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INTERVENTIONS FOR PROMOTING EARLIER ENROLLMENT INTO HOSPICE AND PALLIATIVE CARE AMONG PATIENTS WITH A TERMINAL ILLNESS

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Interventions for Promoting Earlier Enrollment into Hospice and Palliative Care Among Patients with a Terminal Illness

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I dedicate this project to my Aunt Shirley who was enrolled in palliative care and hospice during her terminal illness. Special thanks to Kristin Sandau who has been on this journey with me.

Abstract

Background: Although research supports palliative care (PC) to improve symptoms and quality of life for patients with terminal illnesses, these services are underutilized. While 80% of people prefer to die at home, the majority still die in an acute care facility, sometimes receiving aggressive interventions that may increase suffering up until the very end of life. Earlier referral to PC or hospice care can improve symptom management and facilitate end-of-life (EOL) wishes.

Purpose: The purpose of this critical review of literature was to identify barriers as well as evidenced-based interventions to promote earlier enrollment into hospice and PC among patients with a terminal illness.

Conceptual Framework: Kotter's 8-Step Change Theory was condensed into three phases to enhance simplicity for proposed interventions for change.

Methods: Studies (n=18) were reviewed to identify barriers and interventions to promote earlier enrollment into hospice and PC.

Results: Across the studies, a consistent barrier was inadequate education. Undergraduate nurses and practicing nurses did not feel they had been prepared to converse with patients and caregivers about the services of hospice and PC. Barriers and interventions were summarized into three tables: for nursing students, practicing nurses, and terminally ill patients and families.

Implications: Suggested interventions centered on assuring curriculum includes specific components of EOL care for undergraduate nursing students and practicing nurses with an emphasis on interprofessional collaboration and communication. Further studies with higher level of evidence are needed to test interventions for earlier enrollment into hospice and PC. Additionally, post-death studies about caregivers' experiences with hospice and PC are needed to identify additional barriers and interventions to earlier access and management related to progression of terminal illness.

Conclusion: Inadequacies in preparation can be addressed through a variety of introductory and ongoing interventions such as classroom lectures, case studies, clinical and role playing experiences for undergraduate and practicing nurses.

Key Words: hospice care, palliative care, terminal illness, nursing barriers, end-of-life, nursing education, and Kotter's Change Theory

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Chapter One: Introduction

Terminal illness at any age can be difficult for a patient and their caregiver. Patients are not always aware of the confines of their illness and trajectory of the disease as it progresses. What does it mean when a member of the interdisciplinary care team tells the patient it is time to stop active treatment? “For terminally ill patients, hope and hopelessness are constructs that significantly impact quality of life” (Sachs, Kolva, & Pessin, 2012, p.121).

When one is diagnosed with an acute illness, treatment is initiated. However, when an individual is diagnosed with a chronic condition, the treatment goal is to manage the symptoms. Unfortunately, sometimes treatment is continued for a patient even when it is no longer effective and may end up reducing one’s quality of life. Patient and caregiver may not understand the difference between a curative or terminal illness. Healthcare professionals struggle with having difficult conversations when a terminal illness progresses. Health care providers, patients, and families need support and guidance to facilitate discussions on when it may be appropriate to transition from palliative care (PC) measures to end-of life (EOL) care.

Extent of the Problem

“Over the last decade, research has demonstrated the benefits of PC for patients facing serious illnesses” (Buller, Virani, & Malloy, 2019, p. E5). For example, PC for the patient with a specific cancer can include select interventions, which would help to alleviate related symptoms but not prolong life. However, there continue to be gaps in the care patients are receiving with a terminal illness. Disparities across the continuum of care range from not receiving the appropriate care to over treating patients. There are patients who are still receiving curative type treatments up until the day they die. This may result in unwarranted testing, procedures, and even uncomfortable treatments.

According to MacPherson and Parikh (2017, p. 94), “The United States spends $3.4 trillion annually on healthcare”. However, the high costs and advanced technology used in health care are, at times, prolonging life without necessarily improving the quality of care or the patient’s quality of life at EOL. “Of the 1.5 million Americans who die of a chronic illness each year, more than 70% are admitted to the hospital during the last 6 months of life” (Gardner, 2012, p. 4). Based on a literature review, this capstone’s present findings will reflect why the money spent on health care does not always improve the end of life experience for the patient and caregiver.

“Nurses are integral to the delivery of hospice and palliative care, they are pivotal in efforts to improve quality” (Lindley, Herr, & Norton, 2017, p. 160). Nevertheless, nurses are not adequately prepared to assist patient and caregiver with their questions on PC, hospice care, and EOL decisions that need to be discussed. Nurses struggle with initiating conversation or implementing interventions to benefit patients.

Need for Critical Review

“More than 1.7 million new cancer cases are expected to be diagnosed in 2018” (American Cancer Society, 2018, p. 1). Having access to PC in a timelier manner helps patients and caregivers manage symptoms related to disease progression. However, nurses often cite lack of training and education to initiate conversations introducing the benefits of PC and hospice care when the patient’s terminal illness progresses. Additionally, nurses themselves may not even understand the difference between PC and hospice care. If nurses are not able to speak confidently on this topic, how are they able to educate the patient in a compassionate manner? Thus, it is important to have clear ongoing education for nurses on PC, hospice care, and how to have conversations about EOL.

Within the interdisciplinary care team, the physician or advanced practice provider is usually the one who makes sure the patient is aware that the disease is no longer curable. This helps to lay the foundation of knowledge concerning disease progression and what to anticipate. "The difficulties in accessing palliative care programs in the different health care settings and the lack of follow up in the home are barriers to effective transition of care" (Carrillo, Rojas, & Carreno, 2018, p. 303). The nurse is commonly an advocate for the patient to assure needs are met in a holistic way, questions are answered, and treatment is in line with patient values. The nurse's role is vital to building a trusting relationship through the transitional phase while demonstrative of caring actions.

What tools should a nurse be given in order to be prepared? The nurse should be able to support the educational needs of a multidisciplinary team approach in order to improve the overall care of the patient while also meeting the needs of the caregivers. The findings from the literature review will include identification of educational needs, ongoing training, and how knowledge and skills required for nurses to support quality care during end of life can be sustained.

Purpose of the Review

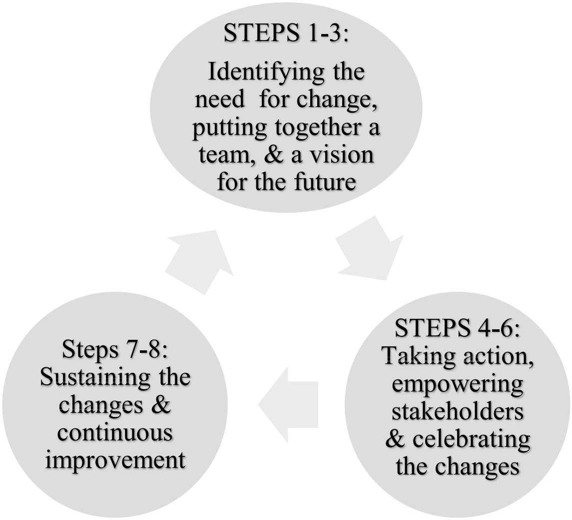
Are nurses prepared to have a conversation in order to promote earlier enrollment into hospice and PC? "Family members and-or healthcare professionals often delay having discussions and making decisions about the goals of care when a patient's condition becomes progressively worse" (Given & Reinhard, 2017, p. 51). Thus, the purpose of this critical review of literature is to identify interventions effective in promoting earlier enrollment into hospice and PC among patients with a terminal illness.

Conceptual Framework

Kotter's 8 Step Change Theory (Small, Souza, & Magney-Normilus, 2016) is the framework used in this literature review. The purpose of the literature review is to identify barriers and facilitators for nurses to have a conversation to promote earlier enrollment into hospice and PC. Kotter's Change Theory has been used by others (Mbamalu & Whiting, 2014) to help facilitate changes with businesses and healthcare organizations. Kotter's Change Theory is comprised of eight steps, which can be placed into three main areas: "creating a climate for change, engaging and enabling the organization, and implementing the change" (Teixeira, Gregory, & Austin, 2017, p. 199).

Kotter's 8-Step Change Theory can be used to remove the barriers that prevent enrollment into PC or hospice care in the terminally ill patient. For the purpose of this literature review, articles were grouped according to three groups of stakeholders: nursing students; practicing nurses; and terminally ill patients with their caregivers. A summary of Kotter's eight steps was condensed into three phases for this review for the undergraduate nurse, practicing nurse, and the terminally ill patient. Steps one through three focus on why a change in current practice should be made with using (PC) and hospice care in patients with a chronic or terminal illness. Steps four through six address how to identify appropriate stakeholders to make recommendations and implementation of interventions identified. Steps seven and eight identify the state of the future, managing the changes, and ongoing assessment of evidence-based findings for ongoing recommendations of what is best practice for nurses, patients, and caregivers.

Figure: Kotter's 8-Step Change Theory. Adapted from Kotter (2014).



Kotter's (2014) Change Theory can be used to facilitate clear identification of the problem, to determine which components are needed to implement change to address the problem and to consider what is needed to maintain sustainability of the interventions. Additionally, Kotter's Change Theory focuses on how key stakeholders help with shaping the future needs of ongoing training.

Significance to Nursing

One of the most difficult conversations for a nurse is talking about EOL decisions when an illness becomes terminal. "Nurses must identify or develop the professional expertise to hold conversations with patients and their families" (Gardner, 2012, p. 226). When nurses are provided with the education, resources, and training on end-of life care, confidence will ensue and make it easier to talk with their patients. Nurses will be able to talk about the progression of a terminal illness and what it looks like to transition into palliative and/or hospice care. They will be able to promote the benefits of these services to enhance the quality of care and support to the family.

“Nurses are often on the frontlines of care and play a key role assisting patients and families to establish goals of care, discuss barriers to care, and find resources to help patients navigate their illness journey” (Buller, Virani, & Malloy, 2019, p. E5). Effective communication is not a skill that all nurses have but a skill they can develop with training. EOL training should be ongoing while providing resources that focus on communication and nursing interventions to support the patient and their caregiver. According to Lewis (2013), during palliative and EOL care, the nurse will perform the functions of four roles when caring for a patient: care provider, educator, advocate, and facilitator. Thus, interventions to enhance timeliness of EOL care will facilitate earlier multifaceted support by nurses.

Summary

Having to make difficult choices when an illness becomes terminal can negatively affect the patient, family, nurses and interprofessional care team when they are not prepared physically and emotionally to talk about their wishes at end of life. This literature review will address what may be the barriers nurses encounter in discussing hospice and PC patients and family members.

Chapter Two: Methods

This chapter describes the search strategy used to identify evidence for barriers and facilitators to enrollment of terminal patients into PC and hospice, including nursing communication. Definitions, inclusion and exclusion criteria, as well as criteria used to evaluate type and level of evidence will be identified. First, a definition of terms is provided.

Definitions

The following words occur frequently upon review of evidence in the literature:

Caregiver: An individual who is providing care whether he or she is related by blood, marriage, or a personal connection.

Do Not Resuscitate (DNR): "When a person states that healthcare providers should not perform cardiopulmonary resuscitation if his or her heart or breathing stops" (NCI Dictionary of Cancer Terms, 2018).

End-of-Life (EOL) Care: "National Quality Forum (2012) defines end-of-life care as comprehensive care that addresses medical, emotional, spiritual, and social needs during the last stages of a person's terminal illness" (Given & Reinhard, 2017, p. 51).

Hospice: A service that is offered when a patient is given six months or less to live with their terminal illness. Hospice will help to address EOL questions such as pain and other symptom management measures to provide comfort.

Intervention: An action or task that a nurse performs on behalf of the patient.

Palliative Care (PC): " Palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (Vadivelu, Kaye, & Berger, 2013, p. 8.)

Terminal Illness: When an illness or disease progresses where to the point death becomes the end outcome. There is no cure or reversing of disease progression.

Search Strategy

To identify research studies for this paper, the following words were used: *hospice care, palliative care, terminal illness, nursing barriers, EOL, nursing education, and Kotter's Change Theory.* The databases utilized for this search were CINAHL Plus, PUBMED, Science Direct, and Scopus. The preliminary search yielded 308 articles. When filters were placed to define age of patient and time period, 37 articles were identified for review.

Inclusion/Exclusion Criteria

Inclusion criteria included articles published between 2010 and February 2019. Articles were considered if the patients and their caregivers were 18 years of age or older. Articles were excluded if they did not include a focus on at least one of the following: nurses, self-perceptions of nurses introduced to PC, EOL, hospice, barriers, and nursing interventions. Once articles were reviewed using the search words, 18 articles met the criteria of the research question.

Criteria for Evaluating Evidence

Studies were critiqued using the criteria from *Johns Hopkins Nursing Evidence-based Practice: Model and Guidelines* (Dang & Dearholt, 2018). Each article was evaluated for level of evidence and quality as defined in *John Hopkins* (2018) appraisal tool. Both level of evidence and quality ratings were placed in the matrix (see Appendix).

Studies for Selected Review

Once the research evidence appraisal tool was completed, compilation of articles included two Level II articles of good quality; fourteen Level III articles (one of low quality and thirteen of good quality). One article of Level IV (good quality) and one of Level V (good quality) completed the list of sources for the critical review.

Summary

The literature review included research articles on terminal illness, PC and hospice care in adults. Definitions, inclusion and exclusion criteria, as well as criteria used to evaluate type and level of evidence identified.

Chapter Three: Literature Review and Analysis

The goal of this critical review is to clarify the barriers in enrolling patients into hospice and PC, as well as to identify interventions that would encourage patients and caregivers to enroll earlier to improve outcomes. Major findings will be presented in this chapter and level of evidence will be presented reflecting the strengths and weaknesses of the research.

Major Findings

Articles were reviewed and identified by the appropriate level of evidence. These are presented in the matrix (Appendix). Major findings will be synthesized from the following levels of evidence identified through the literature search.

Level II Evidence. A total of two Level II were included in this review and were of good quality.

Level III Evidence. Fourteen Level III articles were reviewed. One article was of low quality and thirteen were of good quality.

Level IV Evidence. One article in Level IV was reviewed of good quality.

Level V Evidence. One article of good quality was included in Level V.

All articles were summarized in a matrix (Appendix).

Barriers and Facilitators: for Undergraduate Nursing Students

Five articles of Level III Evidence of good quality indicated both barriers and interventions related to EOL care with the undergraduate nursing students. “Research demonstrates that nursing students have difficulties in dealing with death, and often feel emotionally unprepared to care for dying patients” (Ek, et al., 2014, p. 509). Barriers identified included curriculum in nursing programs that may not always be the most current regarding EOL care. Undergraduate nursing students are often not emotionally prepared to care for someone who is dying and death due to limited exposure. Communication skills are another area identified as a barrier. Lack of self-confidence and knowledge regarding diagnosis will prevent asking appropriate questions amongst peers and care team. Simulation laboratories within nursing education consist of a nursing instructor and nursing student, while not utilizing the whole interdisciplinary team (Smith et al., 2018). Ek et al. (2014) stated that nursing students who do not receive the support and training throughout their nursing program might not be able to connect emotionally with the dying patient.

Nurse educators need to develop interventions that facilitate professional growth for the nursing student. Being able to care for a terminally ill patient during a clinical rotation will provide exposure. The nursing instructor should use this as an opportunity for the student to share about their experience when the class is brought back to debrief on their day. This will allow for immediate feedback, emotional support to the student while exposing nursing students who may not have the opportunity to care for a dying patient during their education. EOL curriculum should include disease specific process in a terminal illness, practicum skills, and ethical issues that they may encounter (Hold et al., 2015). Empowering the nursing students with knowledge and communication techniques will help them to gain self-confidence as respected and valued members of the care team. Including various members of the care team during simulation labs will teach them the role one another plays in the care of a dying patient. Allowing students to be present during care team meetings will teach them the benefits of a cohesive team and communicating the same message to patient and family.

Table 1: Summary of Barriers and Interventions for Nursing Students

Barriers:	**Interventions:**
• Curriculum that has no EOL content and/or outdated EOL content (Ek et al., 2014; Glover et al., 2017) • Curriculum that is not standardized with specific PC, hospice and EOL objectives and outcomes for post evaluation (Smith et al., 2018) • Curriculum that is lacking in therapeutic communication (Gillett et al., 2016)	*Student curriculum can include:* • Opportunity for students to care for patient in the dying process and to debrief with instructor and peers after their experience (Ek et al., 2014) • Role play in a practicum skills lab (Hold et al., 2015) • End-of-Life Nursing Education Consortium (ELNEC) modules (Glover et al., 2017) • Explanation about trajectory of a terminal illness and symptom management (Hold et al., 2015; Glover et al., 2017) • Education about ethical issues that may need to be discussed with patient and family (Hold et al., 2015)

Barriers and Facilitators: for Nurses in Practice

The literature review revealed there were eight articles that addressed barriers and facilitators for nurses in practice. The level of evidence and quality were as follows: two Level II Evidence (good), five Level III (good), and one Level III (poor). Lee et al. (2018) stated that although 80% of people would prefer to die at home, 60% still die in an acute care facility. "Nurses in the oncology and palliative settings are well positioned to facilitate this transition from curative to palliative care" (Canzona et al., 2018, p. 4158). However, in this literature review nurses revealed multiple barriers that impeded the change to (PC) and (EOL) hospice care. Barriers identified demonstrated how nurses struggle with initiating EOL conversations with the patient and family. Barriers included lack of training, collaboration between members of the health care team, organizational investment in having PC and EOL policies, ongoing education, and competencies. McDarby et al. (2019) also suggested that one's personal belief, experience, and attitudes towards PC and EOL could deter nurses from educating patients and families to talk about their wishes.

"People are living longer than ever before, often at the cost of living with the debilitating multiple comorbidities requiring complex care or interventions (likely to require hospitalization), which may well result in end-of-life care" (Rawley et al., 2019, p. 8). When healthcare facilities invest in ongoing education for their nurses on PC and EOL, patients and families will benefit. Several interventions were identified, including providing education on the difference between curative treatment versus comfort care and hospice; this education should be provided before the chronic illness becomes terminal, even while the patient is receiving early PC. Supporting nurses with ongoing, standardized education and competencies will allow them to keep current with guidelines and recommendations from the Hospice and Palliative Nurses Association (Anasari et al., 2018).

Offering ongoing training and support for nurses will help them to deal with their stress, anxiety and other emotions (Canzona et al., 2018). Providing up-to-date resources from an organization such as End-of- Life Nursing Education Consortium (ELNEC) is one way to teach communication techniques, symptom management, and collaboration between members of the healthcare team. According to Lee et al. (2018), having care team meetings to discuss the patient's prognosis will ensure consistent information is being shared and can help to initiate discussion on the patient's wishes. Incorporating communication techniques in the didactic training will allow and encourage feedback from peers who may have experience in caring for someone who is dying.

Table 2: Summary of Barriers and Interventions for Nurses in Practice

Barriers:	**Interventions:**
• Lack of initial education & training for EOL upon hire (Canzona et al., 2018) • Lack of ongoing education and competencies (Canzona et al., 2018) • Lack of collaboration between members of the health care team (Canzona et al., 2018) • Lack of organizational investment in having PC and EOL policies (Canzona et al., 2018) • Lack of support for nurses to seek help with their personal feelings, beliefs and exposures to a difficult death (McDarby et al., 2019)	*Health care institutions can:* • Support nurses with ongoing, standardized education and competencies based on guidelines from Hospice and Palliative Nurses Association (Anasari et al., 2018). • Offer courses on PC and EOL communication from an interdisciplinary approach (Gillett et al., 2014) • Incorporate communication techniques in training & encouraging feedback from experienced peers (Lee et al., 2018) • Have care team meetings to discuss the patient's prognosis to ensure consistent information (Lee et al., 2018) • Support the practice of having more than one discipline talk with patients so that patients hear consistent information (Gillett et al., 2014)

Barriers and Facilitators: for Patients and Families with Terminal illness

In addition to identifying barriers and interventions that undergraduate nursing students and practicing nurses share, it is necessary to know how these affect the EOL experience for patients and families. There were three articles of Level III Evidence of good quality and one article each of Level IV, V Evidence of good quality. An et al. (2014) noted that ensuring one's awareness of prognosis would improve communication between physician, patients, and families while encouraging the use of palliative and hospice care services. Often times, patients and families do not understand the disease process and what it means to be terminal. "Technology has enabled the life of patients to be sustained well past their ability to make decisions" (Gardner, 2012, p. 224). When patients or families do not understand the intent of treatment in relation to their diagnosis, they may experience misunderstanding and mistrust when the physician suggests it is time to look at comfort cares.

Unfortunately, sometimes caregivers make decisions without talking to their family member about their EOL wishes. According to Goebel et al. (2016), conflicting information and collaboration on behalf of the interdisciplinary team prevents the patient and family from proactively discussing their wishes and being able to act on them. "Communication between families and nurses about withdrawal is fraught with difficulties related to emotions, uncertainty, lack of communication skills in providers, and conflict over goals of care" (Peden-McAlpine, Liaschenko, & Traudt, 2015, p. 1147).

Interventions should focus primarily on the patient's needs, not the caregivers, (Ewing et al., 2018). It may be challenging to identify how to equip the caregivers to best support their dying family member's wishes. However, this is vital. Patients and families should be educated on the benefits of PC. The benefits of PC consist of addressing one's physical comfort, distress from poorly managed symptoms, emotional and quality of life (Devi, 2011, p. 15). The benefits of hospice care at EOL include helping support the patient and family with pain control, symptom management, medical equipment, guidance for care of the patient, grief support, and respite care (National Hospice and Palliative Care Organization, 2018).

Developing and implementing a care plan (whether the patient remains hospitalized or at home) will establish expectations for all parties involved. Providing education and resources will improve quality of care, enable communication that is open and forthcoming, while meeting the patient’s needs (Jack et al., 2016). Educational interventions should include conversations on what the future may look like for the terminally ill family member as well as anticipated physical cares, while supporting the emotional, psychological, and spiritual dimensions of the terminally ill family member (Jack et al., 2016).

Table 3: Summary of Barriers and Interventions for Patients and Families

Barriers:	**Interventions:**
• The nurse's personal belief, experience, and attitudes towards PC and EOL • Lack of communication between patient, caregiver, nurse, and other members of the care team (Goebel et al., 2016) • Lack of involvement with family when preparing for hospital discharge (Soraka et al., 2018; Ewing et al., 2018)	*Health care institutions can:* • Offer ongoing training and support for nurses to deal with patient's stress and anxiety (Canzona et al., 2018) • Offer care team meetings with the patient and caregiver to promote a unified approach to care and EOL wishes (Goebel et al., 2016) • Offer a standardized discharge assessment with resources to use in home settings (Ewing et al., 2018)

Strengths and Weaknesses of the Research Studies

All studies were critiqued using the guidelines of Johns Hopkins Nursing Evidence-Evidence-Based Practice (2018). Guidelines were used to evaluate literature on nursing research to identify barriers and interventions on PC and EOL that affect the undergraduate nurse, practicing nurse, patient, and family. Eight of the articles presented the findings from the perspective of practicing nurses, five came from undergraduate nurses, and five from patients. These studies addressed the needs of nurses across the trajectory of their career, novice to experienced.

Weaknesses of the studies reviewed included small sample sizes in several studies as well as inability to validate findings of self-reported outcomes in self-evaluations. Samples were typically limited to specific inpatient units such as critical care, ICU, and oncology units. Self-selection of participants into studies may have altered findings. One study had only white female nurses represented in the findings. Studies did not include follow-up findings related to family perception of having PC and hospice involved in patients' care. Not all authors validated surveys prior to initiation of surveys, some of which were self-designed and used only at a single site, thus limiting comparisons (Rajdev et al., 2018).

Strengths of the studies reviewed included the fact that the majority utilized eight nationally developed tools for assessing data. ELNEC was most commonly used to assess and recommended to use for educational interventions. Use of open-ended questions, structured interviews, focus groups, and surveys that maintained anonymity in the qualitative studies identified the areas of future study.

Summary

When a person has been diagnosed with a terminal illness, it can be a time of uncertainty. Whether patient, undergraduate nurse, or the practicing nurse, barriers may be encountered that cause unnecessary stress. First and foremost, it is important to identify the barriers and interventions that may facilitate processes to help to eliminate them. “Doctors find it difficult to make early referral to PC for many reasons, including being unsure of the disease process, inadequate communication skills, lack of knowledge about PC, and lack of team accessibility” (Devi, 2011, p. S15). A common misconception in PC is that it is associated with a hastening of death. However, the major goals of PC are to improve quality of life and symptom management. EOL and hospice care *are* associated with terminal illness but offer proactive, evidence-based strategies to facilitate comfort care for the patient, while supporting the family. Communication is one of the most prominent factors in eliminating barriers in PC and EOL. This was noted in all three areas of findings: from the perspective of the undergraduate nurse, practicing nurse, and patient.

Therefore, the major strength of the literature reviewed regarding common barriers and interventions in PC and EOL revealed a consistent recommendation that further education, whether initial or ongoing, is necessary for students, practicing nurses, as well as patients and their families. This education is an important investment for institutions if they want to facilitate early enrollment of terminally ill into the care and support provided by PC and hospice. Further, standardization of care, policies, and processes with commitment to PC and EOL care in an academic setting, inpatient or at home will improve the quality of care.

Chapter Four: Discussion, Implications, and Conclusions

This chapter will review interventions to promote patients enrolling into palliative and hospice care. This chapter will provide a summary of the literature illustrating these interventions, with implications for nursing practice as well as recommendations for additional nursing research in the future. Lastly, Kotter's Change Theory (2014) is applied to the practice question.

Answer to Practice Question

The purpose of this critical review of literature is to identify interventions effective in promoting earlier enrollment into hospice and PC among patients with a terminal illness. Nurses are instrumental in providing education to patients based on diagnosis and disease management. However, after a patient is informed that their illness is now terminal, nurses will describe personal emotions of fear and anxiety when they have limited nursing experience with palliative, hospice, and EOL care. People with a terminal illness continue to be admitted to ICUs while receiving aggressive therapies. "Persons aged 65 years and older will make up 20% of the American population by 2030, and those older than 85 years are currently the fastest-growing segment" (Grant et al. 2013, p. 121). Twenty-five percent of Medicare spending is due to the cost of acute care during the last year of one's life (Grant et al., 2013).

Articles used in this literature review presented barriers from the perspective of the undergraduate nurse, practicing nurse, terminal patient, and family. Various educational initiatives are being used to demonstrate interventions to promote the services of palliative and EOL care for the terminally ill patient. Assessing the knowledge base of nurses about PC and symptom management of a chronic illness will help to develop nursing curriculum. Identifying the needs of the patient before they become terminal and faced with EOL decisions can be difficult. Lee et al. (2014) stated using evidence-based practice interventions could help to provide communication skills, improve attitudes, and impact nurse burnout and turnover, while improving patient and family care experience. Tables 1-3 were provided identifying barriers and interventions for stakeholders.

Trends in the Literature

All studies identified lack of education as a barrier for the undergraduate nurse, practicing nurse, and patient. Nurses reported that hands-on experience was not adequate training to assist patients with transitioning from PC to EOL. Undergraduate nurses and practicing nurses lacked the confidence in their ability to adequately care for a terminally ill patient

Gaps in the Literature

There were no randomized controlled trials available to provide Level 1 evidence for interventions to enhance earlier enrollment of terminally ill patients into palliative and hospice care. There were no follow up studies with the caregivers after the patient had passed away to evaluate their concerns and recommendations for future practice. Even though there were recommendations for nursing interventions, there were no Level V studies to assess quality improvement and increased referrals to PC and hospice among clinicians and organizations.

Implications for Nursing

The undergraduate nurse, practicing nurse, and patient's family struggle with difficult conversations about EOL in a terminal illness. Nurses need to develop a trusting relationship with the patient and family members in order to talk to them about PC and hospice. National Comprehensive Cancer Network (NCCN) guidelines are updated annually on how to transition the patient from PC to hospice care. Curriculum taught to the undergraduate nurses have not kept up with recommendations from ELNEC and NCCN. Practicing nurses reported PC, hospice, and

EOL is not routinely a part of new employee orientation and ongoing education. It is difficult for practicing nurses to develop communication skills to talk with patients about their EOL wishes. In preparing undergraduate and practicing nurses, didactic training should include specific case scenarios, role-playing, and competencies in the classroom and clinical settings. The patient needs to understand his or her own illness, management of the illness, and the potential of it transitioning from a chronic illness to a terminal illness. Tables 1-3 provide summaries of barriers and interventions identified in the studies reviewed for the nursing student, practicing nurse, terminally ill patient, and caregiver.

When nurses are adequately trained and experienced in caring for terminally ill patients, they will be able to initiate a dialogue with their patient and family, including a discussion of their prognosis, what to anticipate, and what the patient would like at EOL. The patient is better emotionally prepared for death if they feel their personal wishes at EOL will be fulfilled.

Recommendations for Nursing Research

Patients are living longer with chronic illnesses, while being hospitalized for exacerbation of their symptoms. Living with a serious illness can lead to poor quality of life if unnecessary testing and aggressive treatments are being performed to extend life without offering comfort measures to promote quality of life in the time left with loved ones. Thus, the need for additional research with randomized controlled trials (RCT) to identify what interventions are beneficial to patients and caregivers overall experience with a terminal illness. One area for an RCT is to compare caregivers of patients enrolled versus not enrolled in hospice or PC. Improvements in nursing care need to start with the undergraduate nurses and instructors having up-to-date curriculum. In order to prepare undergraduate and practicing nurses, curriculum should include topics such as pain control, symptom management, and communication techniques that are appropriate to the individual's cultural and spiritual beliefs. In addition, nurses need to be able to address the caregivers' concerns and provide resources to assist with their loss and grief. Other areas to research include EOL education by health care organizations, including nurses' preferences for delivery. Nurses may have different learning preferences and thus evaluation of specific methods (i.e. classroom, online, interactive case studies, videos to show examples of communications techniques, patient stories) has a higher rate of success. A shared curriculum could be used with both students and practicing nurses.

Integration of Theoretical Framework

Kotter's Change Model (2014) was the theoretical framework used in this literature review. Kotter's 8-Step Change Model has been utilized to provide the framework when a change is necessary for organizations. In order to promote enrollment into palliative or hospice care, change is needed in the undergraduate nursing programs and health care organizations that care for terminally ill patients. There are multiple forces that drive change in health care including evidenced-based findings, technology, financial pressures, and initiatives from the insurance payers, and quality initiative drivers. Kotter's Change Theory, according to Malmberg et al. (2014), can help to create a sense of urgency, planning, and implementation.

Integration of Kotter's Change Theory theoretical framework can provide a guiding format for successful change. Kotter's model (summarized into three areas of focus) reflects a continuous ongoing process. Change does not stop once the interventions are implemented. Steps 1-3 identify the need for change by addressing the concerns nurses struggle with professionally and personally. The problem identified has been that nurses are not equipped to care for terminally ill patients, as demonstrated by Moir et al. (2015) who described nurses' discomfort with initiating conversations addressing end of life when they are not knowledgeable about the progression of the patient's illness and related expectations for the patient's future. If nurses had this knowledge, they could converse with patients and caregivers about their fears and wishes. Steps 4-6 include encouraging the stakeholders to invest in improving the care for their patients who are terminal; patients and families deserve to receive the services of hospice and PC. Curriculum for nursing programs and hospital orientations may lack EOL education. Further, nurses do not uniformly have hands-on experience with patients who have a chronic illness that may become terminal According to Glover et al. (2017) the need to invest in preparing nurses whether it is in a nursing program, orientation, or ongoing learning will help decrease the gap when providing care for a population that is aging. Allowing the members of the multidisciplinary team to debrief about what they learned, witnessed, and experienced during this planning and implementation phase will validate the value of the changes for patients and nurses. Finally, steps 7-8 include encouraging nursing programs and healthcare organizations to routinely assess changes after the interventions identified are implemented into the curriculum for students and practicing nurses. Hospice and PC programs should plan to assess changes in number of patients enrolled as well as timeliness of enrollment pre- and post-interventions. Finally, organizations should have a plan to regularly review what the latest evidence-based recommendations are and update what is being taught.

Summary

This critical literature review identified barriers that prevented early enrollment into hospice and PC among patients with a terminal illness. Patients and their caregivers are not being introduced to the services of PC when diagnosed with a chronic illness and hospice care when the illness becomes terminal. Undergraduate nurses reported their nursing curriculum did not prepare them for the emotional impact of caring for their first patient who is dying. Curriculums in nursing programs do not keep up with the most recent evidence-based findings when teaching about hospice, PC, and EOL in theory classes and practicum laboratories. Practicing nurses reported that during their classroom orientation upon employment and ongoing learning, education regarding PC, hospice, and EOL cares were not routinely provided. Nurses reported a lack of understanding for the key role they played in an interdisciplinary PC model. "Nursing organizations and clinical leaders must embrace these challenges by working collaboratively to create innovative, accessible learning experiences and a core curriculum for the application of high-quality palliative nursing in both academic and clinical practice settings" (The Hospice and Palliative Nurse Association, 2018, p. E10).

Interventions to enhance earlier enrollments into hospice and PC were summarized into three tables: for nursing students, practicing nurses, and terminally ill patients and families. Suggested interventions centered on assuring curriculum including specific components of EOL care for undergraduate nursing students and practicing nurses. Courses are available from expert professional organizations such as ELNEC. Interprofessional collaboration and communication among health care teams should be emphasized. An example of this includes team meetings to assure all clinicians understand and deliver the same messages to terminally ill patients and families. Additionally, incorporating communication techniques and encouraging feedback from experienced peers is a promising interprofessional intervention. Although the end of life is a challenging time for patients and informal as well as formal caregivers, there is a growing body of expertise to enhance quality of life and symptom management; PC and hospice delivers this expertise. Connecting patients and caregivers to this expert knowledge should be a priority we embrace.

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Appendix: Evidence Synthesis Matrix

Source: Grant, M., Wiencek, C., Virani, R., Uman, G., Munevar, C., Malloy, P., & Ferrell, B. (2013). End-of life care education in acute and critical care. *American Association of Critical Care Nurses, 24*(2), 121-129. doi: 10.197/NCI.0b013e3182832a94.

Purpose/Sample	Design (Method/Instruments)	Results	Strengths/Limitations
Purpose: Evaluate if acute and critical care nurses have the appropriate education to care for patients in end stages of life. **Sample/Setting:** Participants in ELNEC-CC/Archstone courses between 2007 and 2010 (n=388). Of the 388 participants: Nurses (n=359) Other allied health care professionals (n=29). **Johns Hopkins Evidence Appraisal** **Level of Evidence:** III **Quality:** Low.	Qualitative analysis. Participants completed an electronic application with demographic information, details of workplace, quantity and quality of palliative education offered, and post course goals. Post course and preassessment participants were to complete surveys at 6- and 12-month interval on number of courses completed or taught for post qualitative analysis.	94% of participants were able to meet implementation teaching goal and outcome as identified in pre-survey analysis. 6% were not able to implement action secondary to lack of time, lack of staff availability, financial, and administrative support. **Conclusion:** Ongoing education and training is needed to improve nurses' proficiency in acute care and critical care settings. This will aid in improving patient and caregiver experience with end-of-life situations.	**Strengths:** Qualitative methods identified themes in post survey outcomes. Collected data over 3-year period. Used a national organization ELNEC & CC/Archstone tools and education modules to teach the teachers. **Limitations:** Not able to connect reported outcome back to participant's unit of work. Outcome was self-reported, not able to validate. Not able to put date/timeframe of when goal was achieved. Independent results versus group results may not accurately reflect in scope of qualitative analysis.

Author Recommendations: In order to integrate and improve EOL experiences for patient and family, ongoing training and educational modules are necessary for nursing and multidisciplinary team.

Implications: Members from the multidisciplinary team had the most resistance in implementing successful education modules and training on palliative care. Lack of correct information on palliative care services and negativity led to barriers identified.

Source: An, A. R., Lee, J., Yun, Y. H., & Heo, D. S. (2014). Terminal cancer patients' and their primary caregivers' attitudes toward hospice/palliative care and their effects on actual utilization: A prospective cohort study. *Palliative Medicine, 28*(7), 976-985. doi: 10.1177/0269216314531312.			
Purpose/Sample	**Design (Method/Instruments)**	**Results**	**Strengths/Limitations**
Purpose: To report attitudes of patients with terminal cancer and caregivers toward hospice/palliative care and their association with use of inpatient hospice/palliative care facilities. **Sample/Setting:** Patient-caregiver dyads (n=359) completed baseline questionnaires. After the patient's death, caregivers were interviewed (n=257). Participants were from 12 hospitals in the country of South Korea. **Johns Hopkins Evidence Appraisal** **Level of Evidence:** III **Quality:** B	Mixed methods, multisite, prospective, observational cohort study. Quantitative: Immediately after cancer diagnosis, information was abstracted from patient medical records. Patients and caregivers completed baseline questionnaires. Instrument: Questionnaire looked at patient demographics, self-awareness of the terminal illness, personal feelings about hospice and palliative care. (HPC). Reliability and validity not reported. Qualitative: Contact with caregivers via telephone was made three months after the patient's death. Instrument: Telephone interview with caregiver if patient and family are aware of terminal status and if they chose to seek out inpatient hospice/ palliative care versus life sustaining measure.	**Results:** Preference for HPC was expressed by 137/359 (38.2%) of patients and by 185/359 (51.5%) of caregivers. Reasons for not preferring HPC were: • Lack of sufficient information (46.4% of patients; 40.8% of caregivers) • Patient's disfavor (27.9% of participants; 17.8% of caregivers) • Cost (7.7% of patients; 11.5% of caregivers) Agreement of preferences between patients and their caregivers was very low (48.2%). *Factors Associated with Preference for HPC:* in univariate analysis, among *patients,* preference for HPC was significantly associated with patient's age <60 years, Christianity, awareness of terminal status, presence of metastatic lesion, poor performance status (as measured by Eastern Cooperative Oncology Group), and terminal diagnosis for reason	**Strengths:** 1. Authors provided CONSORT flow diagraming subject participation. 2. Research design included both quantitative and qualitative analysis. 3. Researchers gathered data from both patients and family caregivers, including post-death data from caregivers. **Limitations:** 1. In the setting of S. Korea, there was limited access to outpatient services as opposed to inpatient hospice/palliative care facilities. 2. Clinicians in the U.S. may have limited exposure to the health care services in S. Korea as opposed to the health care delivery system in the U.S. 3. The definition of terminal cancer does not clarify a time frame when looking at life expectancy.

		"other than worsening condition" (p. 979). Among *caregivers,* preference for HPC was significantly associated with college degree and awareness of patient's terminal status. In multivariate analysis, preference for HPC was significant for awareness of terminal status, for both patients and caregivers. Among patients, a preference for HPC was significantly associated with being Christian, having a metastatic lesion, and poor performance status. *Post-Bereavement Questionnaire Results:* Less than half (40.5%) of the patient-caregiver dyads used HPC, with the most common reason for lack of use of HPC being due to lack of information about HPC (27.1%), followed by preference for active anticancer treatment (14.3%), and concern about separating the patient form the family (12%). **Conclusion:** Caregiver's preference and affiliation with Christianity influenced whether or not hospice/palliative care was instrumental in end of life decision making. No patient-related factors influenced use of HPC. Communication	4. Validity/reliability of questionnaire not reported: authors did not describe survey development. 5. Specific questions of telephone interview were not listed; no report given as to how the interviewers were trained.

		among physician, patient, and caregiver need to improve in order to facilitate referrals for this service.	
Author Recommendations: Educating patients and caregivers about what end of life means in relation to their terminal illness will assist to making decisions about hospice and palliative care.			
Implications: When patients and caregivers are informed of their terminal status, they have better quality of life and understanding if their options in decision making towards terminal care.			

Source: Ek, K., Westin, L., Prahl, C., Osterlind, J., Strang, S., Berg, I., Henoch, I., & Hammarlund, K. (2014). Death and caring for dying patients: Exploring first-year nursing students' descriptive experiences. *International Journal of Palliative Nursing, 20*(10), 509-515. doi: 10.12968/ ijpn.2014.20.10.509.			
Purpose/Sample	**Design (Method/Instruments)**	**Results**	**Strengths/Limitations**
Purpose: To identify nursing students' attitudes, feelings, and perspective on caring for a dying patient throughout their program. **Sample/Setting:** Three universities in three cities of Sweden. Nursing students enrolled in a three-year Bachelor of Science degree. Nursing students interviewed (n=17). Age of students ranged between twenty and forty, all female, and born in Sweden. Interviews were obtained in 2012. **Johns Hopkins Evidence Appraisal** **Level of Evidence:** III **Quality:** Good Quality	Thematic analysis. Longitudinal interview project. Frommelt Attitude toward Care of the Dying Scale model (FATCOD) was used to measure the students' attitude towards death and dying.	Interviews identified four themes: • Thought of death is more terrifying then the actual death. • Struggles with being present and offering oneself to the patient. • Being confronted with one's own feelings. • Feeling of inadequacy and not enough time to spend with patient and family. **Conclusion:** Nursing students struggled with communication with the patient, seeing a patient die, and handling a dead body was traumatic the first time. Nursing students needed to have time to debrief and reflect on end-of-life experience. Ongoing education, guidance, and reflection for nurses to gain confidence is necessary from instructors to teach how to process and cope with end-of-life.	**Strengths:** Allowing students to experience patient death would prepare them for later in their practice. Evaluates palliative care through transition into end-of-life care. Standardized text used with open-ended questions during interview process. **Limitations:** Even though three universities in Sweden participated, only one student at one university was interviewed. Only Swedish females participated and may have affected results.

Author Recommendations: Recommended future research to evaluate whether the nursing students' experiences change how they feel with additional exposure to end-of-life over the three years in the nursing program.
Implications: Allows students to encounter multitude areas of progression when a patient is transitioning from palliative symptom management to end-of-life.

Source: Hold, J. L., Blake, B. J., & Ward, E.N. (2015). Perceptions and experiences of nursing students enrolled in a palliative and end-of-life nursing elective: A qualitative study. *Nurse Education Today, 35,* 777-781. doi: 10.1016/j.nedt.2015.02.011.

Purpose/Sample	**Design (Method/Instruments)**	**Results**	**Strengths/Limitations**
Purpose: To determine the benefits of taking a nursing elective course on palliative care and end-of-life. **Sample/Setting:** Baccalaureate nursing students attending a state university in southeastern United States. Eligible participants (n=52). Volunteer participants (n=19). Females (n=17). Males (n=2). Caucasian (n=14). Mean Age (n=24). No previous experience caring for a dying person (n=14). **Johns Hopkins Evidence Appraisal** **Level of Evidence:** III **Quality:** Good	Qualitative exploratory study: focus group Student anonymity protected on written consent prior to focus group meeting. Focus group sessions were audio recorded. Researchers used: credibility, dependability, conformability, and transferability to assess the reliability of the data collected. Focus group lasted one hour using open-ended question guide. Nursing students journal about their five-week experience with the same family.	Three themes identified: • Learning from stories • Learning from being there • Learning from caring **Conclusion:** Students developed an understanding of personal suffering at the end of life and what it meant to be there for the patient and family.	**Strengths:** Nursing students were able to care for terminally ill patients. Students were able to participate in service learning and bring their experience back to focus group for discussion. **Limitations:** Small sample size. Participants were from one university.

Author Recommendations: Allowing students to participate in end-of-life clinical experience will expose them to experience grief, empathy, ethical decision making, and family beliefs.

Implications: When students are able to witness end-of-life experiences and discuss with their peers, they will be able to implement nursing theory into professional practice.

<table>
<tr><td colspan="4">Source: Moir, C., Roberts, R., Martz, K., Perry, J., & Tivis, L. J. (2015). Communicating with patients and their families about palliative and end-of-life care: Comfort and educational needs of nurses. <i>International Journal of Palliative Nursing, 21</i>(3), 109-112. doi:10.12968/ijpn.2015.21.3.109</td></tr>
<tr><th>Purpose/Sample</th><th>Design (Method/Instruments)</th><th>Results</th><th>Strengths/Limitations</th></tr>
<tr>
<td>Purpose:
Assess how prepared inpatient nurses feel when discussing end-of-life care versus palliative care with patient, and family.

Sample/Setting:
Inpatient nurses (n=60)
At a 378 bed hospital in Idaho:
Critical care nurses (37%)
Oncology nurses (26%)
Telemetry nurses (37%)

Johns Hopkins Evidence Appraisal

Level of Evidence:
III

Quality:
Good</td>
<td>Non-experimental survey design.

Recruitment emails sent to 175 nurses with active email addresses on the telemetry, oncology, and critical care units at an Idaho hospital.

Flyers were posted on the inpatient units to recruit nursing participation.

Surveys were offered electronically on line or handwritten.

Nurses completed End of Life Professional Caregiver Survey (EPCS) which focused on communication within three domains:
• Among patient and family
• With cultural and ethical values
• Effectiveness of care
Results were examined by the following categories: experience, age of nurse, and type of hospital unit.</td>
<td>The sample was primarily made up of nurses 30-49 years old, with experiences fairly divided between 2-5 years, 5-10 years, or >10 years.

Oncology nurses scored the highest in all categories of the EPCS surveys.

Conclusion:
Oncology nurses had a greater level of comfort in palliative care and end-of-life conversation.</td>
<td>Strengths:
Characteristics of nurses were examined thoroughly in the following areas: Patient and Family Centered Communication (PFCC), Cultural and Ethical Values (CEV), Effective Care Delivery (ECD).

Limitations:
Demographics and characteristics of nurses who completed the surveys were from one hospital. Inpatient nurses invited to participate were limited to telemetry, oncology, and critical care units. Small sample size.</td>
</tr>
<tr><td colspan="4">Author Recommendations: Nurses should be educated and trained to talk with patients and caregivers about palliative care and end-of-life decisions. This will build their confidence when needing to have a difficult conversation. Based on the findings from the survey, educational models will be developed based on the palliative care needs identified by the respondents.</td></tr>
<tr><td colspan="4">Implications: Nurses need to be able to distinguish between palliative care and end-of-life indications with patients and caregivers. This will enable them to be prepared when it is time to have these conversations.</td></tr>
</table>

Source: Gillett, K., O'Neill, B., & Bloomfield, J. G. (2016). Factors influencing the development of end-of-life communication skills: A focus group study of nursing and medical students. *Nurse Education Today, 36,* 395-400.

Purpose/Sample	Design (Method/Instruments)	Results	Strengths/Limitations
Purpose: Identify what influences nursing students and medical students in learning end-of-life communication techniques. **Sample/Setting** Second year nursing students (n=2 focus groups with n= 9 participants) Fourth year undergraduate medical students (n=3 focus groups with 10 participants). London University. **Johns Hopkins Evidence Appraisal** **Level of Evidence:** III **Quality:** Good Quality	Qualitative study comprised of five focus groups. Recruitment of students who had cared for end-of-life patients in their clinical practice. Placed in focus group on first come-first serve basis with a goal to have four to six per focus group. Moderator led the interactive focus group with semi-structured topics to initiate discussion and participation.	Intrinsic and extrinsic factors affect how nursing and medical students communicate with patients and caregivers. Themes of intrinsic facilitators: • Self-confidence. • Relationships with patients. • Previous experience. Intrinsic barriers: • Coping with emotions. • Educational accuracy. Extrinsic facilitators: • Patient and relatives. • Role models Extrinsic barriers: • Professional cultures. • Gatekeeping. • Lack of formal discussion. • Uncommunicative patients. **Conclusion:** End-of-life learning opportunities with qualified facilitators will foster on-going learning with nursing and medical students. Focus groups allow for sharing and developing interventions to eliminate communication barriers.	**Strengths:** Identifying communication gaps between nursing and medical students will help to develop end-of-life interventions to strengthen cohesive working relationships. Study focuses on relationships between nurses, physicians, patients, and caregivers being able to communicate. **Limitations:** Based on the voluntary participation, this study may influence the outcomes due to personal feelings of the participants.

Author Recommendations: Developing end-of-life curriculum for nursing students and medical students should mimic real life circumstances in the simulation labs and role-playing. Qualified facilitators will be able to teach effective, confident communication techniques.
Implications: If the interdisciplinary team does not know how to communicate in an empathetic manner, patient and caregiver will not be prepared to deal with end-of-life decisions.

Source: Goebel, J. R., Guo, W., & Wood, K. (2016). Teamwork and perception of palliative care quality. *Journal of Hospice & Palliative Nursing, 18*(3), 242-248. doi: 10.1097/NJH.0000000000000239.			
Purpose/Sample	**Design (Method/Instruments)**	**Results**	**Strengths/Limitations**
Purpose: Evaluate interprofessional education and organizational structure to improve palliative care quality. **Sample/Setting:** Hospice or palliative care units Participants (n=460) Palliative Care providers (n=371) **Johns Hopkins Evidence Appraisal** **Level of Evidence:** IV **Quality:** Good	Cross-sectional design. TeamSTEPPS Teamwork Perception Questionnaire. This tool was developed by Agency for Healthcare Quality and Research, and Department of Defense to assess quality improvement. Online survey May 2013 to May 2014. Assess PC team structure, teamwork processes, and perception of quality of care (QoC). Statistical Package for Social Sciences version 22 for Windows was used for analyzing data.	Individuals from the United States and 4 countries completed survey. Participants: RN (n=81%) Females (n= 89.9%) Greater than master's level education (n=48.9%) Quality of overall care rated: Excellent 50.4% Good 44.8% Fair 3.5% Poor 1.3% **Conclusion:** Participants who had an educational degree less than a bachelor's degree felt the QoC within their organization was excellent. Professionals with higher education are more subjective on what is best practice.	**Strengths:** Disciplines that participated: physician, registered nurse, chaplain, social worker or other. Higher level of education provided more in-depth critical analysis of what is best practice. **Limitations:** Financial constraints may affect development of palliative and hospice care programs. Selection bias may compromise the validity of the study and not representative of larger selection of PC providers and diversity (white female nurses). Did not include patient or family perception of overall experiences.
Author Recommendations: Demographic characteristics and educational background influenced higher collaboration and communication ratings on the survey.			
Implications: Collaboration of a multidisciplinary team with higher educational background were felt to offer improved quality of care and participation in palliative and hospice care facilities.			

Source: Jack, B. A., Mitchell, T.K., Cope, L.C., & O'Brien, M.R. (2016). Supporting older people with cancer and life limiting conditions dying at home: A qualitative study of patient and family caregiver experiences of Hospice at Home care. *Journal of Advanced Nursing, 72*(9), 2162-2172.

Purpose/Sample	Design (Method/Instruments)	Results	Strengths/Limitations
Purpose: To develop understanding of patient and caregiver experiences and perception of allowing people with a terminal illness to die at home. **Sample/Setting:** Adult English-speaking patients receiving Hospice at Home care who had life-expectancy timeframe of days (rather than weeks) Total participants (n=41) Comprised of: Patients (n=16) Family caregivers (n=25). Hospice at Home is a homecare program in the United Kingdom (UK) in which nurses and nursing assistants supported by physicians. **Johns Hopkins Evidence Appraisal** **Level of Evidence:** III **Quality:**	Prospective descriptive qualitative study. Participants were enrolled in Hospice at Home. Patients and family members were given information about the study if they met inclusion requirements. If they expressed interest the research team set up time to interview them. Semi-structured recorded interviews inclusive of patients and caregivers. Interviews were done in participants' homes, on the telephone and while attending day therapy. Patient and caregivers were able to answer questions separately or jointly. Identification of patient and caregivers were removed from the transcripts of the interviews to allow anonymity and prevent bias in interpretation.	Results were evaluated and reported out in categories with similar reporting. Results were classified into two themes: 'Embracing Holism and Service organization'. **Conclusion:** Using data from interviews allowed prospective study to help evaluate data earlier then later. It allowed the patients who were dying to provide insight about what they wanted from their end-of-life care. Patient felt their wishes were honored due to experience of the hospice nurses being able to prevent unnecessary visits to the hospital.	**Strengths:** The nurses were skilled and confident in having difficult conversations about death and dying, which made it easier for participants to take part in discussions. Three researchers viewed the data independently and marked their interpretations independently prior to bringing it to the group with a fourth researcher to discuss their findings. **Limitations:** Participants that were interviewed came from Hospice at Home organizations. Findings may not be generalized to a younger patient and caregivers. Patient populations in this study were elderly along with their caregiver who may have had their own morbidities that prevented them to provide hospice care at home. The fact that the same hospice organization that provided the services also conducted the study. Having only

<table>
<tr><td>Good</td><td></td><td></td><td>one hospice organization from which participants were obtained may affect the overall results. It is possible that patients and caregivers may have refrained from sharing their true experiences for fear of not having the same opinion.</td></tr>
<tr><td colspan="4">Author Recommendations: The findings from this study could support recommendation of additional specific areas of research to evaluate the services and effectiveness of home hospice when attempting to grant wishes to die at home.</td></tr>
<tr><td colspan="4">Implications: This study allowed for terminally ill patients to share their experiences while having their wishes of dying at home be fulfilled. Collecting data from the patients allowed for earlier interventions and resources to be offered to the caregivers within one hospice organization.</td></tr>
</table>

Source: Glover, T. L., Garvan, C., Nealis, R. M., Citty, S.W., & Derrico, D.J. (2017). Improving end-of-life care knowledge among senior baccalaureate nursing students. *American Journal of Hospice and Palliative Medicine, 34*(10), 938-945. doi: 10.1177/1049909117693214.

Purpose/Sample	Design (Method/Instruments)	Results	Strengths/Limitations
Purpose: To assess end-of-life and palliative care knowledge of baccalaureate nursing students prior to and post End-of-Life Nursing Education Consortium (ELNEC) core course. **Sample/Setting:** Baccalaureate students attended ELNEC 2-day course with preassessment prior to, and one-week post course in January 2015. Participants (n=92). **Johns Hopkins Evidence Appraisal** **Level of Evidence:** III **Quality:** Good	Descriptive cross-sectional study. Pre- and post-assessment evaluation questionnaire with qualitative assessment	Before course, one-third of students had cared for a dying patient in their clinical rotation. 85% felt they had not received the appropriate training prior to taking the course. Posttest showed significant knowledge after attending ELNEC course ($P<.05$). ELNEC course is effective to present and improve knowledge on palliative and end-of-life care. **Conclusion:** Palliative and end-of-life education should be a requirement in all nursing programs. Additional research would be beneficial while looking at the various teaching styles and tools used.	**Strengths:** Valid and reliable tool to test knowledge; ELNEC Knowledge Assessment Test. **Limitations:** Sample was not racially or ethnically diverse. Participation was voluntary therefore limited sample size.

Author Recommendations: Implementing palliative and end-of-life courses in nursing programs will decrease the gap when preparing nurses to care for an aging population. Improving the comfort level of nurses who care for patients dying will improve patient and caregiver experience.

Implications: Study confirmed that nurses feel inadequately prepared to care for palliative or end-of-life patients.

Source: Canzona, M.R., Love, D., Barrett, R., Henley, J., Bridges, S., Koontz, A.,…Daya, S. (2018). “Operating in the dark”: Nurses’ attempts to help patients and families manage the transition from oncology to comfort care. *Journal of Clinical Nursing, 27*(21-22)*,* 4158-4167. doi: 10.1111/jcon.14603.

Purpose/Sample	Design (Method/Instruments)	Results	Strengths/Limitations
Purpose: To identify barriers oncology nurses encounter when their patient transitions from curative to palliative care. Also, to identify educational needs for the nurses working in this field. **Sample/Setting:** Nurses who worked in oncology or palliative care in south-eastern health care network including clinics, outpatient centers, and hospitals. Oncology nurse: (n=14). Palliative care nurse: (n=14). Data collection was between January 2017 through October 2017. **Johns Hopkins Evidence Appraisal** **Level of Evidence:** III **Quality:** Good	Interpretive design. Semi-structured interviews. Recruitment through organizational list serves, verbal presentations, and personal email. Interviews conducted via telephone from a semi-structure interview guide.	Challenges identified: Patient denial, family relationships, boundaries, and emotional burden during end-of-life care. Lack of clear communication between physician and patient on the goal of treatment. Discrepancies on what is being communicated to patient and what is being understood about life expectancy. **Conclusion:** Nurses are requesting ongoing educational opportunities to aid in communication techniques revolving around denial, anger, and despair. Nurses develop burnout secondary to interpersonal conflict, depression, and emotional exhaustion as a result of miscommunication between care team and patient. Negative interactions between physician and nurses about end-of-life care can have a negative effect.	**Strengths:** Participants went through analytical analysis to identify if they were qualified to speak on behalf of comfort care and end-of-life measures. Audit measures were put in place to track processes, themes, and quotes during period of decision making for patient. **Limitations:** Did not use a national tool for survey. Sample size: (n=28). Study evaluated nursing challenges without breaking down what the obstacles were between patient and interdisciplinary team.

Author Recommendations: Initial and ongoing educational modules are necessary to teach communication techniques that are meaningful and supportive between a multidisciplinary team, patient and caregiver.
Implications: Poor communication can interfere with building a trusting and supporting relationship between nurse and patient when treatment goal and prognosis is ambiguous.

Source: Ewing, G., Austin, L., Jones, D., & Grande, G. (2018). Who cares for the carers at hospital discharge at end of life? A qualitative study of current practice in discharge planning and the potential value of using The Carer Support Needs Assessment Tool (CSBAT) Approach. *Palliative Medicine, 32*(50), 939-949. doi: 10.1177/0269216318756259.			
Purpose/Sample	**Design (Method/Instruments)**	**Results**	**Strengths/Limitations**
Purpose: To assess the needs of caregivers at time of discharge from a hospital facility when patients are at end-of-life. **Sample/Setting:** Three National Health Service (NHS) Trusts in England. Study conducted between December 2014 and November 2015. Hospital and community-based practitioners focus groups: (n=40) Carer interviews: (n=22) Two workshops. Practitioners: (n=14) Carers: (n=5) **Johns Hopkins Evidence Appraisal** **Level of Evidence:** III **Quality:** Good	Qualitative Thematic analysis Focus Groups: Healthcare professionals Interviews: Carers/next of kin Workshops: Healthcare professionals and carers. The Carer Support Needs Assessment Tool (CSNAT) Approach. Two researchers independently reviewed data and placed in a coded framework based on data and topics identified.	**Findings** Representing the viewpoint of the healthcare professional and carer: • Barriers to support carers at time of discharge from hospital. • Use of CSNAT at time of discharge. • Use of CSNAT during the hospitalization. Allowed for carers to discuss struggles with caring for patient with end-of-life needs, while evaluating the healthcare preparation to provide care. **Conclusion:** Looks at how to prepare for discharge care in the home that prevents future readmissions to the hospital.	**Strengths:** Use of CSNAT is a copyright tool. Tool reaffirmed the role that family carers play in discharge planning, caring, and supports needed in order to keep the patient home per their wishes. **Limitations:** Many carers declined to participate in the study secondary to the sensitivity of the subject.

Author Recommendations: When looking at discharge planning interventions and preparation to provide care in the setting of the home, one must include the caregiver. This will prevent barriers in being able to keep patient in the home.
Implications: Discharge planning should be inclusive of what patient and caregivers may need at home to prevent rehospitalization. Additional interventions should be aimed at the caregiver.

Source: Lee, S.B., Forehand, J.W., St. Onge, J. L., & Acker, K.A. (2018). Helping bridge the great divides; supporting nurse communication at end of life. *Nurse Christian Fellowship,* 35(4), 258-262. do: 10:1097/CNJ0000000000000542.			
Purpose/Sample	**Design (Method/Instruments)**	**Results**	**Strengths/Limitations**
Purpose: To understand challenges nurses encounter when it comes to initiating conversations with patients and families about end of life challenges. **Sample/Setting:** Acute care nurses (n=115). Age 20 to 25 (n=61, 53%). 0 to 5 years of experience (n=97, 84.3%). Associate degree in nursing (n=94.81%) **Johns Hopkins Evidence Appraisal** **Level of Evidence:** II **Quality:** Good	Quasi-experimental one group pretest/posttest design. End-of-Life Nursing Education Consortium (ELNEC) curriculum was taught in a six-hour workshop. Material was presented by lecture, video and interactive role playing. 30 questions to assess attitudes towards care of dying patient and family.	Between basic nursing educations and communication scores pre-course, post-course, and one-month post course evaluating interventions. Scores: Showed improvement Pre-intervention to post intervention: (p<.001). Pre-intervention to one month follow up post intervention: (p<.001). However, post intervention to one month follow up did not show significant improvement (p>.05). **Conclusion:** When including evidenced-based interventions attitudes and communications scores improved between nurse, patient and family at end-of-life.	**Strengths:** Use of Frommelt Attitude Towards Care of the Dying (FATCOD) evaluation tool. Evaluated nurse level of comfort pre-course work, post-course work, and one-month post-course completion. **Limitations:** Data collected from two campuses of a regional medical center in southeastern United States. Did not provide feedback from nurses with years of experience > 5years and their comfort/knowledge level with end-of-life care.
Author Recommendations: Include end-of-life care into nursing curriculum and orientations. Using curriculum, such as what is taught with ELNEC, will help with communication skills, attitudes and less anxiety.			
Implications: Not being able to discuss end of life care with patient and family about spirituality, expectations, and end of life wishes can lead to unfulfilled needs.			

Source: Rajdev, K., Loghmanieh, N., Farberov, M. A., Demissie, S., & Maniatis, T. (2018). Are health-care providers well prepared in providing optimal end-of-life care to critically ill patients? A cross-sectional study at a tertiary care hospital in the United States. *Journal of Intensive Care Medicine,* 1-15, https://doi.org/10.1777/088506661881794.

Purpose/Sample	**Design (Method/Instruments)**	**Results**	**Strengths/Limitations**
Purpose: Identifying barriers in the ICU with health care providers providing palliative and end-of-life care. **Sample/Setting:** Northwell Health Staten Island University Hospital is a tertiary care hospital in the United States. Health care providers: • Residents, Internal medicine, and general surgery • Fellows • Attending physicians • Registered nurses • Nurse practitioners • Physician assistants. **Johns Hopkins Evidence Appraisal** **Level of Evidence:** III **Quality:** Good	Cross-sectional study. Questions were developed from review of literature on PubMed and Endnote. Electronic surveys were emailed to eligible employees. Email addresses provided by human resources.	Responses: Respondents (n=238) (36%). End of Life (EOL) survey: Self-reported knowledge not prepared: (34%). Self-reported attitude in providing EOL cares did not feel comfortable: (31.33%). Self-reported behaviors of not being able to provide accurate and truthful outcomes: (51.%) C**onclusion:** Palliative has many benefits to assist with symptom management and improving patient experience. Hospice is geared towards a terminal illness, whereas EOL encompasses supportive care. However, it may be difficult to determine when patient's illness progressed to the point where hospice may be best.	**Strengths:** Multidisciplinary approach on participants' self-perceived knowledge base, attitudes and behaviors of EOL in the ICU. **Limitations:** Surveyed only one health care facility. Questions and results were of quantitative data and did not look at qualitative data. Survey questions were self-designed and not a national tool. Validation of survey was not performed prior to initiation of survey.

Author Recommendations: Additional research is needed to develop curriculum for educational, and training courses focusing on palliative and end-of-life care in the critically ill patients.
Implications: Health care providers who participated in survey did not feel adequately trained or had confidence to initiate a conversation about palliative or hospice care when the patient is terminally ill.

Source: Smith, M.B., Macieira, T.G.R., Bumbach, M.D., Garbutt, S. J., Citty, S.W.,…Keenan, G. (2018). The use of simulation to teach nursing students and clinicians palliative care and end-of-life communication: A systematic review. *American Journal of Hospice & Palliative Medicine, 35*(8), 1140-1154. doi: 10.1177/1049909118761386.

Purpose/Sample	**Design (Method/Instruments)**	**Results**	**Strengths/Limitations**
Purpose: Determine if simulation-based learning experiences (SBLEs) help prepare nurses and clinicians to communicate about palliative and end-of life care to patients and their caregivers. **Sample/Setting:** Records screened (n=442) Records excluded (n=389) Full text articles assessed for eligibility (n=53) Full-text articles excluded (n=23) Studies included in systematic review (n=30)	Systematic review of articles from electronic databases inclusive of CINAHL, MEDLINE, PsycINFO, ERIC. Web of Science, Grey Literature resources included ProQuest Dissertation & Theses Global, Worldcat Dissertations and Theses, NLM Gateway Initial literature search was initiated on February 15, 2017 with no timeframe, study, or subject filters identified at time of literature request. **Instrument:** Kirkpatrick's Level of Evaluation was used to review each article in the four areas: • Reaction to training • Learning • Behavior • Results	Additional research needs to be done to identify best practices when developing SBLE scenarios specific to palliative and end-of-life care. It is necessary for these case studies to be all-inclusive to the healthcare team on how to communicate. **Conclusion:** Recommend identifying additional methods in preparing the health care team to initiate difficult conversations.	**Strengths:** Author had specific criteria for article selection for the literature review: • Defined simulation • Technology utilized • Participants in learning labs included nursing students and practicing nurses • SBLEs included palliative care or end-of-life conversations • Post evaluation of SBLEs. **Limitations:** Training in the SBLEs lab did not include multiple disciplines acting out their role in the various scenarios. Standardization of materials taught in the SBLEs was not consistently allowing individuals to be assessed the same across the continuum of role-playing.

Johns Hopkins Evidence Appraisal **Level of Evidence:** V **Quality:** Good			
Author Recommendations: Having a multidisciplinary approach when preparing curriculum for the simulation labs and objectives would be constructive in teaching and assessing communication techniques.			
Implications: It was difficult to assess whether the learning labs were effective when the criteria did not have detailed criteria or outcomes. Organizations should use case studies that have been validated. This will allow for evaluation based on objective criteria instead of subjective interpretation.			

<table>
<tr><td colspan="4">Source: Soroka, J. T., Froggatt, K., & Moris, S. (2018). Family caregivers’ confidence caring for relatives in hospice care at home: An exploratory qualitative study. <i>American Journal of Hospice & Palliative Medicine, 35</i>(12), 1540-1546. doi: 10.1177/1049909118787779.</td></tr>
<tr><th>Purpose/Sample</th><th>Design (Method/Instruments)</th><th>Results</th><th>Strengths/Limitations</th></tr>
<tr>
<td>Purpose:
To determine the confidence and preparedness a caregiver of hospice patient has to care for friend or loved one at home with a terminal illness.

Sample/Setting:
Caregiver (n=16)
14 individuals
1 brother/sister dyad.

Location:
Midwestern United States.

Patients were from one hospice organization.

Johns Hopkins Evidence Appraisal Exploratory, Cross-sectional

Level of Evidence: III

Quality: Good</td>
<td>Exploratory, cross-sectional design qualitative study.
Semi-structured in-depth interviews.

Qualitative:
Information was collected from the caregivers after the patient passed away.
Caregiver was able to choose location of interview (home or hospice office).

Instrument:
Semi-structured in-depth interview.

Questions were geared towards following a chronological narrative analysis of four storylines.
1. Story of values and relationships.
2. Experiencing terminal illness.
3. Story of needs.
4. Story of journeying together and support.</td>
<td>Results:
Caregiver confidence was based on sense of commitment, responsibility to the patient.
Beliefs and upbringing help to convince caregivers things will work out.
When patient’s illness became terminal, it caused the caregiver to question their ability to provide the end of life care.
Caregivers felt they lacked the knowledge of when illness progressed to the next phase where death was imminent.
Would they be able to face the challenges?
Caregivers preferred help from friends and family to hospice staff.

Conclusion:
Healthcare professionals and providers should have a better understanding of caregivers’</td>
<td>Strengths:
Analysis of open-ended questions and answers were interpreted based on a hospice tool widely used in the United States: The Family Evaluation of Hospice Care (FEHC).
Bandura’s Social Cognitive Theory (SCT) tool was used to help evaluate the challenges and goals of caregivers of terminally ill patients.

Limitations:
1. N=16. Participant size small.
2. Interviewed patients from one hospice organization.
3. Limited location confined to the Midwestern United States.
4. Limited ethnic diversity.</td>
</tr>
</table>

		knowledge and comfort of providing care in the home setting. Patients with a terminal illness prefer to die at home.	
Author Recommendations: Developing an understanding of the caregivers’ confidence, resources, and ability to care for their loved one at home will help identify what tools and resources need to be shared right from the beginning.			
Implications: Caregivers are from a diverse background. Which identified where they received strength in caring for the terminally ill patient. This strength came from faith, relatives, and hospice.			

Source: Anasari, M., Rassouli. M., Akbari, M. E., Abbaszadeh, A., Akbarisari, A., & Haghighat, S. (2019). Process challenges in palliative care for cancer patients: A qualitative study. *Middle East Journal Cancer, 10*(1), 43-53.

Purpose/Sample	**Design (Method/Instruments)**	**Results**	**Strengths/Limitations**
Purpose: To look at cancer patients' perception of palliative care challenges in Iran. **Sample/Setting:** Hospitals in Tehran, Iran. Interviews from February 2016 to August 2017. Participants: Patients, family caregivers, health care providers, and policy-makers. (n=22) **Johns Hopkins Evidence Appraisal** **Level of Evidence:** III **Quality:** Good	Qualitative Study. Semi-structured interviews. Participants were recruited through purposeful sampling Interviews analyzed by qualitative directed content based on Donabedian model. Data collection and analysis were simultaneously performed with MAXQDA 10 software.	Data collected categorized into a main process, three subcategories, and nine secondary categories: • Weakness of stakeholders' engagement policies. • Standardized care. • Applying educational and research approaches. **Conclusion:** Palliative care is an essential component in each country's health care system. To train generalist and palliative medical group on palliative care, curriculum needs to inform public about cancer and empower patient and caregivers on end-of-life challenges.	**Strengths:** Program of Action for Cancer Therapy (PACT) of the International Atomic Energy Agency and World Health Organization (WHO) provided expect opinion on data collected. Donabedian model used as the conceptual framework. **Limitations:** Small number of participants, narrow generalizability. Participants were from one area of the country, Iran.

Author Recommendations: Palliative care is a new service in Iran. Findings revealed there is work to be done to standardized models of care inclusive of educational requirements.

Implications: Additional research should be completed to evaluate resources, cultural needs, and social implications to provide policymakers in Iran an outline to work on.

Source: McDarby, M., & Carpenter, B.D. (2019). Barriers and facilitators to effective inpatient palliative care consultations: A qualitative analysis of interviews with palliative care and nonpalliative care providers. *American Journal of Hospice, 36*(3), 191-199. doi: 10.1177/1049909118793635.

Purpose/Sample	**Design (Method/Instruments)**	**Results**	**Strengths/Limitations**
Purpose: To find what impedes or facilitates collaboration between palliative and noncollaborative specialists in the care of their patients. **Sample/Setting:** Palliative care providers (n=19). Nonpalliative care providers (n=29). Interviews were completed at four midwestern hospitals, face to face and over the telephone. **Johns Hopkins Evidence Appraisal** **Level of Evidence:** III **Quality:** Good Quality	Qualitative Study. Semi-structured interviews. Thematic Analysis.	Six themes: • Interaction between providers. • Patient and family perceptions about palliative care. • Provider attitude toward palliative care. • Education and training about palliative care. • Role of palliative care consultation teams (PCCT). • PCCT recommendation for implementation. **Conclusion:** In order to present a unified team, the palliative and nonpalliative care team should be visible during the hospitalization. Organization should invest in educational and marketing opportunities to increase awareness of palliative care to the interdisciplinary team, patient, and caregiver.	**Strengths:** Identification of themes also included potential barriers and strategies to facilitate collaboration between PCCT and nonpalliative care providers. **Limitations:** If providers chose not to participate in the study, it may have been because they have different beliefs. This may have changed the outcome of the findings of barriers and recommended interventions.

Author Recommendations: Additional research analyzing educational barriers will help to identify what is needed to develop collaboration between palliative care providers and nonpalliative care providers. Once these barriers are identified, intervention strategies can be implemented to improve end-of-life teamwork.

Implications: Without collaboration and public awareness on end-of-life choices in relation to progression of disease process, the patient and caregiver expectations will not be met.

Source: Rawlings, D., Devery, K., & Poole, N. (2019). Improving quality in hospital end-of-life care: Honest communication, compassion and empathy. *BMJ Open Quality, 8*(e000669). doi: 10.1136/bmjoq-2019-000669.			
Purpose/Sample	**Design (Method/Instruments)**	**Results**	**Strengths/Limitations**
Purpose: To identify the one thing health care providers can do to improve end-of life care after completing e-modules to improve safe and quality care. **Sample/Setting:** Data collected between a 10-month period November 2016- September 2017. Individuals registered for one of six modules (n=5181). Free texted responses (n=3201). Participants work in acute care hospitals in Australia. **Johns Hopkins Evidence Appraisal** **Level of Evidence:** III **Quality:** Good	Modules were designed for doctors, nurses, and other allied health professionals. Thematic analysis. Six modules were developed from *The National Consensus Statement on Essential Elements for Safe and High-Quality End-of-Life Care.* The question that was asked after module and evaluated for themes: 'Tomorrow, the one thing I can change to more appropriately provide end-of-life care is…'. Data was extracted and deidentified, analyzed, and coded scheme. Data reviewed by a team to identify themes, systematically and coherently compared to look for nuances.	Five themes: • Communication. • Emotional insight. • Professional mindset. • Person-centered care. • Professional practice. **Conclusion:** Findings authenticated the need to make changes in the work place to improve when death occurs in the hospital. Implementing end-of-life care in the hospital should include honesty, compassion, dignity, and empathy.	**Strengths:** This study confirmed the complexity of end-of-life care. Study identified personal changes necessary in addition to organizational changes. Individual changes in attitudes, and behavior. Large participation: (n=3201). **Limitations:** With utilizing the same question after each module, individualization of their answers may not be their own. Participants may only be stating what they just learned from the course module. When looking at how to change practice may reflect individual needs barriers, not big picture of the organization.
Author Recommendations: More than education is needed to improve end-of-life care. A strategic plan is needed to shape education, implementation, and ongoing tools for professional growth for health care providers.			
Implications: End-of-life care is complicated. It affects the patient, caregiver, healthcare team, and organizational environment. There are many healthcare providers who are not prepared to deal with death and dying.			