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Qualitative Exploration of the Perceptions of Nursing Undergraduates Regarding Family Care at End-of-Life

Penny A. Alt-Gehrman
Marquette University

Qualitative Exploration of the Perceptions of Nursing Undergraduates

Regarding Family Care at End-of-Life

by

Penny A. Alt-Gehrman, MSN, RN

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ABSTRACT

QUALITATIVE EXPLORATION OF PERCEPTIONS OF UNDERGRADUATES
REGARDING FAMILY CARE AT END-OF-LIFE

Penny A. Alt-Gehrman, MSN, RN

Marquette University, 2018

Background/Purpose: Family care at end-of-life is delivered by nurses and includes communication and explanations, providing emotional support for the family, creating an environment in which death occurs with dignity, providing privacy, facilitating visitation, and honoring and meeting cultural and personal family values (Beckstrand et al., 2011; Bloomer et al., 2013; Cronin et al., 2015; Heidari & Norouzadeh, 2014).

There appears to be a gap in the empirical evidence and literature on this topic. Regarding the knowledge and comfort of student nurses, and subsequently nurses, in family care at the end-of-life, there is disparity. To determine what must be taught to nursing students, there must first be a needs assessment. The purpose of this study is to investigate what nursing students perceive their needs, challenges, and facilitators to providing competent family care at end-of-life.

Theoretical framework: Mezirow's transformative learning theory was the framework for this study (Kitchenham, 2008). The theory is used as a method for behavior change. Results provided information needed to explore new content and options for nursing education regarding care of families of dying patients.

Method: This study used a qualitative descriptive design. Focus groups were used to interview 19 junior and senior nursing students who were currently in acute care clinical courses. The data was analyzed using thematic analysis.

Results: Four themes emerged from the data: feeling unprepared, importance of communication, experience increases comfort and confidence, and families' emotional responses can be challenging.

Conclusions: This study supports previous findings that students do not feel prepared to provide family care at end-of-life. All nurses need to know the basics of providing family care at end-of-life. This study supported that students prefer experiential learning methods, such as simulation and role playing. This study also demonstrates that nursing faculty should also be knowledgeable and comfortable with family care at end-of-life.

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In Memory of my parents, who did not live to see this endeavor begin. They encouraged me to learn and strive for more.

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Chapter 1

Introduction

This chapter will introduce the topic of this study, and includes the problem statement, the purpose, and aims. In this study, family care at end-of-life is defined as nursing care for families of dying patients (Beckstrand, Lamoreaux, Luthy, & Macinstosh, 2011; Bloomer, Morphet, O'Connor, Lee, & Griffiths, 2013; Cronin, Arnstein, & Flanagan, 2015; Heidari & Norouzadeh, 2014). Family care at end-of-life is delivered by nurses and includes communication and explanations, providing emotional support for families, creating environments in which death occurs with dignity, providing privacy, facilitating visitation, and honoring and meeting cultural and personal family values (Beckstrand et al., 2011; Bloomer et al., 2013; Cronin et al., 2015; Heidari & Norouzadeh, 2014). For the purposes of this study dying patients were defined as adults who are actively dying, usually within hours to days (AACN, 2016). Families of dying patients included family, friends, and significant others of the individuals who are dying. Family is not only blood relation, but close friends can be considered family if the patient chooses them to be (AACN, 2016).

Families of dying patients expect and need nursing care (Boucher, Bova, Sullivan-Bolyai, Theroux, Klar, Terrien, & Kaufman, 2010, Cronin et al., 2015; Heyland, Dodek, Rocker, Groll, Gafni, Pichora, . . . Lam, 2006; Main, 2002). Families wanted pertinent information communicated to the healthcare team (Boucher et al., 2010; Heyland et al., 2006; Main, 2002) and communication about the dying process (Boucher et al., 2010; Cronin et al., 20015; Hyland et al., 2006; Main, 2002). Assistance with

preparing for death (Boucher et al., 2010; Cronin et al., 2015; Hyland et al., 2006; Main, 2002), and nursing vigilance and presence (Cronin et al., 2015) were also expressed. The consequence of the family's dissatisfaction with care can be loss of business to that hospital and a loss of reputation (Mangrolia, 2018). People are willing to share bad experiences to others 95% of the time as opposed to sharing a good experience only 87% of the time (Mangrolia, 2018). Social media is another method to spread bad experiences and 45% of people share bad experiences compared to 30% to share a good experience (Mangrolia, 2018).

Nurses were also surveyed regarding what their perceptions of the family needs (Beckstrand et al., 2011; Bloomer et al, 2013; Heidari & Narouzadeh, 2014). Nurses perceived family needs as facilitating visitation (Heidari & Norouzadeh, 2014), spending time with the family (Bloomer et al., 2011), communication with family (Beckstrand et al., 2011; Heidari & Norouzadeh, 2014), and preparing for death (Beckstrand et al., 2011; Bloomer et al, 2013; Heidari & Narouzadeh, 2014).

When nurses are not prepared to care for families of dying patients, families and nurses may have increased distress and be dissatisfied with the nursing care delivered to dying patients. Families described that nurses did not spend enough time with their dying relative and nurses could have done more (Kruse, Melhado, Convertine & Stecher, 2008). Families also reported that they did not understand what was happening to their loved one (Beckstrand, Lamoreaux, Luthy & Macintosh, 2017).

Disappointment among nurses was reported as feeling as if there was something more they could have done for patients and families or that their interventions may have prolonged death of the patient (Main, 2002). Additionally, caring for dying patients and

their families may generate physical and psychological stress for nurses who are their caregivers (Boyle, 2015; Chitra, 2011; Douglas, 2010; Melvin 2012). These stresses can accumulate and produce compassion fatigue (CF) which cause nurses to provide less than optimal care, leave facilities, and potentially to leave nursing (Boyle, 2015; Douglas, 2010; Hooper, Cragi, Janvrin, Wetsel, & Reimels, 2010; Kelly, Runge, & Spencer, 2015; Melvin, 2012; Michalec, Diefenbeck, & Mahoney, 2013; Showalter, 2010). Nurses' learn to care for patients and their families in their nursing education. The education at the pre-licensure level should include care of the families of dying patients. Knowing how to care for families at the end-of-life and how to handle the stresses of that care, may improve retention of nurses and the quality of care that they provide for dying patients and their families.

Currently, content on end-of-life care for the families of dying patients is inadequate in nursing curricula (Alt-Gehrman, 2017). Further research needs to be conducted to determine what is needed by nursing students in order to care for families at the end-of-life. This study is the first step, surveying the population. A small amount of research focused on the needs of the families has been performed. Some studies focused on nurses' perceptions of care of the dying patients with little focus on the families (Boucher et al., 2010; Cronin et al., 2015; Heyland et al., 2006; Main, 2002).

Many nursing students report feeling unprepared to care for families of patients who are at the end of life (Boyle, 2015; Chitra, 2011; Douglas, 2010; Glover, Garvan, Nealis, Citty, & Derrico, 2017; Henson, 2017; Hooper, Craig, Janvrin, Wetsel, & Reimels, 2010; Kelly, Runge, & Spencer, 2015; Rowe, 2013; Showalter, 2010). At this time, there are no studies from the perspective of student nurses on family care at end-of-

life. Lack of research on this topic is problematic because educators do not know what nursing students need in order to provide optimal care for families of dying patients.

Purpose of the Study

The purpose of this study was to render a greater understanding of what nursing students perceived as their needs, challenges, and facilitators to providing competent care for families, friends, and significant others of dying patients. The results of this study may be used to suggest curricular revisions and activities that fill gaps regarding family care at end-of-life.

Statement of the Problem

The inadequate preparation of student nurses to provide care for families at end of life may contribute to poor outcomes for families and nurses. For families, if they feel dissatisfied with care or feel distressed, they may share their poor experiences with others and attend other facilities (Mangrolia, 2018). For nurses, there may be an increase in compassion fatigue (Boyle, 2015; Chitra, 2011; Douglas, 2010) and may potentially leave the facility and profession (Mangrolia, 2018; NSI Nursing Solutions Inc., 2018). Compassion fatigue (CF) is a term to describe the outcomes of unique stressors that affect people in caregiving professions (Perry, 2015). CF can affect nurses mentally, physically, emotionally, and spiritually (Boyle, 2015; Chitra, 2011; Douglas, 2010; Henson, 2017; Hooper, Craig, Janvrin, Wetsel, & Ramiels, 2010; Kelly, Runge, & Spencer, 2015; Melvin, 2012; Showalter, 2010; Sorenson, Bolick, Wright, & Hamilton,

2017). The costs of CF are many, including diminished productivity, poor morale, and turnover (Showalter, 2010).

Significance of the Problem

Family-centered care (FCC) is an approach encompassing the planning, delivery, and evaluation of care mutually advantageous to patients, families, and health care providers (American Hospital Association, 2017). Some key concepts of FCC are respect, information sharing, encourage families to participate in care, and collaboration (Dokken, Parent, & Ahmann, 2015; Harrison, 2010; Jolley & Shields, 2009; Mastro, Flynn & Preuster, 2014). Family-centered care (FCC) is standard practice in maternal-child, pediatric, and palliative and hospice specialties (Harrison, 2010; Mastro et al., 2014). Families have expressed that rounds are more effective when nurses are present and the family members are involved in the discussions (Kuo et al., 2012). Families prefer to be partners and share core values (Mikkelsen & Frederiksen, 2011). Families also want to be enabled to raise questions and engage in dialogue with clinicians (Coombs et al., 2017). Consensus is that FCC improves care of the patient and satisfaction of the family (Coombs et al., 2017; Dokken et al., 2015; Griffin, 2013; Kuo et al., 2012; Mastro et al., 2014; Mikkelsen & Frederiksen, 2011).

It is important to teach nursing students how to care for families of dying patients because effective nursing end-of-life care contributes to peaceful death and needed emotional support for families (Bloomer et al., 2016; Heidari & Norouzadeh, 2014). Communication has surfaced as an important part of care (Bloomer et al., 2016; Heidari & Norouzadeh, 2014). Nurses recognized that communication was significant when working with families (Bloomer et al., 2016). Nurses also felt that their role was

especially crucial in spending time with and supporting families after death (Bloomer et al., 2016; Heidari & Norouzadeh, 2014). Families have also reported that the most important action of nurses was to provide family support including death with dignity, facilitation of visitation, value orientation, and helping prepare them for distress (Heidari & Norouzadeh, 2014). Other important interventions for families were to attend to cultural differences, provide for privacy for patients and families, provide explanations, and extend condolences (Heidari & Norouzadeh, 2014).

Effective and adequate preparation of nursing students to deliver family care at end-of-life may engender more positive attitudes towards caring for families of dying patients which may carry over into the careers of practicing nurses. Nurses with positive attitudes toward death and the dying have been shown to improve the end-of-life experience for patients and families (Dunn, Otten, & Stephens, 2005; Kurz & Hayes, 2006). Previous researchers found that having a positive attitude toward caring for dying patients resulted in improved care (Bailey & Hewison, 2014; Dunn et.al., 2005).

Nursing education includes some content on death and dying (Alt-Gehrman, 2017). However, this education is limited and many practicing nurses do not feel prepared to care for families of dying patients despite having had some content on end-of-life care for families in theory courses during their nursing education (Cronin et al., 2015; Kurz & Hayes, 2006; Schlairet, 2009; Wallace et al., 2009). When nursing students are not prepared to care for the families of dying patients, it is likely that they will become practicing nurses with inadequate knowledge and skills for end-of-life care for families of dying patients. This may result in practicing nurses feeling as if there was something more they could have done and that their interventions may have prolonged

death (Main, 2002). Families report feeling uncared for when nurses did not spend enough time with their dying relatives (Kruse et al., 2008) or when they did not understand what was happening to their loved ones (Beckstrand et al., 2017).

Educating nursing students to care for families of dying patients may lead to increases in nurses' comfort and confidence. Feeling comfortable and confident to care for suffering families may prevent the development of compassion fatigue. Compassion fatigue (CF) is defined as the physical, psychological, and spiritual costs of caring for others (Boyle, 2015). Compassion fatigue can develop in nurses and nursing students (literature on CF in students will be discussed in Chapter 2). Among practicing nurses, consequences of compassion fatigue include absenteeism, providing poor quality of care, physical ailments such as headaches and stomach aches, psychological issues such as depression and isolation, and emotional issues such as crying and inability to concentrate (Henson, 2017). These consequences can lead to nurses leaving the unit, hospital, and the nursing profession (Hooper et al., 2010). Nearly 20% of nurses leave the profession in the first year (Grote, 2015) and the general attrition rate is nearly 33% (Grote, 2015). Compassion fatigue and burnout are reasons that nurses leave the profession (Cronin et al., 2015; Kurz & Hayes, 2006; Schlairet, 2009; Wallace et al., 2009). Better preparation of nursing students to care for families of dying patients could help to prevent compassion fatigue. However, currently nursing students report feeling ill prepared to care for the families of dying patients (Barrere, Durkin, & LaCoursier, 2008; Bobiansky, Aselton, & Cho, 2016; Cavaye & Watts, 2014; Lippe & Becker, 2015). Nurses learn to care for dying patients in their pre-licensure education. If educators could identify what knowledge is needed regarding end-of-life care of the families of dying patients and

provide that to students, this could result in nurses that might be more knowledgeable, have more positive attitudes, and be more comfortable in the care of families of patients who are at end-of-life.

Conclusion

It is appropriate to learn about family care at end-of-life (EOL) in prelicensure nursing programs. In order to develop appropriate curricula, there must be research performed on students' perceived needs, challenges, and facilitators to providing competent end-of-life care to family, friends, and significant others of dying patients. By knowing the challenges students face, curricular changes can be made to prepare students to care for families of dying patients.

Definitions

For purposes of this study, these terms are defined as follows:

- For this study, family care at end-of-life is defined by the Primary Investigator as care delivered by nurses and includes communication and explanations, providing emotional support for the family, creating an environment in which death occurs with dignity, providing privacy, facilitating visitation, and honoring and meeting cultural and personal family values (Beckstrand, Lamoreaux, Luthy, & Macinstosh, 2011; Bloomer, Morphet, O'Connor, Lee, & Griffiths, 2013; Cronin, Arnstein, & Flanagan, 2015; Heidari & Norouzadeh, 2014).
- End-of-life care is care given to people who are near the end of life and have stopped treatment to cure or control their disease. End-of-life care includes

physical, emotional, social, and spiritual support for patients and their families. The goal of end-of-life care is to control pain and other symptoms so the patient can be as comfortable as possible. End-of-life care may include palliative care, supportive care, and hospice care (National Cancer Institute, 2018).

- Dying patients refers to the individuals who are actively dying. The time period is the hours and days prior to death. Death is when the physiologic functions cease (Kintzel, Chase, Thomas, Vancamp, &Clements, 2009).

- Families of dying patients refers to family, friends, and significant others of the individuals who are dying. Family is not only blood relation, but by choice. Close friends can be considered family if the patient chooses them to be (AACN, 2016).

- Attitude is defined as a way of thinking or feeling that is reflected in the behaviors of an individual (Oxford Living Dictionary, 2017).

- Knowledge is an accumulation of facts, skills, and information acquired through education or experience (Oxford Living Dictionary, 2017).

- Competence is when the nurse possesses the knowledge, skill, or qualification to provide care (Smith, 2012).

- Compassion Fatigue is a term to describe the outcomes of unique stressors that affect people in caregiving professions (Perry, 2015).

Chapter 2

Review of Literature

Introduction

This chapter discusses the design and methodology of this study. The first section presents the study design and rationale. The recruitment process and measures to protect human subjects are described. The focus group method was used; including a discussion of focus groups and data collection is included. Instrumentation includes the demographics form and the interview guide. The process of data analysis was detailed. The chapter ends with a discussion of rigor.

Philosophical Framework

Constructivism is a philosophical paradigm that guides research (Appleton & King, 1997; Earle, 2010; Giorgi, 2005; Stevenson & Beech, 2001). In constructivism, the researcher has a subjective and transactional approach to study the phenomenon (Appleton & King, 1997; Earle, 2010; Giorgi, 2005; Stevenson & Beech, 2001). This method requires interaction of the researcher and the participants so that the phenomenon can be described and explained (Appleton & King, 1997; Earle, 2010; Giorgi, 2005; Stevenson & Beech, 2001). Qualitative methods of research work well with the constructivist paradigm (Appleton & King, 1997; Earle, 2010; Giorgi, 2005; Stevenson & Beech, 2001). Interviews and focus groups are commonly utilized in the constructivist

paradigm (Appleton & King, 1997; Earle, 2010; Giorgi, 2005; Stevenson & Beech, 2001).

Constructivism builds meaning and expands knowledge of a concept (Appleton & King, 1997; Appleton & King, 2002; Stevenson & Beech, 2001). A constructivist researcher delves into a concept and understands it from the point of view of the individual who has lived the concept (Appleton & King, 2002). The constructivist philosophy also acknowledges that there are multiple ways to experience and understand the phenomenon (Appleton & King, 2002). Constructivism derived from psychology and the social sciences with early constructivists such as John Dewey, Jerome Bruner, Jean Piaget, Lev Vygotsky, and Egon Guba and Yvonna Lincoln (Appleton & King, 1997). The focus groups used in this study attempt to describe the concept of what a nursing student needs to know in order to provide family care at end-of-life. The study builds the understanding from the perspective of the nursing student and allows the educators to understand what the student requires. With the above purpose in mind, constructivism is appropriate as the philosophical framework builds meaning and understanding.

This study explored the perceptions of undergraduate nursing students to describe the phenomenon of caring for families of dying patients. The description of the phenomenon correlates with the constructivist paradigm. This study will use focus groups to elicit information. Focus groups allows the participants to express themselves freely and explain their understanding and viewpoint of the concept. The theoretical framework used for this study uses the constructivist philosophical framework as well. This relationship is discussed below in the theoretical framework section.

Theoretical Framework

The theoretical framework underpinning this study is Mezirow's Theory of Transformational Learning. This framework was chosen because it correlates well with the process of this study: to gather perceptions of students with the next step being to recommend curricular changes. The theory of transformational learning is an educational theory that has been widely used in educational studies including nursing research (Cooley & De Gagne, 2016; Holley, 2009; Morris & Faulk, 2007). Using Mezirow's theory, nursing researchers have investigated new nursing faculty's experiences in academia (Cooley & De Gagne, 2016), interdisciplinary learning initiatives in higher education (Holley, 2009), and teaching-learning strategies to increase professionalism (Morris & Faulk, 2007).

The theory of transformative learning is a process of making changes within a frame of reference (Mezirow, 1997). Transformative learning is a rational, analytic, cognitive, intuitive, creative, and emotional process (Grabove, 1997). Transformative learning discerns between learning objectives and the ultimate goal of learning: to become an autonomous and socially responsible thinker (Grabove, 1997). This theory is based on constructivism, which emphasizes that meaning exists within ourselves rather than in the external world (Cranton & Taylor, 2012). Constructivists hold the view that people interpret experiences in their own way and the way one sees the world is a result of those perceptions (Cranton & Taylor, 2012).

Transformative learning theory follows a ten-phase process (Kitchenham, 2008). This study involved the first four phases. Phase one identified a disorienting dilemma.

The dilemma in this study was caring for families of dying patients (Kitchenham, 2008).

Phase two consisted of self-examination which occurred during the focus groups. The

students in the sample needed to self-examine in order to respond to the questions. The

answers to the questions assisted in creating education and activities. Phase three

included a critical assessment of assumptions. Revealing one's assumptions regarding

family care at end-of-life is part of the education program developed. The sample

population of students needed to assess their assumptions regarding family care at end-of-

life. Phase four had several components. The first involved recognizing one's own

discontent (Kitchenham, 2008). Next, the participant understood that the processes of

transformation are shared their process (Kitchenham, 2008). Lastly, the students

acknowledged that other people have gone through this same process (Kitchenham,

2008). By understanding the challenges with EOL care of families of dying patients,

educators can develop curricula that will meet those needs. The focus groups will yield

examples of where improvement can be made.

The later phases of the theory were used to develop the education and activities

for teaching family care at end-of-life. Briefly, the remaining phases of the theory of

transformative learning are to plan a new course of action, acquire knowledge and skills

to implement the plan of action, provisional trying of new roles, building self-confidence

in the new roles and relationships, and to reintegrate the new roles into one's life

(Kitchenham, 2008). The information from the focus groups will assist in creating and

implementing curricular changes.

This study is not an interventional study, but the data gathered here were used in

future studies. Future research will continue the phases of the theory of transformative

learning. The information from this study was used to develop education and practice situations for undergraduate nursing students to become more knowledgeable, comfortable, and confident in caring for families of dying patients.

Outline of Literature

The literature review includes the three topics that support this study, families of dying patients, nursing education for families of dying patients, and compassion fatigue. The review of literature begins with research on the families of the dying patients. Studies have been performed to elicit what families feel they need from nurses. The next section of literature goes into depth describing research related to current nursing education for families of dying patients. Previous researchers have identified that attitude, knowledge, and confidence/competence/comfort are concepts that are influenced by education and are fundamental to providing family care at end-of-life. Each of these concepts are reviewed. The last section includes literature regarding compassion fatigue among student and practicing nurses.

Families of Dying Patients

The families of the dying patients are often present when patients are actively dying. Nurses must care for the families in addition to the patients. There is some literature on what families want or need while their loved ones are dying. Good communication among the team and with the family is one aspect that was desired in many studies (Boucher, Bova, Sullivan-Bolyai, Theroux, Klar, Terrian, & Kaufman,

2010; Cronin et. Al, 2015; Heidari & Norouzadeh, 2014; Heyland et al., 2006; Main, 2002). Communication was the number one theme in a qualitative study of the next-of-kin (Boucher, et al., 2010), a prominent theme in the qualitative study on family members' perception of most helpful interventions (Cronin et al., 2015), and a main theme in a qualitative study interviewing the relatives of currently dying patients (Main, 2002). Families preferred communication that included information on patients' progress and course of illnesses (Boucher et al., 2010; Cronin et al., 2015; Heidari & Norouzadeh, 2014; Main, 2002). Families also requested that the nurses were present, provided comfort to patients and family members, and helped them to prepare for imminent death (Boucher et al., 2010; Cronin et al., 2015; Heidari & Norouzadeh, 2014; Main, 2002). A second theme was the importance of a clean, pleasant, restful and peaceful environment (Boucher et al., 2010; Cronin et al., 2015). Family values and preferences were discussed in one study as an important aspect of nursing care (Boucher et al., 2010). Lastly, one study revealed that trusting the caregivers and physicians was important (Heyland et al., 2006). Trust and confidence that their loved ones were well cared for and in good hands was important to families (Heyland et al., 2006).

When families are dissatisfied with care, they will share their displeasure with others either in person or via social media (Mangrolia, 2018). People are more likely to share a bad experience than a good one (Mangrolia, 2018). The disgruntled family's opinions can damage the reputation of the facility (Mangrolia, 2018). In addition, the facility can lose business (Mangrolia, 2018).

End-of-Life Concepts in Nursing Education

A literature review was conducted using Cumulative Index to Nursing and Allied Health Literature (CINAHL), Health Sciences on ProQuest, Web of Science, and Eric EBSCOhost. The search was limited to the years 2000-2017. This search yielded 1001 responses, and after removing duplicates, 321 articles remained. The abstracts of these articles were reviewed for relevance. Thirty-one articles were chosen for complete review. Due to limited literature on the care of the families of dying patients, literature was included on care of dying patients. Of the 32 articles, 16 articles were eliminated due to not meeting inclusion criteria, leaving 16 articles to include in this literature review. Inclusion criteria included: the article must be research, subjects were undergraduate nursing students, EOL care for terminally ill adults. Articles were excluded if they were not research, if they dealt with a particular patient population, such as pediatrics or maternity; if subjects were graduate nursing students, nurses, medical students, or physicians; or if they focused on a specific aspect of EOL, such as decision making. Reference lists were also reviewed for additional articles. Because there was a lack of published studies conducted in the United States on this topic, research regarding EOL concepts for nursing education conducted outside of the US were included in this review, knowing there may be different cultural EOL beliefs.

Attitudes

Attitude is defined as a way of thinking or feeling that is reflected in the behaviors of an individual (Oxford Living Dictionary, 2017). Five studies revolved around the attitudes of student nurses toward EOL care. These studies examined the attitudes of nursing students regarding EOL and palliative care; none of these studies focused on families.

Barrerre and colleagues (2008) examined the influence of the ELNEC curriculum on the attitudes of student nurses. The Frommelt Attitudes toward Care of the Dying (FATCOD) was used to measure the attitudes of the nursing students. The FATCOD was administered before and after the ELNEC curriculum. The results show that there was a significant difference between the pre-test and post-test scores (p=.000) and there was no difference in age, degree program, and previous experience with death (Barrere et al., 2008). Another study by Barrere and Durkin (2014) integrated the ELNEC into the curriculum of both generic and accelerated baccalaureate programs. Gender, type of degree program, and previous education on death and dying were not factors in changing attitudes, but the authors found that age and experience were predictors of an attitude change (Barrere & Durkin, 2014). The findings suggest that emotional and psychological support is required for individuals to explore their feelings about caring for those at the EOL.

The FATCOD tool was also used in a mixed methods study using a one-day workshop on Critical Moments (Bailey & Hewison, 2014). The Critical Moments workshop presented nursing students with real-life end-of-life scenarios to allow the students to explore components of care a developmental model one of the authors designed. This study administered the FATCOD before and after the workshop. Results revealed that all students had a positive attitude about caring for the dying before the workshop, but afterward, positivity increased in 90% of the participants (p<.001). The authors found that the increase was greater among those students who had some education on death and dying in their coursework. The qualitative data revealed that

many students did not feel prepared to care for dying patients and were anxious about communicating with patients and their relatives (Bailey & Hewison, 2014).

Dobbins (2011) completed a quasi-experimental study on the addition of EOL content in an Associate Degree Nursing (ADN) program. The intervention group viewed the movie, "Wit." The movie chronicles an English professors' journey through the medical system after being diagnosed with terminal ovarian cancer. During the movie, she reflects on her past, present, and significant events in her life. The movie was shown during either a medical-surgical course or an elective on EOL. The study used the Frommelt Attitude Toward Care of the Dying (FATCOD) scale before and after viewing the movie. While both the intervention and control groups exhibited significant increases in more positive attitudes toward caring for dying patients (p = .008), the students in the intervention group had a significantly higher increase than the control group (Dobbins, 2011).

Jo et al. (2009) used an EOL education program that consisted of lectures, movies, quizzes, discussions, and other tasks. The program, in a Korean University, was a 16-week course that met face-to-face. Students were surveyed about their own demise to elicit a response. Along with the Fear of Death Scale, the EOL Care Performance tool, and a 22-item EOL performance tool prior to and after the course. The authors found that there was a significant increase in having a positive attitude toward death (p=.011) and in EOL performance (p=.003) as compared to a control group (Jo et al., 2009). The authors concluded that EOL education improved EOL performance in nurses (Jo et al., 2009).

Lippe and Becker (2015) developed an elective course that included a simulation about EOL. Attitude and perceived competence were measured before and after the

simulation, which required the students to care for an EOL patient. Three cohorts of

students participated in the simulation and survey as a requirement of the course. The

post-test scores were significantly increased (p<.01) for both perceived competence and

attitude. Participating in a simulation increased the preparedness of the nurses to care for

dying patients.

Evidence within the literature supports that education specific to EOL can

improve nursing students' attitudes about death and dying. In these studies, various

teaching methods were used such as simulation, movies, quizzes, discussions, and a

companion program. Developing positive attitudes toward death and dying among

nursing students, should carry into their professional practice and assist nurses in

providing quality and compassionate care at the end-of-life. All of the above

interventions increased attitudes of nursing students toward EOL care of dying patients.

None of the above studies focused on the care of the families of dying patients.

Knowledge

Nine studies evaluated different teaching methods to increase knowledge of EOL

care in nursing students (Bush & Shahwan-Akl, 2013; Fink, Linnard-Palmer, Ganley,

Catolico, & Phillips, 2014; Fluharty, Hayes, Milgrom, Malarney, Smith, Reklau, Jeffies,

& McNelis, 2012; Gillen, Parmenter, van der Reit, & Jeong, 2013; Kwekkeboom, Vahl,

& Eland, 2006; Glover et al., 2017; Moreland, Lemieux, & Myers, 2012; Tuxbury,

McCauley, & Lement, 2012; Twigg & Lynn, 2012). Of these nine studies, four resulted

in significant changes in EOL knowledge (Fluharty et al., 2012; Fink et al., 2014;

Moreland et al., 2012; Glover et al., 2017), three reported qualitative increases in

knowledge (Bush & Shahwan-Akl, 2013; Tuxbury et al., 2012: Gillen et al., 2013) and two reported no changes in knowledge (Twigg & Lynn, 2012; Kwekkeboom et al., 2006).

Fluharty et al. (2012) used a recorded master lecture on EOL care prior to a simulation on caring for a dying patient. The content on the voice-over PowerPoint was not revealed. The authors reported significant increases in knowledge between pre- and post-test among baccalaureate (p < .000) and associate degree students (p = .02) following the lecture and simulation. The conclusion was made that a simulation with a recorded lecture can assist in increasing general knowledge of EOL care of the patient.

Standardized patients were used in a quasi-experimental study to determine the knowledge of spirituality in EOL care of junior year nursing students to measure knowledge and confidence (Fink et al., 2014). A perception of knowledge and skill regarding spiritual care at EOL care questionnaire was administered before and after the simulation using a standardized patient. Students were divided into two groups, intervention and control. The control group received usual education and the intervention group received usual education plus a simulation. The simulation included a dying patient of either Muslim, Catholic, or Jewish affiliation. Both the control and simulation groups demonstrated increased knowledge; however the simulation group demonstrated higher scores and a larger increase in knowledge.

Moreland et al. (2012) used a mixed methods quasi-experimental design to research knowledge of EOL care of the patient focusing on the signs and symptoms and perceived self-efficacy of the nursing student. Knowledge assessment and self-efficacy questionnaires were administered before and after a simulation of an EOL patient. Their results revealed that students significantly increased from pre- and post-test scores on the

knowledge and self-efficacy tests (p=.03) using a simulation. The qualitative data was

gleaned from the transcripts of the debriefing sessions. The follow themes surfaced:

caring versus curing, the big picture, and great expectations. Caring versus curing

required the students to change their perspective from completing tasks to just being

there. The big picture was more visible after the simulation because the students could

see how important palliative and end-of-life care were to the patient and their family.

Great expectations revealed that there were conflicts of role, performance, self-efficacy,

and the global experience. Students noted differences between actual patient care and

what was presented in movies such as when patients were attached machines that

provided a flat line when they died which was not always present in real life. Students

also identified cultural differences death experience. This simulation allowed the

students to more closely examine their self-efficacy, skills, and knowledge as it related to

end-of-life care.

Glover et al. (2017) performed a similar study by assessing pre-and post-ELNEC

course knowledge for senior baccalaureate nursing students. Using the ELNEC

Knowledge Assessment Test, a general EOL knowledge assessment, students were given

the test before and after their ELNEC core course. The results show students

significantly (p<.05) increased their knowledge about EOL care. However, the care of

the family was not specifically mentioned.

Bush and Shahwan-Akl (2013) performed a descriptive/exploratory study on

whether completing an oncology and palliative care course increased knowledge of

general EOL care of the patient in third year undergraduate students in Australia. Female

students more than males stated that the course increased their understanding of palliative

care. None of these studies addressed student knowledge of caring for the family at end of life as part of their research.

Gillen et al (2013) used an EOL simulation with Australian pre-licensure nursing students to gather quantitative and qualitative data on five aspects of the use of simulation as an educational intervention for increasing general knowledge of EOL care. The five aspects were linking of theory to practice, approaching families of dying patients, an encounter with death, 'hands on' experience in a 'protected environment', and importance of post simulation discussion and debriefing. The quantitative data consisted of a scale from one to ten on the simulation experience and showed that students enjoyed the simulation and found it valuable. The qualitative data revealed the link between theory and practice by allowing students to practice their skills in simulation. Some students stated that having family members present in the simulation was helpful in approaching family members and knowing what to say. Lastly, for some students,' this was their first encounter with death and they reported value in participating in a simulation related to care at the end of life. The analysis did not include general knowledge regarding family care at end-of-life.

Tuxbury et al. (2012) used a form of simulation, Forum Theater, to have pre-licensure students participate in a death experience. Actors played the roles of the patient and family, and two nursing students were the nurses. The two nursing students cared for the patient and the family. The students then wrote a reflective journal about the experience and completed a quantitative set of questions. The quantitative answers were examined along with the qualitative responses. Students expressed in their journals that they had increased their knowledge of care of the patient and the family. The authors

found that observing the simulation was informative, and the discussion following was helpful in learning what to say or do with family members. No specific details were given regarding the patient and family in the simulation nor about the care given to the patient or their family.

A quantitative pre-test/post-test design was used to study the effect of a hybrid simulation experience on general EOL knowledge of undergraduate nursing students (Twigg & Lynn, 2012). The hybrid simulation in this study used a high-fidelity mannequin and standardized participants. Established test questions on EOL care of the patient were administered to students before and after viewing movies that dealt with death and participated in a simulation. There was no significant difference in knowledge (p=.451) between the pre- and post-tests (Twigg & Lynn, 2012).

Kwekkeboom et al. (2006) designed a pre-test and post-test study to evaluate the general knowledge of EOL patient care using a student companion program for patients dying alone in hospice. In comparison to a control group that received standard curriculum, there were no significant change in pre-and post-test knowledge scores. However, students in the companion group had increased comfort with caring for dying patients and the control group showed no changes in comfort.

Quantitative and qualitative methods were used to evaluate if education interventions increased the knowledge of EOL and palliative care. Two studies did not show an increase in knowledge (Twigg & Lynn, 2012; Kwekkeboom, 2006). The first study by Twigg and Lynn (2012) reported that the knowledge scores did not rise due to the students lack of exposure to the content prior to the simulation and knowledge assessment. The second study by Kwekkeboom (2006), the author attributed the lack of

knowledge increase to a problem with internal consistency. Time dedicated to EOL care

within a medical-surgical course or a stand-alone EOL course proved useful to increase

knowledge of EOL and palliative concepts. Only one study included a simulation that

focused on the care of the family. The simulation helped the nursing students how to

communicate with the family. More research on complete care of the family should be

conducted.

Confidence/Competence/Comfort

In five studies simulation was used as a teaching method for experiential learning

and practice. Use of simulation was found to increase in confidence, competence and

comfort with simulation, workshops, and forum theater. (Bobianski, Aselton, & Cho,

2016; Fink et al., 2014; Lippe & Becker, 2015; Liu, Su, Chen, Chiang, Wang, & Tzeng,

2011; Tuxbury et al., 2012). The education that students received influenced the delivery

of EOL care of the patient for these students. Two studies evaluated the care of the

family.

Bobianski and colleagues (2016) used an EOL home care simulation and found

that as students reflected on the experience, their comfort with death increased. This

qualitative study used an unnamed post-simulation evaluation tool. One major concept

that emerged through reflection and discussion was recognizing the family members as

recipients of care. A post-simulation evaluation showed that students reported increased

comfort and confidence in caring for dying patients (Bobianski, et al., 2016). Discussion

revealed that family members become the focus of EOL care. More research is needed

on the care of the family of dying patients.

In a quasi-experimental study, a visual analogue scale was used to measure confidence before and after receiving education on EOL. The control group received classroom education and the intervention group received the classroom education and a simulation. The paired confidence scores from pre- and post-survey were significantly improved for knowledge (p=.001) and confidence (p=.022) in the intervention group (Fink, et al., 2014). Differences were significant between the intervention and control group after (p=.005) the simulation.

Lippe and Becker (2015) measured perceived confidence and attitude about caring for end-of-life patients with a pre- and post-simulation on withdrawal of care. The measures used were the Perceived Competence in meeting ELNEC Standards, Concerns About Dying scale, and FATCOD. The researchers found a significant increase (p < .001) in perceived competence and attitude after the simulation. The results suggest that the simulation was effective in increasing competence and attitude. Tuxbury and colleagues (2012) used a forum theater concept to display an end-of-life scenario where one student simulated the nurse and actors played the patient and family. The remainder of the nursing students were observers. The scenario comprised of a 54-year old Jewish woman dying at home with her daughter present. The remainder of the students watched the simulation unfold on stage. The students wrote reflective journals regarding the simulation in addition to an evaluation of the simulation. The authors found that 61% of students felt more confident caring for dying patients after viewing the simulation.

Two studies found that there was an increase in either comfort, confidence, or competence after an intervention, while three studies found an increase in comfort. Methods varied among these studies: one used simulation, two used surveys, one used

Forum Theater, and one used a workshop. Experiential learning was present in three

studies and lends credibility for learning this material. Two studies acknowledge family.

Lippe & Becker (2015) conclude that nurses need to learn to communicate and show

compassion for the family as well as the patient. Bobianski and colleagues (2016)

acknowledge that the family becomes the focus of care at EOL. However, more research

should be conducted on the care of the family.

Conclusion

The literature review supports that there are various factors involved in the

education of nursing students in EOL care for patients and family members. An

educational intervention can increase a nursing student's attitude impacting EOL care

(Barrere & Durkin, 2014; Jo et al., 2009; Lippe & Becker, 2015). The method of

education also does not appear to be significant, as students learned from lecture,

simulation, and other interventions (Jo et al., 2009; Lippe & Becker, 2015). Multiple

methods of education delivery have all shown to increase nursing students' knowledge

about the topic of EOL care (Bush & Shahwan-Akl, 2013; Gillen et al., 2013;

Kwekkeboom et al., 2006; Mooreland et al., 2012; Tuxbury et al., 2012). Significant

increases in knowledge were noted in studies testing different educational methodologies

including videos, simulations, journals.

Different measurement instruments, various methods of education delivery, and

multiple types of content were used to increase knowledge regarding the care of the dying

patient (Bush & Shahwan-Akl, 2013; Fink et al., 2014; Fluharty et al., 2012; Gillen et al.,

2013; Glover et al., 2017; Kwekkeboom et al., 2006; Moreland et al., 2012; Tuxbury et

al., 2012; Twigg & Lynn, 2012). A variety of methods were used to increase knowledge

of care of the dying patients and their families (Bailey & Hewison, 2014; Barrere, 2008; Barrere & Durkin, 2014; Dobbins, 2011; Jo et al., 2009; Kwekkeboom et al., 2005; Lippe & Becker, 2015; Twig & Lynn, 2012). Several methods of education, such as simulation, elective oncology and palliative care course, ELNEC course, companion care course, and forum theater were used to instill confidence (Bobianski et al., 2016; Fink et al., 2014; Lippe & Becker, 2015; Tuxbury, 2012). Confidence (Bobianski et al., 2016; Liu et al., 2011) and competence (Lippe & Becker, 2015) were both examined. Confidence was examined using qualitative measures while competence was measured through the use of the ELNEC curriculum and quantitative measures. Multiple education methods as well as both qualitative and quantitative research methods were used to determine that some form of education in an undergraduate nursing program can improve education outcomes.

None of the nursing education studies were randomized controlled trials with most studies having under 100 participants (Barrere et al., 2008; Barrere & Durkin, 2014; Bobianski et al., 2016; Bush & Shahwan-Akl, 2013; Dobbins, 2011; Fink et al., 2014; Jo et al., 2009; Kwekkeboom, 2006; Liu et al., 2011; Moreland et al., 2012; Twigg & Lynn, 2012; Tuxbury et al., 2012). About half of the studies are qualitative, which tend be smaller numbers (12-16). The studies were well-performed, but since there is an agreement in outcomes, the results can be considered promising although more confirmatory testing is needed.

EOL education is essential for nursing students. Experiential methods of EOL education have been successful in improving attitudes, knowledge, and confidence of students. Didactic methods appeared to increase knowledge. Experiential forms of education, such as clinical and simulation, develop confidence and competence as well as

advance a positive attitude toward the dying. Discussions in class or debriefings in simulation can improve comfort.

There is a lack of education regarding family care at end-of-life. Few studies mentioned awareness of the family or how the students should care for the families, but none mentioned any education specific to care of family members for nursing students. The topic of care of families of dying patients requires more research, particularly how best to educate nursing students to care for these families.

Compassion Fatigue

A literature search for CF and nursing students using CINAHL, PubMed, Proquest, and Web of Science with a date range of 2005 to 2017 yielded a total of ten articles. Out of that ten, one was a concept analysis, one discussed moral distress, and three articles did not discuss CF. The remaining five articles are discussed below.

Compassion fatigue is a term to describe the outcomes of unique stressors that affect people in caregiving professions (Perry, 2015). Compassion fatigue has been shown to affect nursing students physically, mentally, emotionally, and spiritually (Boyle, 2015; Chitra, 2011; Douglas, 2010; Henson, 2017; Hooper, Craig, Janvrin, Wetsel, & Ramiels, 2010; Kelly, Runge, & Spencer, 2015; Melvin, 2012; Showalter, 2010; Sorenson, Bolick, Wright, & Hamilton, 2017). Compassion fatigue contributes to students providing poor care, leaving their facility of employment, or leaving nursing altogether (Boyle, 2015; Chitra, 2011; Henry, 2014; Henson, 2017; Hooper et al., 2010; Sorenson et al., 2017). When nursing students experience compassion fatigue without

any assistance of how to cope with the stresses of the job, the students become nurses with compassion fatigue. The literature produced studies on nurses and nursing students.

Antecedents to CF include working as a nursing student or nurse, exposure to traumatic events, empathy for the individual who is suffering, and a need to integrate the suffering of others into one's self (Sorenson et al., 2017). These antecedents may be present during the clinical practicum for nursing students. Nursing students are exposed to the same traumatic events that nurses are during their clinical experiences. One study compared the first- and second-year nursing students to the third- and fourth-year students as it related to CF (Michalec, Diefenbeck, and Mahoney, 2013). There was no significant difference in CF.

High patient satisfaction is directly related to high compassion by caregivers (Hooper et al., 2010). But the opposite can also occur, high levels of CF and burnout can lead to a high dissatisfaction from patients (Hooper et al., 2010). Compassion fatigue has been studied in nurses specializing in emergency, oncology, nephrology, and intensive care units (Hooper, et al., 2010; Kelley et al., 2015; Melvin, 2012; Wu, Singh-Carlson, Odell, Reynolds, & Su, 2016). All of these studies illustrated that nurses experience CF. Experiences that contribute to CF included repeated deaths, lack of support, physical and emotional costs of work, age of nurse, and team cohesiveness (Hooper, et al., 2010; Kelly et al., 2015; Melvin, 2012; Wu et al., 2016).

One qualitative study was performed with nurses in hospice and palliative care (Melvin, 2012) with the purpose of evaluating compassion fatigue and coping mechanisms used by the nursing staff. A central theme was that without adequate coping strategies, caregivers will develop CF. Other themes included repeated deaths over time,

emotional and physical costs of working with hospice and palliative care patents, and coping strategies were required. The study confirmed that there are significant emotional and physical effects of working with hospice and palliative care patients (Melvin, 2012).

Summary of Compassion Fatigue

Compassion fatigue can develop while a student nurse. Caring for families of dying patients is stressful on the caregiver. The more stress the caregiver experiences CF will develop and create physical, psychological, emotional, and spiritual issues in the caregiver. Lack of preparation in students can result in unprepared nurses. Students experience stress for various reasons – academic workload, clinical hours, mastering content and skills, coping with emergencies, fear of making errors, traumatic experiences in their clinical such as death or negative encounters, and the overall emotional toll of nursing school (Mathias & Wentzel, 2017). As students progressed through the program, their stress increased, which put them at risk for CF (Mathias & Wentzel, 2017).

The literature agrees that there is pervasive CF and burnout among nurses. Some specialty areas, such as hospice and palliative care, critical care and the emergency department appear to have higher levels of CF (Hooper, et al., 2010; Kelley et al., 2015; Melvin, 2012; Wu et al., 2016). Research has shown that CF takes a toll on the caregiver impacting patient care (Boyle, 2015; Chitra, 2011; Douglas, 2010; Henson, 2017; Hooper et al., 2010; Kelly et al., 2015; Melvin, 2012; Showalter, 2010; Sorenson et al., 2017). The facility can be impacted by nurse turnover and the costs associated with hiring and training new staff. With better preparation for EOL care in their undergraduate education, nurses will have tools needed to prevent CF and to provide compassionate, quality care at the end-of-life (Marcial et al., 2013).

Summary of Literature

The literature supports that education is important in EOL care for student nurses. Research findings support that any form of education – workshop, course, unit in a course, simulation – increases knowledge, attitude, comfort, and confidence in the ability to care for dying patients. However, few studies discuss the family of the dying patient, this is an identified gap. Six of seventeen studies, or 35%, utilized simulation or standardized patients. This method appears to be engaging and has yielded good results in teaching end-of-life care to nursing students.

Lack of preparation has been shown to lead to compassion fatigue in both nursing students and nurses. (Mason & Nel, 2012; Mathias & Wentzel, 2017; Michalec et al., 2013). Repeated exposure to traumatic situations and negative personnel can also affect a nursing students and nurses. Compassion fatigue can cause students and nurses to leave the profession (Hooper et al., 2010; Kelly et al., 2015; Showalter, 2010; Sorenson et al., 2017; Wu et al., 2016). Educating student nurses about CF and how to cope with it is an essential part of education. Nursing curricula must provide the student with the tools to provide compassionate, competent care for persons experiencing suffering, such as the families of dying patients.

The family needs and wants care as well. Frequent communication from the health care staff is vital. All studies on the families cited communication as an important attribute of care. Using the principles of family centered care, the family is as much in the nurses' care as the patient. Hence, nurses must care for the family as well as the patient. As discussed in the background and significance, nurses do not feel comfortable caring for dying patients and their families. In order to become more comfortable,

undergraduate nursing programs should integrate education on the care of the family as well as caring for the dying patient. This way, nurses will learn, as students, how to better communicate and care for the patient and their family at the end of life may be more comfortable.

Assumptions

The assumptions listed below are those of the author. In qualitative research, the researcher must be aware of any assumptions regarding the topic in order to reduce bias (Braun & Clarke, 2013).

1. Other nurses believe that caring for families of dying patients is important.

2. Students have limited knowledge, confidence and skill on the topic of end-of-life care of families of dying patients.

3. Students want to have greater knowledge, confidence, and skill to be able to care for the families as well as the patients.

4. Dying patients and their families expect competent and compassionate care.

Research Questions

RQ1: What is the perception of nursing students regarding what is needed to provide care to families, friends, or significant others of dying patients?

RQ2: What do nursing students perceive as challenges of providing care for families, friends, or significant others of dying patients?

RQ3: What do nursing students perceive as facilitators of providing care for families, friends, or significant others of dying patients?

Summary of Gaps in the Literature

There are a few gaps in the literature that have been noted in this discussion. The first gap is that there is little research on the care of families of dying patients (Boucher et al., 2010; Cronin et. al, 2015; Heidari & Norouzadeh, 2014; Heyland et al.,2006; Main, 2002). The research completed on families of dying patients provides nurses little information regarding what families of dying patients would like to have as care. The literature supports the notion that current EOL care of families of dying patients is inadequate.

Nursing students are unprepared to care for EOL families of dying patients is the second gap (Bush & Shahwan-Akl, 2013; Fink et al., 2014; Fluharty et al., 2012; Gillen et al., 2013; Kwekkeboom et al., 2006; Glover et al., 2017; Moreland et al., 2012; Tuxbury et al., 2012; Twigg & Lynn, 2012). Students surveyed reported that they feel unprepared to care for families of dying patients. Many students also felt that they were unprepared to care for the patient. If nursing students do not receive adequate education and preparation, it is expected that they will not be prepared to care for families as nurses.

Compassion fatigue (CF) comes from being unprepared to provide care. Students may develop CF during their pre-licensure education (Hooper et al., 2010; Kelley et al., 2015; Mason & Nel, 2012; Mathias & Wentzel, 2017; Melvin, 2012; Michalec et al., 2013; Wu et al., 2016). The problem may only escalate after licensure without the proper preparation. Preparation for nursing students to prevent CF is to be prepared to care for the families of dying patients and how to handle the stresses of caring for those individuals.

More research on the care of the family of dying patients is needed. Research and education should focus on the care of the family. Continued research is needed to ensure that the gap is filled and the care improved. This study will fill that gap by outlining what undergraduate nursing students perceive as their needs and challenges when providing care to the families of dying patients. This information can be used to develop curriculum for EOL care.

Chapter 3
Research Design and Methods

Introduction

This chapter contains the design and methodology of this study. The first section presents the study design and rationale. The recruitment process and measures to protect human subjects are described. The focus group method was used; a description of focus groups and data collection. Instrumentation included the demographics form and the interview guide. The process of data analysis was detailed. The chapter ends with a discussion of rigor.

Research Design and Methodology

Qualitative research originated in the social sciences, where observations could be conducted and maintain the real-world context (Sandelowski, 2000; Sandelowski, 2010). End-of-life care is an area that some have had personal experiences, but possibly not any professional experience. A qualitative method will allow the researcher to extract the perceptions of the participants from the perspective of the caregiver from their clinical experiences (Guba, 1990; Guba & Lincoln, 1994; Sandelowski, 2000; Sandelowski 2010). Qualitative research, especially descriptive, correlates with a constructivist framework (Cranton & Taylor, 2012; Guba, 1994; Guba & Lincoln, 1994).

The outcome of a qualitative descriptive study is to comprehensively describe the events in everyday language (Sandelowski, 2000; Sandelowski, 2010). According to

Sandelwoski (2000, 2010), all inquiry requires description and all description requires interpretation. The descriptions evolved from the perceptions, inclinations, sensitivities, and sensibilities of the describers, leading to descriptive validity (Sandelowski, 2000; Sandelowski, 2010). Qualitative descriptive was the method of choice when the aim of the study is to provide an accurate, straight-forward description of the events or phenomenon (Kim, Sefcik, & Bradway, 2016; Lambert & Lambert, 2012).

Participants

The participants were recruited from a convenience sample from a small Midwest private, faith-based women's college. This college enrolls approximately 1400-1500 undergraduate students. The student population was similar in the fact that they were all female and between 19 and 39 years of age, on average. The majority were first-time college students. The college boasts approximately 45% ethnic diversity and has been designated as a Hispanic Serving Institution. The primary researcher was on faculty at this institution, but not the faculty of record for these students during the data collection portion of the study. One hundred and twenty-five students enrolled in clinical courses in their junior and senior year were solicited for participation. This level of student was chosen because they were in a clinical setting where there was potential for being involved with care of families of dying patients.

The participants in the study were undergraduate nursing students in clinical courses. Many of the students were "millennials" due to the average age of college students. The definition of a millennial is a person born between 1982 and 2004 (Billups, 2012). Millennials like to share their opinions (Billups, 2012). Focus groups with

college students can offer an avenue that fits well with the millennial student,

encouraging a dialogue that can be meaningful and significant (Billups, 2012).

Participant Recruitment

Recruitment began by attending classes in which the volunteer pool was enrolled.

The purpose of the study and the methodology were presented and any questions were

answered. The schedule of the focus groups was presented and volunteers were asked to

sign up for a spot in a focus group through a google document that was emailed to them

shortly after the presentation. An information sheet about the study was given to

participants (Appendix B). Individual meetings were offered to all students who do not

wish to participate in a group and share their opinion with others. Several participants

had individual interviews, but this was due to scheduling issues, not due to a request. A

total of 19 participants were recruited from 125 eligible participants.

Protection of Human Rights

The volunteer participants were given an explanation of the study and consent

forms (Appendix A) were signed as a group at the start of the session. The information

sheet (Appendix B) was also given to them again to review. Internal Review Board

(IRB) approval (Appendix C) was sought prior to the start of data collection in order to

protect the rights of the human subjects. Participants were informed that they were able

to opt out at any time during the focus group. However, contributions that were already

on the recorder and could not be deleted. A demographic form (Appendix D) was

obtained from each participant after consent forms were signed. A list of resources was

created and given to each participant in the study if they have difficulties with the topic of

the focus group. Resources include the two counselors employed by the college as well as some local resources (Appendix G). Names and contact information was on the resources sheet.

A professional transcriptionist was hired to transcribe the audio recordings of the focus groups. The transcriptionist was required to sign a HIPPA form for privacy of participants. The audio recordings were transferred from a portable recorder to a password protected computer immediately after the focus groups. The recordings were then deleted from the portable recorder. All audio files were maintained until the completion of the study on the password protected computer. The transcripts, as they are de-identified, will be kept indefinitely for secondary analysis or teaching purposes. All participants signed an informed consent form (Appendix A).

Data Collection

Data were collected via a demographic form in the focus groups. Focus groups are often used as a method of data collection in qualitative research as multiple descriptions can be garnered at one time (Cote-Arsenault, 2013; Sandelowski, 2000; Sandelowski, 2010). Multiple small group sessions were scheduled to allow students to sign up for a session that best met their availability. Five to eight participants were planned for each group to allow time to hear from each person and to minimize the risk of shy participants from feeling intimidated by the size of the group (Cote-Arsenault, 2013). No more than eight participants per session were allowed. Eleven sessions were conducted. Eight of the sessions had only one participant, one session had six, one session had three, and one session had two.

A quiet conference room on campus was used to conduct the focus groups. Comfortable chairs and refreshments were provided. A sign was put on the door to alert others that there was an interview in process and to not disturb the group. Participants were anonymous. The demographic form had only a participant number and the students were instructed to not state their name prior to speaking on the recording.

Once the consents were signed, everyone was comfortable, and instructions had been given, the interview began. The recorder was turned on, a brief paragraph was read to set the context, and the first question was asked. The questions revolved around the perception of the student regarding care of the families of dying patients, the perception of challenges and facilitators in caring for families of dying patients. The questions and prompts are outlined in the interview guide (Appendix E).

The interviews from each focus group sessions were audio recorded. Field notes were made by the primary researcher after each focus group. The recordings were directly transcribed by a professional transcriptionist. The transcripts were reviewed while listening to the recordings for accuracy and to remove any identifying person or institution. A de-identified demographic form was used. All information collected was de-identified and kept in a locked file cabinet in a locked office. All information gathered from the participants was maintained in the Dedoose© data storage and analysis system. The system was password protected to ensure privacy.

Instrumentation

There were two instruments for this study: the demographic form and the semi-structured interview questions. The questions on the demographic data form (Appendix D) were related to age, race, first degree, experience in health care, and experience with

dying patients and their families. The rationale for using the demographic form was to determine the composition of the participants. The interview guide was developed by first looking at the research questions. As an experienced educator, the Primary Investigator (PI) drew from the literature and worked with an experienced qualitative researcher to develop the introduction, the questions and prompts. The first questions asked the participants to put themselves into the position of a family member of a dying a patient. The next two questions inquired about what the participants imagined would make it easier and more challenging to work with the family of a dying patient. Questions that were asked during the focus groups can be found in the interview guide (Appendix E). The rationale for the interview guide was to ensure that each group was to have some questions that would be asked of all groups and prompts if needed.

Data Analysis

This study used thematic analysis to interpret the data. Thematic analysis assists in gathering the meaning of phenomena and establish models to explain the behaviors, feelings, and thinking (Joffe, 2012). Thematic analysis has been used for years but has only recently been acknowledged as an actual method (Clarke & Braun, 2013). Thematic analysis is a method of extracting meaning from data (Joffe, 2012). This method highlights important themes, or recurring concepts, in order to make meaning of the phenomenon. Thematic analysis can conceptualize perceptions, thoughts, and feelings (Clark & Braun, 2013; Kim et al., 2016; Joffe, 2012).   Another reason researchers might use thematic analysis is to generate descriptive themes closer to participants' points of view as opposed to developing theories or highly abstract themes that describe the essence of the phenomenon (Clark & Braun, 2013; Kim et al., 2016; Joffe, 2012).

Thematic analysis was a multi-phase process which begins with a line-by-line coding followed by the evolution of descriptive themes (Thomas & Harden, 2008). As suggested by Cote-Arsenault (2013), analysis will include an across code and theme comparison. This can confirm and validate the results and imply transferability (Cote-Arsenault, 2013).

In this study, analysis consisted of a multiple step process to code and interpret the data requiring the researcher to delve into the data, make connections, and interpret the information provided by the participants (Clark & Braun, 2013; Joffe, 2012; Kim et al., 2016; Sandelowski, 2000; Sandelowski, 2010). As with most qualitative research, analysis began immediately when the first data were collected. Analysis continued throughout the data collection process.

The seven-step process outlined by Braun and Clarke (2013) was used. Step one was to transcribe the data into written text. After transcription, the transcripts were entered into Dedoose© in their entirety immediately. Step two was reading and familiarizing. In this step, the researcher read and re-read the transcripts and began to notice points of interest. There were no preconceived codes, all codes emerged from the data as the data was reviewed. Step three was coding. Aspects of the data that related to the research questions were identified. Step four was searching for themes. Relevant concepts that portrayed an important aspect were selected to represent meaning in the responses. The transcripts were read initially, then re-read and the codes came from the data. As subsequent transcripts were transcribed, subsequent transcripts were entered, coded, and compared with previous transcripts. After each successive session was added and coded, the primary researcher compared the codes from each session to the other

sessions. Step five was reviewing themes. In this step, the researcher reviewed the themes and the codes and determined if the story was told. This was considered the quality control step of the process. The dissertation committee was able to review the themes related to their area of expertise. Step six was defining and naming themes by stating what was specific and unique about each theme. A few sentences were written to describe each theme. Step seven was writing the report. Cogent and powerful examples are chosen to support each theme (Braun & Clarke, 2013).

During the data analysis, some of the remaining phases of the theory of transformative learning were integrated when appropriate. The phases of exploring options, planning a course of action, acquiring knowledge, trying new roles, building competence and self-confidence, and reintegrating into life were used when looking at the coded data and themes. The phases of the theory will assist the researcher in using the codes and themes to create the education and activities.

The dissertation committee consisted of three members: the chair was a qualitative researcher, one member was a palliative and hospice specialist, and the third was an education specialist, with quantitative and qualitative research experience. After the primary researcher coded the transcript, the chair and the education specialist coded some transcripts. The codes from all three were compared and contrasted to find that the codes were consistent. The remaining committee member entered the process after the initial coding and theme development was completed. This contributed to rigor.

The rationale for using thematic analysis was that the method allowed in-depth review of the data with multiple readings and review of the data. Comparing the codes assigned between the focus groups also provided for a more in-depth review and

comparison. The continual comparison enabled the researcher to be certain of the connections and development of themes that describe the perspective of the undergraduate nursing student.

Methodological Rigor

Rigor was defined as creating trustworthiness of the collection, analysis and interpretation of the data. Trustworthiness includes the concepts of credibility, transferability, dependability, and conformability (Prion & Adamson, 2014). Credibility was adequately captured and describes the experiences of the participants. Credibility reflects the point of view of the participants. Credibility and confirmability were obtained with between groups as well as within group analyses (Cote-Arsenault, 2013). Once some focus groups were completed and analysis had begun, the primary researcher brought up the codes and themes to subsequent groups during the other sessions to obtain confirmation that these themes were accurate. Transferability is the ability to apply the results to other populations or situations. This cannot be determined by this researcher. Each reader of the results will need to determine if there is transferability for their situation. The primary researcher will publish the results with thick description and ample quotes to allow others to review for use in their programs. Dependability is the ease with which people can understand the researcher's process and results. Confirmability is the lack of researcher bias and the outlining of the assumptions and making the assumptions of the researcher well-defined (Prion & Adamson, 2014). Confirmability was established by asking the group at the end of the interview if the summary by the group leader was what they heard (Cote-Arsenault, 2013). The biases

and assumptions of the primary researcher have been written down and were reviewed as the process unfolded.

As this research unfolded, the primary researcher detailed the process and took field notes. The field notes were collected with a template that was completed immediately after each focus group. The template format allowed for consistency in the notes (Appendix F).   Some of the field notes had methodology comments to document the process. The field notes allowed the researcher to separate personal values, feelings, and emotions form those of the participants. These notes were reviewed along with the transcripts. Rationales for decisions was noted so that all aspects of this study were open and accessible.

Rigor was maintained by following the process for thematic analysis. In the process outline by Braun and Clarke (2013) above, the review step in the process is part of rigor. By comparing across codes, validity was confirmed (Cote-Arsenault, 2013). This entailed comparing data within the code to identify a relationship within the data and eventually within the themes. Consistent facilitator of the focus groups also assisted the group process to be the same. The identical questions were posed to each group for consistency.

Bias is a potential issue in qualitative studies. One approach to combatting bias was to lay out the assumptions. The assumptions of the Primary Investigator (PI) have been outlined in Chapter 2. Another technique to control bias was that the PI and the committee members collaborated and monitored each other.

Limitations

As with any study, several limitations were noted. One being that the study was conducted at an all-women's college. Another limitation is the fact that the study was conducted at only one college. The study took place in a large Midwestern city, the results may not apply to small towns or other areas of the country. The sample size is limited, which is also be a limitation, but is typical for qualitative studies. The participants were undergraduate nursing students, associated degree and completion degree programs were not included. Lastly, limitations include the lack of diversity in the sample. The generalizability of this study is reduced due to these limitations.

Chapter 4

Publication

Education Provided to Undergraduate Nursing Students About End-of-Life Care

Penny Alt-Gehrman, MSN, RN

Many nurses do not feel prepared to care for patients and families at the end of life (EOL). Because nurses are the health care professionals who spend the most time with patients and their families at the EOL, this is concerning. Nurses will experience death as a part of their practice and must care for the patients" significant others during times of sorrow and stress. The purpose of this literature review was to determine what is provided to undergraduate nursing students regarding EOL. The literature shows that a nurse with a positive attitude can improve the EOL experience for the patient and family. Three main themes emerged from the literature: a positive attitude, knowledge, and confidence/competence/comfort. One glaring omission is the care of the family of the dying patient. More research must be performed.

erature review was to determine the types of education provided to undergraduate nursing students regarding EOL care.

METHODS

Several databases were accessed: Cumulative Index to Nursing and Allied Health Literature, Health Sciences on Proquest, Web of Science, and Eric from EBSCOhost. The search terms used were ''EOL'' and ''nursing'' and ''education.'' The search was limited to the years 2000 to 2017 with a cumulative yield of 1001 articles. After removing dupli-cates, 321 articles remained. The abstracts of these articles were reviewed for relevance. Thirty-one articles were chosen for complete review. Of the 31 articles, 17 articles were

eliminated because of not meeting

inclusion criteria, leav-

KEY WORDS

end of life, family of dying patients, undergraduate nursing education

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Penny Alt-Gehrman, MSN, RN, is Assistant Professor, Department of Nursing, Alverno College, Milwaukee.

Address correspondence to Penny Alt-Gehrman, MSN, RN, Alverno College, 3400 S 43rd St, PO Box 343922, Milwaukee, WI 53234- 3922 (pennter@yahoo.com).

any nurses do not feel prepared to care for patients and families at the end of life (EOL).[1-4] Because nurses are the health care professionals who spend the most time with patients and their families at the EOL, this is concerning.[1,4] Nurses will experience death of patients as a part of their practice and need to care for the patients" significant others during times of sorrow and stress. One of the most stressful encounters for nursing students is with dying patients and their families.[5] Nurses with positive attitudes toward caring for EOL patients can improve the EOL experience for the patient and family.[2,5-10] Caring for the patient at the EOL and meeting family needs are challenging without appropriate knowledge and experience. The purpose of this lit-

ing 14 articles to include in the review (Figure). Inclusion criteria include research, undergraduate nursing students, EOL care, and a general patient population. Articles were excluded if they were not research; if they dealt with a particular patient population, such as pediatrics or maternity; if subjects were graduate nursing students, nurses, medical students, or physicians; or if they focused on a specific aspect of EOL, such as decision-making. Reference lists were also reviewed for additional articles.

Education Consortium into the curriculum of both generic and accelerated baccalaure- ate programs. Sex, type of degree program, and previous education on death and dying were not factors in changing attitudes, but the authors found that age and experience were predictors of an attitude change. The study also

RESULTS

This literature review focused on 3 main themes: attitudes, knowledge, and comfort/confidence/competence of the nursing student. The Table provides a summary of articles reviewed for this study.

Attitudes

Studies focused on factors that influence the attitudes of the nursing student about EOL care[11] and various methods of education that changed student attitudes on caring for dying patients.[12-14] Four studies examined the attitudes of nursing students about EOL and palliative care[11]; none of these studies focused on families. Barrere and Durkin[11] inte- grated the End-of-Life

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Feature Article

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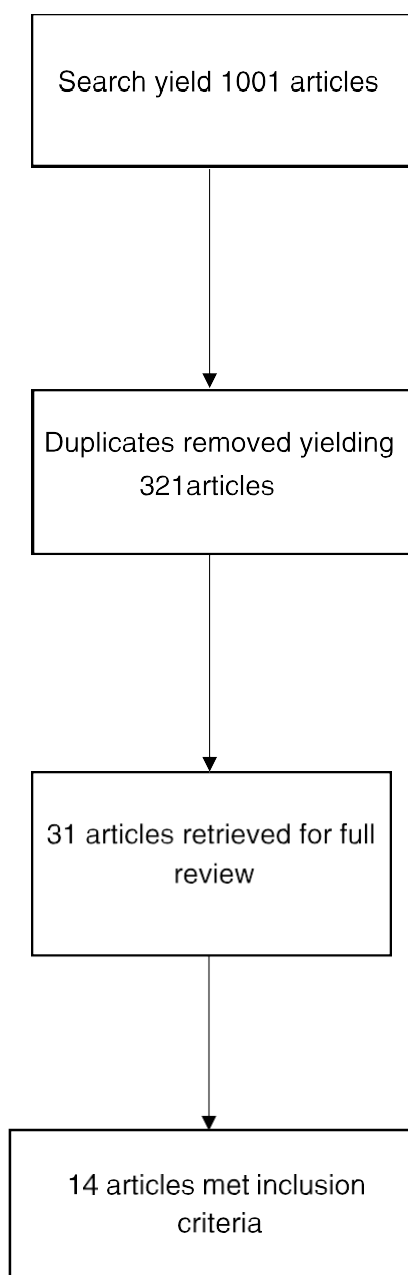
Documented that support is required for individuals to explore their feelings about caring for those at the EOL. They noted that it is difficult to measure the impact of education on patient care and outcomes at EOL due to a number of factors.

Jo et al[12] used an EOL education program that consisted of lectures, movies, quizzes, discussions, and other tasks. The program, in a Korean university, was a 16-week course that met face to face. Students were surveyed about the suffering experience of the nurse with the Fear of Death Scale and the EOL Care Performance tool and a 22-item EOL performance tool before and after the course. The authors found that there was a significant increase in attitude (P = .011) and in EOL performance (P = .003) as compared with a control group.

Kwekkeboom et al[13] developed a companion program for patients dying alone. The theory of experiential learning was used when developing the program where students spent time as companions for dying patients in hospice care. Baseline knowledge and attitude scores were obtained before participating in the program. Knowledge scores increased significantly (P G .05) for the student companions as compared with students in the control group who received the standard curriculum. Attitude scores also significantly increased (P G .01). The authors acknowledged that, because the program was voluntary, this may have skewed their results.

Lippe and Becker[14] developed an elective course with a simulation about EOL. Perceived competence and attitude were measured before and after the simulation, which re- quired the students to care for an EOL patient. Three cohorts of students participated in the simulation and survey as a requirement of the course. The posttest scores were significantly increased (P G .01) for both perceived competence and attitude.

The literature supports some form of education specific to EOL to increase the attitude of the care provider. The literature suggested various methods such as simulation, movies, quizzes, discussions, and a companion program. All of the mentioned interventions increased attitudes of nursing students toward EOL care.

Knowledge

Seven studies addressed knowledge of nursing students[4,15-20] by evaluating different methods of teaching EOL care. Fluharty et al[15] developed a module to review before a simulation and found a significant difference be- tween pretest and posttest in baccalaureate ($P <$ .000) and associate degree students (P = .02) using a module and simulation.

Moreland et al[16] used a mixed methods quasi-experimental design to research knowledge of EOL signs and symptoms and perceived self-efficacy. Knowledge assessment and self-efficacy questionnaires were administered before and after a simulation of an EOL patient. Their results revealed that students significantly increased from pretest and posttest scores on the knowledge and self-efficacy tests (P = .03) using a simulation.

Kwekkeboom et al[17] designed a pretest and posttest study to evaluate the knowledge of EOL care using a student companion program for patients dying alone in hospice. The researchers found no significant change in pretest and posttest scores but did find a lower concern score in the student companion group versus the control group (P = .07). The control group received the standard curriculum.

TABLE	Table of Literature					
Author (Year). Title. Country	Purpose/Research Question(s)	Sample	Intervention	Design/Method	Key Findings	Limitations
Barrere, Durkin, and LaCoursiere[24] (2008). The influence of end-of-life education on attitudes of nursing students. United States	Evaluate the influence of ELNEC education content integrated into a BSN program curriculum on students" attitudes toward caring for dying patients	103 Seniors BSN students: 61 from traditional and 42 from accelerated	ELNEC curriculum content throughout the traditional and accelerated BSN program, where it fit with the specific courses topics	Quasi-experimental, longitudinal repeated measures design, FATCOD instrument	Younger age was the most powerful predictor of a change in student attitudes as with significance, measured by FATCOD. Previous experience with caring for a dying person was a second factor	Small, convenience sample, 1 university, availability of text and curriculum content; choice of clinical assignment, opportunity to care for terminally ill clients varied.
Bobianski, Aselton, and Chee[21] (2016). Home care simulation to teach culturally based competencies in end-of-life care. United States	Infusing cultural component to EOL care.	43 Students participated in simulation, 38 completed surveys. The level of student or the degree program were not noted	EOL simulation with a specific culture	Not stated, difficult to discern. Qualitative data obtained in debriefing	Many students reflected on death and dying, increased comfort	Small sample, 1 school, level of experiences with death and dying among participants
Bush and Shahwan-Akl[18] (2013). Palliative cared education⩔does it influence future practice? Australia	Determine if the completion of an oncology and palliative care course aided a group of undergraduate students in the clinical provision of palliative care	Third-year undergraduate students who took the course, N = 51	Oncology and palliative care course. Does not state whether course is mandatory or elective	Descriptive/exploratory mixed methods	Females more than males: appreciated inclusion in program; course influenced their understanding of palliative care; topics of loss, bereavement, and grief changed their ability to care for a dying person. Males more than females: more influenced by topic of how cancer develops. More males requested clinical placement in this area	Unable to generalize due to small sample and 1 school. Findings only related to third-year students Possibility of bias toward palliative care because students self-selected themselves for the course

(continues)

TABLE	Table of Literature, Continued					
Author (Year). Title. Country	Purpose/Research Question(s)	Sample	Intervention	Design/Method	Key Findings	Limitations
Fluharty, Hayes, Milgrom, Malarney, Smith, Reklau, Jeffries, and McNelis[15] (2012). A multisite, multi-academic track evaluation of end-of-life simulation for nursing education. United States	1. Increase students' knowledge from pretest to posttest VKREC instrument 2. Level of students" confidence in caring for dying patients after simulation VSCDP tool 3. Level of students' self-reported communication skills with EOL patients after simulation EOLV communication assessment tool 4. Are students satisfied with learning methodology for EOL issues V satisfaction with instruction method tool	370 Associate, baccalaureate, and accelerated students	Students viewed a voice-over PowerPoint presentation, simulation	Quasi-experimental	Significant increase in knowledge from pretest to posttest (P G .000) associate degree with significantly higher scores (P = .02)	Did not provide data on presentation and simulation separately; self-report instruments; communication and self-confidence only measured after the simulation; reliability and validity of tools not established
Gillan, Parmenter, van der Reit, and Jeong[19] (2013). The experience of end of life care simulation at a rural Australian university. Australia	Report on the evaluation of use of simulation for EOL education	120 Students	EOL lectures before the simulation	Quantitative and qualitative	Themes: linking theory to practice, approaching families of dying patients, an encounter with death, hands-on experience in a protected environment, postsimulation debriefing	Small sample size, some limitations have risen from the simulation itself (realism, nonverbal communication, physical changes)

Hjelmfors, Stromberg, Karlsson, Olsson, and Jaarsma[25] (2016). Simulation to teach nursing students about end-of-life care. Sweden	Increase knowledge about EOL care simulation in nursing education by describing and evaluating the delivery of simulation when teaching third-year nursing students	60 Nursing students, third year	EOL simulation was completed, audio and video recorded	Ethnographic observations on simulations and debriefings	Themes: pain and worries about the family, mother's focus on other things, talking to the mother after the daughter had passed away, the debriefing	Not generalizable

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TABLE	Table of Literature, Continued						
Author (Year). Title. Country	Purpose/Research Question(s)	Sample	Intervention	Design/Method	Key Findings	Limitations
Jo, Doorenboos, and An[12] (2009). Effect of an end-of-life care education program among Korean nurses. Korea	Identify educational effects of an end-of-life program for Korean BSN students	47 RN to BSN students	EOL education program	Quasi-experimental	No statistical significance in suffering experience scores between the groups Significant change in attitude toward death and EOL care performance after the implementation of the program	Small sample, 1 school, 1 program, not generalizable
Lippe and Becker[14] (2015). Improving attitudes and perceived competence in caring for dying patients: an end-of-life simulation. United States	Changes in BSN students" attitudes and perceived competence after exposure to an EOL simulation	118 BSN students (RN to BSN and BSN); three cohorts (19, 53, 56)	Elective course, simulation then in an adult health course	Pretest-posttest design	Cohorts had significantly improved scores on the perceived competence and attitude measures after the simulation	Small sample size, samples were limited by enrollment, most students were high achievers, not generalizable
Kwekkeboom, Vahl, and Eland[13] (2005). Companionship and education: a nursing student experience on palliative care. United States	Provide experiential experience for students and companionship for dying	N = 35, 20 experimental, 15 control	Companionship program = 15 h volunteering at a hospice with dying patients who have no family	Quasi-experimental	Increased attitude about care at EOL Fewer concerns about providing nursing care to dying patients	Small sample They made changes from first to second semester Students self-selected Control group chosen from friends of participants in program Control group chose not to participate

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Kwekkeboom, Vahl, and Eland[17] (2006). Impact of a volunteer companion program on nursing students" knowledge and concerns related to palliative care. United States	Evaluate impact of the palliative care companion program on nursing students" knowledge, attitudes, and concerns about providing palliative care and describe companion students" volunteer activities	N = 52 (32 experimental, 20 control)	Companionship program = 15 h volunteering at a hospice with dying patients who have no family	Quasi-experimental	Attitude scores not analyzed because of poor internal consistency of tool Knowledge change scores did not change Trend toward lower scores in companion group versus control group	Small sample size Fewer control problems with internal consistency of questionnaire Students who participated revealed that they had other experiences that influenced their knowledge and opinions about palliative care

(continues)

TABLE	Table of Literature, Continued						
Author (Year). Title. Country	Purpose/Research Question(s)	Sample	Intervention	Design/Method	Key Findings	Limitations
Liu, Su, Chen, Chiang, Wang, and Tzeng[22] (2011). Facing death, facing self: nursing students" emotional reactions during an experiential workshop on life-and-death issues. Taiwan	Exploring experiences of undergraduate nursing students imagining the possibility of their own death during a workshop on life-and-death issues	N = 20	During a workshop on life-and-death issues, students completed a reflective journal. One of the topics was their own imminent death	Qualitative, exploratory; use of reflective journals and field notes from workshop	Showed that encouraging students to use their imagination to role-play their own demise was successful in helping them take a different viewpoint, express themselves in a new way, and acknowledge responsibility for their own learning	Small sample size Asian nursing students May not be representative of all nursing students No comparison group Convenience sample
Mooney[23] (2005). Tactical reframing to reduce death anxiety in undergraduate nursing students. Australia	Effectiveness of a death education program in reducing anxiety about death in Australian undergraduate nursing students	97 In experimental group, 122 in control	Didactic/experiential course, 13 wk, 39 h for a credited course	Quasi-experimental, nonequivalent control group design	Increase in comparison group's scores was unanticipated. This prompted an inquiry. A subset of the comparison group had intermingled in another course with students in the death education course	No specific limitations listed. One school may not be generalizable outside of Australia. Problem with intermingling of students
Moreland, Lemieux, and Myers[16] (2012). End-of-life care and the use of simulation in a baccalaureate nursing program. United States	Pilot study to evaluate undergraduate nursing students" knowledge and self-efficacy in caring for patients at EOL	N = 14	Simulation in caring for a patient at the EOL	Mixed methods	Student knowledge increased significantly from pretest to posttest ($P = .03$) Self-efficacy increased from pre to post ($P = .05$) Qualitative themes include difficulty changing perspective from cure to care, can see the big picture, "great expectations" conflicts of expectations involved role, performance, self-efficacy, and global experience	Small sample size This authors were unsure if questionnaires were validated not clear in article

TABLE	Table of Literature, Continued					
Author (Year). Title. Country	Purpose/Research Question(s)	Sample	Intervention	Design/Method	Key Findings	Limitations
Tuxbury, McCauley, and Lement[20] (2012). Nursing and theatre collaborate: an end-of-life simulation using forum theatre. United States	Pilot V to evaluate the use of forum theater to teach EOL care to undergraduate nursing students	45 Nursing students V 2 participated, 43 observed	Simulation with live actors as patient and family members. Nursing students provided care	Qualitative and quantitative	61% of students strongly agreed that they feel more confident, and 62% strongly agreed that they learned from observation Qualitative data taken form journals: learned a lot, got more out of it than they anticipated, helpful to learn about EOL	One major limitation is that the morning after the evening simulation, there was a test in another subject, which caused students to divert their attention from the simulation
Wallace, Grossman, Campbell, Robert, Lange, and Shea[4] (2008) Integration of end-of-life care content in undergraduate nursing curricula: student knowledge and perceptions. United States	Provide current state of EOL nursing education in the literature and report on EOL knowledge and experiences in 2 groups of students	111 Undergraduate nursing students (61 = sophomores, 50 = seniors)	Integration of ELNEC content into undergraduate curriculum	Qualitative and quantitative	Qualitative themes: role of nurses in providing palliative care, personal and professional experiences in palliative care, student educational needs regarding palliative care, and perceptions of good and bad death. Quantitative: EOL knowledge increased from sophomore to senior year	None listed 1 school May not be generalizable

Bush and Shahwan-Akl[18] performed a descriptive/ exploratory study on whether completing an oncology and palliative care course aided third-year undergraduate students in Australia in caring for EOL patients. Female stu- dents, more than males, stated that the course increased their understanding of palliative care. None of these studies addressed student knowledge of caring for the family at EOL as part of their research.

Gillan et al[19] used an EOL simulation with Australian prelicensure nursing students to gather quantitative and qualitative data regarding simulation as an educational intervention. The quantitative data consisted of a scale from 1 to 10 on the simulation experience. The quantitative data showed that students enjoyed the simulation and found it valuable. The qualitative data revealed the link between theory and practice by allowing students to practice their skills in simulation. Some students stated that having family members present in the simulation was helpful in approaching family members. Lastly, this was some of the students" first encounter with death, and the students found value in participating in a simulation related to care at the EOL.

Tuxbury et al[20] used a form of simulation, forum theater, to have prelicensure students participate in a death experience. Actors played the roles of the patient and family, and 2 nursing students were the nurses. The students then wrote in a reflective journal about the experience. The authors found that observing the simulation was informative and the discussion after was helpful in determining what to say or do with family members.

Various methods of research were used to evaluate knowledge of EOL. Quantitative and qualitative methods were used to find that education increased the knowledge of EOL and palliative care. Time dedicated to EOL within a course or a stand-alone course proved useful to increase knowledge of EOL and palliative concepts.

Confidence/Competence/Comfort

Three studies used simulation as a teaching method for experiential learning and practice to increase proficiency in caring for dying patients.[14,20,21] All the studies found an in- crease in confidence, competence, or comfort. Education influenced EOL care, and education increased positive attitudes toward death itself and in caring for the dying.

Bobianski and colleagues[21] used a home care simulation and found that, as students reflected on the experience, their comfort with death increased. One major concept that emerged through reflection and discussion was recognizing the family members. The authors also found that culture played a role in students" attitudes and beliefs about EOL.

Lippe and Becker[14] measured perceived confidence and attitude with a presimulation and postsimulation on withdrawal of care. The researchers found a significant increase (P G .001) in perceived competence and attitude

after the simulation. The questionnaire used for perceived competence may not have been a valid and reliable tool. Psychometric information was not available, and the tool was designed before this study.

Tuxbury and colleagues[20] used a forum theater concept where 1 student simulated the nurse and actors played the patient and family. The remainder of the students watched the simulation unfold on stage. The students wrote reflective journals regarding the simulation in addition to an evaluation of the simulation. The authors found that 61% of students felt more confident after viewing the simulation.

Three studies found that there was an increase in com- fort, confidence, or competence after an intervention. Two of the studies used simulation whereas the third used forum theater where a few students acted out the situation and the remainder of the students observed. All 3 studies gathered preintervention and postintervention data. Experiential learning was present in all 3 studies and lends credibility for learning this material.

Other Concepts

Two studies addressed other concepts related to educating prelicensure nursing students on EOL care.[22,23] Liu et al[22] performed a qualitative study in Taiwan that used a work- shop for students to address their own demise. The re- searchers felt that, to become more comfortable with death and take more responsibility for their own learning, they must look at their own death. The

authors analyzed the reflective journals from the students and found that there was increased awareness of other viewpoints, with students stating they can better express themselves in a new way. This study could have been integrated into the mentioned category, but the method was more dramatic and needed to be discussed separately.

Mooney[23] developed a 13-week course in Australia and found that unexpectedly both the experimental and control groups had a decrease in anxiety about and toward death. After further inquiry, it was found that many of the students in the control group had an experience related to this topic in another course.

DISCUSSION

The literature review establishes that there are multiple factors involved in the education of nursing students in EOL care. The literature reveals that an educational intervention can increase a nursing student's attitude regarding EOL care. A positive attitude can affect the care delivered at EOL. Age and experience are 2 factors that influence attitudes about EOL, whereas sex and degree program do not seem to alter attitudes. The method of education also does not seem to be significant, as students

learned from lecture, simulation, and other interventions.

Multiple methods of education delivery have all shown to increase nursing students" knowledge about EOL care. Different educational methodologies have been implemented, and pretest and posttest show an increase in knowledge. Degree program also does not have an effect on knowledge acquisition.

As knowledge and attitude increase, self-confidence rises and the student feels more competent and more comfortable with EOL. Several methods of education were used to instill confidence. All of the research used in this literature review used some form of experiential learning to increase the confidence, competence, and level of comfort in student nurses.

CONCLUSION

End-of-life education is essential for nursing students. This education increases nursing students" attitudes, knowledge, and confidence regarding EOL care. Experiential methods of EOL education have been successful in increasing attitudes, knowledge, and confidence of students. There seems to be a lack of education, however, regarding families of dying patients. Few studies mentioned aware- ness of family or how students should speak with them, and not 1 study mentioned any education specific to care of family members for nursing students. The area of care of families of dying patients requires more research particularly how best to teach nursing students to care for these families. In addition, many studies were not performed in the United States. Because health care differs among countries, the care delivered may also vary. A recommendation for future research in the United States should be investigating educating nursing students on caring for the families of dying patients.

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Chapter 5

Manuscript 2

Qualitative Exploration of Perceptions of Nursing Undergraduates

Regarding Family Care at End-of-Life

Penny A. Alt-Gehrman, PhD, RN

Aimee Woda, PhD, RN

Susan Breakwell, DNP, RN

Kristin Haglund, PhD, RN

Abstract

For many nurses, caring for families at the end of life is stressful. Many nursing students do not feel prepared to provide family care at end-of-life. The purpose of this qualitative study was to elicit perceptions of family care at end-of-life from undergraduate nursing students. Junior and senior nursing students in focus groups identified their perceived needs, challenges, and facilitators of family care at the end-of-life. Four themes were identified: feeling unprepared, importance of communication, experience increases comfort and confidence, and families' emotional responses can be challenging. The data from this study can be used to develop end-of-life curriculum and learning activities to provide the education needed to make nursing students, and subsequently nurses, more comfortable providing family care at end-of-life.

Background

For many nurses, caring for families of dying patients can be stressful (Boyle, 2015; Chitra, 2011; Douglas, 2010; Melvin 2012). Many nurses do not feel prepared to care for families of dying patients despite having had some content on end-of-life (EOL) care during their nursing education (Cronin et al., 2015; Kurz & Hayes, 2006; Schlairet, 2009; Wallace et al., 2009). Research has been performed on nurses as it relates to caring for dying patients, but there is limited research involving family care at end-of-life. On one hand, not feeling prepared to provide family care at end-of-life often leaves nurses feeling that they could or should have done something more to help patients and families (Main, 2002). On the other hand, feeling prepared and comfortable providing family care at end of life engenders a positive attitude, which in turn can improve end-of-life care for both patients and families (Dunn, Otten, & Stephens, 2005; Kurz & Hayes, 2006). Effective nursing care at end-of-life care contributes to peaceful deaths and needed emotional support for families (Bloomer, Morphet, O'Connor, Lee, & Griffiths, 2016; Heidari & Norouzadeh, 2014).

Some research has been conducted with families of dying patients to determine their expectations for nursing care. Families of dying patients expect and need competent nursing care (Beckstrand, Lamoreaux, Luthy, & Macinstosh, 2011; Bloomer et al., 2013; Cronin, Arnstein, & Flanagan, 2015; Heidari & Norouzadeh, 2014). Families have reported that the most important action of nurses was to provide family support including death with dignity, facilitation of visitation, value orientation, and helping prepare them for distress (Heidari & Norouzadeh, 2014). Other important interventions for families

were to attend to cultural differences, provide privacy for patients and families, provide explanations, and extend condolences (Heidari & Norouzadeh, 2014).

Currently there is little research on nursing students and end-of-life care, with no research focused on the families of dying patients. Many nursing students reported feeling unprepared to care for families of patients at the end-of-life (Boyle, 2015; Glover, Garvan, Nealis, Citty, & Derrico, 2017; Henson, 2017; Kelly, Runge, & Spencer, 2015). When nursing students are not prepared to care for the families of dying patients, poor outcomes may occur for the nursing students as well as the families.

Effective and adequate preparation of nursing students to deliver family care at end-of-life may lead to more positive attitudes towards providing family care at end-of-life, which can carry over into the careers of practicing nurses. Nurses with positive attitudes toward death and the dying have been shown to provide better nursing care and improve patients and their families' experiences at end-of-life (Bailey & Hewison, 2014; Dunn et al., 2005; Kurz & Hayes, 2006). The purpose of this study was to investigate what nursing students perceived as their needs, challenges, and facilitators to providing competent end-of-life care to families, friends, and significant others of dying patients. The results of this study may be used to suggest curricular revisions and activities that fill gaps regarding family care at end-of-life.

Theoretical Framework

The theoretical framework underpinning this study is Mezirow's Theory of Transformational Learning. This framework was chosen because it correlates well with the process of this study: to gather the perceptions of students with the next step being to recommend curricular changes. Transformative learning discerns between learning

objectives and the ultimate goal of learning: to become an autonomous and socially

responsible thinker (Grabove, 1997). This theory is based on constructivism, which

emphasizes that meaning exists within ourselves rather than in the external world

(Cranton & Taylor, 2012).

Method

This study used a qualitative descriptive method with focus groups to gain a better

understanding of the perceptions of undergraduate nursing students regarding family care

at end-of-life. Data were collected using focus groups with undergraduate nursing

students who were currently in a hospital based clinical course.

Participants/Setting/Recruitment

After receiving IRB approval junior and senior nursing students were recruited

from a small, private, faith-based, women's college via email invitation. Students had

had at least one acute care clinical rotation with adult patients, which increased the

likelihood that they or their classmates had cared for a dying patient and their family.

Recruitment began by attending classes in which the volunteer pool was enrolled. The

purpose of the study and the methodology were presented and questions were answered.

The schedule of the focus groups was presented and volunteers were asked to sign up to

attend a focus group. From 125 eligible participants, 19 agreed to participate.

Data Collection

Eleven sessions were conducted with a total of 19 participants. Eight of the

sessions had only one participant, one session had six, one session had three, and one

session had two. After all participants arrived, the aims of the study were reviewed, the

consent was obtained, and handouts with resources were given to all participants.

Once consent was obtained sessions were recorded. The Primary Investigator (PI) read a statement to frame the context of the discussion and asked if all were ready to begin. After all participants communicated readiness the interview began. A professional transcriptionist transcribed each audio recording verbatim.

Data Analysis

Thematic analysis was used in this study as the method of analyzing the qualitative data. Thematic analysis is a multi-phase process that begins with a line-by-line coding followed by the evolution of descriptive themes (Thomas & Harden, 2008). In this study, analysis consisted of a multiple step process to code and interpret the data requiring the researcher to delve into the data, make connections, and interpret the information provided by the participants (Clark & Braun, 2013; Joffe, 2012; Sandelowski, 2000; Sandelowski, 2010). As with most qualitative research, analysis began immediately with the first session. Analysis continued throughout the data collection process.

The seven-step process outlined by Clarke and Braun (2013) was used. Step one was to transcribe the data into written text. After transcription, the transcripts were entered into Dedoose© in their entirety immediately. Step two was reading and familiarizing. In this step, the researchers read and re-read the transcripts and began to notice points of interest. Step three was coding. There were no preconceived codes, all codes were identified from the data. The transcripts were read initially, then re-read and the codes came from the data. As subsequent transcripts were transcribed and entered into Dedoose©, they were also coded and the previous transcripts reviewed for any new codes that emerged from the new transcript. After each successive session was added

and coded, the primary researcher compared the codes from each session to the other sessions. Step four was searching for themes. The PI reviewed the codes and grouped codes together to create the themes. The PI reflected on whether the codes told the story about the data and made a relationship with the theme. Step five was reviewing themes. In this step, the PI reviewed the themes and the codes and determined if the story was told. This was considered the quality control step of the process. Step six was defining and naming themes by stating what was specific and unique about each theme. Each theme had its boundaries set and a few sentences to describe them. Step seven was writing the report. Cogent and powerful examples were chosen to support each theme (Clark & Braun, 2013).

After the PI coded the transcript, two co-researchers coded transcripts. The codes from all three were compared and contrasted to find that the codes were consistent. The remaining researcher entered the process after the initial coding and theme development was completed. As suggested by Cote-Arsenault (2013), analysis will include an across code and theme comparison. This can confirm and validate the results and imply transferability (Cote-Arsenault, 2013). This contributed to rigor.

Four themes emerged from the data. Themes included, *feeling unprepared, importance of communication, experience increases comfort and confidence*, and *families' emotional responses can be challenging.* Each theme will be discussed below.

Results

Nineteen undergraduate students participated in the study. Ages ranged from 20-36 years of age, mean age was 27.16 years. Fourteen participants were Caucasian (74%), three were Hispanic, one Asian and one student was African American. There was a

fairly even distribution of level of students. About one third of the participants had a previous degree. Most of the participants currently worked in health care with approximately three to five years of experience.

Feeling Unprepared

Most participants voiced that they did not feel ready to provide family care at end-of-life. The few that reported feeling prepared, stated that their work experience contributed more to their readiness than their education. One participant stated, "first of all, it is never going to be easy" while another stated, "no amount of reading can prepare you" for providing family care. Lack of experience and practice with dying patients and their families contributed to feeling unprepared. Most participants stated that they did not know what to say or do when caring for the family of a dying patient. One participant said "I offer coffee and a chair, but mainly focus on the comfort cart." The participants also stated that they did not feel that they learned enough in their nursing education to feel prepared. They mentioned that they learned a lot about communication, such as how to actively listen, how tone can imply an emotion, such as anger, and how non-verbal communication can be viewed by others. They also mentioned knowing the physiologic changes of dying patients. Some stated that they felt better prepared to care for the dying patients rather than the families.

Another participant summed it by stating "lack of experience and the unknown I think are definitely about that [care of the dying] and the- your own experiences really all contribute to the fear and unpleasantness of interacting with the families that are losing somebody." Participants perceived that feeling under-educated on family care, contributed to having a fear of the unknown. When asked, "What are some challenges of

family care at end-of-life?" many participants noted that the range of emotions the family might have would be difficult to confront. Several mentioned that they were "sympathetic criers" and they cried when they were with others who were crying. Those participants felt that the nurse would not be as effective if he/she was also crying.

Importance of Communication

During each session, participants revealed that communication was an important part of caring for families. In addition, knowing what to say in this difficult time was reported as the most important. Many participants stated that they did not want to say anything that would make the family more upset. Participants noted that communication was more encompassing than only speaking; listening was also a vital part of communication. Many participants in multiple sessions mentioned that listening to families and patients was very important. If the nurse listened to the family, he/she would understand what the family needed and would be able to care for them more effectively. A related aspect that emerged was that nurses needed know the available resources within the facility as well as outside of the facility. If the nurse was knowledgeable regarding resources, he/she could refer or suggest a resource without having to take time to look for the appropriate resource. The participants acknowledged that it might take some time to learn the resources. Some participants stated that there should be a resource list at all facilities, if there were not currently available.

Experience Increases Comfort and Confidence

Comments about being comfortable and having confidence in providing family care arose in all sessions. The participants discussed that the only way to obtain comfort and confidence was through practice and experience. One participant worked in a

hospice environment and two worked in an ICU environment as nursing assistants. Those participants reported feeling more confident and comfortable than the others due to their experiences at work and observing the nursing staff. Participants in all groups discussed that some practice with family care at end-of-life during their education would greatly benefit their nursing careers. Suggestions included a clinical assignment in hospice, role playing, or a simulation. Even in clinical assignments not in hospice, participants felt that when there was a dying patient on the unit, the clinical faculty did not assign that patient, thus decreasing the potential for exposure and experience.

Participants in several groups suggested that a simulation where the mannequin was the patient and actors played the family would be beneficial. In a few groups that did not specifically mention a simulation, the moderator told the participants that other groups had suggested a simulation. There was a positive reaction to the idea of participating in a simulation by all except one participant who stated "I'm not very excited about sim, but maybe in this situation it would be like social interaction practice. I think that would be helpful too." In one group, the participants became very excited and provided suggestions for topics that could be included in the simulation. Details such as one family member could be crying during the simulation and the students would have practice with consoling them. Another family member could be angry and argumentative. The participants suggested that there be family members exhibiting different stages of grief. The participants suggested that this would give them practice and experience, but also reinforce the stages of grief. The participants also suggested that some family members could disagree with the treatment of the patient. For example, in a simulation, one family member might feel that the patient should be a full code where

another family member might feel that they should be a no code. This situation would allow the participants to mediate the family and provide information.

Families' Emotional Responses Can Be Challenging

In most groups, participants discussed the range of emotions that might be felt and exhibited by families such as anger, disagreements with the patients' treatment plans, depression, and crying. Anger was one emotion that most participants did feel a little better prepared to deal with. "Families can get angry and become rude or aggressive," said one participant. Most participants stated that anger is part of the grieving process. The participants did not have any suggestions of how to deal with anger. The participants stated that anger is part of the grieving process, but reported feeling unprepared to deal with another person's anger.

Several expressed that crying families would make them cry. One participant stated, "I don't want to cry in front of them if I am trying to help them." Several participants reported that this was not an easy emotion with which to deal. The consensus was that more experience and practice would help nursing participants to learn how to accept families' emotions and support them through painful experiences.

Disagreements among family members concerned several participants. One participant stated "if you have all of these people making decisions and none of them are the same" it is difficult to know the wishes. Another participant stated, "who do you listen to" when a decision needs to be made. In one session, participants discussed the possibility that family members might disagree with one another on treatment or care of the patient. Participants stated that they did not know how to address a family in disagreement.

Discussion

This study supports previous findings that nursing students did not feel prepared to provide family care at end-of-life (Alt-Gehrman, 2017; Boyle, 2015; Glover et al., 2017; Henson, 2017; Kelly et al., 2015). It is important that nursing students know the basics of providing family care at end-of-life so they might be better prepared to deliver this care when they are nurses. Communication has been mentioned in this study as in others (Bloomer et al., 2016; Heidari & Norouzadeh, 2014) as a key educational topic. Communication was the number one theme in a qualitative study of the next-of-kin (Boucher, Bova, Sullivan-Bolyai, Theroux, Klar, Terrian, & Kaufman, 2010). Communication was also a prominent theme in the qualitative study on family members' perception of most helpful interventions (Cronin et al., 2015). Families desired communication that included information on patients' progress and course of illnesses (Boucher et al., 2010; Cronin et al., 2015; Heidari & Norouzadeh, 2014). Nursing education must include topics such as communication, listening, and provide practice and opportunities to acquire experience.

The instruction should also instill the qualities that are needed, such as honesty, empathy, and a positive attitude toward caring for the dying and their families. Adequate preparation, knowledge, and knowing resources are associated with challenges as student nurses must have knowledge to answer questions and give information to families. Learning the resources of the facility and the area are also essential. Nursing education can include some generalities regarding resources; however, each facility will have some specific resources that must be learned after employment. Participation in simulation has

been shown to improve the attitude, increase knowledge, and increase comfort and confidence in providing care to the dying patient and their family (Alt-Gehrman, 2017).

End-of-life education improves nursing students' attitudes, knowledge, and confidence regarding EOL care (Alt-Gehrman, 2017; Schlairet, 2008; Wallace et al., 2008). Experiential methods of EOL education have been successful in increasing attitudes, knowledge, and confidence of students (Alt-Gehrman, 2017; Edo-Gaol, Tomas-Sabado, Bardollo-Porras, & Monteforte-Royo, 2014). By providing additional practice and experiences for nursing students through practice in the classroom or simulation center, may increase confidence and comfort. Practice can be via role-playing, case studies, or simulation. All of these methods have shown success (Alt-Gehrman, 2017).

Practice and experience with dealing with emotional family members will increase nursing students' comfort and confidence. As mentioned above, role-playing, case studies, or simulation may better prepare nursing students to know how to handle emotional patients. The participants in this study suggested practice and experience, whether that practice be simulated or actual in a clinical setting.

Nursing faculty need to know about family care and be more comfortable with assigning dying patients and their families to students in clinical courses. Education for the faculty could be implemented in order to provide nursing students experiences in family care at end-of-life. The faculty should be comfortable with death and dying prior to supervising students who could be caring for a dying patient and their family at any time during the clinical course.

Implications for Nursing Education

There are several implications for nursing education. Nursing programs need to incorporate end-of-life care of the patient and the family into curricula. The End-of-Life Nursing Education Consortium (ELNEC) (2017) offers a pre-written curriculum can be utilized in nursing schools. The core curriculum can be used in full or in part to educate nursing students on end-of-life care. Specialty curricula are also available. Literature has been written on how to integrate end-of-life concepts into nursing curricula (Alt-Gehrman, 2017; Barrere, Durkin, & La Coursier, 2008; Bobianski, Aselton, & Cho, 2016; Lippe & Carter, 2015; Smith-Stoner, 2009). The CARES document from AACN also supports this conclusion (AACN, 2016). This study revealed that all nursing students should be educated on basic end-of-life care. Nursing education programs are the logical place to provide this education. The participants in this study agreed that the information should be reinforced in the working environment, especially if the unit does not have many dying patients and families.

There appears to be some work to do in the area of family care at end-of-life. Educating students on what family care entails with practice is needed prior to graduation. Additionally, faculty training may be needed regarding how to facilitate student learning in regards to family care at end-of-life. It was clear that participants in this study did not feel that they were comfortable or confident caring for families. Students need to practice their communication and listening skills in order to feel more confident in providing family care at end-of-life.

Potential policy changes may be needed to ensure that all nursing programs teach EOL concepts, including family care. Setting standards for EOL care in nursing curricula

would ensure that the information has been imparted. Also, to integrate more opportunities for practice and gaining experience would benefit nursing students.

Limitations

As with any study several study limitations were noted. A small sample size from one college that lacked diversity was utilized. All participants were enrolled in an undergraduate nursing program, so the results may not be generalized to associate degree, degree completion, or accelerated degree programs. The study was conducted in a large Midwestern city, so the results may not be relevant to a small city or another area of the country.

Conclusion

This study sought to render a greater understanding of undergraduate nursing students' needs, facilitators, and challenges to providing family care at end-of-life. Participants expressed that they did not feel prepared to provide family care at end-of-life. The key findings included the need for end-of-life education but more importantly, the need for practice and experience in providing family care at end-of-life. Participants suggested role-playing, case studies, clinical placements, and simulations to obtain practice and experience. These results suggest the nursing programs need to develop curricula to include practice and experience for students to increase the comfort level when providing family care.

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Appendix A

Consent Form
MARQUETTE UNIVERSITY
AGREEMENT OF CONSENT FOR RESEARCH PARTICIPANTS
A Qualitative Exploration of the Perceptions of Caring for Families of Dying Patients in
Undergraduate Nursing Students

Penny A. Alt-Gehrman, MSN, RN

Marquette University, College of Nursing

You have been invited to participate in this research study about caring for the families of dying patients. Before you agree to participate, it is important that you read and understand the following information. Participation is completely voluntary. Please ask questions about anything you do not understand before deciding whether or not to participate.

PURPOSE: The purpose of this study is to investigate what nursing students perceive their needs, challenges and facilitators to providing competent care to families, friends, and significant others of dying patients. The results of this study will be used to design curriculum that fills the gap regarding caring for dying patients and their families.

PROCEDURES: You will be asked to participate in a focus group style interview. The researcher will ask a few questions and invite you to tell your story on this topic. The interview will audio recorded, then transcribed and analyzed. Demographic data will also be gathered. All information will be de-identified and your faculty will not have access to this information. Participation will not affect your grade in your classes in any way.

DURATION: Your participation will consist of one focus group lasting approximately one hour.

RISKS: The risks associated with participation in this study are no greater than you would experience in everyday life. Your faculty does not have access to this information. Your grade will not be compromised or accentuated. You may have an emotional reaction to some of the questions due to the nature of the topic. A list of resources will be made available to you following the focus group.

BENEFITS: There are no direct benefits to you for participating in this study. This research may benefit other nursing student in the future.

CONFIDENTIALITY: All information you reveal in this study will be kept confidential. All your data will be assigned an arbitrary code number rather than using your name or other information that could identify you as an individual. Interviews, notes, transcription, and codes/themes will be saved on a password protected computer and/or in a locked file cabinet in a locked office for the duration of the study. When the results of the study are published, you will not be identified by name. Audio files of the

recorded interviews will be maintained on a password protected computer and deleted at the completion of the study. Transcribed interviews will be de-identified and stored electronically indefinitely. Consents will be stored in a locked file and destroyed in five years. Your research records may be inspected by the Marquette University Institutional Review Board or its designees, and (as allowable by law) state and federal agencies.

VOLUNTARY NATURE OF PARTICIPATION: Participating in this study is completely voluntary and you may withdraw from the study and stop participating at any time without penalty. You may simply ask to no longer continue without any explanation as to why you no longer wish to continue.   If you opt out, your information will not be used for the study.

CONTACT INFORMATION: If you have any questions about this research project, you can contact Penny A. Alt-Gehrman at 414-651-9452 or penny.alt@marquette.edu. If you have questions or concerns about your rights as a research participant, you can contact Marquette University's Office of Research Compliance at (414) 288-7570 or orc@mu.edu.

I HAVE HAD THE OPPORTUNITY TO READ THIS CONSENT FORM, ASK QUESTIONS ABOUT THE RESEARCH PROJECT AND AM PREPARED TO PARTICIPATE IN THIS PROJECT.

_____
(Printed Name of Participant)

_____   _____
(Signature of Participant)   Date

_____
(Printed Name of Individual Obtaining Consent)

_____   _____
 (Signature of Individual Obtaining Consent)   Date

Appendix B

Information sheet for participants

Dear Student,

You are invited to participate in a qualitative study on your perceptions of what is needed to care for the families of dying patients. This study is part of the doctoral studies of Penny A. Alt-Gehrman, MSN, RN at Marquette University. Through participation, you will assist in determining what undergraduate nursing students needs are when caring for the families of dying patients. You have been asked to participate in this study as you are the target population of the study. The information will be gathered in focus groups of no more than eight persons.

To be considered for this study, you must have enrolled in N375, N455, or N470. Participation is voluntary and you would be able to opt out at any point if you so desire. Participation is confidential. Your name will only be known to the researcher. You will be assigned a number and your focus group transcription will only be associated with a group number. An informed consent is required in order to participate. The focus groups will take approximately one hour and will consist of you answering a few questions and discussing your thoughts and needs. The interview will be audiotaped for accuracy of your information.

The study has been approved by the Marquette University Institutional Review Board. If you have any questions or concerns, please feel free to contact me vie email (penny.alt@marquette.edu) or phone (414-651-9452). If you chose to participate, the researcher will only then contact you by phone. If you have any questions or concerns regarding your rights or participation in this study, please contact Marquette University's Office of Research Compliance at 414-288-7570.

Thank you for your consideration of participation in this study.

Sincerely,

Penny A. Alt-Gehrman, MSN, RN
Marquette University Doctorate Student

Appendix C

IRB Form

Human Research		**Protocol #:**
	MARQUETTE UNIVERSITY	**ORSP #:**
		Sponsor Tracking #:

Institutional **R**eview **B**oard

Protocol Summary Form

Directions: Complete the form. Contact orc@mu.edu with any questions or if you would like feedback on a draft of your protocol prior to IRB review.

Type of Review being sought: Exempt ☐ Expedited ☒ Full Review ☐

Principal Investigator (PI): *Penny A. Alt-Gehrman*

Department: *Nursing*

Phone: *414-651-9452*

E-mail: *penny.alt@marquette.edu*

Project Title: *A Qualitative Exploration of the Perceptions of Caring for Families of Dying Patients in Undergraduate Nursing Students*

PI Certification

By submitting this document, I agree to accept primary responsibility for the conduct of this project as approved by the IRB. The project cannot begin until I receive documentation of IRB final approval.

 Penny A. Alt-Gehrman   11/4/15

Principal Investigator Name   Date

FOR STUDENTS, a Marquette faculty member must supervise your project. By agreeing to serve as faculty supervisor for this project the Marquette faculty member listed below agrees to review the research plan before submission and provide ongoing supervision and guidance for the project to ensure compliance with human subject research guidelines.

Kristin Haglund, PhD, RN   College of   Faculty Supervisor
                                            Nursing   Name

                                                                          Faculty

Supervisor Department

Please note that in order to choose any of the check boxes on this form, you must double click the box and select "Checked" as the Default Value

Section A: RESEARCH PROJECT CHARACTERISTICS

1. This is a:

☐ Research Proposal

☒ Thesis/Dissertation

☐ Class Project (list Dept. & Course #)*:*

   ☐ Other (specify)*:*

2. Grant or Contract Funded: ☐ Yes   ☐ Funding is Pending   ☒ No

Sponsor/Source of funding*:*

If external funding, have you registered your project with Research and Sponsored Programs (ORSP)? ☐ Yes   ☐ No

---

Submission Instructions: Email this completed form and any supporting documents including consent forms,

information sheets, surveys, interview questions, etc. as attachments to orc@mu.edu with the following subj

line:

New Study Submission for [first and last name of PI]

- In the body of e-mail, include the title of the study and an itemized list of attachments.
- The email address of the sender must be the Principal Investigator's Marquette email.
- If the PI is a **student**, the faculty advisor **must** be cc'd.

Once submitted, the IRB will e-mail back a response of receipt. If you do not receive an e-mail confirmation o

submission within 3-5 days of submission, please contact the IRB by phone (288-7570) or email (orc@mu.edu

If Yes, Please list your ORSP Reference #*:_____*

If your project is grant funded, submit a copy of the funding/grant proposal and list the AGENCY GRANT NUMBER*:_____*

If the project title listed on page 1 of this application is different from your grant title, list the grant title:_____

If the funding agency requires an official IRB approval letter or form, list the program area, contact person, title and complete mailing address*:*

3. Does the investigator or key personnel have a potential financial conflict of interest in this study that should be disclosed?

☐ Yes   ☒ No   If Yes, Please explain*:*

4. PI Status:

☐ Undergraduate

☒ Graduate

☐ Faculty/Administrator

☐ Other (specify)*:*

5. Provide the names, titles and affiliations of **all** investigators (include yourself, co-Pis, other investigators, and students). Please use an attachment if more space is required.

OHRP interprets an "**investigator**" to be any individual who is involved in conducting human subjects research studies. Such involvement includes:

- obtaining information about living individuals by intervening or interacting with them for research purposes;

- obtaining identifiable private information about living individuals for research purposes;

- obtaining the voluntary informed consent of individuals to be subjects in research; and

- studying, interpreting, or analyzing identifiable private information or data for research purposes.

Note that any collaborative work with another institution will require the submission of that institution's IRB approval letter.

Name	Institution	Status (Faculty, Grad., Undergrad., etc.)	Project Role (Co-PI, Key or Non-Key Personnel, Consultant, etc.)	Contact e-mail	Tutorial* (Attached or On File w/ MU ORC)
Penny A. Alt-Gehrman	MU and Alverno College	Graduate student	PI	penny.alt@marquette.edu	
Kristin Haglund	MU	Faculty	Co-PI	kristin.haglund@marquette.edu	
Susan Breakwell	MU	Faculty	Co-PI	susan.breakwell@marquette.edu	
Aimee Woda	MU	Faculty	Co-PI	aimee.woda@marquette.edu	

*Please note that Training Certificates are required for all human subject investigators. Certificates can be obtained by visiting http://phrp.nihtraining.com/users/login.php and completing the IRB Tutorial Designed by the National Institute of Health. Copies of Training Certificates are to be forwarded to the Office of Research Compliance.

6. Do you wish to have this project considered for Exempted Review?

☐ Yes   ☒ No   (See Submission Requirements on ORC web site for definition and list of categories)

If Yes, identify the Exemption category number you believe covers your project*:*

☐ Category 1   ☐ Category 2   ☐ Category 3   ☐ Category 4   ☐ Category 5   ☐ Category 6

Explain your basis for this level of review here*:*

7. Do you wish to have this project considered for Expedited Review?

☒ Yes   ☐ No   (See Submission Requirements on ORC web site for definition and list of categories)

If Yes, identify the Expedited Review category number you believe covers your project*:*

☐ Category 1   ☒ Category 2   ☐ Category 3   ☐ Category 4   ☐ Category 5   ☐ Category 6   ☐ Category 7

Explain your basis for this level of review here*:*

   8. Inclusive dates of Project: (Project may not start prior to approval)

From*: **IRB Approval Date**   To*: **August 15. 2018 or before for completion***

   9. How long is the active involvement of participants in the study? (e.g. six half-hour sessions over six months)*: **Students will participate in one focus group. Anticipated time of focus group is one hour.***

   10. Research Location: Where will the research be performed (if not on campus, please provide the full address; if online, please indicate online)*?*

Alverno College

Note: If the research will be conducted in a school or institution other than Marquette University, include a letter, on letterhead stationery, of permission from that institution and/or its IRB. This letter must be received by the ORC prior to IRB approval.

   11. What do you intend to do with the data collected?

☒ Publish paper   ☒ Present at conferences/meetings

☐ Other (please describe)*:*

Section B: SUBJECT RECRUITMENT

   12. Indicate which of the following specially protected groups will be specifically targeted as research participants in this study (Check all that apply):

☐ Pregnant Women/Fetuses ☐ Children (minors under 18)   ☐ Prisoners

☒ None of These

13. Indicate which of the following potentially vulnerable populations will be specifically targeted as research participants in this study (Check all that apply):

☒ College Students* ☐ Institutional Residents   ☐ Cognitively Impaired

☐ Physically Disabled   ☐ Terminally Ill   ☐ None of These

*If using Marquette students, please consult HRP Policy 98.102 Participation of Students and Employees in Research (http://www.marquette.edu/researchcompliance/human/documents/HRPolicy98.102-StudentsEmployees.pdf)

14. Will both genders have an equal opportunity to participate as subjects in this research project?

☐ Yes   ☒ No   If No, explain your answer*: **Alverno College is a women's college.***

15. Will subjects of different racial and ethnic consideration have an equal opportunity to participate in this research project? ☒ Yes   ☐ No   If No, explain your answer*:*

16. How many subjects will be recruited into your research project as justified by the hypothesis and study procedures?

a) Total number of subjects required to complete your study*:   **50 or until saturation***

How was this number determined? If a power analysis or other method was used, please include this in your response: No power analysis as this is a qualitative study.

b) Total number of subjects to be recruited (to account for drop out, etc.)*: **64***

c) Explain the reason for difference between (a) and (b) above (e.g. past studies have shown that there is a 50% drop out rate for students, the study is longitudinal and a drop out rate of 30% is anticipated)***:***

Estimated number for saturation is 50. There will be 8 focus groups with a maximum of 8 per group.

Please Note: If at a later time it becomes apparent that you need to increase your sample size, you will need to submit an IRB Protocol Amendment Form, including your justification for additional subjects.

   17. What is the age range of subjects (please provide a specific range)***? 18 and above***

   18. What is the source of the subject list***? Class lists for clinicals in the junior and senior year***

   19. Who will contact the subjects (name and affiliation)***? The PI***

   20. How will subjects be contacted? (Check all that apply)

☐ Advertisements*****   ☐ Letters*****   ☐ Notices*****

☐ Telephone Lists   ☐ Student Pool   ☐ Random Telephone Dialing

☒ Direct person-to-person solicitation   ☒ E-mail*****

☒ Other (please specify)***: The PI will come to class to ask the students to participate***
   ☐ University News Briefs*****

* A copy must be submitted for IRB approval. For letters, notices, advertisements, and others, submit verbatim copies.

   21. Data collection methods: (Check all that apply and **provide copies of all tools**)

☐ Questionnaire or Survey**[1]** ☒ Observation**[4]**   ☐ Interview

☐ Archival Data**[2]**   ☐ Intervention   ☐ Video Recording**[3]**

☐ Instruction/Curriculum   ☒ Focus Groups   ☒ Audio Recording**[3]**

☐ Testing/Evaluation   ☒ Other (please describe)***: demographic form***

[1] If conducting an online survey, consult the University's Online Survey Policy (http://www.mu.edu/upp/documents/upp1-22.pdf)

[2] **If using archival data, describe in the Narrative section (question 48) whether data are de-identified.**

[3] **If you select video and/or audio recording, please provide further explanation in the Narrative section (question 48) regarding confidentiality of the recording(s).**

[4] **If you select observation, please provide further explanation in the Narrative section (question 48) regarding who you plan to observe, where you plan to observe (public or private location), and the type of data you will be collecting.**

NOTE: If data collection tools are provided in a language other than English, provide both the English and non-English versions.

22. If deception or experimental manipulation is used, please explain why it is necessary (as opposed to convenient) for this study. Include plans for how and when subjects will be debriefed and attach a copy of your debriefing sheet, if applicable*: No intervention or experimentation*

23. Does any part of this activity have the potential for coercion of the subject (for example, a student being recruited by a teacher who controls his or her grade may feel coerced)?   ☐ Yes   ☒ No

24. If Yes, explain and describe the proposed safeguards*:*

Note*:* If you are planning to recruit Marquette employees or students, consult the HRP Policy regarding Participation of Students and Employees in Research (http://www.marquette.edu/researchcompliance/human/documents/HRPolicy98.102-StudentsEmployees.pdf)

Section C: CONSENT OF RESEARCH SUBJECT

25. What type of consent will be used? **You must attach a clean copy that will receive the IRB approval stamp. Consult the ORC website for the consent form instructions and <u>required</u> template.**

☒ Written Consent   ☐ Waiver   ☐ Online Consent

☐ Oral Consent   ☐ Information Sheet ☐ Parent Permission & Child Assent

☐ Guardian Permission & Adult Assent   ☐ Other (please describe)*:*

26. If you are requesting a waiver of informed consent, address each of the following:

a) The research involves no more than minimal risk to the subjects;

b) The waiver will not adversely affect the rights and welfare of the subjects;

c) The research could not practicably be carried out without the waiver; and

d) Whenever appropriate, subjects will be provided with additional pertinent information after participation.

Considering the above requirements for a waiver of informed consent, please describe how your research qualifies for this waiver*:*

27. Do you intend to use an informed consent document in a language other than English?

☐ Yes   ☒ No   If Yes, provide both the English and non-English versions.

All of the students speak English.

28. If you are using an oral consent, describe the rationale, how it will be documented, and include a copy of the oral presentation; it must include all information required of written informed consents*:*

Section D: CONFIDENTIALITY

29. Where specifically will consent forms be kept (building location, room #, please include full address if off campus) **AND** who will have access*? Forms will be in a locked file cabinet drawer in a locked office.*

30. How will research subjects be identified in the research data (by name, code, number, etc.)*? Each participant will complete a demographic form that will have no names, only a number.*

31. At any time during your research will a direct link exist between collected data and research subjects? (i.e. participants' data can be directly linked to their name). For example, data collection sheet has a location for participant's name to be recorded.

☐ Yes   ☒ No

At any time during your research will an indirect link exist between collected data and research subjects? (i.e. participants' data can be indirectly linked to their name.) For example, data collection sheet has a location for subject number to be recorded. In addition, a spreadsheet exists that links that subject number to a participant's name. Many multi-session and longitudinal studies use indirect links.

☐ Yes   ☒ No

If either of the two above questions are answered "yes," please describe the provisions for security of any links*:*

32. When data results are reported/disseminated:

Will identifiers be used (for example: participant's name will be published in article)? ☐ Yes   ☒ No

Will it be presented in aggregate form (For example: Group characteristics only=Yes, Individual Quotations=No)?

☐ Yes   ☒ No

33. Will research data (raw data) be available to anyone other than the IRB, sponsor and study personnel?

☐ Yes   ☒ No

If Yes, who will this data be shared with, describe how the data will be safeguarded, and be sure to include this information in the consent form (if applicable)*:*

34. Describe how research records, data, electronic data, **(including deidentified data)** etc. will be stored (i.e. locked file cabinet, password protected computer file, etc.) **AND** for how long (research records must be maintained a minimum of 3 years; if kept indefinitely, please state this and indicate it on the consent form)*: paper demographic forms will be kept in a locked file cabinet in a locked office until publication. Recordings will be kept on a password protected qualitative data analysis program on a password protected computer. Recordings will be erased from the portable audio recorder after they have been transcribed, checked for accuracy, and transferred to the computer program. Paper data will be kept until publication.*

35. Describe how the research records, data, electronic data, **(including deidentified data)** etc. will be destroyed (i.e. shred paper documents, delete electronic files, etc.), **AND** address whether they may be used for future research purposes (If records will be used in the future, please indicate this on the consent form)***: Paper documents will be shredded after publication. Computer files will be deleted after publication. Audio recordings will be erased from the portable recorder after they have been transcribed and entered into the computer program. There are no plans for a secondary analysis in the future at this time.***

36. Could any part of this activity result in the potential identification of child/adult/older adult abuse?

☐ Yes   ☒ No

If Yes, is the mandatory report of child/adult abuse outlined in your consent?

☐ Yes   ☐ No

37. Could any part of this activity result in the potential identification of communicable diseases or criminal activities? ☐ Yes   ☒ No

Section E: BENEFITS AND RISKS TO RESEARCH SUBJECTS

38. Are the direct and indirect benefits to the research subjects for involvement in this project described in their informed consent form? ☒ Yes   ☐ No

39. Describe the possible direct benefits to the subjects. If there are no direct benefits, please state this. Also, describe the possible benefits to society***: There are no direct benefits for the participants. The benefit will come in the form of better education for the future.***

40. Will any electrical or mechanical systems that require direct human contact be used (does not include use of computers for data keeping and surveys)? ☐ Yes   ☒ No

If Yes, attach a copy of the manufacturer's electrical/mechanical <u>safety</u> specification information for each instrument/device. If the device is custom made, attach

detailed description/information on design and safety with respect to human subjects application.

***Also include the most recent safety inspection information documented on either the [Marquette University Electrical Safety Testing Documentation](#) form or an equivalent electrical safety testing documentation form.

NOTE: Electrical and mechanical safety inspections must be performed and documented on an annual basis. Documentation of the most recent safety inspection must be submitted with the initial protocol, as well as with any subsequent 3-year renewals.

41. Are the nature and degree of potential risks to research subjects described in the consent? Risks can be physical, psychological, economic, social, legal, etc.

☒ Yes ☐ No

42. Describe the risks to participants and the precautions that will be taken to minimize those risks (these risks should also appear on the consent form). If no risks identified, explain why*: **The topic is end-of-life, so a participant may become overcome with emotion or memories. A list of resources will be available to all students.**

Resource List

 Counselors on campus:

Meg Pledle	414-382-6119	AF208
Laci Oyler	414-382-6117	AF208

Off campus counseling services:

My Good Mourning Place	4005 W. Oklahoma	(414)-719-5385
Miracle Counseling Life Coaches, LLC	6724 W. Morgan	414-405-1682
Your own clergy		

Section F: COMPENSATION FOR RESEARCH SUBJECTS

43. Will research subjects be compensated or rewarded? ☐ Yes*   ☒ No

If Yes, describe the amount of compensation, how and when it will be disbursed, and in what form*:

* If subjects are recruited from MU classes, indicate whether students are receiving course credit (regular or extra credit) and, if so, what alternatives are offered to those students who do not wish to participate in the research.

Section G: NARRATIVE DESCRIPTION

For the following questions, try to use **non-technical** language that provides a first time reader (from any discipline) with a clear understanding of the research, and avoid abbreviations. **Do not "paste" text from the grant proposal, and do not refer to the grant proposal page numbers or include literature citations.** Information given should provide the first-time reader with a clear understanding of the proposed research. Focus your answers on the involvement and treatment of human subjects.

PROPOSED RESEARCH RATIONALE

44. Describe why you are conducting the study and identify the research question(s) being asked*:*

Background/Purpose: Research on caring for families of dying patients is limited in scope. Effective nursing care can provide support for families and promote peaceful deaths for patients. When nurses are not prepared to care for families of dying patients, it can result in poor outcomes for patients, families, and nurses. Many nurses do not feel prepared to care for the families of dying patients. This lack of preparation can lead to compassion fatigue and burnout and lead to nurses leaving their jobs or the profession. There is a gap in research about education for undergraduate nursing students regarding care of the families of dying patients. To determine what must be taught to nursing students, there must first be a needs assessment. The purpose of this study is to investigate what nursing students perceive their needs, challenges and facilitators to providing competent care to families, friends, and significant others of dying patients.

RQ1: What is the perception of nursing students regarding what is needed to become providers of good care to families, friends, or significant others of dying patients?

RQ2: What do nursing students perceive as challenges of providing care for families, friends, or significant others of dying patients?

RQ3: What do nursing students perceive as facilitators of providing care for families, friends, or significant others of dying patients?

SUBJECTS TO BE INCLUDED

45. Describe any inclusion and/or exclusion criteria*: **Inclusion criteria are that the participant is in a clinical course in the junior or senior year at Alverno College undergraduate nursing program.***

RECRUITMENT AND OBTAINING INFORMED CONSENT

    46. Describe your recruitment process in a step-by-step manner*: **PI will email potential participants as well as go to their classes and recruit. An information sheet will be given to all students to explain the study. A google doc link will be given to them to sign up for a session. They will all be informed that they can opt out at any time, but what they have already contributed is on the recorder and cannot be erased. A list of resources will be given to them at the focus group. They will be required to sign a consent form and complete a demographic form. If they are uncomfortable sharing information in the presence of one or any other person or persons, they can make an individual appointment with me. At this time, the only contact that the PI has with potential students is in the simulation center. This is an ungraded aspect of a theory or clinical course. The PI is not compiling the final grade. Faculty teaching these courses are not involved in the study and will not be given any information regarding the group interviews.***

    47. Describe your informed consent process in a step-by-step manner:

After all are present in the focus group, the study will be reviewed once again and the consent form signed prior to asking any questions.

SPECIFIC PROCEDURES TO BE FOLLOWED

    48. Describe the methodology to be used and describe in a step-by-step manner the involvement and treatment of human participants in the research, through to the very end of participation. Identify all data to be collected*:*

All students will be treated with respect. A private environment will be obtained for the focus groups. The focus group interview will begin after all have consented. The students will be told that they can stop participation at any time. Their names will be unknown, they will have a participant number for their demographic sheets. All information is de-identified to protect the identity of the student. The demographic data form will be completed. Demographic form asks gender, race, age, level in program, first degree, health care experience, and years of experience. The interview will begin questions provided. All participating students will receive a resource sheet with people and places they can go if they need consoling or to speak with anyone regarding any emotions that may have been elicited in the focus group. Interview questions below:

Interview Guide

    The dilemma that we will be discussing is end-of-life care for families of dying patients. Families of dying patients refers to family, friends, and significant others of the individuals who are dying. Family is not only blood relation, but by choice. Close

friends can be considered family if the patient chooses them to be (AACN, 2016). I want you to think about your experiences thus far as a nursing student as you answer these questions. If you have not had any personal experiences, imagine that you are caring for the family of a dying patient.   There are no right or wrong answers. Feel free to share information in everyday language (this isn't a class!). If you would prefer not to share certain things, that is ok.

Question 1: Imagine you are caring for a dying patient whose family is present. Tell me about how you would care for the family as a nursing student.

Prompts:

1. Tell me about what a nursing student should do to care for families of dying patients?

2. What do you think families need, want or expect from the nursing staff?

3. Tell me about what will you need to do when you are a nurse to care for families of dying patients? (cognitive, psychomotor, and affective)

3. If you have cared for a family of a dying patient, what was surprising about your experience with a family of a dying patient?

4. Tell me about what changed your perceptions or what was not what you expected.

Question 2: Some nursing students feel unprepared to care for families of dying patients. Let's talk about your preparation in school for caring for families of dying patients. Three areas of preparation including attitudes (for ex., confidence), knowledge, and skills

Prompts:

1. Tell me about what you have learned in nursing school that has prepared you for caring for families of dying patients.

2. Tell me about what you think is missing in your nursing education to prepare you for caring for families of dying patients.

2a. Such as, what knowledge do you feel you need in order to be more confident in caring for the family of a dying patient?

2.b   What skills do you feel you need in order to be more confident in caring for the family of a dying patient?

2b. What would help you to be more confident in caring for families of dying   patients?

2. Tell me about what knowledge and skills you learned in school that prepared you for dealing with difficult situations and how that preparation might help with caring for families of dying patients.

Question 3:   Tell me about what makes it challenging to care for the family of a dying patient?

Prompts:

What nursing behaviors might make it harder to care for the family of a dying patient?

Question 4:   Tell me about what would make it to care for families of dying patients.

Question 5:   What kind of an attitude do you feel that you need to care for the family of a dying patient?

Prompts:

1. How does your attitude affect the care that you give?

2. What do you think could change your attitude?

Appendix D

Demographic Data Collection

Gender: Male   Female

Age: _____ years

How would you describe your ethnicity? _____

Level in program: 2nd semester junior year _____

1st semester senior year _____   2nd semester senior year _____

Is nursing your second degree? If yes, what is/are your degree?

_____

Have you had any experience in healthcare?

CNA _____   LPN _____   RN _____   Intern/Extern _____

Other _____

How long?

0-1 years _____   3-5 years _____   5-10 years _____   > 10 years _____

Appendix E

Interview Guide

The dilemma that we will be discussing is end-of-life care for families of dying patients. Families of dying patients refers to family, friends, and significant others of the individuals who are dying. Family is not only blood relation, but by choice. Close friends can be considered family if the patient chooses them to be (AACN, 2016). I want you to think about your experiences thus far as a nursing student as you answer these questions. If you have not had any personal experiences, imagine that you are caring for the family of a dying patient. There are no right or wrong answers. Feel free to share information in everyday language (this isn't a class!). If you would prefer not to share certain things, that is ok.

Question 1: Imagine you are caring for a dying patient whose family is present. Tell me about how you would care for the family as a nursing student.

Prompts:

4. Tell me about what a nursing student should do to care for families of dying patients? (Cognitive and psychomotor)

5. What do you think families need, want or expect from the nursing staff? (cognitive and affective)

6. Tell me about what will you need to do when you are a nurse to care for families of dying patients? (cognitive, psychomotor, and affective)

3. If you have cared for a family of a dying patient, what was surprising about your experience with a family of a dying patient? (affective)

4. Tell me about what changed your perceptions or what was not what you expected. (affective)

Question 2: Some nursing students feel unprepared to care for families of dying patients. Let's talk about your preparation in school for caring for families of dying patients. Three areas of preparation including attitudes (for ex., confidence), knowledge, and skills

Prompts:

1. Tell me about what you have learned in nursing school that has prepared you for caring for families of dying patients.

2. Tell me about what you think is missing in your nursing education to prepare you for caring for families of dying patients.

2a. Such as, what knowledge do you feel you need in order to be more confident in caring for the family of a dying patient? (affective)

2.b   What skills do you feel you need in order to be more confident in caring for the family of a dying patient? (psychomotor)

2b. What would help you to be more confident in caring for families of dying patients? (cognitive)

3. Tell me about what knowledge and skills you learned in school that prepared you for dealing with difficult situations and how that preparation might help with caring for families of dying patients. (cognitive, psychomotor)

Question 3: Tell me about what makes it challenging to care for the family of a dying patient?

Prompts:

What nursing behaviors might make it harder to care for the family of a dying patient? (cognitive, psychomotor)

Question 4:   Tell me about what would make it to care for families of dying patients.

Question 5:   What kind of an attitude do you feel that you need to care for the family of a dying patient?

Prompts:

1. How does your attitude affect the care that you give?

2. What do you think could change your attitude?

Appendix F

Field Note Template

Date_____   Time _____

Group dynamics: (briefly describe the group dynamics)

What worked. What did not work.

Observations and insights:

Other:

Appendix G

Resource List

Counselors on campus:

    Meg Pledle   414-382-6119   AF208

    Laci Oyler   414-382-6117   AF208

Off campus counseling services:

    My Good Mourning Place   4005 W. Oklahoma   (414)-719-5385

    Miracle Counseling Life Coaches, LLC   6724 W. Morgan   414-405-1682

    Your own clergy

Appendix H

IRB approvals

Marquette University:

Date: 1/26/2018
HR-1801022011
Principal Investigator: Penny A. Alt-Gehrman
Faculty Advisor: Dr. Kristin Haglund
Department: Nursing
Study Title: *A Qualitative Exploration of the Perceptions of Caring for Families of Dying Patients in Undergraduate*
Nursing Students
New Study Approval
This protocol has been determined to be Exempt under category **2** as governed by 45 CFR 46.101(b).
This protocol has been approved as minimal risk under Expedited category **#** as governed by 45 CFR 46.110.
This protocol has been reviewed by the Institutional Review Board on [date] and approved as:
Minimal risk
Greater than minimal risk
Approval Date
This exempt determination was made on **1/26/2018**.
This study was approved on [date] for a period of twelve months. This IRB approval will expire on [date]. Please
submit a continuing review application if approval is requested beyond this date.
Consent
Please use the final version of the exempt information sheet or consent form submitted to the IRB. Contact the
IRB office if you have questions about which document you should be using.
The IRB approved informed consent form is attached. Use the stamped copies of this form when enrolling
research participants. Each research participant should receive a copy of the consent form.
This study has been approved for waiver of documentation of consent under 45 CFR 46.117I(1) or (2). Please
use the approved consent information sheet with your participants.
This study has been approved for alteration or waiving of consent under 45 CFR 46.116(d).
Study specific notifications
The IRB approved recruitment materials are enclosed with this letter. Use stamped copies of these documents for
recruitment purposes.
This study involves students collecting data through surveys- please review the MU Questionnaire/Survey
Procedures: http://www.marquette.edu/osd/policies/survey_procedure.shtml
This study involves recruitment emails for online surveys to be sent to 100 or more Marquette students, faculty or

staff. Please review the website of the Online Survey Review Group:
http://www.marquette.edu/onlinesurveys/
This protocol involves the use of electrical or mechanical systems that require direct human contact. Electrical and
mechanical safety inspections should be conducted per Marquette University Human Research Protection
Equipment and Electrical Safety Testing Policy 98.106.

HIPAA

This study involves accessing PHI from a HIPAA covered entity. The IRB has granted approval to access the
following protected health information for the purpose of this study:
• x
A HIPAA Authorization form has been approved and should be used to with study subjects.
A waiver of authorization has been approved for this study.
All changes to this protocol must be reviewed and approved by the IRB before being initiated, except when necessary to
eliminate apparent immediate hazards to the human subjects. If the study is exempt, please email the requested changes
to orc@marquette.edu. If the study is not- exempt, please submit personnel changes using the personnel amendment
form or any other changes using the amendment submission form.
If there are any adverse events or deviations from the approved protocol, please notify the Marquette University IRB
immediately.
An IRB Final Report Form must be submitted once this research project is complete. The form should be submitted in a
timely fashion, and must be received no later than the protocol expiration date.
The principal investigator is responsible for ensuring that all study staff receive appropriate training in the ethical
guidelines of conducting human subjects research and documenting that this requirement has been met.
Unless a separate reliance agreement is in place, please note that approval of a study with non- Marquette investigators
does not indicate that Marquette University is assuming oversight for the research activities occurring outside of
Marquette's purview.
Please contact the Office of Research Compliance with any further questions. Thank you for your cooperation and
best wishes for a successful project.
Jessica Rice, MPH, CIP
IRB Manager
Office of Research Compliance

Alverno College

From: Paul Smith
Sent: Friday, February 02, 2018 4:51 PM
To: Penny Alt-Gehrman <penny.alt-gehrman@alverno.edu>
Cc: Denise Sanders <Denise.Sanders@alverno.edu>
Subject: Alt-Gehrman study IRB-064M-18

 Penny –

 I have reviewed your request for exempt determination and agree that your proposal meets Category 2 Exemption.

You can go right ahead with your data collection at any time. Your study is approved. The identification number for your study is IRB-064M-18. Please use that number in any communications with us about the study. Remember that you have a duty to report any negative incidents to us. We would also appreciate it if you would notify us when you have closed the study (that is, completed data collection) so we can update our records.

Thanks,

Paul Smith

Appendix I

Manuscript Submission verification

Dear Dr. Alt-Gehrman,

Your submission entitled "Qualitative Exploration of Perceptions of Nursing Undergraduates Regarding Family Care at End-of-Life" (JNE-2018-629) has been received by the Journal of Nursing Education.

You will be able to check on the progress of your paper by logging in to Editorial Manager as an Author. The URL is https://jne.editorialmanager.com/.

Thank you for submitting your work to the journal.

Kind regards,

Journal of Nursing Education

_____
In compliance with data protection regulations, please contact the publication office if you would like to have your personal information removed from the database.