PALLIATIVE AND END-OF-LIFE CARE IN THE EMERGENCY DEPARTMENT: GUIDELINES FOR NURSES

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An ambulance arrives at the emergency department with an unconscious, unresponsive 40-year-old man. After intubation and stabilization, an intracranial hemorrhage with a brain shift is found on a computed tomography scan of the head. The family, arriving shortly after the computed tomography scan is performed, states that the patient fell in the bathroom. They report that he has a history of end-stage multiple myeloma with metastasis, which he manages with daily doses of methadone for pain.

The family is presented with the option of surgical intervention with the high risk of death as a result of hemorrhage or to provide comfort measures for the patient and allow death to occur. The family chooses to proceed with the surgery. Thirty-six hours later, in the intensive care unit, the patient dies without clinical improvement.

The goals of emergency care are to “preserve life, restore health, relieve suffering, limit disability, and reverse clinical death.” Emergency nurses who provide that care have a complex, multidimensional role that includes the “provision of care that ranges from birth, death, injury prevention, women’s health, disease, and life and limb saving measures.” While emergency departments frequently are characterized as fast-paced, heroic environments, many patients present in the emergency department with chronic end-stage diseases, terminal illnesses, and other physiologic issues that are incompatible with life. These patients do not require resuscitation or life-saving procedures but would benefit more from palliative and end-of-life (EOL) care.

Palliative care is defined as care that “affirms life and regards dying as a normal process; intends to neither hasten or postpone death; uses a team approach to address the needs of patients and their families.” It includes “[providing] relief from pain and other distressing symptoms; [integrating] psychological and spiritual aspects of patient care; [enhancing] quality of life; [and] helping the family and patient to cope during illness and after death.” The term “end-of-life” is reserved for the care delivered during the last few weeks of life and, in the ED setting, the time directly preceding death. Care of these patients has become the direct responsibility of the emergency nurse.

Review of Literature

Data gathered from the Study to Understand Prognoses and Preferences in Outcomes and Risks of Treatment (SUPPORT), the largest study of the dying process in the United States, has highlighted the need for palliative and EOL care guidelines, standards, and research initiatives. Despite the emergency department’s reputation for providing life and limb saving care, some efforts prove unsuccessful or are too late, and in these cases, patients are in need of palliative and EOL care. According to the Centers for Disease Control and Prevention and the U.S. Department of Health and Human Services, approximately 249,000 deaths occurred en route or in U.S. emergency departments in 2006. Emergency departments, commonly characterized as fast-paced, life-saving, heroic environments, clearly also are becoming settings for individuals to receive palliative and EOL care.

In 1997, the International Council of Nurses mandated that helping provide a peaceful death is a primary responsibility of the nurse when caring for a patient at the end of life. Additionally, it is the position of ENA that patients at the end of their life, along with their families,
deserve care that respects their dignity and honors their right to refuse treatment. What is unique to the challenge of the emergency nurse is that death presents itself in various ways: the child who is a victim of a drowning, the adolescent who is a victim of a gunshot wound, the adult with a myocardial infarction who undergoes unsuccessful cardiopulmonary resuscitation, and the geriatric patient with end-stage cancer. While end of life is common to all these situations, nursing interventions vary greatly from one person to the other. Thus, in addition to the already required Basic and Advanced Cardiac Life Support training, emergency nurses also would benefit from EOL care education.

A major step in the improvement of EOL care was the collaboration of the American Association of Colleges of Nursing and the City of Hope Pain and Palliative Care Resource Center, which, in 1999, resulted in the creation of the End of Life Nurse Education Consortium. This curriculum has 9 modules: nursing care at the end of life, pain management, symptom management, ethical and legal issues, cultural considerations, communication, bereavement, preparation and care at the time of death, and achieving quality care. Additionally, the American Association of Colleges of Nursing, in partnership with the Robert Woods Johnson Foundation, developed palliative and EOL care nursing competencies to integrate into nursing education curricula, stating that “education preparation for the end-of-life care has been inconsistent at best, and sometimes neglected within nursing curricula.” In 2004, the National Consensus Project for Quality Palliative Care (NCP), in conjunction with multiple palliative care organizations, released the Clinical Practice Guidelines for Quality Palliative Care. The NCP recognized 8 focus areas to build a framework for palliative care: structure, physical needs, psychological needs, social needs, spiritual and religious care, cultural considerations, caring for the dying patient, and ethical and legal features of care. Although the End of Life Nurse Education Consortium Curriculum and NCP guidelines share the focus of providing quality palliative care throughout specific groups of nurses, clarification is needed on applying the recommendations and practices to unique and specific disciplines like the emergency department.

Patients who present to the emergency department and require palliative and EOL care can place both challenging and unique expectations on the nurses providing their care, requiring in many circumstances care and comfort measures in place of heroic and life-sustaining procedures. According to Savoy and Marco, “the chaotic and fast-paced setting is not always conducive to end-of-life planning, communication and ensuring patient comfort. Special skills and attention may be required to overcome these obstacles to ensure the most favorable conditions for a patient near the end-of-life.” Thus, providing adequate and successful palliative care often proves difficult in the emergency department, particularly for nurses. Emergency nurses, however, are in a “unique position to provide a patient’s family with an opportunity to begin the process of grieving by answering their questions, allowing them to express grief, and facilitating the process of saying ‘good-bye’ by initiating appropriate interventions while the patient is still in the hospital.”

Moral and ethical issues also may arise in part because of the conflict between respecting patient autonomy and acting in the patient’s best interest. In addition, instances occur in which a patient’s wishes conflict with the desires of his or her family, or the patient’s wishes are unknown upon arrival and later the team is informed that the patient’s wishes differ from the provided treatment. Some patients arrive in the emergency department unaware of their diagnosis or prognosis. Also, it sometimes can be difficult to assess whether a patient is capable of making decisions. For these and other reasons, moral distress as a result of prolonged life support measures, inadequate pain relief, and poor communication with the patient and family can be a significant stressor for the emergency nurse.

Communication is of key importance in the issue of EOL care in the emergency department. According to research, families consistently identify 5 needs when accompanying critically ill family members in the emergency department: assurance, proximity, communication, support, and comfort. In a study by Heaston and colleagues, communication was seen as a supportive behavior and included good communication between the emergency physician and the emergency nurse and the emergency physician and the family, along with having the family designate a spokesperson. Obstacles to good communication include a heavy nursing workload, some family behaviors (eg, when they are angry and distraught), and disagreement among the family regarding the patient’s EOL wishes despite the fact that the patient already has an advance directive in place.

EOL care requires a great deal of collaboration and communication between the patient, his or her family, and other parties, which becomes extremely difficult in the emergency department given the time constraints. Some patients have seen many doctors and specialists, but no one person can provide the whole picture and help with the decision-making process. Such cases are challenging and time-consuming and require many decisions to be made in a hectic ED environment. Therefore, it is necessary that emergency nurses and ED staff be provided with training and education regarding policies to support...
EOL care in a culturally competent way. In the end, the emergency department will always be a resource for patients, and with the increasing demand of EOL care, "the challenge is to create the knowledge base, communication systems, physical support, and staffing within the environment so that we can provide excellent care for EOL patients."20

Emergency Palliative Care Guidelines

DEALING WITH SUDDEN AND UNEXPECTED DEATHS IN THE EMERGENCY DEPARTMENT

Death is never an easy concept to deal with or understand. However, sudden and unexpected death is even more difficult to comprehend and is perceived as traumatic and unjust. Whether because of sudden cardiac arrest, trauma, or any other process that adversely affects the otherwise healthy patient, sudden death is a common occurrence in the emergency department. Families and friends go through a difficult grief process in which they experience a multitude of emotions. After the sudden loss of a loved one, it is common to go through a cycle of emotions that encompass the grief process. Common grief responses include "shock, denial, disbelief, anger and guilt" and reactions may include "crying, shouting, screaming...bizarre behavior...[and] quiet acceptance."21 Families of deceased loved ones look to medical staff for answers and comfort and will recall these initial interactions months later.21 Emergency nurses are in a unique position to positively affect these families and aid them as they experience their grief.

Studies have shown that appropriate and timely action on the part of the health care provider can have a significant impact on the survivors. Yet many ED employees report little to no training on dealing with sudden and unexpected loss and how to help the survivors of the deceased. Therefore, it is suggested that emergency departments formulate a program that trains and educates staff members on sudden, unexpected death, grief responses, and how to aid families during this devastating time in a caring and compassionate way.22 As with caring for palliative and EOL patients, emergency nurses also may experience difficulties that prevent them from providing the proper therapy necessary for quality care. These difficulties may include high volumes of patients as well as creating a private, supportive, and comfortable environment in which to initiate the grieving process. As a result, it is essential that programs and protocols be created to assist ED nurses and other staff as they strive to properly care for families and friends who are experiencing unexpected loss.

FAMILY-WITNESSED RESUSCITATION

Family-witnessed resuscitation (FWR), defined as the presence of family during the resuscitation of a loved one, is a concept first explored in the United States during the mid-1980s. Since 1994, ENA has supported FWR.23 Despite this support, much controversy still exists around FWR in the emergency department.

Opponents of FWR state that witnessing a loved one being resuscitated may be too traumatic for the family and detrimental to the grieving process.24-26 Another argument is that FWR may be distracting to the health care team, either because it makes them nervous (which many persons described as "being on stage") or because a family’s reaction may interfere with care, such as when a family member faints or becomes hysterical.24,26 Opponents of FWR also have brought up the concerns of increased possibility for lawsuits and the breaching of patient confidentiality.24-26

Studies, however, have shown that FWR facilitates the grieving process by allowing the family to see that everything was done to try to save their loved one.24-26 FWR also provides a sense of closure, allowing families to see and touch their loved one, thus making the death real. FWR erases any mystery of what had happened and improves staff-family communication, which also decreases the risk of liability.24 One nurse stated, “I find that what families actually see is invariably better than their fantasies” (p. 314).24 Because resuscitation in the emergency department tends to be related to sudden causes, FWR also helps families realize the severity of the situation, helping them come to terms with the end result.

In a study by Critchell and Marik,24 ED patients who had and had not experienced resuscitation were interviewed, and it was found that most patients in both groups would prefer family presence during their resuscitation.24 The patients identified family as a sense of support who also could act as advocates for the patient. While the patients expressed a wish for family presence during resuscitation, they also identified limitations. The patients expressed a need for their family to be prepared for what they might witness, screened for the most appropriate member to be present, have a clinical support person there to care for the family, and to ultimately have FWR be the family’s decision. The patients also stated that they would not want the family to interfere, because ultimately they would want the professionals’ full attention focused on saving them. They were not concerned about patient confidentiality as long as the information was given in a sensitive manner. Patients trusted health care providers’ judgment on what information was necessary to share with the family to assist in the decision-making process.
Thus, key to FWR implementation are practice guidelines, availability of a family support clinician, and staff discussion about reservations. While some studies have identified nurses as the ideal support person, having a nurse in this role is not always feasible because of staffing issues and patient loads. In choosing an appropriate family support person, the most important factors are that the person has a working knowledge of what to expect, has the ability to explain the resuscitation efforts to the family, and knows how to support the family and intervene when necessary. Thus hospital social workers and chaplains are other good options for filling this role. For this reason, FWR is an interdisciplinary effort.

CULTURAL AND SPIRITUAL CONSIDERATIONS

Emergency nurses can implement several interventions to facilitate a peaceful and dignified death when caring for patient at the end of life. Providing culturally sensitive care regarding pain and other symptoms seen at the end of life such as dyspnea, fatigue, incontinence, and mental confusion should be a primary goal, because these symptoms cause both suffering and distress. It has been demonstrated that providing information about the patient’s condition and implementing interventions directly aimed at comfort measures helps to promote safety and decrease anxiety for the patient and family. Aggressive comfort treatment includes care of the patient’s emotional, social, and physical needs; family education about the dying process; facilitation of anticipatory grieving and bereavement after death; awareness of the ethical issues surrounding EOL care; and observances of individual cultural practices.

At the core of palliative and EOL care is a humanistic and holistic perspective that realizes the core human right of individual dignity. According to Conner in Hospice and Palliative Care: The Essential Guide (2nd ed.), humanistic care is meeting the patient where he or she is in the disease process and supporting him or her unconditionally. By doing this, providers respect an individual’s autonomy. Holistic care is caring for the physical, psychological, social, and spiritual aspects of a person, recognizing that health of a whole person is composed of these individual aspects of a person. Thus palliative and EOL care focuses on respecting and supporting the entire individual.

Key to caring for the whole person is understanding the person’s cultural and spiritual background. Cultural competency recently has been introduced to nursing and medical education as a means of addressing health care disparities. More important than cultural competency, however, is cultural humility, an idea first presented by Tervalon and Murray-Garcia. According to these authors, cultural competence implies the “static notion” of mastery, something that can be measured by a test. Cultural humility, however, encourages “self-reflection and self-critique as lifelong learners and reflective practitioners” (p.118). This idea of cultural humility is more practical in a busy ED setting. The idea of cultural humility does not assume knowledge about a culture and recognizes that many differences exist within an individual culture. Thus it may be nearly impossible for a single provider to learn the intricacies of every culture. As long as a provider is willing to acknowledge what he or she does not know and be open to trying to best accommodate a patient’s or family’s cultural needs, a provider can provide culturally sensitive care.

Many persons believe that a chaplain is required to address a patient’s or family’s spiritual needs. In the Oxford Textbook of Palliative Medicine, Cassidy and Davies make note of the fact that “pastoral care” can be provided by anyone willing to be present with a patient in a time of need, because “pastoral care expresses the concern human beings show at the illness or distress of other” (p. 951). This notion of pastoral care does not require special religious training but only one’s own willingness to be present in another person’s time of need. For example, a patient or family may need to pray and ask the nurse to pray with them. Although the nurse may not share the patient’s or family’s religious beliefs, meeting their spiritual need is not about what the nurse believes but about bearing witness to the patient’s and family’s situation and being present to them. This knowledge of spiritual care can be most useful in a busy emergency department, where staffing can be tight and all hospital personnel and community resources may not be readily available.

INSTITUTIONAL CHANGES

Since 1997, the Joint Commission on Accreditation of Healthcare Organizations has endorsed a consistent set of “Core Principles for End of Life Care.” These principles can be adopted as stated or with modifications. They include but are not limited to respecting the dignity of both patient and caregivers, being sensitive to family and patient wishes, allowing the patient to choose, alleviating pain and other physical symptoms, and managing psychological, social, and spiritual choices. Within the institution, nurses should advocate for the development of EOL protocols as well as for an ethics committee. This committee should be available at all times to recommend a decision-making model in difficult situations. Other recommendations include decreasing the nurse-to-patient ratio to 1:1 or 1:2 whenever possible. Such a measure will enhance the emergency nurse’s ability to care for a complicated, time-consuming case. It also will allow the time necessary to address the multiple needs of the patient and family and
will aid in decreasing the stress level of the emergency nurse. Institutions also should consider the use of “Allow Natural Death” as a replacement for “Do Not Resuscitate.” “Allow Natural Death” reflects the EOL philosophy of providing comfort rather than cure, is seen as a positive choice, and eases the suffering of both the patient and family.32

In emergency departments dealing with high volumes of EOL patients, the presence of an ED palliative care team would benefit health care workers, families, and patients. Comprising several disciplines (eg, physician, nurse practitioner, nurse, social worker, psychologist, and chaplain), such a team supports ED staff, addresses the needs of the patient and family, manages pain and symptom control, gives support to enhance quality of life until death, aids in bereavement, and enhances communication between the patient, family, and health care team. The palliative care team also offers services to assist the patient and family in identifying personal goals and wishes at the end of life.17 An accessible palliative care team can be a valuable tool in a hectic emergency department.

Conclusion: Caring for the Emergency Nurse

Emergency nurses work in a stressful, fast-paced environment that may lead to frustration, depression, stress, and burnout. Because caring for patients at the end of life adds an additional stress to the job, emergency nurses also must be sure to take care of themselves. Effective debriefing and coping often are difficult in a fast-paced environment. Nurses who work with dying patients often become painfully aware of their own losses, contributing to anxiety regarding personal fears of loss and fears about one’s own death.17 At times, acknowledging emotion and admitting sensitivity is sufficient to allow an emergency nurse some sense of closure. Simple acknowledgment, however, should not replace the process of allowing an emergency nurse the adequate time and resources to debrief and deal with his or her thoughts and feelings regarding death and dying.

REFERENCES


