

## Quality Palliative Care

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### Abstract

Most people do not like to think about death. However, at some point, we all are going to die. We do not have a choice about whether we die; but we may have a choice about how we die<sup>13</sup>. There are numerous options available regarding end-of-life care. Palliative care is one choice. Palliative care is considered a broad scope of practice focusing on treatment that enhances an individuals' quality of life; when near the end of life.<sup>12</sup> According to current research, approximately five to fifteen percent of the population has advance directives or palliative care measures documented in their medical records<sup>2</sup>. Shockingly, most physicians are not even aware that these palliative care measures exist<sup>3</sup>. This highlights the need for communication between patients, families and their health care professionals. Discussing the controversial issues surrounding end-of-life care, although often a challenge, is a necessity. A review of literature was performed, which incorporated published literature on end-of-life care to address the following research questions: what are the controversial issues hindering the use of palliative care measures and how can nurses contribute to the quality improvement of end-of-life care? This presentation will also address ethical and economical issues of end-of-life care, barriers, implications for practice to improve the quality of end-of-life care and ways to increase the patient's awareness of their right to choose how to die. Research supports that improving the quality of end-of-life care needs to be a national priority. Therefore, end-of-life care must be flexible, contemplative, and responsive to the patient's needs in order to attend to the uncertainty of death and dying. Nurses need to understand the significant issues facing patients nearing the end of their lives to be able to contribute fully to this transformation.

**Keywords: Nursing, Palliative Care, End-of-Life Care**

## 1. Introduction

Discussing issues surrounding end-of-life care is often a challenge; however, it is a necessity. Initiating these discussions originates from effective communication between patients, families, and their health care providers. Approximately five to fifteen percent of the population has advance directives or palliative care measures documented in their medical records<sup>2</sup>. Shockingly, most physicians are not aware that these palliative care measures exist<sup>3</sup>. This is a significant problem in healthcare that needs to be addressed. Addressing this problem provides a way for healthcare providers to be able to improve the quality of end-of-life care and to promote death with dignity.

### 1.1 Review Of Literature

A review of literature was performed to gain a better understanding of the information available related to palliative care. The review of literature incorporated published literature on end-of-life care/issues to address the following

research questions: what are the controversial issues hindering the use of palliative care measures and how can nurses contribute to the quality improvement of end-of-life care?

The researcher found it most appropriate to begin with a basic knowledge of palliative care. Several of the articles were collected via the internet and institutional library database searches. Google was the search engine of choice for the internet searches. The Google searches yielded in the use of information from the following web pages: National Hospice and Palliative Care Organization, Institute for Clinical Systems Improvement, and WebMD. However, the largest contributing source of information was the Cumulative Index to Nursing and Allied Health Literature (CINAHL – EBSCO Host), through the library database of Salisbury University. A variety of keywords were used for the searches, including: palliative care, nursing, and end-of-life care.

## **2. Palliative Care**

When nearing the end-of-life there are many care options. Palliative care is one end-of-life care option available. Palliative care may be a preference for any patient suffering from a serious illness. It is significant to note that there is no set definition of palliative care. Palliative Care is a broad scope of practice that focuses on treatment that enhances an individual's quality of life at the end of life. The framework of plan of care is based upon the individual's choices and decisions<sup>12</sup>. Palliative care does not just focus on the body; it integrates the mind and spirit<sup>17</sup>. The care also includes various areas that are important in a patient's life: cultural, psychological, social, spiritual, financial, ethical and legal issues<sup>10</sup>.

Since the scope of practice for palliative care is so broad, there is an importance of having advanced directives (living wills, etc.). Advance directives and living wills are simply written documentation of the patient's wishes if he/she shall become unable to make decisions for him/herself<sup>2</sup>. Anyone 18 and older may create advance directives, there is no set form, and the wishes must be in writing and signed by two witnesses<sup>2</sup>.

### **2.1 Advantages Of Advanced Directives**

Having palliative care measures in place poses many advantages for the patients and families. An advance directive is considered one of the primary palliative care measures. An advance directive is a document that informs your healthcare providers, family and others about the health care you desire and do not desire. No individual knows what may occur in the future. Almost everyone, at some point in time, may need someone to make medical decisions for him/herself. It is best to think ahead about your wishes. Although advance directives are not required, choosing someone you trust and talk to them about your choices will help them direct your care.

One of the most significant benefits of having some form of advance care planning in place is that it protects the individual's autonomy<sup>3</sup>. Independence is an important right that all individuals have and in most cases it is not relinquished until death. Therefore, when working with patients nearing the end-of-life encourage autonomy and decision making to promote dignity, even if the patient's decision isn't favorable to that of the healthcare provider and/or family.

No research was found to show that there are any disadvantages to having advanced directives. However, many people believe that having advanced directives means "do not treat"<sup>10</sup>. This is a myth. Having advanced directives simply means "treat me the way I want to be treated"<sup>10</sup>. Clearly, no harm is posed to the patient by having advanced directives and the benefits of having advance care planning outweigh the risks of dying in a non-dignitary way.

## **3. Controversial Issues**

### **3.1 Financial Aspects**

There are various controversial issues surrounding palliative care measures. An important aspect to consider is finances/economics. Due to the high cost of health care at the end of life there is a lot of debate about expensive life prolonging treatment<sup>16</sup>. One research study conducted by Shepardson et al (1998) found that by having Do Not Resuscitate (DNR) orders in place resulted in lower health care cost because it limited aggressive treatment and shortened the length of stay in the hospital<sup>9, 16</sup>. It was found in research that palliative care also saves Medicaid

money<sup>1</sup>. By patients choosing to utilize palliative care they spent less time in intensive care units and received more hospice referrals<sup>1</sup>. The article stated that patients that received palliative care incurred \$6,900 less in hospital cost<sup>1</sup>. That is a significant amount of money that can be saved by not undergoing unnecessary life sustaining treatments.

### 3.2 Emotional Costs

Although cost is often spoken of in the monetary form, there is also emotional cost for families when dealing with end of life care. Family members of patients with advance directives often felt less guilt because they knew their loved one's wishes were being carried out and they did not have to make those difficult decisions<sup>2</sup>. There was a case presented of a woman with advanced dementia. She did not have any advance care plan or a designated power of attorney. In addition she never addressed her medical preferences with anyone; this made her plan of care difficult for the healthcare providers and family<sup>7</sup>. Due to the patient's altered cognitive abilities the family was responsible for making decisions on her behalf, but did not know what her wishes were. This is an important thought to consider because death does not just affect the patient, it affects the whole family. Therefore, another benefit of having advanced directives or palliative care measures in place is to relieve emotional distress from family members.

### 3.3 Ethical Issues

As with all aspects of healthcare, there are many ethical issues surrounding end-of-life care. Research shows that the most common ethical issue is when the patient and family disagree. This is a very sensitive matter that raises a lot of ethical tension. This has been observed in countless clinical experiences. While reviewing the literature, many case studies were presented with similar themes regarding family discrepancies. In these situations, the family requests to continue with all possible medical interventions to promote survival and recovery, but the patient is weary and ready to depart this life<sup>4</sup>. A lot of the disagreements hinge on communication. Occasionally the patients share their wishes and sensitive issues of dying with their families and other times they do not. The lack of communication between the patient and family can make things difficult for the healthcare providers. Other reasons why families and patients disagree include unresolved family conflicts, anger from not being included in decision making, or simply because they want to protect their loved one<sup>6</sup>.

With this ethical dilemma present, what "should" be done? Overall, how the patient chooses to live the remainder of their life is ultimately their decision. Therefore, the decision of the patient ought to outweigh the decision of the family member<sup>6</sup>. However, in some cases when the patient is not capable of making their own decision it is appropriate that decisions will be made by the durable power of attorney or proxy<sup>3</sup>. At times healthcare providers are reluctant to honor the patient's decision because of the family's threat of legal repercussion<sup>6</sup>. The ethical issues surrounding the disagreement between the patient and their family can be very complex and have to be worked out on an individual basis.

There are four things the nurse can do to resolve ethical dilemmas between the patient and their family. Most importantly, help the patient remain in control; next facilitate communication; then request ethics and/or palliative care consults if necessary<sup>6</sup>. The nurse can help the patient remain in control by offering support. This includes reviewing information with patients and educating them of their rights. The nurse is considered one of the primary healthcare providers (HCP), since he/she spends lots of time taking care of the patient and is very familiar with the patient, the nurse is the most appropriate HCP to understand and communicate the patient's perspective<sup>6</sup>. Additionally, nurses' roles include being advocates for patients and providing care based on a holistic approach. After gaining the patient's perspective, the nurse is able to facilitate discussion between the patient and family and/or patient and physician. It may be necessary to request an ethics consultation to manage the disagreement. If indicated, the ethics committee can collaborate with the palliative care consultant. This promotes great outcomes for the patient because goals of care can be established and it promotes open communication<sup>6</sup>. It is important to resolve these ethical dilemmas as patients receiving end-of-life care need a strong support system and oftentimes that support system is the family.

## 4. Barriers to Discussing End-of-life Care

There are a significant amount of barriers to discussing end-of-life care. One barrier to why end-of-life discussions are not occurring is the knowledge deficit of healthcare providers. In undergraduate educational programs, there is

limited information provided on death in dying in the curriculum <sup>4</sup>. Therefore, professionals that feel most comfortable caring for dying patients are those specially trained in hospice, palliative, or oncology. This is a problem that warrants attention since dying patients are not just confined to those three areas. They may appear on any unit (medical-surgical, neurology, etc.). Some healthcare providers report that they are not familiar with advanced directives because they do not have to implement them on an everyday basis <sup>15</sup>. All of these points show a lack of educational knowledge. It is imperative for all nurses to receive proper training in death and dying and to utilize an interdisciplinary team approach to be able to meet the needs of these patients <sup>8</sup>.

There are also cultural knowledge deficits. Death is viewed differently according to a person's culture and religion. For example, the practice of Western medicine emphasizes the idea of doing everything possible to sustain life in hopes of saving or curing all patients <sup>4</sup>. With this said in the American culture death is not openly discussed. Also with the practices of Western medicine, death has moved from the home to the hospitals <sup>5</sup>. The Western way of medicine may be culturally different for some patients. This can be a challenge for patients with strong cultural beliefs because the hospital is a strange place with unfamiliar people to take care of you; which may be an uncomfortable place to spend your final days. Since Western medicine places a strongly emphasis on curing, it can be easy to lose insight of the patient's true needs and desires. This "cure-all" mentality may also cause the provider, patient, and family to have unrealistic expectations of care. Therefore, the nurse must holistically care for the patient. The nurse must be mindful of his/her own personal beliefs and values and not pose them unto the patient. However, the nurse has a duty to be empathetic and knowledgeable about the patient's different cultural values and beliefs.

Another huge barrier is the lack of communication. As previously mentioned, the nurse also plays the role of the patient's advocate. Often nurses are in the position to contribute to decisions between the clinical team and the patient <sup>11</sup>. Therefore, nurses can play a huge role in initiating discussions of end-of-life care. Studies have shown that nurses are more comfortable initiating the conversations if they have the necessary skills and/or previously cared for a patient with advanced directives <sup>15</sup>. This relates back to education; if nurses are competent with their skills they are more likely to initiate end-of-life conversations. It was also reported that some healthcare professionals are timid of having end-of-life conversations because of the fear of upsetting the patient <sup>15</sup>. However, multiple sources have disputed that patient are more willing to discuss end-of-life care when the conversation is initiated by a healthcare provider <sup>14</sup>. To make communication about end-of-life care successful it is important to develop a trusting therapeutic relationship. Encourage the patient and the family to ask questions. Another reason why some patients are hesitant to discussing end-of-life with their physician is due to the lack of a long-trusting relationship <sup>6</sup>. Naturally, nurses get to spend more time with the patient and have the advantage of developing therapeutic relationships.

## **5. Implications for practice**

It has been mentioned all throughout this paper, various ways nurses can contribute to improving quality palliative care and increase patients' awareness. Per evidence-based practices, it is recommended that palliative care should begin at time of diagnosis with a terminal illness, continue through death and the family's bereavement period <sup>10</sup>. Furthermore, it is recommended that the initiation of advanced directives begin before admission to the hospital <sup>2</sup>. When the discussion occurs before a serious hospital admission the communication is believed to be more effective and promotes better patient outcomes <sup>6</sup>. Initiating the communication early allows the patient to make decisions free from distress and it gives them the opportunity to talk with their families ahead of time. It is important to remember that advance care planning is an ongoing process, the end-of-life discussion and the patient's wishes will frequently be reassessed. Any opportunity to encourage patients/families to develop advanced directives or living wills ought to be pursued <sup>2</sup>. Therefore, nurses need to constantly assess all patients since everyone could benefit from palliative care. It is important to remember that patients who would benefit from palliative care are those with chronic illnesses and/or their pain/other symptoms are no longer responding to optimal medical treatment <sup>10</sup>.

## **6. Conclusion**

The following are key points for nurses to consider and implement to improve quality end-of-life care. Remember that a nurse plays the role as the patient's advocate. Develop therapeutic relationships with the patient's and

families. With end-of-life care the patient and the family are one unit. Help the patient remain in control, encourage autonomy, and promote death with dignity. Facilitate communication of the patient's end-of-life preferences with the family, clinical care team, and other necessary personnel. It is also important to remember that palliative care uses an interdisciplinary approach to care. Therefore, request palliative care and ethics committee consultations and resources when appropriate. Lastly, be sure to access your own personal beliefs and values to guide your morals of practice. Addressing palliative care issues is a national priority, not just because of ethical and economical concerns, but to improve the quality of care<sup>8</sup>. As a nation we all have room for improvement and can do much better than what we are currently doing.

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## 8. References

1. Advance directives for palliative care use lower Medicare EOL spending. (2011). *Hospice Management Advisor*, 16(11), 128-129.
2. Alfonso, H. (2009). The importance of living wills and advance directives. *Journal Of Gerontological Nursing*, 35(10), 42-45. doi:10.3928/00989134-20090903-05
3. Beširević, V. (2010). End-of-life care in the 21st century: advance directives in universal rights discourse. *Bioethics*, 24(3), 105-112. doi:10.1111/j.1467-8519.2010.01806.x
4. Clabots, S. (2012). Strategies to Help Initiate and Maintain the End-of-Life Discussion With Patients and Family Members. *MEDSURG Nursing*, 21(4), 197-204.
5. Dobbins, E. (2007). End-of-life decisions: influence of advance directives on patient care. *Journal Of Gerontological Nursing*, 33(10), 50-56.
6. Erlen, J. (2005). When patients and families disagree. *Orthopaedic Nursing*, 24(4), 279-282.
7. Gillick, M. R. (2012). Doing the Right Thing: A Geriatrician's Perspective on Medical Care for the Person with Advanced Dementia. *Journal Of Law, Medicine & Ethics*, 40(1), 51-56. doi:10.1111/j.1748-720X.2012.00645.x
8. Giovanni, L. A. (2012). End-of-Life Care in the United States: Current Reality and Future Promise - A Policy Review. *Nursing Economic\$, 30(3)*, 127-135.
9. Henderson, S., Fins, J.T., & Moskowitz, E.H. (1998). Case study: Resuscitation in hospice. *The Hastings Center Report*, 28(6), 20-22. Retrieved from: <http://www.jstor.org/stable/3528263>
10. Institute for Clinical Systems Improvement. (2011, Dec 5). Health care guideline: Palliative care. Retrieved from: [http://www.icsi.org/palliative\\_care/palliative\\_care\\_11918.html](http://www.icsi.org/palliative_care/palliative_care_11918.html)
11. Mahon, M. (2010). Advanced care decision making: asking the right people the right questions. *Journal Of Psychosocial Nursing & Mental Health Services*, 48(7), 13-19. doi:10.3928/02793695-20100528-01
12. National Hospice and Palliative Care Organization. (2012, June 8). About hospice and palliative care. Retrieved from: <http://www.nhpco.org/i4a/pages/index.cfm?pageid=4648>
13. Nevidjon, B. M., & Mayer, D. K. (2012). Death Is Not an Option, How You Die Is - Reflections From a Career in Oncology Nursing. *Nursing Economic\$, 30(3)*, 148-152.
14. Pautex, S., Herrmann, F., & Zulian, G. B. (2008). Role of advance directives in palliative care units: a prospective study. *Palliative Medicine*, 22(7), 835-841.
15. Seal, M. (2007). Patient advocacy and advance care planning in the acute hospital setting. *Australian Journal Of Advanced Nursing*, 24(4), 29-36.
16. Shepardson, L.B., Justice, A.C., Harper, D.L., & Rosenthal G.D. (1998). Associations between the use of do-not-resuscitate orders and length of stay in patients with stroke. *Medical Care*, AS57-AS67. Retrieved from: <http://www.jstor.org/stable/3767042>
17. WebMD. (2010, July 30). Palliative care center. Retrieved from: <http://www.webmd.com/palliative-care/palliative-care-topic-overview>