

## The Nurse Advocate in End-of-Life Care

Kathy Hebert, RN, BSN,\* Harold Moore, RN, JD,<sup>†</sup> Joan Rooney, RN, MSN, IBCLC<sup>‡</sup>

\*Infection Control and Safety, Ochsner St. Anne General Hospital, Raceland, LA

<sup>†</sup>Intensive Care Unit, Ochsner Medical Center–Kenner, Kenner, LA

<sup>‡</sup>Women's & Primary Care, Ochsner Medical Center–West Bank, Gretna, LA

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### ABSTRACT

End-of-life nursing encompasses many aspects of care: pain and symptom management, culturally sensitive practices, assisting patients and their families through the death and dying process, and ethical decisionmaking. Advocacy has been identified as a key core competency for the professional nurse, yet the literature reveals relevant barriers to acquiring this skill. Challenges exist, such as limitations in nursing school curricula on the death and dying process, particularly in multicultural settings; differing policies and practices in healthcare systems; and various interpretations of end-of-life legal language. Patricia Benner's conceptual model of advocacy behaviors in end-of-life nursing provides the framework in which nurses can become effective patient advocates. Developing active listening and effective communication skills can enhance the nurse-patient trust relationship and create a healing environment.

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### INTRODUCTION

In the United States in the 20th century, with advances in medical technology and science, the care of the dying patient shifted from family and community to health professionals. Throughout history, nurses have sought ways to improve quality of life for individuals, families, and communities during every phase of life's journey. Advocacy is a common thread of quality end-of-life (EOL) nursing care, encompassing pain and symptom management, ethical decision-

making, competent culturally sensitive care, and assistance through the death and dying process. The foundation of advocacy is the nurse-patient relationship. Advocacy has 2 parts: information and support. The nurse experiences the patient as uniquely human, with individual strengths and beliefs, and uses this understanding to intervene on the patient's behalf. Patients exhibit the following traits when in need of advocacy: powerlessness, helplessness, dependency, vulnerability, inability to speak, and loss of self-control. Trigger situations, including illness, hospitalization, or change in diagnosis, require decisionmaking and action; thus, the act of advocacy begins. The nurse's ability to represent the patient and communicate on the patient's behalf is a core behavior at the EOL.<sup>1</sup>

Physicians remain the gatekeepers of information and are usually the ones to break bad news to patients, such as the diagnosis of a terminal condition. However, physicians may be hurried and not always sensitive to the needs of patients and their families. If the physician has not engaged with the patient, the relationship is technical rather than personal. Alternatively, nurses as advocates take on the role of communicator and translator of information and feelings. They explain what the doctor said during the consultation in a different way or help the patient understand his or her feelings in the situation. When making a decision relating to care, the physician and nurse must seek out other disciplines involved in the patient's care to create a holistic atmosphere of care, openness, and compassion. Nurses' accountability in their translation role is in contrast to doctors' accountability for delivering accurate information that patients and their families clearly understand. When a nurse engages with a terminally ill patient and family, the ultimate aim is to work with the patient to obtain the best possible care. Currently, no professional or ethical guidelines include the extended role of the nurse in this special area.<sup>2</sup>

Studies have found that nurses can articulate the benefits of advance directives; however, nurses generally lack the knowledge and training to conduct such discussions.<sup>3</sup> We need to develop programs to encourage clinicians and healthcare systems to conduct regular advance care planning to ensure

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Address correspondence to

Joan Rooney, MSN, RN, IBCLC

Assistant Vice President of Women's & Primary Care

Ochsner Medical Center–West Bank

2500 Belle Chasse Highway

Gretna, LA 70056

Tel: (504) 391-5220

Fax: (504) 391-5050

Email: jrooney@ochsner.org

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patients and families understand their options for EOL care. Only then can we make progress in achieving the right intensity for each individual patient at the EOL. Providing EOL care that is appropriate, compassionate, and in accordance with the patient's wishes is an essential component of the nurse's role, but nurses could be more effective in working with patients. Nurses must be willing and able to begin the difficult dialogue with patients and their loved ones, assist them in understanding their disease state, and explore specific recommendations for care based on their personal values.

## WHY NURSES?

Research conducted by the Agency for Healthcare Research and Quality (AHRQ) indicates that most patients have not participated in advance care planning, yet many are willing to discuss EOL care.<sup>4</sup> In 1991, Congress passed the Patient Self-Determination Act, requiring hospitals and healthcare facilities that receive Medicare/Medicaid funding to provide information about advance directives (living wills, durable power of attorney for healthcare, Five Wishes) to adult patients on admission. Traditionally, the physician has the responsibility for discussing advance directives with patients and families. Yet, according to AHRQ, less than 50% of severely or terminally ill patients studied had an advance directive in their medical record, and only 12% of patients with an advance directive had received input from their physician in its development. For patients with advance directives, their surrogates often were not present to make decisions or were too emotionally overwrought to offer guidance.<sup>4</sup>

In these instances, patients must rely on their physicians and other trusted health professionals for guidance. Nursing professionals are essential to supporting EOL care decisions and advocating for patients and families across all healthcare settings because they spend more time with patients who are facing death than any other member of the healthcare team and are the most trusted professionals.<sup>5</sup>

Patients have a number of misconceptions about advance directives. As nurses, we have personally witnessed both patients and families falsely assume that the patient's condition is grave or worsening when the phrase *living will* is uttered. Another common misconception is that the term *living will* refers to a document dividing the assets of a deceased person among heirs. Furthermore, contrary to popular belief, a general power of attorney does not automatically confer healthcare decision-making capacity upon the agent(s) unless the document specifies that the agent(s) is authorized to make healthcare decisions for the patient. Nurses, as patient advocates, must

change these attitudes and misconceptions. Studies support the need for nurses to assume this role.<sup>6</sup>

## BARRIERS TO NURSING ADVOCACY

A comparative analysis conducted in 3 mid-Atlantic regional hospitals revealed acute care nurses' perceptions of advocacy behaviors in EOL nursing practice and offered insight into supports and barriers that nurses at various skill levels experience.<sup>1</sup> The 3 most frequently identified barriers were the physician, the patient's family, and fear. Novice nurses reported that lack of communication and lack of time/support are barriers to their practice of advocacy. Today's nurse also faces barriers with differing policies and practices in healthcare systems and professional relationships with multidisciplinary caregivers. On the other hand, EOL nursing education and advocacy education positively influenced nurses' perceived advocacy behaviors.

## Education

From an educational standpoint, the literature includes little description of how nurses learn these advocacy behaviors. Although most nursing schools include a core curriculum on death and dying, information is limited to a brief lecture, case study, or assigned readings. Also, current nursing texts lack information on EOL care. Consequently, educational deficiencies in nursing care of the dying exist. Nurses rated the lack of nursing education in EOL care as an obstacle.<sup>1</sup> When asked how well their basic nursing education prepared them for providing EOL care, 71% rated pain management education as inadequate, 62% rated overall content of EOL care as inadequate, and 59% rated management of other symptoms as inadequate. Because of these deficiencies, EOL dilemmas and barriers to providing high quality EOL care are common in nursing practice.

## Grieving Process

Another problem is the failure of nurses to recognize the stages of grief during EOL decision discussions. Dr Elisabeth Kübler-Ross first introduced the Kübler-Ross model, commonly known as the 5 stages of grief, in her 1969 book, *On Death and Dying*.<sup>7</sup> In her book, Kübler-Ross described the stages but emphasized that not everyone feels all 5 nor will everyone experience them in order. The stages, popularly known by the acronym DABDA,<sup>8</sup> include

- **Denial:** "I feel fine"; "There must be some mistake." Denial is usually only a temporary defense for the individual.
- **Anger:** "Why me? It's not fair!" Once individuals reach the anger stage, they recognize that they can

no longer continue in denial. During this stage, the individual is often very difficult to care for because of misplaced feelings of resentment and jealousy.

- **Bargaining:** “If only... then I’ll...” In the bargaining stage, the individual searches for a way to postpone the inevitable: death. The usual form of the dialogue is to bargain for extended life in exchange for a reformed lifestyle.
- **Depression:** “What’s the use, I’m going to die anyway.” During this fourth stage, the dying individual begins to understand the certainty of death and may refuse treatments/medications and visitors. Some individuals become silent and/or cry all the time. Because the depression stage enables the person to disconnect from people and objects of love and affection, attempts to cheer up the individual during this time are not recommended.
- **Acceptance:** “It’s going to be OK. I’m prepared to die.” During this last stage, the individual begins to come to terms with his or her mortality or that of loved ones. However, not all individuals reach this stage. Some continue to struggle with death until the very end.

Some individuals will entirely miss some of the stages, some may see-saw back and forth between stages, and some may get stuck in one of the stages. Kübler-Ross states that a person will always experience at least 2 stages.<sup>8</sup> The grief process is highly personal, and the person experiencing EOL, the family, or the healthcare professional should not try to rush or lengthen it. By understanding the stages of grief, the nurse can play a more effective role as a patient advocate.

### Cultural Competency

According to the *American Family Physician*,<sup>9</sup> ethnic minorities currently compose approximately one-third of the US population. In the 2000 census, about 65% identified themselves as white, with the remaining percentages representing the following ethnic groups: African American (13%), Hispanic (13%), Asian-Pacific Islander (4.5%), and American-Indian/Alaskan native (1.5%).

Family physicians are challenged to learn how cultural factors influence patients’ responses to medical issues, as well as the physician-patient relationship. Cultural proficiency guidelines do exist; however, few resources are available regarding ways to apply these guidelines to direct patient care. Many physicians are unfamiliar with common cultural variations regarding physician-patient communication, medical decisionmaking, and attitudes about formal documents such as code status guidelines and advance directives.<sup>9</sup>

The challenge of respecting cultural diversity is great. The cultural values and beliefs that inform

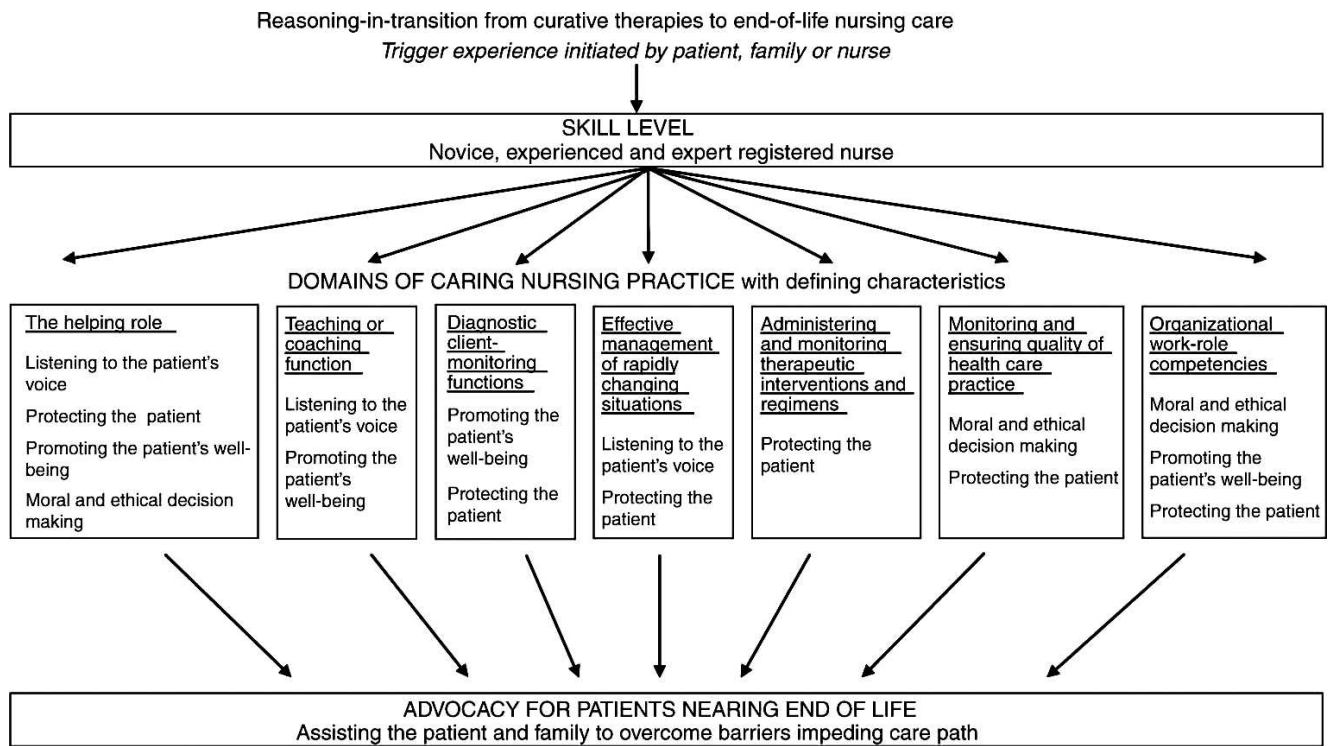
bioethics practices in many American hospitals are white, middle class, and based on Western philosophical and legal traditions that emphasize the individual and individual decisionmaking. We must bear in mind that many other cultures do not share these traditions. For example, in many Asian cultures, directly informing a patient of a cancer diagnosis is perceived as unnecessarily cruel. In Hispanic, Chinese, and Pakistani communities, family members actively protect terminally ill patients from knowledge of their condition. African Americans have more negative attitudes toward hospice and differ considerably from European-Americans regarding advance directives. Surveys have documented the disparities between bioethics innovations and minority populations in the United States. Substantially more African Americans and Hispanics wanted their physicians to keep them alive regardless of how ill they were compared to European-Americans, who agreed that under certain circumstances life-prolonging treatment should be discontinued.<sup>10</sup>

The disparities surrounding cultural beliefs during EOL preparation and following death are as numerous as the cultures themselves. Even among peoples identified externally as a single group, differences exist. For example, Hispanics in America represent a wide variety of backgrounds, including South American, Central American, Cuban, and Puerto Rican. Their cultural differences are distinguishable, and the people are proud of their unique heritages. Because no single Hispanic culture exists, practices related to grief can vary.<sup>11</sup>

Nurses and physicians alike must increase their awareness of cultural disparities and their impact on EOL issues, including the grieving process. As patient advocates, nurses must ensure that patients and families of all ethnicities experience death with dignity. But first, we must be educated about the grieving process and how cultural differences affect that process. Our duty is then to communicate the dying individual’s beliefs to the physician(s) caring for that individual. Communication between physician and nurse is the key to successful advocacy. Cultural sensitivity training should be incorporated into annual nursing and physician competencies.

### WHAT TO DO?

In the figure, Thacker presents Patricia Benner’s<sup>1</sup> framework to help nurses become effective patient advocates. Novice nurses rely on rules, policies, and concrete principles, but experts have developed an intuitive thought process. Benner’s 7 domains of caring practiced in the nurse’s professional career are helper, teacher, promoter of patients’ well-being, manager of rapid changes, protector of the patient,



**Figure. Conceptual model of advocacy behaviors in end-of-life nursing care.** (Reprinted with permission from Thacker K. Nurses' advocacy behaviors in end-of-life nursing care. *Nurs Ethics*. 2008;15(2):174-185.)

moral and ethical decisionmaker, and organizer of care. Two very important learned skills are active listening to the patient and family and then effective communication of their feelings with the rest of the healthcare team. Communication includes documentation in the nursing care plan and medical record and verbal discussion during shift handoffs and multidisciplinary team rounds. To remedy the lack of knowledge and proficiency in conducting advance directive dialogues, nursing school curricula must include this basic knowledge given the paucity of advance directives content in textbooks and curricula.

A more immediate effect can come from educating about and promoting within our nursing staff the use of the Five Wishes document.<sup>12</sup> This document is available at all Ochsner facilities through the website, from pastoral care representatives, and from Ochsner nursing staff. "Five Wishes helps you express how you want to be treated if you are seriously ill and unable to speak for yourself. It deals with all of a person's needs: medical, personal, emotional, and spiritual," according to the creators and purveyors of this document. The document, when fully completed, designates a healthcare power of attorney, a living will, and a desired comfort level and includes 2

sections addressing personal and emotional preferences as death approaches and passes.

The need for better understanding of EOL care has never been greater than in today's healthcare climate. Providing compassionate EOL care that is appropriate and in accordance with the patient's wishes is an essential component of nursing care. It is our ethical responsibility as caregivers to have active discussions with patients and family members and to consider race, culture, and their basic understanding and knowledge of advance directives. The power of advocacy removes barriers to achieve the patient's desired outcomes at the EOL.

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