End-of-life Care
Improving Quality of Life at the End of life

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ABSTRACT
Purpose/Objectives: The purpose of this article is to identify barriers and interventions that influence quality of life at the end of life.
Primary Practice Settings(s): Primary care, acute inpatient care, case management, and end-of-life care settings.
Findings/Conclusion: Death and dying affects the whole family, not just the individual who is dying. Early identification and recognition of end-of-life care choices heavily influence the quality of life an individual experiences during the dying process. Unfortunately, delaying end-of-life care plans is common. Over the years, the social structure and family structure have changed leaving many patients and families searching for viable end-of-life care options. Advancements in technology have affected the way medical professionals approach the end of life making a difficult decision for patients and families even more difficult by offering medical interventions that may not be necessary. To steer end-of-life care toward evidence-based practice standards, there needs to be additional research on the effectiveness of the various types of care available. Because case managers are often on the front lines of communicating and arranging end-of-life care, case managers need a clearer understanding of end-of-life care choices and how to communicate these choices to patients and families. The hospice and palliative care movements have been instrumental in increasing the understanding of end-of-life care and in providing patients alternatives to dying in the hospital.

Implications for Case Management Practice:
• Only 25% of patients eligible for hospice actually enter hospice programs.
• The average time spent in hospice is 3 weeks.
• The most significant barrier in coordinating and providing end-of-life care is inadequate communication.
• Early discussion of prognosis and end-of-life care options helps facilitate earlier entry into hospice and palliative care programs.
• The nursing profession needs additional research to determine the effectiveness of the various types of end-of-life care available and steer end-of-life care toward evidence-based practice standards.

In today’s society, there is an increased interest in end-of-life care. Even with this increased interest, the understanding of end-of-life care is not where it needs to be in society and in the medical community (O’Carrol, 2002). Death and dying affects the whole family, not just the individual who is dying. Early identification and recognition of end-of-life care choices heavily impacts the quality of life an individual experiences during the dying process. Unfortunately, delaying end-of-life care plans is common. Hospice provides care for nearly 25% of those who die with participants spending a meager 3 weeks in hospice care (Casarett, Crowley, & Hirschman, 2004). Questions remain regarding the presentation of hospice to patients and the impact of the presentation on the patient and family’s decision to elect hospice. Physicians often provide initial information regarding hospice but do not usually give adequate information regarding hospice (Casarett et al., 2004). The family and not the patient make many hospice decisions. Many patients and families do not realize the full benefit of hospice until the care begins. The delay is usually a result of unrealistic treatment decisions offered by healthcare providers that create overoptimism in patients and their families, or because of a failure to initiate end-of-life care plans through an advance directive or living will (Casarett et al., 2004). Medicare has attempted to curb the effects of failing to initiate end-of-life care plans by requiring hospitals and physicians receiving payment from government entities to

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provide patients with information on advance directives and the right to accept or refuse treatment (O’Carrol, 2002). Attitudes regarding death differ with experience and belief systems. To improve the quality of life at the end of life, medical professionals need to consider several factors when offering end-of-life care options, namely social and family structure, cultural factors, financial status, pain levels, and life support wishes.

**Social and Family Structure**

Between the years 1980 and 1998, life expectancy rose 2.7 years (Harrison, Ford, & Wilson, 2005). The increasing life expectancy, heavily influenced by advancements in technology, has affected the social structure of society by creating the expectation that individuals will lead a healthy life well into their 80s. The expectation that individuals will live healthy lives into their 80s has prompted the change in retirement age using the assumption that individuals will stay healthy enough to continue to work well into their 60s. This creates a problem for individuals with medical needs who are unable to work into their 60s resulting in a ripple effect on financial needs. Adding to this problem is the change in family structure that has occurred over the years. The change in family structure has created a need to reevaluate end-of-life care options. In the past, families stayed in one central location, providing support to each other in times of need. Now, families are scattered across the United States creating issues with the care of ill family members, end-of-life care options, and end-of-life customs. The lack of family support usually results in placement of the individual in nursing facilities or to acute care facilities to die (Amelia, 2003). By the year 2020, 40% of people over the age of 65 will spend the end of their life in a nursing home compared to approximately 30% today (Forbes-Thompson & Gessert, 2005).

**Culture**

Grief and bereavement begin at the time of diagnosis with a terminal illness. To enhance quality of life at the end of life, nurses and other medical professionals must set aside their own cultural beliefs and seek to understand the patient and family’s beliefs. Culture heavily influences reactions to the dying process namely pain, discomfort, and grief. Common practice is to offer terminally ill patients the opportunity to die at home using the assumption that the patient and family are more comfortable at home. Some cultures do not believe in dying at home, this is important for nurses and physicians to understand. In these particular cultures, if an individual dies in the home, the family either abandons the house or cleanses the house through a ritual ceremony. Other cultures frown on speaking the dying individual’s name. With certain religions, it is important to allow the clergy to anoint the dying individual or perform ritualistic sacraments on the dying individual. Funeral customs range from very private to an extravagant production lasting for days (O’Carroll, 2002). The point is, all humans experience death at one time or another, but that does not mean every human experience it in the same light. Misunderstanding cultural practices can create undue stress during an already difficult time. The increase in stress has a significant impact on the quality of life of the patient and family. As a nurse and a healthcare provider, the most important thing to remember is to avoid making assumptions that all cultural practices are the same, be open to each individual patient’s and family’s needs during the dying process.

**Standards of Care**

**Technology**

Technology advancements have resulted in individuals living longer. Advancements in technology have also created an environment of unrealistic expectations and overoptimism resulting in continued medical interventions that do not promote quality of life at the end of life (Nelson, 2006). Aggressive treatment made available by improvements in technology may be costly and unnecessary at the end of life. Although research shows that some of these costs are unavoidable, the cost of dying in the hospital is significantly higher than the cost of dying in a nursing facility or in a hospice setting (Liu, Korbin, Weiner, & Niefeld, 2006). Ultimately, the goal at the end of life should be...
to promote comfort and decrease suffering by offering the patient and family care that meets all comfort needs. This is accomplished by maintaining open communication, reducing unnecessary treatments and interventions, and offering realistic options regarding end-of-life choices and care (Engleberg, 2006).

End of Life and the Intensive Care Unit

For various reasons, many patients die in the ICU, but on the other hand, many patients are saved in the ICU. In the critical care setting, the goal is to extend life. Critical care nurses and physicians are trained to save patients. This becomes a problem when the patient is terminally ill and the goal should be to provide comfort and quality of life. The ICU staff faces many challenges when caring for patients at the end of life, especially when the patient is on life support. Nurses and physicians need to be more realistic in their approach to patients on life support. This can be accomplished only with an increased awareness and improved training and resources to care for patients at the end of life (Cook, Rocker, Giacomini, Sinuf, & Heyland, 2006). Although there is still much work to be done in getting patients appropriate care at the end of life, the hospice and palliative movement has increased awareness of the problem by implementing more than 1,000 inpatient palliative care programs and placing more than 1 million patients in hospice. This movement has changed the perception of hospice and strengthened the end-of-life experience by improving emotional support for individuals in the hospital (Byock, 2006).

Communication

Physicians have a primary obligation to ensure that the best interests of the patients are considered; however, in the age of managed care, physicians are also charged with the responsibility of ensuring that the patient is receiving the appropriate care at the appropriate level (Minogue, 2000). Nurses, namely case managers, play a critical role in discussing patient prognosis and options as it relates to hospice care (Fine, 2005). Even though the time nurses have to spend with patients has declined over recent years, case managers interact and have more opportunity than physicians to interact with patients. Discussions with the patient and family soon after the rendering of a terminal diagnosis help with acceptance and earlier entry into hospice (Turkos, 2000; Schulman-Green, McCorkle, Cherlin, Johnson-Hurzler, & Bradley, 2005).

What Do Nurses Believe?

A nationwide survey of nurses from various backgrounds revealed that most nurses believe that end-of-life care needs to be improved. Many barriers prevent quality end-of-life care such as prolonged death, the nursing shortage, communication challenges, and physician treatment decisions not in the best interest of the patient (Beckstrand, Callister, & Kirchhoff, 2006). A local survey of 49 case managers involved in coordinating or providing end-of-life care provided similar results. Case managers indicated that the most significant barrier to providing quality end-of-life care is inadequate communication. Other barriers identified include family denial of death, unrealistic expectations, patient denial of death, lack of family participation, and uncertainty of the diagnosis or prognosis. Case managers identified pain management, communication, compassionate care, and timing and frequency of discussions with the patient and family as most important to maintaining quality of life at the end-of-life.

End-of-Life Care Choices

According to Drenning (2006), healthcare needs to make changes to shift end-of-life care toward evidence-based practice standards. To steer end-of-life care toward evidence-based practice standards, there needs to be additional research on the effectiveness of the various types of care available. The 18th International Nursing Research Congress is focusing on evidence-based practice, including evidence-based practice standards for end-of-life care (Sigma Theta Tau International, 2007). One strategy to be discussed at the conference is the effectiveness of advance care planning (ACP) in helping patients express and communicate end-of-life care preferences as well as the impact of “personal influences, decision factors, and ACP on the decision to engage in ACP” (Vander Lann, 2007, para 1). Case managers (nurses need a clearer understanding of the legalities surrounding end-of-life care and advance directives. Time restraints, limited access to nursing literature, and limited computer skills are barriers to increasing the understanding of evidence-based standards. When making end-of-life choices, dying patients consider
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The ability to remain mentally aware, not being a burden on the family, helping others, establishing peace with God, freedom from pain and suffering, and knowing that the family will carry out desired funeral arrangements strongly important (O’Carroll, 2002). Dying at home is least important to many dying patients because they consider dying at home to be overwhelming. With these patients, a skilled environment with medical intervention is a more desirable option. Quality of life at the end of life is achieved through shared decision-making and clear communication. Needless suffering and ignoring the dying patient’s wishes, values, culture, and norms result in what patients and families consider a bad death (O’Carroll, 2002). End-of-life care choices are limited by the availability of benefits or resources to pay for the service, especially for conditions unrelated to cancer. Medicare has stepped in and in an attempt to remedy this problem; Medicare has expanded hospice benefits to diagnoses other than cancer and lifted the 6-month life expectancy restriction (Ferrera-Reid, 2004).

Hospice

Hospice services can be traced back as early as 1879 when the Ireland Sisters of Charity provided care to the dying that focused on comfort, skilled nursing interventions, family counseling, and spiritual needs. Today, the number of individuals hospice provides care for ranges from 25% to 43% (Casarett et al., 2004; Harrison et al., 2005). Over the years, hospice has gained popularity because of the fragmented care patients received after discharge from the hospital (O’Carroll, 2002). In 1983, in an effort to alleviate unnecessary or inappropriate hospital admissions and to provide compassionate care to dying individuals, Medicare and some private insurance carriers began providing coverage for hospice care (Amelia, 2003). An issue that remains is the limited benefit and limited choices in providers offered by private payers. Hospice provides care in the home or in the inpatient setting. Physicians are usually the first to recommend and provide information regarding hospice. Admission to hospice is usually delayed because of a lack of communication, inappropriate presentation of hospice by the physician, or inadequate information given to the patient and family regarding hospice. Many physicians do not give adequate information regarding the purpose and benefit of hospice resulting in a lack of understanding and delayed admission to the program (Casarett et al., 2004). It is important to present hospice as a concept and not a place. Hospice is available in a variety of settings and the service is a means of providing medical, emotional, and spiritual care to the patient and the family at the end of life.

Palliative Care

The Canadian Palliative Care Association defines palliative care as a philosophy of care that provides a combination of active and compassionate therapies intended to comfort and support patients and families who are living with a life-threatening illness, being sensitive and respectful of their religious, cultural, and personal beliefs, values, and traditions. (O’Carroll, 2002, p. xi)

There is a misconception that palliative care is equivalent to hospice care. Although both disciplines focus on providing comfort to patients and families during a serious illness, palliative care is available to anyone regardless of life expectancy. Palliative care is an option even when a patient is receiving curative treatment. Palliative care services are available in hospitals, nursing facilities, clinics, and the home. The goal of palliative care is to provide symptom management and comfort care to patients who do not qualify for hospice services or who are not ready for terminal care provided by hospice. Palliative care bridges the gap between curative treatment and hospice.

Improving Quality of Life

Ensuring optimal quality of life at the end of life begins with the presentation and discussion of the terminal diagnosis. The task of presenting a terminal diagnosis is not easy. The case manager does not have to present the diagnosis to the patient and family, but the case manager does have the primary responsibility of ensuring that the patient understands the implications of the diagnosis and has access to services and benefits to achieve optimal outcomes. To achieve optimal outcomes, which improve the quality of life for the patient and his or her family at the end of life, the case
manager should:

1. Encourage all patients, not just patients facing end-of-life decisions, to have a living will or advanced directive. Have resources and tools available to make it easy to execute these documents.

2. Maintaining open communication with the patient and family to identify needs and answer questions regarding the diagnosis along with the expected outcomes, available treatments, benefits, and alternate care settings. Since families typically play a major role in making end-of-life care decisions, ensure that the family is present for all discussions.

3. Act as a patient advocate by becoming involved at the time of diagnosis and making certain that the entire healthcare team, including payers, understand the patient’s and family’s needs and wishes.

4. Coordinate all care and services, namely the facilitation of early transition into the end-of-life care program that is congruent with the patient’s family structure, religious beliefs, cultural practices, and financial situation.

5. Provide support to the patient and the family throughout the end-of-life care to monitor the effectiveness of pain management and other services.

**CONCLUSION**

Activity has increased to improve the education of nurses and other medical professionals, the quality of care available at the end of life, and the accessibility and affordability of end-of-life care. The hospice and palliative care movements have been monumental in increasing the awareness of end-of-life issues and their importance in maintaining a good quality of life at the end of life. The success of improving end-of-life care is dependent on a collaborative effort of case managers, nurses, physicians, and other members of the medical community. Open communication within the healthcare team and with the dying patient and his or her family is important in setting realistic expectations especially when the prognosis is grim. Failure to recognize and accept a grim prognosis results in reduced quality of life and increased suffering during the last days of a dying individual’s life. The stress of accepting a terminal diagnosis is magnified when nurses do not understand or consider social factors, family structure, and cultural practices when recommending end-of-life care. Because of their direct involvement in educating patients and families regarding end-of-life care options, case managers play a vital role in improving quality of life at the end of life by maintaining and promoting open communication between the patient, the family, and the healthcare team to ensure placement of the patient in the most appropriate setting.

**REFERENCES**


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