & Coyle, 2002).

While barriers exist, health care professionals involved in working with geriatric patients with chronic illness such as cancer and end-stage renal disease, need to find ways to open the discussion on EOL care. While I was in a nurse practitioner program, I had the opportunity to work with two skilled family care physicians. Working in a small rural clinic, they had made an impression on the community by their commitment to the ethical and compassionate care of all their patients. They had a large geriatric patient base in this rural community. At 6-month and yearly visits, both physicians entered into a dialogue with their elderly and chronically ill patients about their thoughts on EOL care. Discussion centered on the need for a Living Will and a Durable Power of Attorney for health care. Resuscitation status was discussed in detail. Did the patient want chest compressions, intubation, and ventilatory support? Did the patient want antibiotics and IV hydration? The physicians started and continued the discussion on EOL in future visits, building on what information had been given and decisions made earlier. Their patients benefitted greatly from their wise and compassionate care and I did as well.

Table 1. Resources for End-of-Life Care

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<th><strong>American Journal of Nursing Series on End-of-Life Care Topics</strong>*</th>
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<td>An overview of palliative nursing care</td>
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<td>Difficulties in managing pain at the end of life</td>
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<td>Symptom management in people with AIDS</td>
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<td>Managing psychological conditions in palliative care</td>
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<td>Ethical concerns in end of life care</td>
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<td>Cultural considerations in end of life care</td>
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<td>Care at the time of death</td>
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<td>Improving the quality of end of life care</td>
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**Final Gifts: Understanding the Special Awareness, Needs, and Communication of the Dying**


**Center to Improve Care of the Dying**

www.gwu.edu/~cicd

**City of Hope Pain/Palliative Care Resource Center**

http://prccoh.org

**End-of-Life Nursing Education Consortium (ELNEC)**

www.aacn.nche.edu/elnec

**The EPEC Project: Education for Physicians on End of Life Care**

www.epec.net

**Hospice Foundation of America**


**Hospice and Palliative Nursing**

www.hpna.org

**Last Acts**

www.lastacats.org

**National Hospice and Palliative Care Organization**

www.nhpco.org

**On Our Own Terms: Moyers on Dying**

Public Broadcasting System (2000, September)
Table 2.
Key Points/Phrases: How to Begin the Discussion

- Acknowledge that this may be a difficult subject to discuss.
- Approach the topic of supportive care. You might say, “Would it be all right to talk about this now?”
- Reinforce that the patient will still be receiving care even though the focus of the care might change. You might say, “Since we can not cure your illness, I want you to know we will continue to care for you and support you.”
- If appropriate, begin discussion on symptoms and management. Give practical and helpful hints on how to deal with specific symptoms and who to call if the symptoms are not being managed.
- Give written information/handouts.
- Clarify resuscitation status and patient wishes. You might say, “If your heart stops beating, do you want us to start it up again by doing chest compression?” Ask if the patient has a Durable Power of Attorney for Health Care or a Living Will. Provide information if the patient wishes to pursue this option.
- Utilize support services such as chaplain, social work, ethics committee, or palliative care consults if appropriate and available.
- Thank the patient/family for allowing you to discuss these important things with them.
- Follow up with a telephone call in 1-2 days to clarify and answer any questions.

Public Confusion

Financial concerns regarding hospice and palliative care services can be confusing to the public. With the ever-growing number of uninsured people in this country and an ever-growing Social Security generation, money or lack of money is an important issue. In 1983, hospice care for terminally ill patients became a benefit under Medicare Part A (Part A is the hospital insurance) and thus is available to all Americans over the age of 65. The benefit was introduced as a concept of managed care. A daily per diem cost is billed to Medicare. From this payment, all hospice care such as professional nursing and home health aide services, social work, chaplain, grief counseling, and volunteer services are covered, as well as medications and home health care supplies.

Private insurances may have a hospice component in their plans. Some private insurance companies have followed the lead of Medicare and have adopted a per diem fee. Others provide a fixed rate for all care given, while others may have no hospice component. A social worker or departmental financial analyst can help nurses and patients understand what their health care plans offer.

Admission criteria has been a barrier for some health care providers and patients and their families. Medicare criteria include (a) the patient is certified as terminally ill and desires palliative care aimed at symptom management versus cure, (b) the individual agrees to hospice care, and (c) the individual’s attending physician or the hospice’s medical director agree that the patient’s medical prognosis suggests a life expectancy of 6 months or less. The 6-month life expectancy remains a significant barrier to admissions and acceptance of the hospice concept. Various EOL organizations are working at the national level to change this 6-month expectancy criteria.

How to Begin the Discussion

Fast forward to today. Mr. K, an 83-year-old patient with prostate cancer, is seen in your clinic with new areas of pain. He rates his pain as a 7 out of 10. His wife states that he has had a 10 pound weight loss over the last 2 weeks. The patient confirms this by saying, “Nothing tastes good anymore. I am so tired that I don’t even have the energy to eat. What am I going to do?” A bone scan confirms widespread metastases to the ribs, sternum, and pelvis. Other co-morbid diseases include diabetes and congestive heart failure, both controlled fairly well by medications. His wife expresses concern that she is tired and near exhaustion.

How would you handle this patient? Many nurses might be hard pressed to enter into a discussion on EOL issues. We have many excuses: the clinic is too busy, we need the room, I don’t want to make the patient give up hope of cure, or it’s the doctor’s job. But how can we overcome our own inexperience or lack of comfort to provide the patient with information and answer his questions? Begin by taking small steps to increase your knowledge and comfort level. Perhaps you can observe while a more experienced staff member sees a patient during a clinic visit. Take advantage of the many educational opportunities in the literature. In an attempt to reach nurses, the American Journal of Nursing has published a series of 11 articles on EOL care, which offer continuing education for nurses (see Table 1). The articles were supported by a grant from the Robert Wood Johnson Foundation. The series editors, Dr. Betty Ferrell and Nessa Coyle, hope that this series will expand nurses’ knowledge of EOL care and can then be used to start the discussion on EOL care.
Attend EOL inservice or continuing education classes at conferences. Ask yourself, have you even discussed your own wishes with your family? Do you have an Advanced Directive or Living Will? Finally, consider incorporating some key phrases or points to help you begin the discussion (see Table 2). However you begin, it is important that you take the first step.

Message for Today

In today’s health care environment, the lines between palliative care and end-of-life care have become blurred. While we can debate the fine points, what needs to be discussed is the lack of talk about EOL issues between health care providers and their patients and families. Many nurses tell me that they are uncomfortable talking about death; they feel it is a physician’s responsibility or they don’t have the knowledge to talk to patients and family members about this sensitive subject. Physicians often share the same comments. They add that they don’t want their patients to “give up hope.” Physicians have been trained in the curative mode while the nursing model is that of the caring mode. We need to begin the dialogue in earnest about declining health, supportive care rather than curative intent, and EOL care issues. Nurses are in a pivotal position to begin that dialogue.

Another Story, Different Ending

On a busy clinic day, the nurse was paged to the front desk of the cancer center. A former patient’s wife needed to talk to her. When the nurse saw her face, she immediately remembered the couple — one of those special couples you’re always happy to see, the kind where you both tried to catch up with each other’s lives. The woman’s husband had been followed for
metastatic prostate cancer and had failed all therapies despite aggressive treatment. Both patient and wife sadly accepted the news and decided to have his care managed at home because of the long travel distance to the university. Mrs. C looked at the nurse and said she needed help. She knew that her husband’s time was limited and she wanted advice. She asked “What will it be like, how will I know?” The nurse put her arm around Mrs. C’s shoulder and walked to a private space where they could talk. The nurse explained the journey that her husband was about to take. She navigated Mrs. C down the road and talked about symptom control, pain, nausea and vomiting, anorexia, and respiratory issues (see Table 3).

Keeping eye contact, the nurse explained to Mrs. C how to identify the final days of her husband’s life: decreased appetite, decreased activity, decreased responsiveness to others, signs of organ shutdown (see Table 4). Mrs. C wrote a few things down. The nurse gave her the appropriate booklets from the clinic, and they talked about the local hospice. The nurse said her goodbyes, both to Mrs. C and to her husband even though he wasn’t there. They hugged and cried.

Months later, the nurse received a page to come to the front desk; a former patient’s wife needed to talk to her. It was Mrs. C. She gave the nurse a big hug and asked, “How did you know? How did you know it would happen that way?” Her husband had gone down the road as the nurse had described. Mrs. C said she had felt prepared and felt okay because she knew what to expect and anticipate. The nurse had made the journey less bumpy. Mr. C died a peaceful death in his home with family present. It was a good thing. Being there in body or spirit is what counts at the end of life. While the nurse was not physically present at Mr. C’s death, she helped him by her presence.

Perhaps we can all find a urology patient or two that we can talk to about the EOL. These discussions should be a part of our everyday clinical practice. The patients you interact with might not be ready to die next week or next month, but perhaps by starting the dialogue, we can help them, and their loved ones feel as ready as possible.

I encourage you, as readers and as health professionals, to explore articles, find continuing education programs, and learn more about specific issues of end-of-life care that are interesting and meaningful to you. Helping patients achieve as good and meaningful death as possible is part of our role as health care providers. We owe this to our patients. We need to be present.

References