Techniques for Dealing with Difficult Discussions at End-of-Life Care

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Abstract

After careful review of current literature related to nursing and end-of-life care, there is no available resource to teach senior level baccalaureate nursing students about how to begin and deal with end-of-life care discussions in the nursing profession. The proposed research in this paper combines current literature on end-of-life care into a concise, complete presentation. This presentation would be used to teach the appropriate audience about end-of-life care and how to begin and deal with difficult discussions that arise. With this presentation, a pre- and post-test would be administered to analyze the effectiveness of the informational session. The research question being addressed is: After attending a presentation on end-of-life care, are senior level baccalaureate nursing students more informed about end-of-life care?
Introduction

End-of-life care can best be described as the healthcare involved in the last hours, days, or months of a patient’s life. End-of-life care brings with many difficult areas of discussion, most importantly the subject of death and dying. Other areas of discussion include palliative care, hospice, legal documentation, withdrawal of life-sustaining treatments, and the upholding of dignity during care (Watson, 2010). As the role of advocate and communicator in the nursing profession, registered nurses have become the major player in end-of-life discussions.

According to Espinosa, Young, Symes, Haile, and Walsh (2010), “In the United States, approximately 2.5 million people die each year, with 60% of these deaths occurring in hospitals, with half of those deaths involving intensive care units (ICU)” (p. 273). Due to this alarming statistic, a major focal point of end-of-life care focuses on the registered nurses’ perceptions, especially ICU registered nurses, with such population. While registered nurses demonstrate great technical skills with maintaining end-of-life care, another aspect to consider is focused on the psychological factors that come into play during end-of-life care. These factors include the nurses’ perceptions and barriers to end-of-life discussions. As registered nurses work in varying locations and levels of care, proper end-of-life care discussions are becoming an important intervention to begin at any stage of life.

Other aspects of end-of-life care discussions are identified. One important factor in end-of-life care and discussion is the aspect of incorporation and education of the dying patient’s family members. Another important factor is the use of community nursing staff to begin end-of-life discussions before acute situations occur. In the United States, there is a great movement towards preventative care; as such, end-of-life care and discussions are starting with community nursing. Finally, the last aspect addressed is that in the Western culture, dying and death are
rarely discussed; as such healthcare policies and initiatives relating to end-of-life care are limited.

After a review of current literature, the gap was the lack of knowledge; the intervention is a teaching plan for senior baccalaureate nursing students on end-of-life care concerns and discussions. The purpose of this project is to propose a research plan which addresses this problem. The teaching plan, geared toward this audience, contains information gathered from current literature into a PowerPoint presentation. Also, the presentation consists of a pre- and post-test to analyze its effectiveness. The basic research question proposed for study is: After attending a presentation on end-of-life care, are senior level baccalaureate nursing students more informed about end-of-life care?
Review of Literature

Introduction

The purpose of this review of literature is to examine what barriers occur and what initiatives work for registered nurses during end-of-life care and discussions. A great deal of the literature’s sampling is focused on intensive care unit registered nurses’ experiences during end-of-life care. As such, many of the perceptions presented are through ICU registered nurses’ experiences. While registered nurses’ experiences are important to consider, a major theme identified is the importance of family involvement during end-of-life care decisions and discussions. Other important sections include community initiatives and health policies related to end-of-life care.

Intensive Care Unit Registered Nurses’ Perceptions and Barriers during End-of-Life Care

To begin this discussion of end-of-life care as related to intensive care unit registered nurses, it is important to note ICU registered nurses’ own perceptions of caring for dying patients. According to McCallum and McConigley (2013), “providing a peaceful, quiet, and private environment is pivotal in maintaining the dignity of a dying patient and realizing an ideal death” (p. 26) Core themes emerged including ‘the nurse as the protector’, ‘conflict of care’, and ‘peace and quiet’ (McCallum et al., 2013, p. 26). According to Vanderspank-Wright, Fothergill-Bourbonnais, Brajtman, and Gagnon (2011), “conflict arose from when the physicians wanting to continue or discontinue life-sustaining treatment, and the family wanting the converse” (p. 33). As one can infer when an ICU registered nurse feels that their opinions are not or cannot be heard in regards to end-of-life care, then their experiences are negatively impacted.

In relation to ‘peace and quiet’, McCallum et al. (2013) state, this theme relates to providing a time for obtaining end-of-life wishes and providing for spiritual needs of the patients
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and their families. According to Vanderspank-Wright et al. (2011), the participants described their role in providing positive interventions to aid in sustaining dignity at end-of-life care. Both studies demonstrate the importance of still engaging the patient and family members in dignity fulfilling life activities during end-of-life care.

McCallum et al.'s (2013) and Vanderspank-Wright et al.'s (2011) work are also reflected in Espinosa et al.'s (2010) work. The findings identified the theme of “barrier to optimal care” which relates to the other researchers’ themes of ‘conflict of care’ and ‘working in professional angst’ (Espinosa et al., 2010, p. 275). A new theme of recognition from Espinosa et al.’s (2010) research is “the coping strategies used by the ICU nurses which include building trust with the family, crying, humor, talking to others about terminal care” (Espinosa et al., 2010, p. 275). While these types of coping strategies may reflect personal preference, they may also reveal another area of concern: the ICU nurse’s ability to handle end-of-life care situations.

While researching ICU nurses’ experiences in end-of-life care, an area of concern is confronting moral distress due to ethical dilemmas. According to Browning (2013), the top three high-scoring issues for moral distress including “follow family’s wishes to continue life support when not in patient’s best interest”, “follow [physician’s] orders for unnecessary tests”, and “follow family wishes for patient care I don’t agree with” (p. 148). The highest scoring topic for psychological empowerment was “I really care about what I do on my job” (Browning, 2013, p. 148). The findings from this study conclude that “psychological empowerment was positively correlated with age, years of experience, collaboration in end-of-life care conferences, and end-of-life care education and were negatively correlated with moral distress frequency” (Browning, 2013, p. 143).
Families and End-of-Life Care

The studies relating to ICU registered nurses’ perceptions during end-of-life care lead to another area of research: the family of the dying patient. While caring for dying patients, it is important to incorporate family members into nursing plans of care. Family members can include actual relatives, friends, and significant others. As a registered nurse, a great deal of time is spent understanding and caring for not only the patient but their supportive loved ones. Three major tasks are identified to balance this unique multi-person relationship, including building a trusting relationship with the patient and their family, actively listening to family concerns, and acting as an educator. Such tasks are important since patients’ family members and loved ones should be seen as an extension of holistic care for a dying patient (Karlsson et al., 2011).

The first major task, building a trusting relationship, including the end-of-life patient, their family members, and the registered nurse, starts with understanding what barriers hinder this process. According to Clabots (2012), certain barriers which hinder building a trusting relationship include the nurse’s inexperience with death and dying and stress, which affects communication with patients and families. To combat these types of barriers, Clabots (2012) suggest “the nurse should examine personal beliefs, values, and fears about death and dying… and should not project his or her values onto the patient” and “should become cultural aware of any family or religious customs” (p. 200) The next step in initiating and maintaining end-of-life discussions with families is through forming a trusting relationship by “offering to answer any questions regarding the plan of care”, utilizing “active listening strategy”, “provide frequent, timely family updates regarding patient status and goals of care”, and “providing anticipatory guidance, support, and frequent follow up to ensure understanding of the plan of care” (Clabots, 2012, p. 200).
The second task to improve care for end-of-life patients is through actively listening to family members’ concerns. Family members and loved ones of a patient can provide great insight and detail into wishes and concerns of a patient who is unable to express such issues. According to McEvoy, Pugh, and Blenkinsopp (2012), communication diaries were given to relatives of patients and “acted as a catalyst to ensure regular communication between nurses and family and carers so that sensitive matters of support were addressed in addition to physical care and symptom control” (p. 27) According to Karlsson, Tisell, Engstrom, and Andershed (2011), “comfort of the relatives’ room is important because the family members spend a great deal of the waiting time there” (p. 15) Karlsson et al. (2011) and McEvoy et al. (2012) provide examples of how family members concerns can be addressed in respect to end-of-life patients.

The final task associated with the relationship between the end-of-life patient, their respective family members, and the registered nurse is through educating family members so they can respectfully act as fellow advocates. In the United States’ hospital system, the adaptation of a palliative care team and advance directives have become more commonplace. According to Clabots (2012), “the nurse should educate them [family members] regarding the underlying goals of palliative and hospice care as improving the quality of life for the patient and family and reliving suffering during the dying process” (p. 198) Also, according to Clabots (2012), “the nurse should discuss advance directives with all patients and families…the idea behind these interventions is to prepare and empower the patient and loved ones, providing opportunities to ensure their wishes will be respected at end of life” (p. 198) Finally in Karlsson et al.’s (2011) research “it is important to emphasize the usefulness of the nurses’ greater participation when the physicians give information, as medical information can be difficult to understand” (p. 16). Through educating family members, the ICU registered nurse broadens the
range of opportunities to explore for end-of-life patients who may not be able to express their own concerns. Consequently, if appropriate, educated family members assert the role of advocate by interceding through with their dying family member’s wishes.

**Community Nursing’s Role in End-of-Life Care**

Since many hospital admissions are a result of acute and life-saving measures, end-of-life care conversations and initiatives need to start with community nursing. Through preparedness and planning of end-of-life care with community nurses, individuals admitted to hospitals can have in place exact dignity maintaining wishes and avoid unnecessary interventions. Community nurses can commence end-of-life discussions and education.

To begin the discussion of community nurses’ impact on end-of-life care, one must understand the public’s opinion of end-of-life discussions. According to Hickey’s and Quinn’s (2012) research through public survey, 63% of respondents wished to die at home. However, according to the National Council for Palliative Care in 2010, “60% of individuals die in acute hospitals when there is no clinical need to do so” (Hickey et al., 2012, p. 244). A final remarkable finding is that 78% of participants believe it is the responsibility of a healthcare professional to commence end-of-life discussions (Hickey et al., 2012). This article demonstrates the importance of healthcare professionals, especially registered nurses,

“to find the confidence, competence, courage, and conviction to recognize and seize opportunities that facilitate open, honest, and timely discussions about planning and choice at the end of life, to ensure that dying well is an integral component of living well” (Hickey et al., 2012, p. 247).
As many individuals express a preference for a ‘good death’ at home, community nurses are helping to make this a possibility. According to Adamson and Cruickshank (2013), certain steps include “establishing a relationship that includes openness and honesty, conserving dignity, comprehensive assessment, alleviating symptom distress from both a physical and psychological perspective, consistent and timely information giving, open dialogue with patients and families, and anticipation and preparation” (p. 41).

A major way community nurses can begin an end-of-life planning conversation is through education and direct contact discussions. According to Jeong, Higgins, and McMillan, (2010), the researchers investigated the implementation process of and experiences of those involved in Advance Care Planning. The findings of the study conclude that successful implementation of advance care planning is through the involvement of an experienced end-of-life care nurse coordinator to educate registered nurses, quality of education discussion with residents about their planning rather than just making written materials available, and the involvement of multidisciplinary teams, such as palliative care, community nurses, and geriatricians (Jeong et al., 2010).

In a quasi-experimental design by Matsui (2010), a sample of older adults, aged 65 years and over, were split into two experimental groups, one group receiving a handout on end-of-life discussions and the other received a video, a lecture using a handout, and discussion among participants. At follow-up, “twice as many in the intervention group had discussed end-of-life matters with family members and/or their physician” (Matsui, 2010, p. 363). By starting these educational strategies in the community, such areas of conflict over end-of-life wishes and concerns can be addressed before entering a hospital or intensive care unit.
Johnston, Ostlund, and Brown (2012) evaluated the feasibility and acceptability of a Dignity Care Pathway. According to the authors, the Dignity Care Pathway (DCP) is a “therapeutic map, guiding health professionals to structure their care actions against conversing dignity” (Johnston et al., 2012, p. 483). The findings concluded that the DCP enabled them to provide more focused care and initiate conversations to start palliative care (Johnston et al., 2012). The impact of the DCP on everyday practice of the community nurses deepened nurse-patient relationships through open communication (Johnston et al., 2012). The overall impact of this study demonstrates that by open communicating about dignity-related concerns for end-of-life care, nurses can address such concerns by individualizing end-of-life plans.

As the United States healthcare moves more towards preventative measures, community nursing bridges the gap between initiating these difficult discussions and the actual implementation of end-of-life care. Community nursing helps to shape future outcomes for possible hospitalized patients and upholds each person’s right to die with dignity and respect.

**Health Policy Related to End-of-Life Care**

In Western society, the topic of death is usually avoided and ignored as a continuum of the life cycle. As such, there is limited end-of-life healthcare policy. To begin this discussion, the distinction between important end-of-life documentation must be addressed. Advance directives are a type of document that allow an individual to outline what type of healthcare he/she would want in an event where he/she is unable to make such decisions. Several types of advance directives exist, including Living Wills and Durable Power of Attorney for Healthcare. Another important type of documentation most commonly seen in a patient’s medical record is Do-Not-Resuscitate orders, which are specific physician orders dictated by the patient stating which lifesaving resuscitation interventions should be implemented in a lifesaving situation.
The first step towards implementation of end-of-life polices began with the United States Patient Self-Determination Act of 1991, which addressed advance directives. According to Watson (2010), this act requires all Medicare or Medicaid funded healthcare facilities and/or providers to address advance directives upon admission and provide education about this type of document.

Another great stride in end-of-life health care policy started with the passing of Patient Order for Life Sustaining Treatment in certain states, including Louisiana as the Louisiana Physician Orders for Scope of Treatment (LaPOST). Whereas advance directives outline a patient’s wishes in legal form, this type of documentation is filled out by one’s physician and relies the patient’s wishes into physician orders. The major topics presented in this document include “cardiopulmonary resuscitation, medical interventions, antibiotic treatment, artificially administered nutrition, other instructions, and summary of goals” (Louisiana Physician Orders for Scope of Treatment, 2013, p. 7).

Moving away from healthcare acts, certain governmental programs, such as Medicare, will feel the strain on increasing end-of-life care needs. According to Nursing Economics, the number of United States adults over the age of 65 years, “by 2050 is predicted to reach 72.2 million” (Giovanni, 2012, p. 128). This growing demographic will directly impact the Medicare budget in the coming years. According to the current Medicare Payment Advisory Commission, “about a quarter of the total Medicare budget is spent on services for beneficiaries in their last year of life, and 40% of that is in the last 30 days of their life” (Giovanni, 2012, p. 128). As life expectancies increase, prevalence of chronic comorbidities rise, and technology advancements propel, more policies need to be adopted to deal with the growing end-of-life issues and budget.
Methods

Through secondary research, data was gathered from the review of current literature on end-of-life care concerns, policies, and interventions. After completing this review of literature, the appropriate information was compiled into a PowerPoint presentation. The information included in the PowerPoint presentation is directed towards senior level nursing school students in baccalaureate programs who wish to learn more about end-of-life care. The information would be presented in a classroom setting at a local nursing school for approximately 50 individuals at a time. The data included in the presentation focuses on teaching these individuals how to deal with difficult discussions during end-of-life care. The total time for the information seminar would be approximately one hour to an hour and a half. The first part of the session would include an oral PowerPoint lecture followed by open group discussion to answer questions and explore items to consider.

To evaluate the effectiveness of the end-of-life care teaching session, a pre- and post-test would be utilized, which is present in Appendix A. According to Boston University (2013), pre- and post-testing is “a measurement of the learning received during the class as a result of comparing what the student knew before in a pre-test and after the class experience in a post-test” (p. 1). Varying reasons for using pre- and post-testing include measuring the amount of pre-existing knowledge of the audience on the topic and the extent of learning facilitated by the information session (Boston University, 2013). After collection of pre- and post-test results, data would be analyzed by performing the bivariate statistical method of t-test to compare the statistical percentage of answers for each question through IBM SPSS statistical program.
Since my secondary research uses human participants, ethical concerns and considerations need to be addressed. Our Lady of the Lake College Institutional Review Board approval for this research project would need to be obtained through completion of an application and presentation of all needed documentation. If approval were obtained, appropriate ethical interventions would be implemented. Before starting the informational session, informed consent from all participants who wish to be involved in the pre- and post-test would be obtained. Elements of the informed consent include clear, precise details about the research, the participant’s right to withdraw and obtain pertinent information, and a declaration that the participant is fully informed and is voluntarily participating in the research. The appropriate informed consent is presented in Appendix B.
Results/Conclusions

For this project, the extent of end-of-life care literature on baccalaureate nursing students has been examined. The creation of the end-of-life difficult discussions slide show combines current research and information into a concise presentation. Results of the pre- and post-test will be analyzed to examine the effectiveness of this presentation on increasing senior level baccalaureate nursing students’ knowledge on end-of-life care. The original problem addressed is the nonexistence of a tool or resource which presents end-of-care in a complete learning plan. The completion of this project adds a useful teaching resource to the body of current knowledge on end-of-life care.
References


Appendix A

Pre- and Post-Test

1) Palliative care is defined as:
   a. A philosophy of care that focuses on relief for terminally ill or seriously ill patients at the end of their life.
   b. A type of legal documentation that allows a patient to specifically outline what type of healthcare he/she would want in an event where he/she is unable to make healthcare decisions.
   c. A type of care provided for the alleviation of symptoms that result from both chronic and acute disease processes.*
   d. Care that assigns those who are in a hospital setting with a companion or ‘pal’.

2) LaPOST stands for:
   a. Louisiana Physician Orders for Scope of Treatment.*
   b. Louisiana Patient Ordered Specific Therapies.
   c. Louisiana Post Office Standard Transit.
   d. Louisiana Palliative Orders with Standard Treatments.

3) All are major components of LaPOST except:
   a. Cardiopulmonary resuscitation.
   b. Artificially administered nutrition.
   c. Location of end-of-life care.*

4) For the registered nurse, what is the first step in caring for an end-of-life patient?
   a. Build a support team including fellow nurses and staff
   b. Learn and understand your own personal beliefs about death and dying*
   c. Ask to change patients with another more experienced nurse
   d. Propose to the patient and his/her family members an appropriate end-of-life care plan

5) All of following are appropriate methods to build a trusting relationship with end-of-life patients’ family members, except:
   a. Offering to answer any questions regarding the plan of care.
   b. Utilizing active listening strategies.
   c. Providing anticipatory guidance, support, and frequent follow-up.
   d. Crying with family members over the end-of-life patients status and circumstances.*
Appendix B

Informed Consent

Techniques for Dealing with Difficult Discussions at End-of-Life Care

The purpose of this study is to examine the effectiveness of the following teaching plan, Techniques for Dealing with Difficult Discussions at End-of-Life Care. You will be asked to complete a pre- and post-test before and after a slideshow informational presentation. Your answers will be recorded and used by the researcher only. Approval has been obtained through Our Lady of the Lake College Institutional Review Board.

The anticipation of inconvenience or risks is not expected. Participation in this study is completely voluntary and refusal to participate does not exempt you from attending the informational seminar. Refusal to participate at any point in time during the study is acceptable.

The results of the study will be presented in an anonymous manner so as not to reveal your identify. The completed data and results will be available only to the Principal Investigator and will be stored in a locked personal file.

Should you have any questions or concerns, feel free to contact: Dr. Michael Dresnick, Director of the OLOL College Institutional Review Board at Michael.dresnick@ololcollege.edu

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By signing the bottom of the page, you agree that you understand the nature of the study and have received a copy of this form.

I understand the nature of this study and agree to participate. I have received a copy of this consent form.

________________________                 __________________________              ____________
Print Name                                                 Signature                                                 Date

__________________________
Signature of Witness