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Nursing Education on Caring for the Dying

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Walden University

College of Health Sciences

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Holley Tyler

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Walden University

2017

Abstract

Nursing Education on Caring for the Dying

by

Holley Tyler

Masters of Nursing Administration, University of Texas at Arlington, 2009
Bachelor of Science in Nursing, University of Texas at Arlington, 2007
Associate Degree in Nursing, Grayson County College, 1999

Project Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Nursing Practice

Walden University
January 2017

Abstract

Healthcare teams can implement care initiatives to promote a positive dying experience. However, there is a lack of knowledge related to how best to care for dying patients. Nurses do not receive extensive training in nursing school to care for patients at the end of life, yet most, at some point in their careers, experience the provision of this type of care. It is important to ensure that nurses caring for dying patients have been educated about end-of-life care. The purpose of the quality improvement project was to address the lack of end-of-life care education among critical care nurses in an acute care hospital by implementing and testing the effectiveness of an end-of-life care educational program. Kolcaba's theory of comfort was chosen as the theoretical framework for the project. Registered nurses (*n* = 34) employed on a critical care unit participated in the one-group pretest/posttest design project. The nurses completed the Healthstream online end-of-life care education, and knowledge improvement was determined through comparison of pretest and posttest scores. Descriptive tests were completed to determine the mean score. The descriptive data analysis and tests showed that participants' level of end-of-life care knowledge improved after they completed the formalized educational program. Participants' scores increased from pretest (68% to 100% correct answers) to posttest (93% to 100% correct answers). The primary populations benefiting from the project are nurses, dying patients, and family members of dying patients. The social change implication of the findings is that if nurses receive education on end-of-life nursing, increased knowledge of appropriate care for dying patients is expected.

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Dedication

This project it dedicated to my mother, *Debbie,* who died August 12, 2013, of lung cancer. I sat by her bedside watching her pass for over 2 weeks, and she had the opportunity to be cared for by palliative care nurses who gave compassionate care each and every time. They comforted my mother and me at times when we needed it the most, through my experience I observed a comfort level of caring with the specially trained nurses as she was dying, and learned that not all nurses are comfortable in this situation. It made me realize we need to provide more education to the nurses on caring for dying patients.

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Mikayla, *my three-year-old daughter,* for always understanding that Mommy has homework and a paper to write.

Ray my boyfriend, Mikayla's father, for always making sure I have time to do my homework. Thank you for keeping the house in order for our family.

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Section 1: Overview of Evidenced-Based Project

Introduction

According to Broad et al. (2013), 54% of all hospital deaths occur in the acute care setting. Therefore, it is imperative that nurses in acute care settings who are likely to care for patients during the end of life (EOL) receive specific training to care for dying patients (Lowey, 2008). EOL care should focus on comfort measures and meeting the expectations set by the patient or family members (Raphael, Waterworth, & Gott, 2014).

According to Valiee, Negarandeh, and Dehghan (2012), people assume that because nurses have been to nursing school, they should be able to care for any type of patient. However, Lowey (2008) identified that nurses are not comfortable caring for dying patients. There is not enough education provided during nursing school that addresses the needs of the patient during the end of life. This quality improvement project was completed to address the educational level of nurses regarding EOL care, with the ultimate goal of improving patients' EOL care and improving the knowledge level of the nurses. Better EOL care education among nurses could result in patients and their families having better experiences during the EOL and to a decrease in nurses' stress levels.

Sleeman and Collis (2013) stated that it is difficult to care for dying patients in hospital settings without adequate training for nursing staff. Hedlund (2013) completed a pilot project by offering educational sessions pertaining to patients at the EOL. The results were that morale and communication improved in the nursing staff when caring for the dying patient. Therefore, more EOL education for nurses should be provided at the hospital level.

This section presents an overview of the evidence-based project. First, the background of the topic is provided, followed by the problem statement and purpose statement. Next, the project question is presented, along with the framework, and definitions of key terms. Assumptions, delimitations, and limitations follow. The implications of the project for healthcare practice is fully described. A summary concludes the section.

Background

According to Tan and Manca (2013), as the patient moves into the dying stage, a certain standardization of care should take place. However, not all nurses are comfortable caring for dying patients (Cevik & Kav, 2013). Many nurses try to avoid the assignment if there is an actively dying patient. Most nurses will try to get an assignment that does not have a patient dying due to the fact that they do not have the knowledge or comfort level needed to care for the patient who is actively dying (Raphael et al., 2014).

Nurses who are educated on EOL care can cope with the dying process and address the patient's needs better than nurses who have not had specific EOL education. Pattison, Carr, Turnock, and Dolan (2013) stated that nurses who are educated about EOL care can focus more on palliative care for patients and less on the machines keeping the patients alive. The World Health Organization (WHO; 2016) defined palliative care as an approach to improving the quality of life for dying patients and their families during the EOL. Once a healthcare team determines that a patient is at a palliative care state, the team can give a palliative care order, directing nurses and other members of the team to engage in EOL-specific practices (Becker, 2009). If possible, the healthcare team should discuss the patient's EOL care with the family and patient to ensure adherence to EOL care wishes.

Dying patients require a different kind of care than those with acute illness. For example, nurses must ensure that dying patients are comfortable at the EOL, and they should support the fulfillment of the patients' last wishes (Becker, 2009). Charnock (2014) stated that advance planning is important to provide emotional, physical, and medical support to the patient and the family. Nurses can provide support for the family of a dying patient, educating the family on steps of the dying process and the grieving process. The palliative care order sets' criteria guide the healthcare team in educating the family, keeping the patient comfortable, and caring for the needs of the dying patient.

Prior to this study, a needs assessment was conducted with a group of staff nurses in the critical care unit (CCU) in an acute care hospital in Brownsville, Texas. The nurses had volunteered to assist with the development of an EOL care education program. The nurses met as a group, and they identified the specific needs associated with caring for dying patients. The nurses stated that, in nursing school, they did not receive training regarding how to address the specific needs of dying patients, and they expressed a lack of comfort discussing death and dying with patients' families. The nurses expressed interest in an educational opportunity to learn to care for dying patients. Additionally, the physician champion supporting this project assisted with the completion of the needs assessment and stated concerns that the nurses had a limited amount of knowledge in caring for dying patients.

Problem Statement

According to Tan and Manca (2012), it is important that each patient experience a good death and that the healthcare team follow a patient's wishes until death. However, there is a knowledge deficit among nurses regarding caring for dying patients, because nurses lack education on EOL care. Many nurses are uncomfortable caring for dying patients (Tan & Manca, 2012). There is minimal education provided in nursing schools related to caring for dying patients. Nursing school curricula address EOL care briefly but do not provide the nursing students with thorough training on caring for dying patients. Therefore, there is a need for hospitals to provide additional training on EOL care.

This problem is particularly significant in acute and intensive care settings. Fridh (2014) stated that intensive care nurses may lack knowledge regarding caring for patients during the EOL and identified a need for EOL care related to difficulties in communication during the dying process. A needs assessment was conducted with a group of staff nurses in the critical care unit (CCU) in an acute care hospital in Brownsville, Texas. Both the nurses and the physician championing the project identified a need for additional EOL care education among nurses at the hospital. Currently, the hospital does not provide specific training on EOL care to the nursing staff. Therefore, the specific problem of this project is a lack of EOL care education among CCU nurses in an acute care hospital in Brownsville, Texas.

Purpose Statement

The purpose of this quality improvement project was to address the lack of EOL care education among CCU nurses in an acute care hospital in Brownsville, Texas, by implementing and testing the efficacy of an EOL care educational program. The project was conducted in the CCU due to the high number of dying patients in this setting (Sleeman & Collis, 2013). Through the quality improvement project, education was provided to the nurses on caring for the dying patient and addressing the needs of the family. This project addressed a gap between the level of education regarding EOL care among nurses at the hospital and the need for additional EOL knowledge, as identified during the needs assessment. The goal of this project was to improve the knowledge level of nurses caring for patients during the EOL, thereby improving the dying process for patients. An attempt was made to achieve this goal by implementing a project with the objectives of (a) utilizing an evidence-based program to increase the knowledge level of nurses caring for the dying patient and (b) developing an evaluation plan and summarizing the results of the intervention.

Based on the objectives stated above, this educational program for EOL care incorporated existing educational materials on EOL care, standards of care, and needs identified by the nurses in the CCU at the acute care facility in Brownsville, Texas through the Healthstream Program. The literature on EOL care and caring for the dying patient were the foundation for the development of the program. The baseline knowledge of the nurses related to providing EOL care was measured with a pretest, the formalized education was provided, and then the pretest results were compared to the results of a posttest questionnaire. Section 3 contains a detailed description of the project approach.

Project Question

The project question was:

PQ: Did the implementation of an EOL education program improve the level of EOL care knowledge among nurses caring for dying patients in a CCU setting?

$H_{0:}$ Nurses' level of EOL care knowledge would not improve after the completion of the educational program.

$H_{a:}$ Nurses' level of EOL care knowledge would improve after completion of the educational program.

The dependent variable was nurses' level of EOL care knowledge. The independent variable was the educational program on EOL care.

Framework

Kolcaba's (1994) theory of comfort was the theoretical framework for this project. I chose this theory because it related to the method of ensuring that patients have the most comfortable and supportive dying experiences possible. The theory of comfort was utilized to guide the educational program regarding EOL care, which focused strongly on patient comfort according to techniques that Kolcaba suggested.

According to McEwen and Wills (2011), middle-range theories are more specific to patient care, involve fewer concepts, and may limit aspects of nursing practice. It is important to choose a theory that will drive practice change. Unlike the middle-range theories that McEwen and Willis criticize, Kolcaba's (1994) theory of comfort is practical, guiding support of the dying patient during the EOL.

Moir, Roberts, Martz, Perry, and Tivis (2015) stated that clear communication addressing expectations and comfort improves the dying experience during EOL. Clear communication enables nurses to meet the patient's physical, psychospiritual, environmental, and social needs. Physical needs relate to the illness and sensations associated with dying. Psychospiritual needs pertain to the feeling and awareness of what is going on inside the patient. Environmental needs include creating a pleasant place that includes light, decreased noise, and other natural elements. Social needs pertain to family support and other supportive relationships (Moir et al., 2015). This understanding of comfort as encompassing multiple needs, which nurses can elicit through clear communication, was important to the development of the EOL educational program for this project. Following the theories of Kolcaba (1994) and Moir et al. (2015), I strove to emphasize communication, comfort, and whole-person care.

Definitions

Advance directive: Legal documents stating a patient’s wishes during EOL treatment and care (Tan & Manca, 2013).

Anticipatory grief: Mourning and preparing for loss or death before a loved one has died (Kondo & Nagata, 2015).

Bereavement: Deprivation from someone or something (Walter et al., 2013.

Caring: Demonstrating concerns or displaying kindness to others (Kolcaba, 1994).

Comfort: A state of ease or free from pain (Kolcaba & DiMarco, 2005).

Critical care unit: A specialty department in the hospital that cares for patients with the most severe or life-threatening illnesses or injuries (Johansson & Lindahl, 2012).

Death: The termination of all functions from a living being (Kinoshita et al., 2015).

Delirium: Confusion and decreased awareness of surroundings brought about by sickness (Sleeman & Collis, 2013).

Dying: Approaching death, expiring (Walter, 2012).

End of life care: Healthcare delivered to patients during their final hours of their lives (Adams, 2010). Scholars often use thee terms EOL, palliative care, and comfort care interchangeably.

Evidence-based practice: Healthcare practice that may involve complex decisions and that uses the most current research available to help practitioners guide their decisions (Grove, Burns, & Gray, 2013).

Grief: Deep sorrow caused by death (Walter, 2012).

Healthstream program: Healthstream is an online education tool that each nurse employed by the Hospital Corporation of America (HCA) can access. Healthstream offers over 20,000 courses with specific needs of the healthcare industry in mind. There are 167 hospitals in the HCA that currently use the Healthstream program for educational needs of nurses. HCA has used the Healthstream program for over 16 years. The company adopted the program based on its use of evidence-based practice and research. Nurses with experience in education develop the programs. The programs address specific needs of nursing staff who participate in direct patient care. Hospitals can utilize Healthstream, a cost-effective program, to track education provided to all staff. Users can generate reports to track compliance and completion of any assignment given to the staff. There are no reliability or validity data available for any of the educational programs, according to a representative from the Healthstream Company. The educational program implemented as part of this project provides comprehensive education to the nurses on caring for patients during EOL. The program covers communicating with the patient and family. It addresses techniques to use during crucial conversations with the family and patient. The program addresses some of the feelings nurses may experience when caring for the dying patient. Permission was obtained in writing to use the Healthstream program through the Healthstream company representative.

Multidisciplinary: Involving multiple professionals from different specialties

(Peschman & Brasel, 2015).

Palliative care: Addressing a patient's pain and caring for their symptoms and not the disease (Corner, 2010).

Assumptions

According to Polit and Beck (2006), assumptions are statements a person believes to be logical and true without any proof. The assumptions for the project were that the nurses will want to improve their knowledge and to care for patients who are dying. It was assumed that adequate education would remove some of the anxiety the nurses deal with while caring for the dying patient. There is also an assumption that nurses would want to participate in the educational program. Nurses may not have wanted to participate in the program and may not feel it is necessary to have formalized training for EOL care. Another assumption was that there would be improvement in patient care resulting from increased EOL care knowledge among nurses. This assumption was reasonable given the evidence-based nature of the educational program, but it was not certain that EOL care education led to improved patient outcomes.

Scope and Delimitations

Evidence shows that nurses are often not comfortable caring for dying patients during EOL, and they find it to be often difficult (Lowey, 2008). Nurses' stress levels increase when caring for dying patients. Nurses not only care for dying patients, but they also care for the patients' families. Nurses trained in providing EOL care are more comfortable caring for dying patients. Nurses who have had more education are able to address the concerns more comfortably than nurses who do not have training in EOL care (Tan & Manca, 2013).

Providing programs that educate nurses and healthcare providers on how to care for patients during the dying process improves the comfort level of the nurses who must care for the dying patient. EOL care programs and evidence-based order sets can improve EOL care (Melvin, 2012). The hospital in Brownsville, Texas does not have a system for providing adequate care for dying patients, and there are no educational programs offered to the nursing staff on EOL care. The project boundaries were the CCU at a hospital in Brownsville, Texas, and the improvement project included only Registered Nurses. The practice problem was the lack of knowledge among nurses related to the best practices in EOL care and the resulting inconsistency in care provided to dying patients.

Limitations

The limitations of the project were the small sample size, which consists of nursing staff in in the CCU. The limitation of providing education to nurses only in the CCU was a weakness. Outcomes for the nurses in CCU may differ from the outcomes of nurses in other units due to the types of patients for whom CCU nurses provide care. Another limitation was the variation in education and experience levels of nurses in the CCU. Further, the lack of a control group is a limitation of the study design.

Regarding the study's outcomes, there was no guarantee that outcomes would be sustainable after the program. It was important to address how to continue this EOL education program after the implementation of the project. Another limitation was the use of an educational program without any structured implementation program. Additional research could explore different aspects of improving care for dying patients, such as a formalized palliative care program versus an educational program for nurses.

Some biases could have affected the project outcomes. First, participants took the same test before and after the educational program, so the nursing staff had already seen the material. That may have skewed the results and given a false impression of improvement. Because this is a quality improvement project aimed at improving nurses' level of EOL care knowledge, the education provided to the nurse may have led nurses to develop a false perception that they were competent in caring for the patient during EOL. This could have a paradoxically negative effect on patient outcomes as nurses proceed out of a sense of false confidence. Therefore, the education and quality improvement project will require more than just one educational component to improve the overall quality of care.

Implications for Practice

Providing care to dying patients takes an emotional toll on nurses (Melvin, 2012). The lack of knowledge that nurses have in caring for the dying patient causes unnecessary stressors on the nurse responsible for the patient (Minton, Kerkvliet, Mitchell, & Fahrenwald, 2014). During the EOL, patients experience different needs and deserve competent nurses to care for them during their last days. Cevik and Kav (2013) stated that nurses experience an array of emotions while caring for dying patients. Some nurses experience fatigue and exhaustion. The emotion that families face during the process is stressful on most nurses that are caring for dying patients (Cevik & Kav, 2013). Providing tools and techniques that nurses can use during caring for patients in the dying stages will ease some of the stress on the nurse and the family of the dying patient.

Most nurses receive minimal training on how to care for patients as they are dying (Cevik & Kav, 2013). Nursing schools teach the minimum about EOL care. Nurses who have to care for dying patients need to be educated on techniques that can minimize the stress placed on the nurse, family, and the dying patient. There are palliative care programs available for nurses who want in-depth training on caring for the dying patient. However, there is currently no EOL care program or education provided at the facility in Brownsville, Texas. Improving the nurses' knowledge regarding caring for patients during EOL could significantly change the dying experience for patients at this Brownville, Texas hospital.

The significance of developing an educational program for nurses about caring for patients during EOL is demonstrated by the lack of knowledge and level of discomfort that nurses have caring for the dying. The aging population is increasing, and the need to provide a comfortable death is important in hospital settings (Johansson & Lindahl, 2012; Tan & Manca, 2013). Many hospitals do not have programs available to nurses to educate them on EOL care and the dying process. Implementing programs such as the one used in this project could help hospitals address the needs of the increasingly aging population.

The social impact of this project is the increased knowledge among nurses caring for dying patients. Nurses with increased education could provide better care to patients at the EOL, which could result in improved patient and family experiences. Providing a dignified death is important for supporting the family and the patient who is dying (Efstathiou & Walker, 2014). Patients receiving care from specially trained nurses could have a better dying experience (Walter, 2012).

EOL care promotes patients who are dying to make decisions about their expectations during the dying process. According to Hinkle, Bosslet, and Torke (2015), nurses trained in EOL care are more comfortable identifying the needs of the dying patient and discussing the wishes of the patient during EOL. Nurses will be more prepared in caring for the dying patient, which will reduce anxiety during EOL (Jeffers & Ferry, 2014). Improved communication between the healthcare team and the patient could improve patient and family experiences. According to Jeffers and Ferry (2014), nurses are inadequately trained and educated to care for patients during the dying process. The education program implemented in this project could provide the foundation for nurses to care for the dying patients and their families in a more competent manner.

Summary

Nurses are not comfortable caring for patients during EOL due to lack of education. An educational program could improve the knowledge level of the nurses, thereby improving patient care. Dying patients deserve to have a competent nurse who has knowledge on providing EOL care caring for them during the dying process. Nurses trained adequately in EOL care can improve the care of the dying patient during EOL. It is imperative that nurses receive the education that they need to care for the patient and family during EOL. Section 2 includes an overview of related literature and the conceptual model of this project.

Section 2: Review of Literature

Introduction

The purpose of the project was to create a program to educate CCU nurses in a hospital in Brownsville, Texas, on how to care for dying patients, with the goal of improving nurses' knowledge of EOL care, thereby improving patient and family experiences. The problem is a lack of EOL care education among CCU nurses in an acute care hospital in Brownsville, Texas. Nurses do not receive sufficient training on caring for dying patients. This section contains a review of literature related to the project topic, providing evidence that nurses are inadequately trained for EOL care and are not comfortable caring for dying patients (e.g., Walter, 2012). There is a gap in nurses' knowledge regarding caring for the dying patient. Section 2 will include the literature search strategy, a review of literature related to the specific topic of this project, a review of literature more generally related, and a presentation of the conceptual models pertinent to the project. The review includes evidence-based articles describing initiatives that have used nursing education as a tool to improve the care of the dying patient. A summary concludes the section.

Literature Search Strategy

Jaffe and Cowell (2013) stated that a literature review provides evidence of previous work that summarizes findings on a particular topic. I conducted the literature search for this review using the following databases: CINHL, Medline, and EBSCO. The following key words were used: *comfort theory, end of life care, dying, caring for the dying, educational programs for end of life, death, pain,* and *palliative care.* The search parameters were set from 2005 to 2015, then narrowed to 2010 to 2015 owing to the volume of current literature. The majority of articles included in the review were less than five years old. Helpful articles related to the history of nursing care theories were included even if they were over five years old.

The review includes over 64 articles on the topic of EOL care. These articles guided me in determining best nursing practices for EOL care, which guided the development of the educational program piloted in this project. The strategy was to research articles related to dying and EOL, which included multiple peer-reviewed articles. The search included best practices in caring for the dying patient and education provided to the nursing staff regarding EOL care. Most of the articles found were peer-reviewed and from professional journals. The search with the broad topic of “end of life care” did not provide specific information related to nurse education. Therefore, to make the search more manageable, terms were added emphasizing nurse education. The results are described and reviewed in the following sections.

Specific Literature

The literature review revealed that there is a lack of training and knowledge among nurses about caring for dying patients. This lack of knowledge may lead to burnout, negativity in the workplace, turnover, added stress, and anxiety. Nurses have stated that they are not comfortable in caring for the dying patients (Choi, Lee, Kim, Kim, & Kim, 2012). Many nurses face the situation of caring for dying patients and may be unprepared from an educational standpoint.

It is important to ensure that nursing staff receive adequate training so they have the knowledge to care for the patient during the EOL (Efstathiou & Walker, 2014). Formalized training programs have been successful in improving the knowledge level of nurses regarding EOL care. Hedlund (2013) stated that providing education and support to nursing staff caring for dying patients improved the overall perception of providing EOL care and improved nurses' knowledge of EOL care.

Death can sometimes be hard to cope with when caring for patients. Griffiths, Ewing, Wilson, Connolly, and Grande (2015) stated that nurses who have adequate training in end of life care understand the stages of death more clearly and are able to care for dying patients with more ease. The nurses must be able to properly manage an actively dying patient and must have the necessary tools to provide the best care to the patient and family.

Jeffers and Ferry (2014) stated that the population is aging, and nurses must have a skill set to care for dying patients, since an aging population makes EOL cases more frequent. Nurses are not receiving appropriate training to assure competency to care for patients during EOL, and lack of training causes fear and anxiety (Fernandez et al., 2012). More educational opportunities need to be available for the nurses to be competent in caring for dying patients (Raphael et al., 2014).

McCourt, Power, and Glackin (2013) completed a literature review on nurses' experiences in caring for dying patients. The review identified that nurses who had not had specific EOL care training were not comfortable caring for dying patients. Nurses specially trained to care for dying patients are more comfortable providing the care (Lange, Thom, & Kline, 2008). The comfort level of the nurses will improve when they receive education on caring for patients experiencing death.

Yim, Voco and Wai (2013) stated that nursing staff face mental and physiological strains if they have not received training on caring for dying patients. Peterson et al.

(2010) stated that the most common clinical stressors while caring for a dying patient are watching the patient suffer, death, and listening or talking to a patient about death. Macaden et al. (2014) stated that nurses must understand when it is time to limit unnecessary treatment and accept the inevitable, which is death. This may cause added stressors to the nurse caring for the patient.

Minton et al. (2014) completed a study of healthcare facilities, over half of which had no EOL care program, and the authors identified a need for a specific program to train nurses to care for patients during the EOL. Dying patients require a different type of care during this time, and, in 80% of the facilities in the Minton et al. study, the nurses were caring for dying patients but had no specific training in doing so (Minton et al., 2014).

Providing EOL care is essential to all healthcare providers, especially those in critical care areas (Peschman & Brasel, 2015). Many patients wish to die in their homes, but that is not always possible, so it is important to provide nurses with the necessary training to care for the dying in the healthcare setting. Taylor (2015) stated that high quality EOL care is important even in acute care settings. Nurses must be provided adequate training to care for patients when they are not able to die in the home setting.

The problem addressed in this DNP project is the lack of a program to provide education to the nursing staff in a CCU unit in Brownsville, Texas, to care for dying patients. There needs to be an established educational program on techniques and consistent care for patients during the EOL. Formalized EOL care programs with evidence-based practice education and standardization of care provide formalized training to the staff. Hinkle et al. (2015) stated that family satisfaction increased after nurses received training on EOL care. The families were educated on expectations, easing some of the anxiety associated with the dying process of their loved ones. Coping strategies can be an effective way to decrease anxiety in regards to caring for the patient during end of life. Efstathiou and Walker (2014) completed a study where nurses completed training on EOL care and found that nurses following specific treatment guidelines were more comfortable caring for the dying patient, and stress levels reduced among the nursing staff. The training helped the nurses have a better understanding of end of life care.

Peterson et al. (2010) stated that nurses often become emotionally distressed when death occurs, and an EOL educational program may provide nurses techniques to decrease the added stress that occurs after the patient dies. The training program implemented for this project includes specific coping mechanisms for nurses. Nurses often develop relationships with patients and become emotionally attached, especially if a patient spends time on a unit with consistent care from specific nurses. Emotions get involved, and it is imperative for nurses to be able to provide support to the family, patient, and themselves to ensure effective coping for all parties involved. Nurses commonly experience watching a patient suffer, discussing imminent death with the patient or family, and watching a patient deteriorate and finally succumb. Nurses often come into the profession wanting to help people get better, not watch them die (Melvin, 2012). It is important that nurses are provided with the adequate education to address the death and dying of a patient.

General Literature

Researchers have stated that nurses are not comfortable caring for dying patients (Cevik & Kav, 2013). Evidence is available that explores the attitudes of nurses caring for dying patients, but this evidence is primarily related to hospice, homecare, and medical surgical nurses. Most nurses do not receive formalized education regarding the stages of death and the necessary support for dying patients (Tan & Manca, 2013). Nurses receive some training during nursing school, but it is not enough to prepare nurses adequately to care for patients during EOL. Clearer education about the dying process will improve the knowledge level of the nurses, enabling them to communicate more information to the family about what to expect.

According to Peterson et al. (2010), specially trained palliative care nurses are comfortable caring for dying patients, but not all nurses have received palliative care training. Many hospitals do not offer palliative care nursing, so nurses care for dying patients without the expertise to do it. Raphael et al. (2014) stated that general practitioners are not comfortable caring for dying patients, so having established healthcare providers with training in EOL care will improve the care of the dying patient.

Peterson et al. (2010) stated that nurses get burned out when they are not adequately trained in caring for patients in certain situations, and, given a current nursing shortage, opportunities to prevent nurses from burnout must be identified early. Stress levels increase when nurses are not comfortable, and dying patients may cause additional stressors if nurses are not adequately educated. Nurses’ stress levels increase when dealing with the family of a dying patient (Adams, 2010). Adequate training can help improve communication and assist the nurse in utilizing appropriate terms during this stressful time (Corner, 2010).

During EOL, families have a multitude of questions and need explanation on what to expect as the patient experiences the stages of dying. Clear communication eases families' anxiety as the patient is dying. Blackford and Street (2012) stated that advanced communication and planning reduces families' stress during the dying process. According to Fernandez et al. (2012), nurses are challenged with being comfortable communicating with the family about death and dying in the acute care setting. The authors developed a tool to measure and assess communication techniques that were successful in improving communication with the families of dying patients. Communication is one of the concepts that guided the development of an educational program for this project.

Conceptual Models

Kolcaba's theory of comfort is a middle-range theory that provides support to promote end of life treatment. Kolcaba (1994) stated that comfort exists in three forms: ease, relief, and transcendence. The educational program implemented for this project involved educating nurses on each of these three stages of comfort. During the relief phase of the dying process, healthcare practitioners administer pain medication. Thus, ease is accomplished.

During the EOL, when nearing death, a patient may need comfort in the form of medication, repositioning, emotional support, spiritual support, financial assistance, and holistic care (Pattison et al., 2013). A patient may or may not have specific ideas or wishes at the EOL. A palliative care program provides the best care for the patient and family by providing a holistic approach to the death and the dying process (Pattison et al., 2013). Making EOL plans when a patient has a chronic or irreversible condition is important to ease the stress placed on the family and promotes conversation to address the wishes of the patient before the patient is unable to make decisions (Macaden et al., 2014). The long-term goal would be to create a palliative care program that addresses specific needs of the patient with evidence-based care.

Kolcaba (1994) defined comfort as satisfying the basic human needs. The rationale for choosing Kalcaba's comfort theory was that it addresses comfort, and one of the main concerns during the dying process is keeping the patient comfortable and free from pain. Comfort is a patient outcome and can be an outcome for the family, if the patient is unresponsive. The comfort theory supports nurses, physicians, patients, and families identifying the patient's needs during the illness and dying. Based on the identified needs, nurses should provide holistic care and outcomes should be measureable and nurse driven (Kolcaba, 1994). Nurses can measure comfort attainment by the perceptions from either the family or the patient. The family's and patient's perception of comfort determines whether the patient's comfort needs were met.

My role in the project included obtaining permission from the facility for the improvement project, communicating to staff about the program, and encouraging participation. I guided the project and communicated with all participants involved. Additionally, I endeavored to communicate clearly and precisely with the administration team, so there was a clear understanding of the process and the project. I reported follow up and progress to the administration on a regular basis.

Summary

This literature review revealed a lack of training among nurses related to EOL care. Existing research shows that educational programs are helpful in increasing knowledge of EOL care among nurses. The present quality improvement project could advance nursing practice by providing a more evidence-based approached to education on caring for dying patients. The literature review offered further support for the need for an EOL education program. Improving nurses' knowledge of EOL care could improve patient care during the dying process. Although there is scant literature regarding whether nurses should receive training specifically in EOL care, when they did receive such training, the care of the patients improved during the dying process. Providing education on EOL care fills the gap of the nurses needing education on caring for the dying patient. Section 3 contains a description of the approach to the project, including the rationale for the quality improvement project and the data collection and analysis procedures.

Section 3: Approach

Introduction

The purpose of this project was to address the lack of EOL care education among CCU nurses in an acute care hospital in Brownsville, Texas, by implementing and testing the efficacy of an EOL care educational program. I collected quantitative data consisting of participants' pretest and posttest scores on an assessment of EOL care knowledge. After collecting the data, I used graphs to present the data and to demonstrate the successful implementation of the educational program in improving the knowledge level of nurse participants. I obtained permission from the facility for the improvement project, communicated to staff about the program, and encouraged participation. Currently, I have no direct involvement with the institution; the setting for the project was a facility where I previously worked as the Chief Nursing Officer. The facility is within the corporation where I currently work, the HCA. My direct involvement in EOL care includes witnessing my mother die of cancer in a facility with a formalized palliative care program. I observed exceptionally well-trained nurses caring for her, and wanted to mirror the program within my organization. I identified a need for all patients who are dying to experience a peaceful death with evidence-based order sets and a palliative care program that includes specially trained nurses such as my mother experienced. This section contains a description of the approach, rationale, population, data collection, and data analysis of this study.

Approach and Rationale

This project used a one-group, pretest/posttest design. The hospital staff and administration directed the quality improvement project. Specific demographic data for the project was not obtained. The facility granted approval for the quality improvement project. Raya et al. (2013) stated that the one-group, pretest/posttest design is a good way to measure outcomes of an intervention. This design allowed a comparison of the before and after results of an assessment. The population consisted of all Registered Nurses employed in the CCU of a hospital in Brownsville, Texas; all received an invitation to participate in the project. The administration team and director of the CCU were supportive of the project and assisted in encouraging participation among the nursing staff, but participation was strictly voluntary. The nurses received payment at their regular hourly rate to complete the pre- and posttest questionnaires and to complete the 55-minute training course on Healthstream.

Healthstream is an online education tool that each nurse employed by the HCA can access. Healthstream was contacted, and the company responded that all their courses are evidence-based and sent a list of references for the EOL course used for this study. The purpose of Healthstream's EOL course is to provide nurses with education on caring for patients during EOL. The administrator of the Healthstream system assigned the course to all of the nurses in the CCU. The nurses had 30 days to complete the assignment. Nurses completed an electronic pretest questionnaire related to EOL care knowledge prior to completing the Healthstream EOL program. The Healthstream system administered the pretest questionnaire and measured the baseline knowledge of the participants. The system also administered a posttest questionnaire to nurses after they completed the 55-minute educational program. Participants could complete the program at their leisure, but the program was only available for 30 days.

After the educational program was implemented, a comparison was conducted of pretest and posttest scores to see if the nurses' level of knowledge of EOL care increased after the training was completed. Terry (2010) stated that pretest/posttest designs compare scores before intervention and after intervention to determine if an intervention is successful. Success was defined as a situation in which, after implementation, the participants' scores had significantly increased compared with their scores before implementation.

A limitation of the study was the small sample size and the lack of a control group, but the results demonstrated the intervention's effectiveness for the nurses who participated. With this design, it may be difficult to correlate causation to the intervention. Additionally, the posttest questionnaire may result in skewed data, because the participating nurses already knew what questions would be asked after the implementation of the EOL educational program. The hospital staff implemented the education as a staff development quality improvement project. Institutional Review Board (IRB) approval was completed from Walden University before data collection.

Educational Program

The Healthstream EOL education program is contained in Appendix A. It included the following topics:

- Basic care of the dying patient, including signs and symptoms as the patient progresses and the care the nurse should provide.
- Crucial conversations to improve communication with patient and family, including techniques on how to communicate with families regarding EOL and expectations of the healthcare team.

- Decision making during EOL, including advance directives and living will information.
- Techniques for providing emotional support to patient and family.
- Preparing the patient and family for death, including evidence-based order sets, comfort care medications, and support measures to keep the patient comfortable during the dying process. Learners are prepared to provide clear expectations to family members regarding the stages of death.

Population and Sampling

The population consisted of registered nurses in Brownsville, Texas, who worked in the CCU in a 214-bed acute care hospital. Thirty-eight nurses were on the unit and available to participate, and the hospital agreed to pay the nurse participants their hourly rate to complete the pretest, education, and posttest. Participants were recruited by sending all eligible nurses an e-mail describing the study and requesting participation. The e-mail contained a detailed explanation of the study, including what was expected from participants and what project involvement entailed. Participants could withdraw from participation at any time by e-mailing me or communicating with their nursing director.

The EOL education program took approximately 55 minutes to complete. To protect participants, responses were tracked using a unique 3- or 4-digit identification number that the Healthstream system assigned to them. The participants had 30 days to complete the educational program, and, after the program was completed, data was analyzed. The data are stored in my computer on a Healthstream-generated report. There was no demographic data collected on the nurses completing the project.

Data Collection

Walden University granted IRB approval 05-05-16-0482072 for this quality improvement project. Participants were protected by utilizing unique 3- or 4-digit identification codes created through the Healthstream program. These codes did not permit any association between the scores and the participants, so all information was confidential. The facility's management provided approval to implement the project. An e-mail was sent to the administrative team and nurse leaders introducing the educational training and asking the staff to participate in the educational program on EOL care. After obtaining administrative approval, an e-mail was sent to the CCU nurses to recruit participants. The e-mail contained a vote button; if they wanted to participate, they could click on the button, and the program then automatically created the list of participants. Then, the director of education at the facility assigned the Healthstream EOL care course to the participants. The facility implemented the program as a quality improvement project, so there was no need of additional budget.

The Healthstream system automatically sent an e-mail to each person on the list of participants to let the participants know the course was available and that the timeline for completion was 30 days. Using the Healthstream system, reports were generated weekly during the 30-day period to determine who had and had not completed the education. There were weekly e-mail reminders sent to participants who had not completed the educational program. After the 30-day period, data were collected of the pretest and posttest questionnaires and graphs generated to visualize whether nurses' knowledge of EOL care improved after they completed the educational program. The data were within the Healthstream program and stored in a secure location within

Healthstream. A unique identification code provided a facility director with access to the data. There is currently access to Healthstream, but not the administrative data. The director of education at the facility gave the student the data.

Instrument

The instrument selected for the project was the Healthstream EOL program. Healthstream is an online educational company that offers over 20,000 courses with specific needs of the healthcare industry in mind. Over 1,800 of the courses offer continuing education hours for nursing staff. Healthstream serves approximately 65% of hospitals in the United States and has over 4.4 million users. The program required a unique 3- or 4-digit identification code to log in to access the educational program. Many of the programs available are optional to employees, but administrators may assign additional educational programs as mandatory.

The Healthstream program is evidence-based; in a personal communication, the company claimed that it had tested the reliability of its courses, but that reliability and validity data were not available to the public (Deborah Lilly, personal communication, May, 2016). The Healthstream company annually reviews and updates materials, and each course undergoes a rigorous six-step validation process to ensure statistical reliability and compliance with statistical guidelines. Healthstream offers more than 125 validated and statistically reliable tests, according to www.healthstream.com (Healthstream, n.d.).

Data Analysis

Data analysis was completed by comparing the pretest and posttest results to see if the posttest scores were higher after the completion of the educational program. Graphs were created in Microsoft Excel to demonstrate the change in scores by percentage. Further, a comparison was done between the pre- and posttest scores. Healthstream stores all the data in the Healthstream database, which HCA manages. The data were available as a report from Healthstream; upon the completion of the program, each nurse could view her or his scores, and the Director of Education of the facility also had access to all scores. No demographic data were collected. The data will exist in the Healthstream database for a period of 5 years, after which the system will automatically delete them.

Summary

Providing adequate EOL care to patients and their families is important during the dying process. Education is an important component for addressing issues with the dying process. The implementation of an education program on EOL care could increase nurses' knowledge, thereby improving the experience for the family and the dying patient. This quality improvement project involved implementing a Healthstream EOL care program among CCU nurses in a hospital in Brownsville, Texas, with the goal of improving their knowledge of EOL care. The project was identified to determine whether the program was effective by administering pre- and posttests related to EOL care and analyzing the data to determine whether there was a statistically significant difference in scores after the completion of the training program. Clear data analysis is important in any improvement project. The approach to and rationale for the project enabled me to identify whether the project was successful based on the collection of the data and the data analysis. Section 4 includes an evaluation of the project, implications, strengths, limitations, and a discussion of my development and growth throughout the DNP program.

Section 4: Findings, Discussion and Implications

The purpose of this quality improvement project was to address the lack of EOL care education among CCU nurses in an acute care hospital in Brownsville, Texas, by implementing and testing the effectiveness of an EOL care educational program. Educating nurses in EOL care is important to ensure that nurses are comfortable caring for dying patients and to improve nurses' knowledge level in best practices of EOL care. Nurses must be competent and have education in caring for patients during EOL; otherwise the nurses may experience stress and burnout, and the patients may experience pain and discomfort. In this section, I present the findings of the project, showing an improvement in test scores after the implementation of an EOL care educational program.

Evaluation and Findings

During the first phase of the project, the Healthstream administrator assigned the EOL care educational program to the participants who volunteered to complete the program. The participants had 30 days to complete the pretest, educational program, and posttest. According to the Healthstream completion report, the participation rate was 58.62% (*n* = 34). All of the 34 respondents met the 30-day completion deadline. Of the participants who were invited to participate, 41.38% (*n* = 24) chose not to complete the program.

See Appendix B for the full set of data from all participants. The nurses scored higher on the posttest than pretest (Figure 1). The educational program improved the posttest scores compared with pretest scores. The pretest scores prior to any education ranged from 68% to 100% and the posttest scores ranged from 93% to 100% after the participants completed the EOL education through Healthstream. The improvement in the scores supports the conclusion that the education improved nurses' EOL care knowledge level.

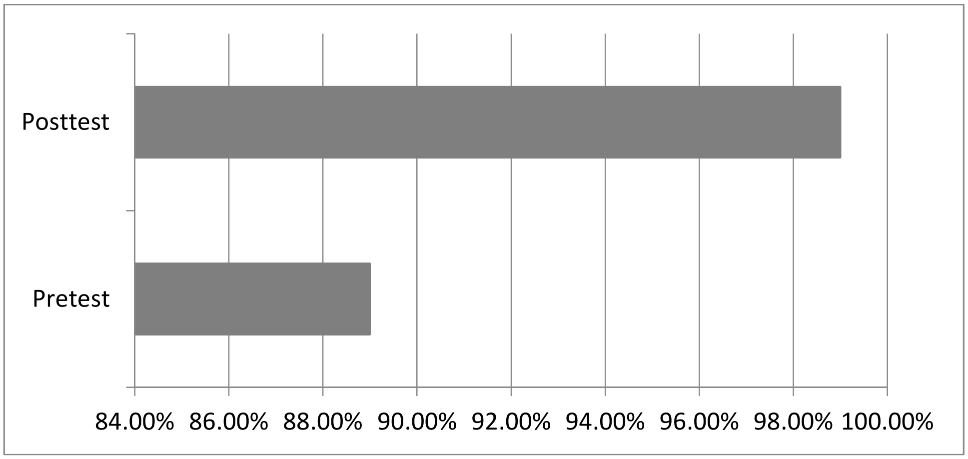

Figure 1. Pretest and posttest average scores on Healthstream knowledge test.

Implications

This project supports online EOL education as a way to increase EOL knowledge among nurses. The recommendation based on the project outcomes would be to assign the EOL program module to all newly hired registered nurses. This recommendation could ensure that nursing staff have increased knowledge on how to care for dying patients. Rather, the practice change would occur during the orientation phase, wherein new nurses in the areas of the hospital where care for patients during EOL is provided would receive the specialized training module. This training could benefit many nurses in caring for dying patients. The education could create social change in that patients and families could begin to expect expert nurses to care for their loved ones during the dying process. EOL education could become a new expectation for nursing staff, leading to better outcomes for patients and their families.

Strengths and Limitations of the Project

In this section, the apparent strengths and limitations of the project are described. There are opportunities to improve the project by analyzing the data and gathering statistics to be more precise. Several strengths and limitations are described below.

Project Strengths

The Healthstream module used in the improvement project was a strength of the study. Healthstream has tested and validated the module, and in many facilities across the country used it for nursing education. The program is easy to assign, and it is easy to track participation rates among staff. The Healthstream system provided data upon completion of the educational program in a secure manner. The educational program provided the CCU nurses in this study with an evidenced-based program on how to care for patients during EOL. The staff were comfortable utilizing Healthstream, because it is the current educational program available at the facility. It did not cost any additional money to use the program.

The second strength of the project was the ease of using the EOL care program itself. The program consisted of a video provided via Healthstream that walked the nurses through the educational program. The video assisted in educating the nurses on EOL care and lasted only 55 minutes from start to finish.

Project Limitations

The first limitation was the small sample size. The participants were recruited from one nursing unit, so there were only 34 participants. Other nursing units could have benefited from the project, but the focus was on one unit that often cares for dying patients. In the future, researchers could expand the project into other nursing areas to get a better sample size of participants.

A second limitation was that statistics such as length of time the nurse had been practicing or prior experience with dying patients was not collected. In future projects, researchers could collect data to see if nurses' scores on the test relate to the length of time they have been practicing nursing. A final limitation was that it was a one-group, pretest and posttest design with no control or comparison group.

Analysis of Self

Since I became a nurse over 17 years ago, my career has evolved, and I have become more interested in research and improving patient care. Three years ago, my mother died of lung cancer, and I had the privilege of having her in a hospital that had a formalized palliative care program. This experience is what drove my passion to improve care for dying patients. During the process of exploring what was lacking, nurses stated to me that they were not knowledgeable about caring for patients during the EOL. This realization has made me an advocate to ensure that nurses receive the tools they need to care for each patient they may meet.

As a chief nursing officer, I have often been involved with dying patients and their families; they often seek some clarity or direction regarding what to expect during the dying process. This has caused me emotional distress, because I know that nurses need specific tools to care for dying patients, but they are not receiving those tools through formal or continuing education. It is apparent that not all nurses receive adequate training to care for the patient during EOL. It is my passion to ensure that nurses receive this training in the future. I am determined to do all I can to improve the care delivered to dying patients.

The tool used in this study is available to all HCA facilities, and all nurses in HCA could complete the training today. HCA employs over 75,000 nurses at over 167 hospitals across the United States. Using educational material that is already in place is cost effective and can improve the nurses’ EOL care knowledge level. The DNP program has inspired me to become more scholarly and has motivated me to pursue this dream to improve the knowledge of nurses caring for patients during the EOL. The DNP program has given me the confidence I needed to pursue something that seemed so far from my personal reach and now is so attainable. After completion of my DNP project, I plan to recommend to HCA leadership that the company adopt the practice of providing all nurses with the module on EOL care.

Summary

This project demonstrated that the Healthstream EOL care educational program can improve nurses’ knowledge of EOL care. Not all facilities address EOL care, so there is an opportunity to improve the knowledge of nurses caring for dying patients. It is imperative that nurse leaders work to bridge this gap and address EOL care to meet patients’ EOL needs. Specific nurse education on EOL care could lead to better outcomes for patients and a higher knowledge level for the nurses caring for the dying patient.

Section 5: Scholarly Product

Project Dissemination

Nursing curricula do not contain comprehensive instruction on EOL care in order for nurses to have the best knowledge to care for dying patients. It is important that nurses receive specific training to care for patients during EOL. The patient and family have specific needs that nurses should address during the final days of life. Using an evidenced-based educational program to educate nurses improved the EOL care knowledge level of a sample of CCU nurses caring for the dying.

The findings led me to believe that educating nurses will improve care and clinical practice, promoting more knowledgeable care for the nurses in taking care of dying patients. I plan to disseminate this finding by advocating at HCA to utilize a Healthstream program already in place at all hospitals within the company. The first means of communicating the success of the project will be to the administrative team at the participating facility. It is important to relay the results to the team that allowed me to complete my project. The next step will be to present the results at the Chief Nursing Officer division council, where all CNOs meet monthly to address possible practice changes. I will create a poster presentation to display the results. I will use the poster at both the executive presentation and the CNO presentation.

After graduation, I would like to continue with data collection to expand the project. I would like to know the number of years that nurses have practiced and correlate results with the test scores. A further analysis of the scores based on years of tenure as a nurse could provide some insight into whether the nurses are learning how to care for dying patients after nursing staff has had the opportunity and exposure to care for the dying patient. It would be interesting to see if the knowledge level increases after a nurse has practiced nursing for a specific amount of time.

Scholarly Product

The scholarly product is a manuscript for publication, based on this project. The remainder of this section contains the manuscript.

Title: **Nursing Education: Caring for the Dying**

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Objective: To use an educational program provided through Healthstream to validate the increase in the knowledge level nurses caring for dying patients. The objective is to improve the knowledge level of the nurse caring for the patients of a Texas hospital during EOL.

Background: Not all nurses are comfortable caring for the dying patient (Cevik & Kav, 2013)**.** Nurses do not get enough specific training to care for the patient during EOL. Nurses who are educated on EOL are able to cope with the dying process and address the patient's needs more than the nurse who has not had the specific education. Nurses improved knowledge level will improve the care provided to the dying patient.

Method: The method was a one-group pretest, education, posttest design to assess the success of an online educational module in increasing nurse EOL knowledge. The participants took a pretest and received a score. They then completed an educational program on end-of-life care. Lastly, the participants completed a posttest. All of the project was completed within the Healthstream program.

Participants: The participants were CCU nurses from an acute care facility. The participants were all Registered Nurses who currently worked in the CCU ($n = 34$). The participation was voluntary for the nurses.

Results: Scores improved from pretest to posttest for all participants. The pretest scores prior to any education ranged from 68% to 100% correct answers and the posttest scores ranged from 93% to 100% correct answers

Conclusions: Based on the pretest and posttest evaluation process, scores did improve and the educational program was beneficial in increasing the knowledge level of the nurses. Implementing the EOL care educational module will improve the level of knowledge on caring for the dying patient.

Keywords: End-of-life care, evidence-based practice, medical intensive care unit, palliative care education, staff education and development

INTRODUCTION

Nurses are not comfortable caring for the dying patient due to lack of educational training (Cevik & Kav, 2013). There is not enough education provided in nursing school to prepare nurses to care for the dying patient. Caring for a patient requiring curative versus palliative care if extremely different and requires different education. Nurses who are educated on EOL care are more comfortable addressing the needs of the family and the dying patient. According to Broad et al. (2013), 54% of all hospital deaths occur in the acute care setting which supports the need for nurses to be comfortable managing the care of the patient during EOL. The quality improvement project to improve the knowledge level of the nurse would support a more cohesive approach to providing care to the dying patient. The improvement of support to the family and patient will provide a better dying experience and make the experience less difficult (Sleeman & Collis, 2013).

BACKGROUND AND OBJECTIVES

Nurses who are educated on providing EOL care are able to cope with the dying process and address the needs of the patient more than the nurse who has not had specific training in caring for a patient during EOL. Nurses who have been adequately trained on caring for the dying patient are more focused on the patient than just keeping the patient alive (Pattison, Carr, Turnock, and Olan, 2013).

The objective of the project was to utilize an educational program through Healthstream to measure the knowledge level of the nurse caring for the dying patient. Improving the knowledge level of the nurses caring for the patient during EOL can improve the care provided to the patient and family.

EDUCATIONAL PROGRAM EVALUATION

PROJECT METHOD

A literature review was completed and there is evidence that supports nurses are not adequately trained for EOL care are uncomfortable caring for the dying patient (Walter, 2012). There is a gap in the knowledge level caring for the patient during EOL. There is a lack of training and education provided to nursing staff during nursing school in caring for the dying patient.

METHODOLOGY

Participants:

The participants were selected from the single population in the CCU in an acute care facility. The participation was strictly voluntary and communicated to the participants via email. Emails were sent to recruit participants with a vote button at the top if they wanted to participate. The module was assigned to the participant list and communicated via email with the deadline date. The participants had 30 days to complete the pretest, educational program, and posttest. There was a 58.62% (*n* = 34) participation rate. All 34 participants met the 30-day deadline.

Evaluation Tool:

The evaluation tool that was used was the pretest and posttest that was utilized from the EOL program through Healthstream. The test consisted of 16 multiple choices questions. The same test was used for pretest and posttest. The participants received a score for each test that was taken. A comparison done between the pre and post scores to determine effectiveness. All questions required an answer. The participants could not skip any questions.

RESULTS

The posttest results did show an increase in test scores from the pretest. The data was pulled from the Healthstream reports with the test scores. The mean score was 89% prior to the education and after the education the mean score was 99%, which demonstrated an increase in the knowledge level of the nurse.

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Appendix A: Educational Program

HealthStream Acute Care Regulatory Script

End-of-Life Care

Release Date: May 2014 HLC non-PA Version: 604 HLC PA Version: 604
Courseware Exchange Copy Version: 2

Lesson 1: Introduction
Lesson 2: Definitions: Palliative
Care, End-of-Life Care, Hospice
Care Lesson 3: Guidelines for
the Care of the Dying Patient
Lesson 4: Ethical and Legal Issues
Lesson 5: Addressing the Needs of the Family

Lesson 1: Introduction

1001

Introduction	
Welcome to the introductory lesson on end-of-life care. *As your partner, HealthStream strives to provide its customers with excellence in regulatory learning solutions. As new guidelines are continually issued by regulatory agencies, we work to update courses, as needed, in a timely manner. Since responsibility for complying with new guidelines remains with your organization, HealthStream encourages you to routinely check all relevant*	

regulatory agencies directly for the latest updates for clinical/organizational guidelines.

If you have concerns about any aspect of the safety or quality of patient care in your organization, be aware that you may report these concerns directly to The Joint Commission.

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2

Course Rationale

Death can be frightening. This can be especially true for patients in the terminal stages of chronic disease. These patients often wish for a "good death." However, they often fear that they will die alone, in pain, abandoned by their caregivers.

Clinicians must provide excellent end-of-life care to all dying patients.

In this way, healthcare providers can:

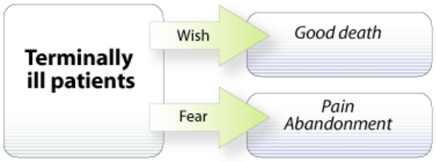
- Help patients have a "good death"
- Calm the fears of dying patients
- Support the patient's family

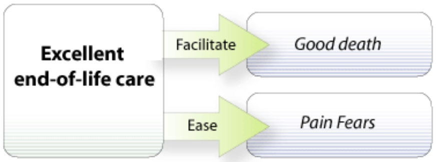
This course will teach you how to

provide excellent end-of-life care.

You will learn about:

- Palliative care, end-of-life care, and hospice care
- Guidelines for providing end-of-life care according to a patient's wishes for a "good death"
- Ethical and legal considerations at the end of life
- Guidelines for helping loved ones when a patient is dying





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Course Goals

After completing this course, you should be able to: • Differentiate palliative care, end-of-life care, and hospice care as they relate to patients in an acute care setting. • Apply discussed methods of quality care to a patient at the end of life in an acute care setting. • Identify ethical and legal issues related to the end-of-life care in an acute care setting.	NO IMAGE
	Page 3 of 4

Course Outline	
This introductory lesson gave the course rationale and goals. Lesson 2 presents definitions and background information on end- of-life care. Lesson 3 presents guidelines for provision of care to the dying patient. Lesson 4 discusses ethical and legal considerations at the end of life. Finally, lesson 5 describes practices and guidelines for addressing the needs of the family when a patient is dying.	Lesson 1: Introduction Lesson 2: Definitions: Palliative Care, End-of-Life Care, Hospice Care • **Palliative care** • End-of-life care • Hospice care Lesson 3: Guidelines for Care of the Dying Patient • Interdisciplinary Care Team • Physical Care • Psychosocial Care • Spiritual Issues • Cultural Aspects of Dying • Imminent Death Lesson 4: Ethical and Legal Issues • Patient self-determination • Advance directives Lesson 5: Addressing the Needs of the Family • Communication • Caregiver support • Grief and bereavement
	Page 4 of 4

Lesson 2: Definitions: Palliative Care, End-of-Life Care, Hospice Care

2001

Introduction	
Welcome to the background lesson on palliative care, end-of-life care, and hospice care.	Lesson 2: Definitions: Palliative Care, End-of-Life Care, Hospice Care

- Palliative care
- End-of-Life care
- Hospice care

Page 1 of 12

Palliative Care

Clinical Practice Guidelines for Quality Palliative Care states:

"The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies."

This definition is consistent with those of the Centers for Medicare and Medicaid Services (CMS) and the World Health Organization (WHO).

References 1-3

"Palliative care focuses on quality of life."

Page 2 of 12

Palliative Care

Palliative care is appropriate at any stage of illness, be it early or late. In addition, it may be provided:

- In conjunction with therapy aimed at prolonging life
- When curative therapy [glossary] has been discontinued

Palliative care ideally bthegins with the diagnosis of a serious illness and continues until it is cured or death occurs.

Reference 1

Page 3 of 12

End-of-life Care

The final phase of life is difficult to define and may last hours to years. Any care focused on the issues surrounding this phase may be termed end-of-life care.

Palliative care is appropriate at the end of life, but is not exclusive to this stage.

End-of-Life Care Palliative Care

Reference 4

Page 4 of 12

Hospice Care

Hospice is a philosophy and a system that provides palliative care for a patient with a terminal illness.

Hospice care is typically initiated when the patient's life expectancy is six months or less.

Reference 2

.

End-of-Life Care Palliative Care Hospice

Page 5 of 12

Hospice Care

Hospice focuses on dying pain free and with dignity. Care may be provided in:

- The patient's home
- A freestanding hospice center
- A hospital
- A long-term care facility

Hospice care is covered under Medicare, Medicaid, and many forms of health insurance.

References 2, 5

Hospice and palliative care involve:

- Team-oriented approach
- Pain and symptom management
- Emotional and spiritual support to the person and his or her loved ones

Page 6 of 12

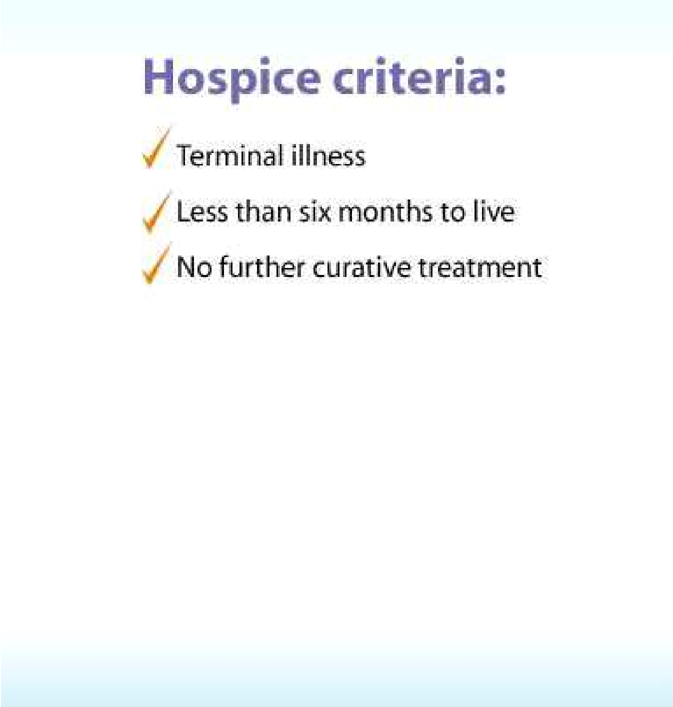
Hospice Care

For a patient to qualify for the Medicare Hospice Benefit:

- The patient must have a terminal illness.
- A medical professional must certify that the patient has no more than six months to live.
- The patient must agree

to give up all curative

treatment. Reference 6



Hospice criteria:

✓ Terminal illness

✓ Less than six months to live

✓ No further curative treatment

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Hospice Care

Hospice myths:

- **You have to have cancer to be in hospice.**
- **After 6 months, you are no longer eligible for hospice.**
- **You will lose your doctor if you elect hospice.**
- **Once you begin hospice care, you cannot return to curative treatment.**

Click on each myth to

reveal the facts.

References 6, 7

CLICK TO REVEAL

- **You have to have cancer to be in hospice.**
  In 2007 about 43% of patients admitted to hospice had a cancer-related diagnosis. About 11% had heart and circulatory diseases, 7% had dementia, 5% were admitted with chronic obstructive pulmonary disease (COPD) or other related disorders, and 4.5% were admitted with cerebrovascular disease.

- **After 6 months, you are no longer eligible for hospice.**
  If the patient lives beyond the initial 6 months, he or she can

continue to receive hospice care as long as the physician certifies that the patient is terminally ill.

- **You will lose your doctor if you elect hospice.** Hospices work closely with the primary physician and encourage the patient-physician relationship.

- **Once you begin hospice care, you cannot return to curative treatment.** Patients have the right to restart aggressive treatment at any time.

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Palliative Care: What and Why

Remember: The goals of palliative care at the end of life are to:

- Comfort, not to cure
- Increase quality of life

Comfort means:

- Controlling pain and other physical symptoms
- Treating the patient with dignity
- Respecting the patient's cultural beliefs around death and dying
- Respecting the patient's wishes not to receive life- sustaining treatments that do not improve the quality of life
- Meeting the patient's psychological and spiritual needs
- Meeting the patient's social and

interpersonal needs In short, palliative care

treats the whole person.

The goal is to give the patient the highest possible quality of life during his or her final days, weeks, or months.

Reference 1

Page 9 of 12

2010

Palliative Care: Where	
A patient may receive end-of-life palliative care: • In the hospital • At home • At a nursing home • At a dedicated hospice facility Hospice can give palliative care in any of these settings. In hospitals and other healthcare facilities, all clinical staff should know how to provide palliative care. This ensures that all patients will have excellent end-of-life care, whether or not they have hospice. Many organizations have developed palliative care teams. They can direct a patient’s care and provide expertise about end-of-life issues. For the remainder of this course, the term “palliative care” will refer to palliative care at the end of life. Reference 1	
	Page 10 of 12

Review	
Select the answer that best fits the question. Hospice workers visit hospitalized patients. Therefore, core hospital staff do not need to be knowledgeable about palliative care. • True • False	Correct: B Feedback for A: Incorrect. This statement is false. All clinical staff should know how to provide palliative services. This ensures that all patients who die in hospitals will have excellent end-of-life care, whether or not they have hospice. Feedback for B: Correct. All clinical staff should know how to provide palliative services. This ensures that all patients who die in hospitals will have excellent end-of-life care, whether or not they have hospice.
	Page 11 of 12

Summary	

You have completed the lesson on palliative care, end-of-life care, and hospice care.

Remember:

- The primary goal of palliative care is comfort and quality of life.
- Palliative care treats the whole person. Therefore, the care team must be interdisciplinary.
- Hospice care is palliative care given at the end of life.
- All clinical staff should know how to provide excellent palliative care.

NO IMAGE

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Lesson 3: Guidelines for Care of the Dying Patient

3001

Introduction

Welcome to the lesson on care of the dying patient.

This lesson will address the domains of quality end-of-life palliative care. This includes the interdisciplinary care team, physical aspects of care, psychosocial and emotional support, and cultural aspects of dying. The state of imminent death will also be discussed.

Lesson 3: Guidelines for Care of the Dying Patient

- Interdisciplinary Care Team
- Physical Care
- Psychosocial Care
- Spiritual Issues
- Cultural Aspects of Dying
- Imminent Death

Page 1 of 25

Interdisciplinary Team

Remember: Palliative care treats the whole person. Therefore, the care team must be multidisciplinary [glossary].

Members of the care team may include:

- Physicians
- Nurses
- Pharmacists
- Social workers
- Counselors
- Clergy
- Physical therapists
- Occupational therapists
- Music therapists
- Art therapists
- Dietitians

- Speech and language pathologists
- Volunteers

References 1, 8

Page 2 of 25

Interdisciplinary Assessment

The members of the team should assess the patient for:

- Appropriateness for end-of-life care. This includes documentation of disease status, prognosis, and patient and family goals.
- Presence of physical symptoms.
- Presence of psychological and psychiatric issues.
- Status of the patient's social network and needs.
- Spiritual and religious needs.

This team must function in a way that is sensitive to the cultural aspects of each patient's family and community.

Reference 1

Page 3 of 25

3004

Improving Communication

Certain approaches can help clinicians communicate with patients near the end of life.

These approaches include:

- **Begin with open-ended questions [glossary].**
- **Follow up on the patient's initial responses by asking more questions. Use the patient's own words.**
- **Move on to specific questions about palliative care and other end-of-life choices.**
- **Ask direct questions about the patient's symptoms.**

CLICK TO REVEAL

Begin with open-ended questions.
Open-ended questions can help you:

- Understand the patient's view of his or her illness or prognosis
- Identify the patient's values, concerns, and goals for care

Follow up on the patient's initial responses by asking more questions. Use the patient's own words.
This method:

- Shows the patient that you are listening
- Shows the patient that you understand his or her viewpoint
- Encourages the patient to share additional concerns, feelings, fears, etc.

Click on each method to learn more. References 1, 8	**Move on to specific questions about palliative care and other end-of-life choices.** Ask about: • Home care vs. hospital care at the end of life • Use of life-sustaining treatment • Any specific concerns and fears the patient has shared **Ask direct questions about the patient's symptoms.** To give appropriate palliative care, you must know your patient's symptoms. Screen for: • Pain • Fatigue • Shortness of breath • Symptoms of the illness • Depression
	Page 4 of 25

3005

Improving Communication	
Other approaches for communication include: • **Try a less direct approach to screening for distress.** • **Involve the family.** • **Make sure all terms are clearly defined and understood.** Click on each method to learn more. References 1,8	CLICK TO REVEAL **Try a less direct approach to screening for distress.** Some patients will not give useful answers to direct questions about symptoms and concerns. You may need to take an indirect approach. For example: • Ask the patient how family members are dealing with his or her illness. • Ask the patient how friends or family members have dealt with a similar illness. **Involve the family.** Ask the patient for consent to include family members in the conversation. Family members often raise additional issues or concerns. **Make sure all terms are clearly defined and understood.** To avoid any misunderstandings: • Do not use jargon [glossary]. • State diagnoses, prognoses, and care options clearly.

	• Define any terms that may be unfamiliar to patients.
	Page 5 of 25

3006

Review	
Select the answer that best fits the question. Good communication involves which of the following: • Using open-ended questions • Involving all the appropriate people in the discussion • Avoiding jargon and unfamiliar words • Restating items discussed in the patient's own words • All of the above	Correct: E Feedback for A: Incorrect. This is important, but so are all the other choices. The correct answer is E, all of the above. Feedback for B: Incorrect. This is important, but so are all the other choices. The correct answer is E, all of the above. Feedback for C: Incorrect. This is important, but so are all the other choices. The correct answer is E, all of the above. Feedback for D: Incorrect. This is important, but so are all the other choices. The correct answer is E, all of the above. Feedback for E: Correct. All of these techniques improve communication.
	Page 6 of 25

Physical Symptoms	
Pain is a common problem in patients experiencing a life-limiting illness. Pain level is sometimes called the fifth vital sign, and regular assessments of pain status should be performed. These should be repeated on a regular basis, if there is a complaint or appearance of pain, and after any treatment for pain. An objective measure of pain may be useful. A Visual Analog Scale is one such tool. References 1, 9	
	Page 7 of 25

Pain Treatment

Multiple options for treating pain exist. Nonpharmacologic pain treatment: • Acupuncture • Heat and/or ice • Massage • Transcutaneous Electrical Nerve Stimulation (TENS) • Distraction: music, art, movies, reading, audio books • Hypnosis • Aromatherapy • Complementary and alternative therapies • Radiotherapy Pharmacologic pain treatment that may be ordered includes: • Nonsteroidal anti-inflammatory drugs (NSAIDS) • Opioids • Bisphosphonates (specifically for bone pain) References 9, 10	

Dyspnea

Dyspnea at the end of life may be effectively treated with opioids, as ordered. In addition, oxygen therapy or inhaled beta agonists [glossary] may also be ordered in certain cases, especially COPD.

Reference 9

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Nausea

Nausea may be a result of the disease process or medication side effect. Many pharmacologic agents may be ordered to treat nausea and vomiting. If one is necessary, the physician may order a single medication or a combination of agents, based on the cause(s) of the symptom.

Oral administration may prove challenging; therefore, the physician may order these drugs to be given as rectal suppositories, subcutaneous infusions, intravenous or intramuscular injections, and orally disintegrating tablets, as available.

References 11, 12

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Other Symptoms

Other symptoms such as fatigue, weakness, loss of appetite, insomnia, and constipation should

be evaluated and addressed with the physician as necessary. Reference 1	
	Page 11 of 25

Psychological Care	
Psychological issues are commonly brought about by the losses and stress associated with a life-limiting illness. Think about some things that patients may lose as they face the end of life, and enter them here: Now click submit to reveal some possible answers. References 1, 13	FEEDBACK Patients at the end of life may experience loss of: • Health • Independence • Relationships • Money • Bladder control • Bowel control • Appetite • Weight • Control Related to these losses, anxiety, depression, delirium [glossary[, and anticipatory grief [glossary] may all be present. These should be addressed in a sensitive and caring manner.
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Psychiatric Care

Both pharmacologic and non-pharmacologic therapies may be effective for anxiety or depression.

Some options that may be ordered include:

- Cognitive Behavioral Therapy [glossary]
- Tricyclic antidepressants [glossary]
- Selective serotonin reuptake

inhibitors [glossary] References 1, 9

Social Aspects of Care

The patient's and family's social needs should be identified and addressed as needed.

This may include family relationships, social support, work and school situations, finances, caregiver availability and ability.

Particular attention needs to be paid to children and their needs, whether they are patients or loved ones of a patient.

References 1, 14

Spiritual Care

The end of life often brings about spiritual concerns. This may include life review and thoughts about meaning and purpose, as well as beliefs about afterlife and what comes next. Guilt and forgiveness are common themes.

An appropriate professional, such as a chaplain or clergy member, should be available for the patient and his or her loved ones to address these issues as necessary.

Reference 1

Page 15 of 25

Review

Select the answer that best fits the question.

Drugs should always be the first choice when treating physical symptoms or psychiatric disorders in those at the end of life.

- True
- False

Correct: B

Feedback for A: Incorrect. Non-pharmacologic options should be considered initially for treating pain, anxiety, depression, and other symptoms.

Feedback for B: Correct. This statement is False. Non- pharmacologic options should be considered initially for treating pain, anxiety, depression, and other symptoms.

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Cultural Aspects of Care

Palliative care at the end of life should address the patient, family, and their community in a culturally sensitive manner.
This includes assuring that:

- Cultural background, concerns, and needs are explored.
- All communication with the patient and the family is respectful of cultural preferences regarding disclosure and decision-making.
- All communication occurs in a language and manner the patient and family understand, utilizing interpreters as needed.
- Ritual practices

are respected and

accommodated.

Reference 1

COMMUNICATE

Communication is key to understanding a patient's desires.

Cultural Aspects of Care

Remember: Healthcare providers must understand what their patients need and want near the end of life.

This requires good communication.

To improve communication with a patient from a different culture:

- Educate yourself about the patient's culture. Use what you learn as a guide. However, be careful not to stereotype the patient.
- Allow the patient to reveal his or her values, beliefs, concerns, fears, and goals for care. Do not impose your beliefs and biases.

- When necessary, use a medical translator. Translators can be particularly useful when discussing end-of-life care. They often know acceptable euphemisms [glossary] for taboo words and subjects.

References 1, 15

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Cultural Competence

There are many cultural norms and taboos [glossary] around death and dying.

For example, a patient's culture may:

- Forbid the use of certain types of life support
- Dictate that a patient should not be told of a terminal diagnosis
- Require that a patient die at home
- Forbid all talk of death or dying. Speaking of death may be thought to cause death
- Specify a particular family member to make all healthcare decisions for the family

Clinicians must be aware of their patient's cultural norms and values around death and dying. Otherwise, they risk losing their patient's trust. They also risk distressing their patients by:

- Breaking taboos
- Providing unwanted or improper

end-of-life care Reference 16

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3020

Review	
Select the answer that best fits the question. Which statement is **incorrect**? • Palliative care should address the patient and his or her community in a culturally sensitive manner. • It is important to avoid the trap of treating others based on stereotypes. • Patients of all cultures should be told directly exactly what their diagnosis is	Correct: C Feedback for A: Incorrect. This is a correct statement. Feedback for B: Incorrect. This is a correct statement. Feedback for C: Correct. This is an incorrect statement. In some cultures,

and how much time they have left to live. - It is wise to learn all you can about the culture of the people with whom you are interacting.	discussion of death and dying with patients is inappropriate. Feedback for D: Incorrect. This is a correct statement.
	Page 20 of 25

Imminent Death	
Signs and symptoms of impending death should be recognized and communicated with respect to family preferences. An actively dying patient may: • Lose interest or ability to eat or drink • Sleep more • Develop delirium • Become difficult to arouse • Have an altered breathing pattern with irregular breathing and periods of apnea [glossary] • Have pooling of oral secretions creating noisy, rattled breathing • Run a fever • Slip into a coma • Show mottling of the extremities • Have glassy, unseeing eyes • Have a lowered heart rate and blood pressure • Develop cool, clammy skin This stage may last a few hours or as long as 2 weeks. References 17, 18	NO IMAGE
	Page 21 of 25

Imminent Death	
At this point it is appropriate to consult the physician in regards to discontinuing anything that does not contribute to comfort, such as: • Pulse oximetry • IV lines • Antibiotics • Finger sticks • Frequent vital signs • Lab tests	

Particular attention must be paid to oral and skin care for a patient who is actively dying.

References 18, 19

Death

Death is often heralded by what is thought to be the last breath followed by one or two long spaced breaths. The absence of cardiac and respiratory activity signals death.

Reference 18

After Death

Post-death care should be undertaken in a respectful manner allowing the loved ones their freedom to respond according to their cultural and religious beliefs.

Some activities that may be appropriate include:

- Providing a quiet room
- Bathing the body
- Changing linens
- Provi

ding time and

space to

grieve

Reference 1

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Summary

You have completed the lesson on care of the

dying patient. Remember:

- An interdisciplinary team can treat the whole person.
- Pain, dyspnea, nausea, and other symptoms should be monitored and treated, as ordered.
- Psychological issues should be addressed by the appropriate members of the team.
- The patient and family’s social situation should be assessed and assistance offered where needed.
- Spiritual and religious needs should be met as best as possible.
- All care should be provided with attention to the cultural background of those involved.

NO IMAGE

- The actively dying patient has a somewhat consistent trajectory of signs and symptoms. - Comfort and dignity are the goals for death and the post- death period.	
	Page 25 of 25

Lesson 4: Ethical and Legal Issues

4001

Introduction	
In this lesson, we will discuss some ethical and legal issues relevant to the end of life, including medical decision making, patient autonomy, surrogate decision makers, discussing prognosis, and advance directives [glossary].	Lesson 4: Ethical and Legal Issues - Patient self-determination - Advance directives
	Page 1 of 10

Medical Decisions	
Many complicated and difficult decisions may be necessary during a terminal illness. Some examples are: - The level of aggressiveness of diagnostic and therapeutic procedures such as surgery, radiation treatments, or chemotherapy. - Where to receive care such as in the hospital, at home, or at a nursing facility - Whether to have cardiopulmonary resuscitation (CPR) - Whether or not to donate organs or tissues - How to pay for healthcare - Use of a ventilator - Use of antibiotics and other drug treatments - Use of tube feeding and hydration - Utilization of blood transfusions - Consideration of dialysis Reference 8	Advance Care Planning Involves: - **Informed consent** - Documenting wishes - Identifying a surrogate decision maker
	Page 2 of 10

Medical Decisions	
Communication about these decisions should be with the patient unless:	

- The patient is not competent.
- He or she has delegated the responsibility to a surrogate.
- Culture or religion dictates an alternate course of action.

In these cases, the patient’s proxy decision maker should be consulted.

This person should attempt to make choices based on what the patient would want, and with his or her best interests at heart.

Reference 8

Prognosis: Time Left

People often do not like to answer the question, “How much time do I have left?” However, patients need this information to make important decisions.

The answer can never be exact or certain.

Remember: **Patients often need and want this information.**

Therefore, physicians often provide an estimate. They explain that predictions of “time left” are always uncertain. This is especially true:

- For prognoses beyond three to six months
- If multiple health factors are involved
- If the clinician making the prediction is inexperienced
- If the prognosis is for a disease other than cancer

Do your best to reassure the patient that he or she will not be abandoned and that comfort is a priority.

Reference 20

Page 4 of 10

Personal Goals for End-of-life Care

Once the patient knows his or her prognosis, the next step is for the patient to decide on personal end-of-life care goals.

This often requires input or help from healthcare providers and family members.

The patient may consider goals such as:

- Managing pain and other physical symptoms
- Taking care of psychological, spiritual, or social issues and concerns
- Avoiding unwanted postponement of dying
- Maintaining control over the course of care by completing an advance directive
- Creating a comfortable inpatient environment
- Returning home
- Avoiding future

hospitalization Reference

20

Page 5 of 10

Review

Select the answer that best fits the question.

A terminally ill patient asks, “How much time do I have left?” A straightforward answer to this question can help the patient:

- Prepare psychologically for death
- Make informed treatment decisions
- Set personal goals for end-of-life care
- All of the above
- None of the above

Correct: D

Feedback for A: Not quite. The best answer is D. Many clinicians prefer not to give estimates of “time left.” However, knowing their “time left” can help patients make treatment decisions, set goals for end-of-life care, and prepare psychologically for death.

Feedback for B: Not quite. The best answer is D. Many clinicians prefer not to give estimates of “time left.” However, knowing their “time left” can help patients make treatment decisions, set goals for end-of-life care, and prepare psychologically for death.

Feedback for C: Not quite. The best answer is D. Many clinicians prefer not to give estimates of “time left,” However, knowing their “time left” can help patients make treatment decisions, set goals for end-of-life care, and prepare psychologically for death.

Feedback for D: Correct. Many clinicians prefer not to give estimates of “time left.” However, knowing their “time left” can help patients make treatment decisions, set goals for end-of-life care, and prepare psychologically for death.

Feedback for E: Incorrect. The best answer is D. Many clinicians prefer not to give estimates of “time left.” However, knowing their “time left” can help patients make treatment decisions, set goals for end-of-life care, and prepare psychologically for death.

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Advance Directives

Patients often do not explain what they need and want near the end of life, because they think that their family, friends, and doctor already know.

In fact, family members and physicians often do not know what patients need and want.

Therefore, encourage **all** adult patients to complete an advance directive [glossary]. This could be a living will or a healthcare power of attorney.

An advance directive helps ensure that a patient’s wishes for end- of-life care will be respected, whenever the time comes.

References 1, 8

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4008

Advance Directives

Advance directives cover issues such as: • Identifying a decision maker if the patient is no longer able to make his or her own choices • Do Not Resuscitate (DNR) options • Intubation and mechanical ventilation choices • Use of antibiotics • Use of tube feeding and artificial hydration All patients should be encouraged to discuss their wishes with loved ones and care providers. • A Five Wishes or Physician Orders for Life-Sustaining Treatment (POLST) or other living will document can facilitate such discussions. References 19-21	NO IMAGE
	Page 8 of 10

Review	
Select the answer that best fits the question. A patient has a prognosis of less than six months to live. Communicate effectively with this patient by: • Reassuring the patient that he should not give up hope for a full recovery • Informing the patient of his prognosis using medical and technical jargon • Strongly encouraging the patient to enroll in clinical trials of a promising new drug • Asking open-ended questions to help identify the patient's values, concerns, and goals for care	Correct answer: D Feedback for A: Incorrect. Clinicians often wish to keep hope alive. However, it is important to provide accurate information, rather than false hope. The correct answer is D. Ask open-ended questions to find out what the patient needs and wants. Feedback for B: Incorrect. Jargon may make it easier for the clinician to talk about death and dying. However, the patient needs clear and accurate information that he can understand. The correct answer is D. Ask open-ended questions to find out what the patient needs and wants. Feedback for C: Incorrect. This is not the best answer. The patient may wish to try an experimental drug. However, this should not be the first topic of conversation. The best answer is D. Ask open-ended questions to find out what the patient needs and wants. Feedback for D: Correct. Ask open-ended questions to find out what the patient needs and wants.

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Summary

You have finished the lesson on ethical and legal issues relevant to end-of-life care.

Remember:

- The healthcare team should communicate with the patient whenever possible and appropriate.
- If unable to do that, the healthcare team should communicate with the patient's proxy decision maker.
- The surrogate should act in the patient's best interest and try to make choices as the patient would make them.
- Advance directives like Five Wishes and POLST can make these difficult and complicated situations easier.

NO IMAGE

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Lesson 5: Addressing the Needs of the Family

5001

Introduction

Welcome to the lesson on addressing the needs of the dying patient's family.

In this lesson, we will discuss practices and guidelines for addressing the needs of the loved ones when a patient is dying.

Lesson 5: Addressing the Needs of the Family

- Communication
- Caregiver support
- Grief and bereavement

Page 1 of 24

Palliative Care and the Family

Palliative care recognizes that death does not happen in a vacuum. Instead, death and dying have far-reaching consequences. The patient's family and social network are profoundly affected.

Therefore, end-of-life care must consider the needs of the patient as well as his or her loved ones.

References 1-3

Page 2 of 24

Caregiver Needs: Education

Family members or friends often assume the role of caregiver for patients at the end of life. In the United States, caregivers spend an average of 18 hours per week caring for their loved one.

Clinicians must remember that caregivers need to be active partners in the patient's care.

They should be part of:

- Planning care
- Implementing the plan of care

In order to successfully participate, caregivers need to understand what the patient needs and why. Education is essential for caregivers of patients at the end of life.

Reference 22

Page 3 of 24

Caregiver Needs: Physical and Emotional

Caring for a dying patient can be fulfilling for a caregiver. However, it can also be stressful.

Caregivers at the end of life may experience:

- Extreme emotional burden
- Physical strain
- Financial strain
- Strained family relationships
- Disrupted activities

These strains can lead to:

- Guilt
- Sadness
- Anger
- Resentment
- Feelings of inadequacy

Clinicians can provide needed support to caregivers. This can lessen the burden of caring for a dying patient.

Reference 22

	Page 4 of 24

Addressing Caregiver Needs	
Remember to reassure caregivers that you are committed to helping the patient remain: • As independent as possible • Free of distressing symptoms You also can address caregiver needs by: • **Providing needed education** • **Supporting caregivers** Click on each for specific suggestions. Reference 22	CLICK TO REVEAL **Providing needed education** Caregivers should be educated about: • The patient's disease • What to expect • How to care for the patient • What supports are needed • How to advocate for the patient • How to get needed help for the patient • How to manage the patient's pain and other symptoms • How to respond to medical situations • When to call a provider and whom to call **Supporting caregivers** Clinicians can support caregivers by: • Encouraging them to maintain their health • Listening to their feelings, concerns, hopes, etc. • Knowing where to find needed resources • Encouraging them to delegate responsibilities

	Page 5 of 24

Shared Experiences	
Caregivers and healthcare providers may share experiences related to caring for a person who is dying. These include: • Feeling powerless to help • Witnessing suffering • Watching the patient decline • Experiencing loss of a patient or loved one • Seeing unmet patient needs and wishes • Realizing the reality of death • Frustrations or difficulties with communication • Dealing with uncertainty Being aware of and sensitive to these issues can help you be empathetic and supportive.	**Caregivers and healthcare providers may have common reactions to a dying patient.**

Reference 23

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Needs of the Family

When a person is dying, some needs of the family may include:

- To be with the person
- To be helpful to the person
- To be informed of the person’s changing condition
- To understand what is being done to the patient, and why
- To know the patient is comfortable
- To express their emotions and be comforted
- To find meaning in the death of the person

On the following screens, let’s take a look at some practices that can help you address each of these needs.

References 22. 23

NO IMAGE

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To Be With the Person

When patients die in hospitals or other facilities, staff should encourage and support the presence of family members.

If at all possible, the patient should be placed in a private room. This allows the patient to have physical and emotional intimacy with family members.

Restrictions on visiting hours should be relaxed as much as possible. Clinicians should be prepared for large groups at the bedside.

If the death involves withdrawal of life support, the withdrawal should be planned (if appropriate and practical) so that distant family members have enough time to arrive.

During withdrawal of life support, distractions and barriers should be removed. Unless it is against organizational policy:

- Monitors should be turned off.
- Leads, cables, and catheters should be removed.

NO IMAGE

- Bedrails should

be lowered. Reference 22

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To Be With the Person

Consider providing simple amenities [glossary]. This can help make the family's stay more comfortable.

A pager or cell phone can allow family members to leave the bedside briefly, without fear of missing the patient's last moments.

Other amenities include:

- Tissues
- Chairs
- Blankets/pillows
- Coffee
- Water
- Telephone

Reference 22

Page 9 of 24

To Be Helpful to the Person

Family members often have a strong desire to be helpful to the dying person. This is especially true of parents of a dying child.

Allow family members to be helpful by teaching them how to perform:

- Mouth care
- Bathing
- Repositioning
- A pain assessment

Also, encourage family members to bring meaningful personal articles that might comfort the patient psychologically.

Reference 22

Page 10 of 24

To Be Informed of the Person's Changing Condition

Healthcare providers should take the time to explain the process of dying to family members. This should include a clear description of:

- How the patient will die
- What the process of dying will look like

Clinicians often need to anticipate and answer questions that family members are unable to put into words.

References 1, 22

Describing Imminent Death

It is especially important to describe the signs and symptoms of imminent death. As discussed before, these include:

- Decrease in consciousness
- Increase in confusion or restlessness
- Visions or hallucinations
- Changes in breathing sounds or patterns
- Cool or bluish arms or legs
- Inability to respond to touch or sound

Family members often wish to be present in the final moments of the patient's life. Describe the above signs and symptoms to these family members both:

- **Before** the signs develop
- **As** the signs develop

This ensures that family members will not leave the bedside at a critical moment.

References 1, 18, 22

To Be Informed of the Person's Changing Condition

Remember: Family members should be informed about the process of dying.

However, avoid making firm predictions about a patient's exact clinical course.

These predictions are:

- Difficult to make
- Often inaccurate

When a loved one is dying, family members need to feel the utmost trust in the knowledge, expertise, and competence of the care team. Inaccurate predictions about a patient's death can cause family members to lose trust.

Reference 21

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To Understand What Is Being Done to the Person and Why

All members of the care team should give the family consistent information about the patient's care.

In most cases, it is best to choose a single member of the care team to communicate all messages. This helps prevent any mixed messages.

Reference 22

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To Understand What Is Being Done to the Person and Why

Some clinicians have concerns that communicating with family members violates the Health Insurance Portability and Accountability Act (HIPAA) privacy rules. However, this is generally not the case. Informal permission by asking, or by circumstances, may be used in the following scenarios:

- A provider may share information with family members when the clinician believes, in his or her best professional judgment, that doing so would be in the best interest of the patient. This includes communicating that death is imminent.
- A provider may discuss treatment with the patient in the presence of family members or friends as long as the patient does not object.
- If consistent with professional judgment, a clinician may discuss an incapacitated patient's condition with a family member at the patient's bedside, or over the phone.
- A consent form is not necessary for the clinician to share information for treatment purposes.

Reference 25

NO IMAGE

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To Be Assured of the Patient's Comfort

Clinicians should be able to tell family members that the patient is comfortable. This message should be honest and believable.

This requires:

- Ongoing assessment and reassessment of the patient's physical pain and suffering
- Treatments for relieving pain and other symptoms, to be used as needed

Very close to death, patients may moan or grunt as they breathe. Family members may fear that the patient is in pain.

Explain that these breathing patterns usually do not have to do with pain. Provide this assurance even if family members do not ask.

References 1, 22

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To Express Their Emotions and Be Comforted

NO IMAGE

Healthcare providers often feel the need to "do" or "fix."

One of the most comforting things you can "do" for a dying patient's family is simply to "be" present at the patient's bedside.

Stay with the family. Allow family members to:

- Sit in comfortable silence
- Review the patient's life
- Express feelings of loss and grief

Immediately after the patient's death, be sure to:

- Express your sympathy. "I'm sorry for your loss" is perfectly adequate.
- Give family members as much time and space as they need to say final goodbyes.

Reference 1

Page 17 of 24

To Find Meaning

After the patient's death, give family members a chance to think about the patient's life.

Honor the patient's life and death by bathing and handling the body according to the family's wishes. Be sure to follow any cultural rules or customs.

The family's need for support does not end with the patient's death. The family should be given information about anticipated bereavement needs and support networks. Hospice provides bereavement services for 13 months following the death of the patient. References 1, 2	
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Review	

When patients die in hospitals or other facilities, staff should encourage and support the presence of family members.
How can staff help family members be present with their dying loved one?
Type your thoughts in the space provided. Then click Submit to check your answer.
	FEEDBACK
	Did you mention some or all of the following?
	• Place the patient in a private room, to allow for physical and emotional intimacy.
	• Relax restrictions on visiting hours as much as possible.
	• Be prepared for large groups at the bedside.
	• Plan the withdrawal of life support so that distant family members have time to arrive.
	• During withdrawal of life support, remove all distractions and barriers. Turn off monitors. Remove leads, cables, and catheters. Lower bedrails.
	• Provide simple amenities:
	  • Pager or cell phone
	  • Tissues
	  • Chairs
	  • Blankets and pillows
	  • Coffee
	  • Water
	  • Telephone

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Review	
Select the answer that best fits the question. Family members should be informed about the process of dying. However, clinicians should not make firm predictions about a specific patient's clinical course. • True • False	Correct: A Feedback for A: Correct. Predictions about a specific patient's clinical course are notoriously inaccurate. Inaccurate predictions can lead to a loss of trust, at a time when family members need to feel the utmost confidence in the care team.

	Feedback for B: Incorrect. This statement is true. Predictions about a specific patient's clinical course are notoriously inaccurate. Inaccurate predictions can lead to a loss of trust, at a time when family members need to feel the utmost confidence in the care team.
	Page 20 of 24

Summary	
You have completed the lesson on addressing the needs of the family. Remember: • A patient's death profoundly affects the family. End-of-life care must consider the needs of the loved ones, as well as those of the patient. • When patients die in hospitals or other facilities, staff should encourage and support the presence of family members. • During withdrawal of life support, all distractions and barriers should be removed. • Allow family members to be helpful to the dying person. This is especially important for parents of a dying child. • Explain the process of dying to family members. Clearly describe how the patient will die, and what this will look like. • Do not make firm predictions about a specific patient's clinical course. Inaccurate predictions can lead to a loss of trust, at a time when family members need to feel the utmost confidence in the care team. • All clinicians should give family members a consistent message about the patient's care. • HIPAA privacy rules do not necessarily prevent clinicians from communicating with families. • Healthcare providers should be able to tell family members that the patient is comfortable. The ability to give this reassurance is based on ongoing symptom assessment and treatment. • Allow family members to express feelings of loss and grief. • Choosing to withdraw life support can be an agonizing decision for family members. Address any doubts or guilt. • After the patient's death, give family members the time and space they need to reflect on the patient's life and say their final goodbyes.	NO IMAGE

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Glossary

amenity	something intended to make circumstances more pleasant
anticipatory grief	mourning in preparation of loss or death
apnea	the absence of breathing.
beta agonist	a bronchodilator that opens the airways by relaxing the muscles
cognitive behavioral therapy	a form of therapy that focuses on changing a patient's thoughts in order to change his/herbehavior or emotions
curative therapy	treatment aimed at restoring health
delirium	a mental disturbance characterized by confusion and decreased awareness, often brought about by illness or medication.

euphemism	an agreeable or inoffensive expression used to replace one that might offend or suggest something unpleasant
jargon	characteristic language used by a particular group
multidisciplinary	involving professionals from more than one specialty
open-ended question	a question worded to elicit a full and detailed response. Opposite of a yes/no question.
selective serotonin reuptake inhibitor	a medication used to treat depression
taboo	something excluded from use or mention
tricyclic antidepressant	a medication used to treat depression

Evaluation

- Which of the following is a key feature of palliative care?
    - One goal of palliative care is to control pain.
    - One goal of palliative care is to cure the patient.
    - One goal of palliative care is to find the cause of disease.
    - One goal of palliative care is to eliminate the source of disease.

Correct: One goal of palliative care is to control pain.
Rationale: Palliative care is comfort care. One goal is to control pain.

- Which of the following best expresses the relationship of hospice care and palliative care?

  - The main goal of palliative care is cure, while hospice care begins when nothing else can be done.
  - Hospice care provides palliative care at the end-of-life.
  - Hospice care is only for those with cancer, while palliative care is appropriate with other diagnoses.
  - Hospice care and palliative care are the same thing.

Correct: Hospice care provides palliative care at the end-of-life. Rationale: Hospice is where palliative care and end-of-life care overlap.

- Palliative care is best provided by:
  - A team of nurses
  - A team of social workers
  - A team of physicians and pharmacists
  - A team of interdisciplinary care providers

Correct: A team of interdisciplinary care providers Rationale: Palliative care is interdisciplinary.

- A good practice for providing adequate end-of-life care is:
  - Offer hope for a cure to the patient, regardless of prognosis.
  - Ask direct questions about the patient's symptoms.
  - Try all possible treatments to prolong a patient's life.
  - Never address end-of-life preferences with patients.

Correct: Ask direct questions about the patient's symptoms

Rationale: It is important to ask direct questions about symptoms, to ensure that all symptoms are addressed.

- Which is the best statement about communication:
  - Simple yes/no questions are best.
  - It is better to talk to the family and leave the patient out when discussing end-of-life care.
  - The use of big medical words will make the patient respect you more.
  - Open-ended questions help the patient to express his or her preferences.

Correct: Open-ended questions help the patient to express their preferences.
Rationale: Open-ended questions help you understand the patient's point-of-view and wishes.

- A good practice for providing adequate end-of-life care is:
  - Not let the patient talk about religion or spiritual concerns
  - Avoid "giving up" on the patient by shifting from curative to palliative care
  - Use appropriate medical jargon when talking about diagnosis, prognosis, and care options
  - Ask open-ended questions to help identify the patient's values, concerns, and goals for care

Correct: Ask open-ended questions to help identify the patient's values, concerns, and goals for care
Rationale: It is important to ask questions that help identify the patient's care preferences.

- During a palliative care evaluation:
  - Avoid giving the patient an estimate of "time left."
  - Help the patient identify possible sources of support.
  - Focus on discussing treatments aimed at curing the disease.
  - Discuss physical symptoms, but avoid discussion of psychosocial needs.

Correct: Help the patient identify possible sources of support
Rationale: One part of palliative care is a discussion of support systems. Help the patient identify possible sources of physical, emotional, and spiritual support.

- When should pain be assessed?
  - Only when the patient complains
  - Only if the family tells you the patient is uncomfortable
  - At each shift change
  - On a regular schedule, with any complaint or appearance of pain, and after administering pain medication

Correct: On a regular schedule, with any complaint or appearance of pain, and after administering pain medication

Rationale: Pain assessments should be done on a regular basis and if the patient appears uncomfortable or complains of pain, in addition to after the administration of any treatment for pain.

- Which is an effective treatment that may be ordered for dyspnea and pain?
  - Opioids
  - TENS
  - Ibuprofen
  - Oxygen

Correct: Opioids
Rationale: Opioids, like morphine, can be effective for pain and dyspnea.

- Which of the following is important for meeting the needs of a dying person's family?
  - Restrict family members from performing simple care tasks.
  - Make firm predictions about the patient's exact clinical course.
  - Provide a clear description of what the dying process will look like.
  - Strictly enforce visiting hours and limitations on number of visitors.

Correct: Provide a clear description of what the dying process will look like
Rationale: Family members need and want to be informed of a dying patient's changing condition. To help meet this need, provide a clear explanation of how the patient will die and what the dying process will look like.

- End-of-life care must consider the needs of the family, as well as those of the patient. A TYPICAL need of family members is:
  - To avoid expressing their emotions
  - To find meaning in the death of the patient
  - To avoid being present at the patient's deathbed
  - To be shielded from information about the patient's changing condition

Correct: To find meaning in the death of the patient
Rationale: Family members typically need and want to find meaning in the death of a patient.

- Which is the most accurate statement regarding spiritual and religious issues?
  - People at the end of life are too preoccupied with pain to consider what happens after death.
  - The interdisciplinary team usually includes a chaplain to assist with any spiritual concerns.
  - You should avoid discussing religion because you might upset the patient.
  - Patients of a different culture from their nurse will never want to discuss their beliefs with you.

Correct: The interdisciplinary team usually includes a chaplain to assist with any spiritual concerns.
Rationale: Clergy members are usually on the interdisciplinary team.

- Choose the true statement about palliative care and hospice:
  - Hospice provides palliative care in the patient's home only.
  - During hospice care, patients may receive treatment aimed at curing their disease.
  - Because hospice provides palliative care, other healthcare providers do not need to know about palliative care.
  - To qualify for hospice, a patient must have a terminal illness and a prognosis of no more than six months to live.

Correct: To qualify for hospice, a patient must have a terminal illness and a prognosis of no more than six months to live.
Rationale: To qualify for hospice, a patient must have a terminal illness and a prognosis of no more than six months to live. In addition, patients must agree not to pursue treatment aimed at curing their disease.

- The patient who is actively dying:
  - Is always fully aware of his or her surroundings
  - Should be isolated from any visitors
  - Tends to have a somewhat predictable set of signs and symptoms
  - Always has an increased appetite

Correct: Tends to have a somewhat predictable set of signs and symptoms.
Rationale: The clinical picture of a patient with an imminent death tends to be fairly consistent.

- Which is **not** an acceptable reason to communicate with a proxy decision maker?
  - You don't like the patient.
  - The patient is incompetent.
  - The patient's culture dictates you should speak with someone else, for example the husband of a female patient.
  - The patient asks you to discuss any issues with a family member.

Correct: You don't like the patient.
Rationale: This is not a legitimate reason to speak with a surrogate decision maker.

- Which is **not** true about advance directives?
  - They are a useful tool for eliciting patient preferences.
  - All patients should be encouraged to make their wishes known.
  - Ideally, they cover proxy decision makers, DNR orders, intubation choices, and the use of artificial hydration and feedings.

- They should be ignored if the doctor doesn’t agree with the choices listed.

Correct: They should be ignored if the doctor doesn’t agree with the choices listed. Rationale: The patient’s wishes outlined in an advance directive are to be honored.

Appendix B: Pretest and Posttest Scores on the Healthstream Knowledge Test

Participant Number	ID	Pretest	Post
1	GRU8927	100%	100%
2	VYJO4114	100%	100%
3	HQU8257	100%	100%
4	FNl9211	100%	100%
5	KIT7750	100%	100%
6	QHl8564	100%	100%
7	GDR4058	100%	100%
8	MQl8398	100%	100%
9	MOC7541	100%	100%
10	HNR6744	93%	100%
11	MUH8105	93%	100%
12	GPl8863	93%	100%
13	RDL0625	93%	100%
14	TVN0183	93%	100%
15	WKW4159	93%	100%
16	PQE9003	93%	100%
17	QD09492	93%	100%
18	LT09525	93%	100%
19	QOT9903	87%	100%
20	KHU9131	87%	100%
21	KYU8248	87%	100%
22	JMU9448	87%	100%
23	HZE7967	87%	100%
24	XXZ3594	87%	100%
25	MM18326	83%	100%
26	FHl9105	81%	100%
27	HKF0867	81%	93%
28	NW08300	81%	93%
29	LRU8857	81%	93%
30	OUX8635	81%	93%
31	PHK3808	75%	100%
32	PKN1214	75%	93%
33	JPL1550	75%	100%
34	CIJ9971	68%	100%

Holley,

This is Ross Nichols who works on the HCA and HealthStream account. You are authorized to use the End-of-Life Care course (PA).

Thank you,

Ross Nichols

Associate Account Executive

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