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SAN JOSE STATE UNIVERSITY SCHOOL OF NURSING

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ADDRESSING STUDENT NURSES' CONCERNS IN END-OF-LIFE CARE

Presented to

The Faculty of the School of Nursing

San Jose State University

In Partial Fulfillment
of the Requirements for the Degree
Master of Science

by
Tami Boroughf
May 1, 2006

Addressing Student Nurses' Concerns in End of Life Care

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Dr. Marian Yoder

Dr. Diane Stuenkel

Abstract

Recently, there has been a great deal of attention to the fact that there are few learning opportunities regarding end-of-life (EOL) care in nursing undergraduate education. One purpose of this research study was to provide an educational seminar for nursing students with information necessary to communicate with patients at the end of life and their families. The educational intervention consisted of an interdisciplinary panel discussion, a brief segment of a video, a case study with small group discussion, and an optional reflective activity. A quasi-experimental, pretest and posttest design was used in a baccalaureate-nursing program in Northern California. A Wilcoxon analysis revealed that there was a statistically significant difference between the pretest and posttest scores measuring student comfort and confidence levels. This seminar was an effective and creative strategy to integrate EOL content without making extensive changes to an existing nursing program.

Background

Recently, there has been an increased awareness regarding the topic of end-of-life (EOL) care. Particular attention has been drawn to the fact that there is little consideration for this topic and few educational opportunities regarding EOL care in nursing undergraduate programs (Matzo, Sherman, Penn, & Ferrell, 2003). An extensive amount of class time and clinical hours are devoted to the beginning of life and the duration of life, but little time is devoted to the end of life. EOL is a pertinent topic for nursing students regardless of their areas of interest or future employment in specialty areas.

Unfortunately, death occurs at all ages encompassing all patient care settings including the hospital, the clinic, and the patient's home. Giving quality care to patients, and their families, depends on the nurse's knowledge and experience with EOL care. Nurses have the potential to give competent and compassionate EOL care with proper education and support. Caring for patients at the beginning, middle, and end of their life is the heart of nursing.

EOL care is an integral part of nursing care. "Nurses spend more time with patients and families facing advanced illness than do any other health care professionals and are intimately involved in all aspects of EOL care" (Ferrell, Virani, Grant, & Rhome, 2000, p. 43). They witness firsthand the major issues and concerns the patients and their families experience when the end of life may be near (Rushton, n.d.). Patients and their families trust nurses and will often look to them for direction and guidance when a loved one is dying. Working as a member of an interdisciplinary healthcare team, the nurse must recognize their patients' unique needs as well as advocate for their desires during this time. It is imperative that nursing faculty provide this specialized education to nursing students so they can become confident and comfortable in delivering EOL care.

Of all of the issues that healthcare workers face, death is considered one of the most challenging (Virani & Sofer, 2003). Although it is important for nursing students to recognize their personal views and attitudes regarding death, many students are not directed to explore their own thoughts and feelings (Field & Cassell, 1997). Nursing curricula often focuses on the curative treatments and technical skills associated with various illnesses. Although death may be viewed as failure, nursing care extends beyond helping a patient simply recover (Rushton, Spencer, & Johanson, 2004; Ferrell et al., 2000). Often EOL issues are not discussed with the patients and their families until all treatment options have been exhausted (Field & Cassell). Nurse educators can teach nursing students to provide dignified and compassionate care to those in the end of life.

The death of a child can be especially traumatic because parents do not expect to outlive their children (Serwint et al., 2002). Whether the death of a child is expected or sudden, it is devastating for the family and can be emotionally draining for the caregivers involved. It is crucial that caregivers have preparation for this especially sensitive time.

Practicing nurses often feel inadequate or unprepared to deal with their patients at the end of life. Researchers asked nurses what they wished they had been taught in nursing school about caring for dying patients (White, Coyne, & Patel, 2001). The response most frequently selected was how to talk with patients and their families (White, Coyne, & Patel). It is important for nurse educators to note what nurses wish they had learned in nursing school and to ensure that changes are made so that future nurses feel prepared to care for their patients at the end of life.

The purpose of this article is to (a) provide an extensive literature review, (b) describe the methodology of this research study, (c) discuss the seminar and class evaluations, (d) explain the

results and implications of this research, and (e) provide a model for other faculty interested in integrating EOL care into nursing curriculum.

Literature Review

Several documents highlighted some important considerations regarding EOL care. The Institute of Medicine report entitled, "Approaching Death," acknowledged that nurses need to be better prepared to care for their patients in EOL (Field & Cassell, 1997). The report further stated that current nursing education was not preparing nurses to apply clinical knowledge in order to meet a dying patient's complex needs (Field & Cassell). An American Association of Colleges of Nursing (AACN) document entitled, "A Peaceful Death" (1997), recommended that all nursing schools develop competencies and curricula to prepare the new nurse to deal with the patient at the end of life. There currently is a national effort with the AACN and the City of Hope National Medical Center to create competencies and assimilate these competencies into undergraduate curricula. The two organizations have together developed the End-of-Life Nursing Education Consortium (ELNEC) (Pimple, Schmidt, & Tidwell, 2003). Researchers reported that 502 faculty from 461 nursing programs from all 50 states have attended the ELNEC courses (Ferrell et al., 2005). They indicated that many faculty members have utilized these new tools and strategies and there has been significant improvement of EOL content in the nursing school curriculum.

Although the ELNEC modules are extremely helpful, there is still a need to bring EOL curriculum to all undergraduate nursing programs. Undergraduate nursing programs have many variations to introduce and integrate EOL content into curriculum. Some schools have implemented an oncology elective or a palliative care course that contains EOL topics (Walsh & Hogan, 2003; Purnell, Walsh, & Milone, 2004). Other schools have set up palliative care courses

with didactic and experiential learning components (Mallory, 2003; Birkholz, Clements, Cox, & Gaume, 2004; Kwekkebom, Vahl, & Eland, 2005). Experiences ranged from going on field trips, participating in observational activities, and volunteering as palliative care companions; all experiences had positive student remarks in class evaluations (Mallory; Birkholz et al.; Kwekkebom et al.).

Other schools of nursing have integrated the EOL topics into existing curriculum. Every area of nursing has its own unique issues with regards to EOL care (Durkin, 2003). Incorporating EOL topics into existing curriculum is supported by the AACN as it recommends how to include specific EOL competencies into offered courses (AACN, 1997; Robinson, 2004). This alternative is useful if a separate, individual course is not an option.

Members of other disciplines of the health care team also have little training and time devoted to the topic of EOL care. Social workers have some training in school, yet they still do not feel prepared to deal with all aspects of EOL care (Csikai & Raymer, 2005). Some medical education programs held off-site seminars for pediatric residents that helped them feel more comfortable in providing EOL care and address other issues such as communication with patients and their family, pain management, and dealing with one's own feelings of death (Bagatell, Meyer, Herron, Berger, & Villar, 2002; Serwint et al., 2002). The University of Los Angeles Children's Hospital conducted a needs assessment with pediatric residents, developed pediatric EOL curriculum, and implemented noon conferences, grand rounds presentations, and seminars to assist the residents in acquiring the necessary skills for dealing with EOL care (Feldman & Slavin, 2000). Reflective activities were used at one medical school along with didactic curriculum to promote awareness of one's own thoughts, feelings, and concerns when caring for patients in the end of life (Rosenbaum, Lobas, & Ferguson, 2005). The American

Medical Association, with funding from The Robert Wood Johnson Foundation, developed the Education on Palliative and End-of-Life Care, a comprehensive training program that uses a variety of strategies to educate physicians on the clinical competencies necessary to provide care to their patients in the end of life (Robinson et al., 2004).

There are also programs that offer an interdisciplinary approach in teaching EOL care. Harvard Medical School developed and implemented a Program in Palliative Care Education and Practice that incorporated palliative care with learning theories and teaching methods for physicians, nurses, and social workers (Sullivan, Lakoma, Billings, Peters, & Block, 2005). In Canada, a school of nursing sent out surveys to medical, nursing, and social work faculty in Canada and the United Kingdom. The surveys revealed that 96% of these schools included EOL content in all courses; 65% of the nursing schools and 83% of the medical schools utilized an interdisciplinary approach to reinforce communication and problem solving within the health care team (Downe-Wamboldt & Tamlyn, 1997). A program in South Dakota devised an interdisciplinary approach for palliative care that included students of medicine, nursing, pharmacy, chaplaincy, and social work. In the evaluation, the students expressed interest in working with all disciplines as a team to deliver thorough palliative care (Schrader et al., 2005).

Hospitals and other institutions, including educational programs, often utilize an interdisciplinary approach with pediatric EOL care and palliative care programs. Some institutions conducted a needs assessment prior to the implementation of a pediatric palliative care program and developed an interdisciplinary curriculum to further educate those caring for children with serious conditions (Contro, Larson, Scofield, Sourkes, & Cohen, 2004; Browning & Solomon, 2005). It is important to consider every staff member when planning a program because each member has his or her own significant role in caring for a child.

There is limited research regarding undergraduate nursing students and EOL education. This researcher integrated concepts from an extensive literature review and planned an educational seminar held during one class period in which a pediatric nurse, a chaplain, and a social worker would explain their roles, describe case studies, and discuss various communication strategies when dealing with EOL care. This seminar incorporated time to practice EOL communication with peers in small groups in a discussion format. Participating nursing students also had an opportunity for guided reflection to further analyze the information learned from the panel presentation and discussion. The purpose of this educational seminar was to provide nursing students with the information and skills necessary to communicate with patients at the end of life as well as their family. The seminar was developed to increase comfort and confidence levels in the undergraduate nursing student when dealing with communication in EOL care. This approach was developed to integrate EOL content into the classroom without making extensive changes in existing curriculum and without using an extensive amount of class time.

Theoretical Framework

The concept of self-efficacy provides rationale for this educational intervention and guides what will be measured before and after the intervention. Self-efficacy is defined as how an individual believes himself or herself as capable in performing in a certain situation (Bandura, 1994). Mastery experience- performing the actual behavior- is the most effective way to improve self-efficacy (Bandura, 1994). The mastery experience for this research study was the case study with peer group discussion; the students were presented with a realistic scenario and discussed what they might say if this were their assgined patient. As Bandura stated, even imagining performing the modeled behavior can improve one's ability (Boeree, 2006).

There is much fear, anxiety, and uncertainty around the topic of EOL care (Walsh & Hogan, 2003). According to Bandura (1994), feared activities, such as EOL care, that are first modeled to the nursing students demonstrate ways to cope in this situation. A part of self-efficacy is being able to identify or acknowledge the need for outside resources. Modeling how to care for a dying patient, including asking for assistance from peers and requesting a chaplain or social worker, may provide strategies for coping with EOL issues and make this an insightful experience for nursing students (Bandura, 1977; Pajares, 2002).

Social persuasion, including verbal persuasion and realistic encouragement regarding one's ability to perform a task, also leads to increased self-efficacy (Bandura, 1994). The panel members and course instructor gave positive feedback to the nursing students in their small group discussion and reflective activity so the nursing students would have more confidence in dealing with EOL care.

Research Question

The question for this study was: Will an end-of-life educational seminar significantly increase the comfort and confidence levels of nursing students in dealing with end-of-life care?

Methodology

Design, Setting, and Sample

A quasi-experimental pretest and posttest design was used for this study. The setting was a baccalaureate nursing program in Northern California. In this program's curriculum, a nursing process class accompanies the theory course and clinical practicum every semester. The maternal-child process class was selected for the educational intervention because the course content focused on the interpersonal aspects of caring for patients and their families, ethical issues that may arise in clinical settings, and therapeutic communication. The convenience

sample included 24 ethnically diverse nursing students enrolled in one section of a junior level nursing process class.

Data Collection

After obtaining permission from the Institutional Review Board and permission from the School of Nursing's Research Committee, students were informed of the study and asked to sign consent forms. With approval from the course instructor, 24 students participated in the pretest, educational seminar, and posttest. Students used the last four digits of their student identification number to ensure confidentiality as well as accuracy in matching the pretest with the posttest. *Instruments*

There were three tools utilized in this research study: (a) The Health Care Providers

Survey of End-of-Life Perceptions, Knowledge, and Attitudes (HCPSELPKA), created by Dr.

Janet Timms (2004), (b) The End-of-Life Confidence Scale, and (c) The Demographic and

Personal Experience Questionnaire. The HCPSELPKA, used with permission from Dr. Timms,

was amended to a four-item survey and one open-ended question to measure students' comfort

levels in dealing with EOL care with. The End-of-Life Confidence Scale was a three-item survey

that measured student confidence and The Demographic and Personal Experience Questionnaire,

(both designed by the researcher) included two demographic questions (age and ethnicity) and

three questions dealing with personal experience with EOL care. Each participant filled out all

three tools as a pretest. The HCPSELPKA and The End-of-Life Confidence Scale were

administered as the posttest. Both surveys used a 5-point Likert-like scale with 1 (least confident

or comfortable) to 5 (most confident or comfortable). Five registered nurses who deal with EOL

issues pilot tested the three tools for content validity. Additionally, a student evaluation form was

provided to each participant to evaluate each panel speaker and the seminar. The students also had reflective activities to journal further thoughts and reactions to the seminar presentation.

Limitations

This study used a small, convenience sample and therefore is only generalizable to a similar diverse student population. Class time for this presentation was 1 hour and 50 minutes. The time constraint was difficult, as time was needed for each panel member to speak, student questions and discussion, and the planned group activity at the end the class.

The Seminar

The educational intervention consisted of an interdisciplinary panel discussion, a brief segment of a video, a case study with small group discussion, and an optional reflective activity. Grief, loss, and EOL care are traditional topics included in this maternal-child process course. In this study, this content was presented utilizing an educational seminar that consisted of a panel of health care team members who deal with EOL care. The panel consisted of a chaplain, a Licensed Medical Social Worker, and a pediatric nurse, all with various experiences and an interest in EOL care. The students also viewed a brief segment of a video of a parent who had experienced the loss of a child.

The panel members each shared their experiences, discussed case studies, provided helpful suggestions of how to deal with EOL care, and role-modeled sample conversations with patients and their families. The nurse gave firsthand examples of dialogues with families and patients, the social worker showed the students a memory box for parents to save precious mementos from their deceased child, and the chaplain explained how to deal with the spiritual and ethical issues of EOL care. Discussion among the panel members and students was encouraged.

After the panel presentation, the students were given a case scenario regarding a young female patient who recently received news of a poor prognosis. Students were divided into small groups and discussed what they might say when entering the room to care for this patient. One panel member and the course instructor facilitated the discussion and validated responses in each group. After the small group discussions, the students reconvened and shared their thoughts.

At the end of class, students were given an optional reflective activity for extra-credit in which they had two weeks to reflect on the content of the class. Questions were designed to challenge the students to think of their own culture and familial views of death and stimulate further thought and reflection on the panel discussion. Students received a resource sheet that included information regarding on-campus counseling services and other resources for EOL care. In class the following week, there was a brief time for students' questions, thoughts, and concerns in a discussion format.

Analysis

The demographic information and responses from the pretest and posttest were analyzed with frequency distribution tables and measures of central tendency and variability to look at trends. The scores in each pretest and posttest were compared using the Wilcoxon test as the scores were not normally distributed. The Wilcoxon test was the appropriate analysis to use because there was a small, convenience sample and one assumption was not met for the equivalent parametric test. The data were analyzed with SPSS version 13.

Results

Of the 24 participants, 58% were of Filipino origin, 15% were Chinese, 15% described their ethnicity as Other, and there were 3% of each White, African American, and Hispanic origin. The students ages ranged from 18-25 (81%), 26-35 (8%), and 36-50 (8%). When asked

about personal death experiences, 77% of participants had experienced the death of a family member, 42% experienced the death of a friend, and 7% experienced the death of a pet or other loved one. Students also had experienced the death of someone else such as a patient or colleague (15%). Using crosstabulations tables in SPSS, there were no patterns observed when correlations with age or ethnicity were crossed with previous death experience and education.

Regarding EOL education, students reported that they had received some type of EOL education in the classroom (92%), some in clinical experiences with EOL care (31%), followed by other work experiences (15%). They indicated that they would like to learn more about EOL education particularly (a) how to talk with patients and their families about dying (89%), (b) dealing with angry patients and their families (81%), (c) learning about other religious and cultural perspectives (65%), and (d) dealing with ethical issues (58%).

Analysis using the Wilcoxon rank sum analysis revealed that there was a statistically significant difference in the medians from the HCPSELPKA pretest and posttest scores measuring student comfort with EOL issues (z = -3.314, p < .002). A statistically significant difference was also found between the median pretest and posttest scores in The End-of-Life Confidence Scale measure (z = -3.178, p < .002). These differences were of practical significance as well for comfort ($eta\ squared = .453$) and for confidence ($eta\ squared = .402$). Table 1 provides descriptive statistics for the pretest and posttest measures from the comfort and confidence instruments.

Student Evaluations

Evaluations of the educational seminar were positive overall. Many students wrote comments stating that panel members were knowledgeable and informative. One student wrote, "The thing I liked best about the presentation was the passion that each presenter had in regards

to the issue of death and dying." Students found the speakers' stories and experiences helpful and appreciated learning about the roles of the different members of the interdisciplinary healthcare team. Some students (20%) suggested that including a physician on the panel would have been helpful. One-third of students wanted more time for questions and discussion. One student summarized the learning experience in the statement, "The speakers gave me an idea of how to talk to patients and their families."

Discussion

The results of this study demonstrate that an educational seminar with members of the interdisciplinary healthcare team significantly increased student comfort and confidence in dealing with EOL care. Panel members with current hospital experience shared compelling case studies and gave candid examples of how to communicate with patients and their families during such a sensitive time. The nursing students not only learned from each panel member, but also learned of each member's role on the healthcare team.

The panel members contributed to learning by describing their individual role on the healthcare team. The nursing students observed the interaction between the members and the different perspective each member has to offer. As reported by Matzo, Sherman, Penn, and Ferrell (2003), parent stories and perspectives are effective teaching strategies for nursing students because they can hear how the parent felt at various stages in the EOL process. In response to a question regarding finding resources for caring for a dying patient with a different culture or religion, many students in the pretest stated they would look on the Internet for information. On the posttest, the many students stated they would ask a colleague such as a co-worker, social worker, or chaplain, for assistance.

Role modeling, social persuasion, and the mastery experience contribute to improving self-efficacy. In the small group discussions, students had an opportunity to discuss the case scenario and each panel member gave them realistic encouragement regarding EOL care. Many people providing EOL care think they should say something profound or do an extraordinary deed. Yet when parents are asked what they remembered the most about care they received while their child was dying, small acts of human kindness and humane care were the most often cited (Davies & Connaughty, 2002). Sometimes, listening is the only thing the family needs at that time. Realistic encouragement offered reassurance that these students are capable of caring for patients in the end of their life and strengthens the belief that the nursing students have what it takes to succeed. As Bandura (1977) suggested, people are likely to attempt a certain behavior if they believe they have what it takes to succeed.

After the educational seminar, some students indicated that they felt relieved that they did not have to do anything "meaningful" or say anything "profound" to their patient and their family. In the reflective activities, many students commented on statements made by panel members. One student wrote, "The chaplain said, 'with death, there is no right thing to say'." Another student wrote, "It was very helpful to know that discussion about death is difficult for many people including experienced health care providers and counselors." Some students wrote how a gentle touch on the arm or an "I'm sorry" can be effective and appreciated by some families. Examination of the comments and entries in the reflective activities revealed that the students found the stories and experiences of the panel members to be beneficial and-useful.

Conclusion and Summary

This research demonstrated that a seminar significantly increased nursing students' comfort and confidence levels in EOL care. The educational intervention was an effective way of

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integrating EOL content without making extensive changes to existing course curriculum. This method was an effective option, as the school of nursing of this study did not have a separate EOL course.

Nursing students need bedside experience, but they also need adequate support, resources for dealing with EOL care, and an environment that promotes success. Students who care for dying patients need individualized attention and guidance, yet the instructor may not have adequate time due to the many responsibilities to all students in the clinical setting. Instructors cannot guarantee that all students will have clinical opportunities to care for patients at the end of life. If a school of nursing does not have an individual EOL course, this seminar may be a viable option in covering the content. It was not intended to replace clinical experiences, but rather to supplement EOL education.

EOL can be a difficult and sensitive topic to discuss with nursing students. It is crucial that nursing students learn therapeutic communication techniques to use with dying patients and their families while in their undergraduate nursing programs. It is anticipated that these students will feel more confident and prepared to care for patients at the end of their life. The seminar presented in the study provided an opportunity not only to learn about EOL care, but also to interact with an experienced interdisciplinary health care team. One student summarized the benefits of the seminar in her reflective journal, "I perceived that supportive communication is an important skill just as any nursing technical skill that nursing personnel should acquire and feel comfortable implementing in order to optimize EOL care for dying children and their families." Nurse educators are encouraged to seek creative teaching and learning strategies for EOL care.

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Table 1

Descriptive Statistics

Group	M	Mdn	SD
Comfort			
Pretest	12.21	12	2.14
Posttest	14.17	14	2.08
Confidence			
Pretest	8.04	8	2.71
Posttest	9.71	10	2.49