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STUDENT NURSES' PERCEPTION OF DEATH AND DYING

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DEDICATION

I dedicate this dissertation to my family for their patience, support and encouragement during this long process. Thank you Craig, Anthony, Andrew, Sarah and Anna for your support.

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STUDENT NURSES' PERCEPTIONS OF DEATH AND DYING

JOAN NIEDERRITER

ABSTRACT

Student nurses are involved in caring for patients who are actively dying or who have been told they have a terminal illness and are faced with the process of dying. Students encounter these patients in hospitals, nursing homes, at home or in hospice care settings. According to Robinson (2004), "nurses are the healthcare providers that are most often with individuals at the end of their lives" (p. 89). Nurses should be knowledgeable about end-of-life care. Studies show that only 0.41% of nurses are certified in palliative care (Means to a better end, 2004).

Nursing students often have a difficult time coping with the stress that comes with caring for those who are dying (Johannsson & Lalley, 1990-91). Student nurses need to be prepared to take an active role in caring for patients who are dying or have been told they have a terminal illness. Students are in clinical settings where they may encounter death and dying. These settings include hospitals, nursing homes, and community/home care areas. Understanding students' perceptions of death and dying can help educators prepare students for these situations by using the research available to plan better ways to teach students about the needs of the dying/terminal patient and their family. These needs include physical, spiritual, emotional and social.

A qualitative investigation with thirteen junior level nursing students from a large urban university in Northeast Ohio was used in the research. Findings revealed that an emphasis on the domains of thoughts, feelings, communication, multicultural diversity, education and coping mechanisms are essential in nursing education. Participants reported

a need for additional education in the area of communication and culturally responsive care. This study suggests that there is a great need to educate students about death and dying, cultural competence, communication skills and coping with emotional stress.

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CHAPTER I

INTRODUCTION

I ask my Lord for the strength and wisdom to comfort them, to be at my best for them. I don't ask for miracle cures. I ask for only what is within my own limited reach, you know, let me be able to help somebody today and then, if I can, somebody tomorrow (Kastenboum, 2004, p. 5).

Nurses are involved in caring for patients who are actively dying or who have been told they have a terminal illness and are faced with the process of dying. Nurses encounter these patients in hospitals, nursing homes, at home or in hospice care settings. According to Robinson (2004), "nurses are the healthcare providers that are most often with individuals at the end of their lives" (p.89). Nurses should be knowledgeable about end-of-life care but studies show that only 0.41% of nurses are certified in palliative care medicine (Means to a Better End, 2004).

Loss and grief affect people of all ages and all cultures. Nurses working in any area of the medical field can have experiences with dying patients; however, nurses in some nursing areas are more likely to be in contact with this aspect of life than in others. Nursing students spend time in several clinical areas at the beginning of their student nurse education where they are likely to encounter patients who are dying.

There are two important factors that affect the likelihood of nursing students and

nurses encountering patients who are dying and their families. First, there is a longer life expectancy. The life expectancy of persons in the United States born in 1970 was 70.8 years. For males, it was 67.1 years old and for females it was 74.7 years old (US Census Bureau, 2007). The life expectancy of all persons born 35 years later, in 2005, is 77.8 years (males, 74.9 years and females, 80.7 years). Projections for 2010 have about one more year added for each category (US Census Bureau, 2007). As people live longer, there is a growing proportion of the population that is 60 years and older. According to the 2000 US census, the percent of the population who was over 60 years of age was 16.2 % (US Census Bureau, 2007). It is projected that in 2020, the percent of the population who will be over 60 years of age will be about 22.9% of the population (US Census Bureau, 2007).

The second factor is that medical technology is continuously changing and becoming more sophisticated. This means that we can keep patients alive longer, at higher costs, but not necessarily in better health (Bramstedt, 2001). Medical conditions such as heart attacks that may have killed someone 20 or 30 years ago now can be treated by unblocking the arteries and doing open heart surgeries. Technologies such as dialysis, ventilators, infusion pumps, various procedures, blood products and medication can help keep patients alive longer (Bramstedt, 2001). With more advanced medical technology, the medical community is able to keep patients alive with many procedures and equipment, but may not be able to help them recover from their illness. Nurses now are taking care of these patients and having to work with them and their families to make decisions about end-of-life care.

The racial/ethnic demographics of the United States are changing along with life

expectancy. Although still the majority, the white European descent portion of the population is declining yearly (Crawley, 2005). Hispanics, African American and Asian ethnic populations are increasing. With this change, nurses need to understand the healthcare and end-of-life needs of diverse populations. Nurses also need to be aware of their own beliefs and values, and be able to set these aside, and focus on the client's values and needs.

The demographics of the nursing population do not match the population demographics. According to the American Nurses Association data (2006), 88% of the nurses in the US are white, 4.6 % are black/African American, 3.3 % Asian or Pacific Islander, 1.8 % Hispanic, 0.4 % American Indian/Alaskan and 1.5 % are from two or more racial backgrounds. As of the 2000 census, 52.8% of the population in the US were white, 12.3 % were black or African American, 0.9% were American Indian, 3.6 % Asian and 12.5 % Hispanic (U.S. Census, 2000). Thus, nurses are much more likely to be white. Due to demographic changes in the US population, nurses will eventually provide care for patients of other cultures, religious backgrounds or who have different values and beliefs than their own (Mitchell, Gale, Matzo, McDonald, & Gadmer, 2002). This health care will include caring for the dying.

The healthcare profession must respond to the demographic changes by providing patient care appropriate to the cultural needs of the client (Mitchell et al., 2002). There has been an increase in US hospitals to hire nurses from other countries to try and fill registered nurse positions. A 2004 survey estimated that 3.5 % of the RNs practicing in the US received their nursing education outside the US (American Nurses Association, 2004). Nursing schools are also increasing efforts to try and have a more

diverse nursing workforce through recruitment of minorities into nursing programs (Wieland & Hoerst, 2006).

Even though the representation of other cultures is small in the nursing community, colleagues can learn from minority nurses about their culture or can observe the client-specific interactions and interventions that are applicable to that culture (Tilki, Papadopoulos & Alleyne, 1994). One major problem in the medical field is stereotyping ethnic minority patients which may cause nurses to not provide culturally sensitive care (Jirwe, Gerrish & Emami, 2006). Several articles address the need for developing cultural competence which includes:

- An awareness of diversity among human beings, both of self and others.
- An ability to care for individuals which includes being skilled at assessing individual needs based on culture, being knowledgeable about other cultures and being able to meet specific cultural needs (Kagawa-Singer, 1994).
- Using nonjudgmental openness for all individuals which includes overcoming prejudices and being genuinely interested in the client.
- Making cultural competence a long-term continuous process. (Jirwe et al, 2006).

When working with end-of-life (EOL) patients, nurses need to be culturally competent. The majority of nurses are white/Caucasian and will need to be able to provide patient and family care consistent with the cultural context. According to Schim, Doorenbos and Borse (2006), "hospice nurses can negotiate mutually satisfactory strategies to achieve a dignified death as *defined* by the individual and family needing care. Nurses need to appreciate, accommodate, and negotiate cultural and individual variation in beliefs, values, lifestyles, education and myriad other elements that cultural

context comprises" (p.303). Student nurses, as well as hospice nurses, are in clinical settings where they may encounter death and dying, so examining their attitudes to death and dying and cultural beliefs is important.

Problem Statement

Student nurses need to be prepared to take an active role in caring for patients who are dying or have been told they have a terminal illness, but they often have a difficult time coping with the stress that comes with caring for those who are dying (Johansson & Lalley, 1991). Understanding students' perceptions of death and dying can help educators prepare students for these situations by using the research available to plan better ways to teach students about the needs of the dying/terminal patient and their families. These needs include physical, spiritual, emotional and social.

Working with patients and their families who have to face death and dying can be emotionally demanding. According to Birkholz, Clements, Cox and Gaume (2004), "death is a personal issue for each nurse, and each nurse's unique perspective can affect each patient who dies under the nurse's care" (p.36). Part of becoming a good nurse is being able to understand one's own perceptions about various aspects of nursing including death and dying.

Purpose of the Study

The purpose of this study is to understand the nursing student's experience in caring for dying patients and their families. More specifically, this investigation seeks to gain an understanding of nursing students' (1) thoughts about caring for dying patients and their families, (2) feelings about caring for dying patient and their families, and (3) communication with dying patients and their families. The proposed study provides a

phenomenological approach using interviews with each respondent to identify common themes.

Research Method

Until the late 1800's, quantitative research was the method of scientific discovery used to gain/prove knowledge. In the late 1800's and early 1900's, Husserl began to identify another method of gaining knowledge. He believed that knowledge could be gained from experience (Priest, 2002). The method he developed was within qualitative research methods. Qualitative research has become an acceptable method of inquiry for gaining and adding to knowledge (Krasner, 2001; Cushing, 1994; Priest, 2002; Thorne, Kirkham & MacDonald-Emes, 1997; Bunkers, Petardi, Pilkington & Walls, 1996).

In the 1960's, nursing researchers began looking at methods other than quantitative approaches to increase nursing knowledge. Nursing was influenced by sociology and social theory (Cushing, 1994; Giorgi, 2005). Qualitative methods began to come into the spotlight as a method of research that could be of benefit to nursing (Clarke & Jack, 1998).

Nursing practice looks at questions that may not fit into a quantitative framework. Nursing practice is interested in knowing what is shared by persons in similar situations and knowing about the lived experience of an individual person in a particular situation (Thorne, Kirkham & MacDonald-Emes, 1997; Crowe, 1998). Use of quantitative methods were sometimes "limited in scope and depth and did not always fit the requirements of a holistic, interpretive, relational practice discipline" (Thorne et al, 1998, p. 170).

As a research method, qualitative research has become an alternative way for

nursing to gain valuable knowledge (Sjostrom & Dahlgren, 2002; Bailey, Groggatt, Field & Krishnasamy, 2002, Bailey, 1997). The researcher's goal in the qualitative model is to "interpret and reconstruct subjective meaning" of collected data (Bailey, 1997, p.19).

This study will use qualitative research methods.

While the student characteristics of the class studied vary from semester to semester, the makeup of the student population of the particular class used in this research is: 82 % female, 18 % male, 88% Caucasian, 6% Hispanic, 2% African American and 4% Eastern European. The aim for the research study is to solicit participants who are representative of the student population for this class.

Research Questions

The overall research question for this study is how do beginning nursing students experience death and dying in the clinical setting. The three associated questions are:

1. What are the thoughts that nursing students experience when working with dying patients and their families?
2. What are the feelings that nursing students experience when working with dying patients and their families?
3. How do nursing students report communicating with dying patients and their families?

In addition to the above three research questions, participants will be asked how worldviews and cultural backgrounds affected them with their thoughts, feelings and communication areas.

Framework

The nursing framework used for this study is that of Novice to Expert developed by Patricia Benner. She developed this framework in the 1980's. The assumption of this framework is that nurses go through stages of development within clinical practice. This development of nurses affect how they understand the patients they are caring for as well as how they plan and implement care (Benner, 1984).

Benner felt that "perceptual awareness is central to good nursing judgment and that this begins with vague hunches and global assessments that initially bypass critical analysis; conceptual clarity follows more often than it precedes. Expert nurses often describe their perceptual abilities using phrases such as gut feeling, a sense of uneasiness, or a feeling that things are not quite right. Expert nurses, through experience, have learned to allow their perceptions to lead to confirming evidence" (Benner, 1984, xviii). Benner stresses that this method of learning is not through trial and error. Experienced based skill acquisition is safer and quicker when there is a solid educational base.

Benner's model has five stages of skill development. The five levels that she identified are: novice, advanced beginner, competent, proficient, and expert. According to Benner, a nurse "passes through these five levels of proficiency in their acquisition and development of a skill" (Benner, 1984, p.13). When Benner talks about skills, she is talking about applied skills in a clinical situation and not in a skills lab. The nurse needs to be actively working with patients in order to acquire this learning. The different levels demonstrate changes in three general aspects of skilled performance. The first is that there is "movement from reliance on abstract principles to the use of past concrete experience" (Benner, p. 13). As nurses are able to build on past experience, they can see

what happens when they use the principles learned from the book. This becomes ingrained in their day to day nursing activities and they are able to put together signs and symptoms, medical diagnosis and nursing interventions. The second aspect is that there is “a change in the learner’s perception of the demand situation, in which the situation is seen less and less as a compilation of equally relevant bits, and more and more as a complete whole in which only certain parts are relevant” (Benner, p. 13). With experience, the nurse is able to pick out the relevant information being given by the patient and the important signs and symptoms that they need to focus their attention on. The third is that the nurse passes “from detached observer to involved performer” (Benner, p.13). As the nurse gets more experience, they no longer stand outside the situation but become engaged in the situation.

Students also go through the same phases of learning as a new nurse does as they learn to apply classroom knowledge and skills training to the clinical setting. Although students do not attain the highest levels of the model since these can take years to acquire, they can move from novice student nurse to advanced beginner as they participate in the clinical settings.

The novice student nurse is one who has little or no experience in an area. These students get theoretical knowledge and spend time in a skills lab practicing a particular skill. This basic knowledge and standards is what guides their work. They collect objective data but may not be able to make in-depth analysis of it. They require guidance in the decision making process and need assistance correlating theoretical knowledge to clinical situations (Haag-Heitman, 1999, p.56-57). Student nurses may collect lab work about a patient who has acute renal failure. At this phase, they may not yet understand

how the lab work, the diagnosis, medications and the signs and symptoms correlate with one another. They may recognize that some of the labs are too high or too low but may not understand that the patient may have a low urine output with acute renal failure. They may be giving medications with calcium in them and not understand that they need to be given with food and that they are being used to lower phosphate levels of the patient. The nursing instructor needs to help the students use the knowledge that they acquire from their books and from class and try and put it together. The instructor facilitates their knowledge and helps students understand this particular disease, medications, lab work and nursing interventions.

Advanced beginners use theoretical knowledge. Their decision making is based on rules that they learned in the classroom or from their books. They perform beginning analysis of information. They look at parts of the whole more in tasks of what needs to be done. They are task oriented and depend on others to help identify changes in a client. Students need external validation of their skills from the instructor (Haag-Heitman, 1999). For example, Mary is a student nurse in the clinical setting with a patient who has pneumonia. Mary has learned that it is important to take the patients vital signs including temperature, check the patient's oxygen level and to listen to lung sounds. She is able to do the tasks but may not understand the meaning of what she finds. If the patient's oxygen level is 90% and the doctor wants it greater than 92%, Mary may not put oxygen on the patient right away because she needs to go over the measurements with the instructor and validate the need to put oxygen on the patient. If the patient complained of shortness of breath, Mary would go to the instructor to verify the need to call the respiratory therapist for the patient to get a treatment.

Competent nurses start incorporating past experience in their practice. They are able to see limits of formal learning and complete care plans on their own. They prefer things to be status quo, with no surprises. They set goals, and plan and organize their work as they have mastered tasks and skills. In this stage the nurse is able to make conscious and planned responses to the changing status of a client. In this phase, nurses are involved with the family members and understand their own impact on patient outcomes (Haag-Heitman, 1999). Student nurses at this stage are able to use their past experience to make decisions. For example, Mary would have put oxygen on her patient as soon as she saw that the oxygen level is 90% on room air. She would have also called the respiratory therapist on her own about the patient needing a treatment. Her past experience would tell her it is acceptable and necessary to do this.

Proficient nurses integrate theoretical knowledge with experience. They consult others and provide assistance as needed. Nurses at this stage, still approach new situations in an analytical manner but they are also able to recognize and see relevant changes to a situation. They are able to look at a situation more holistically and have an in-depth knowledge of nursing practice through experience. They use their experience to respond to changes and to establish boundaries with family and patient relationships. The nurse struggles with moral and ethical dilemmas in working with patients and their families (Haag-Heitman, 1999). It is unlikely that nursing students are able to reach this level or the next because it can take years for someone to get to these last two stages. It takes years of experience and practice.

Expert nurses use extensive clinical experience in their practice. They are able to zero in on a problem using intuition as well as synthesize the parts into a whole and see

the whole situation and make decisions based on their findings. They are flexible and innovative in their approach to care. They are able to instinctively respond to rapidly changing situations without spending a lot of time analyzing. They are able to separate personal feelings from moral and ethical dilemmas (Haag-Heitman, 1999). There is also a realization in the medical community that nursing education programs can help nurses become more experienced in their roles as nurses (Schoessler & Farish, 2007).

In this study, students were from varying backgrounds with some experiences in life skills. However, using nursing theory and skills, as well as making decisions that can affect clients and their families in a medical care situation, is new. The students in this study are assumed to be in the novice phase of nursing and basing their interactions more on book knowledge than on experience. However, based on life experiences, there may be students who are at the advanced beginner phase of Benner's theory.

Terms

Terminal illness. This is the diagnosis given to people who have an illness that cannot be cured by modern medicine for various reasons. The person will be moving through the dying process in a very short period of time. It can be as short as a few hours to more than six months (Egan & Labyak, 2006).

Hospice. Hospice is a team-oriented approach in taking care of the dying patient and their family (What is Hospice, 2006). This team includes doctors, nurses, nursing assistants, pharmacist, counselors, social workers, and volunteers. Together they help work with the patient and the family through the dying process. This can be at home or in a facility.

Palliative care. Like the hospice philosophy, palliative care is a medical specialty

that focuses on the management of pain, controlling symptoms and improving the quality of life for the patient. Palliative care is also known as comfort care. The goal is not to cure the patient but to provide comfort and maintain the highest possible quality of life for the patient as long as they are alive (What is Palliative Care, 2006).

Palliative care also uses the interdisciplinary team model that provides support for the whole person and their family. Palliative care can be delivered in hospice centers, home care settings or in the hospital. Pain control and symptom management are the key factors but palliative care also deals with social, spiritual, and emotional aspects of the patient's care.

Death. Death is defined as the cessation of respiration (breathing) and circulation (blood flow) of the body (Huether & McCance, 2004).

Dying. A process where the patient's body systems start shutting down. It is also known as multiple organ dysfunction syndrome. The patient may become unconscious and the body is no longer able to function normally (Ignatavicius & Workman, 2006). There are a number of changes that take place during this time which can last for hours to weeks.

Novice practitioner. The student or learner for whom there is no background understanding of the situation, "so that context-free rules and attributes are required for safe entry and performance in the situation" (Benner, 1984, p. 296). Nursing students fall into this category where they are in the process of learning and using knowledge learned in the classroom and clinical setting.

Assumptions

This study uses Benner's work of Novice to Expert as a framework. There are

three assumptions about the Benner's work that affect this study. The assumptions are:

1. Students advance from one level to the next. There is no skipping of levels.
2. The students are in the novice step of Benner's theory where they have little or no experience to draw from in making nursing decisions. There may, however, be one or more students who are advanced beginners based on their life experiences.
3. The students are in the novice step of Benner's theory with their communication skills in talking to patients and family about death and dying. Again, there may be one or more students who are advanced beginners based on their life experiences.

This phenomenological study focuses' on nursing students' perceptions of death and dying. Students spend many hours in the clinical setting and often work with patients who have been diagnosed with a terminal illness or who are actively dying. Students work with patients and their families in the medical setting and need to be able to communicate and discuss patient and family needs and concerns. Since the students interviewed had exposure to patients who are facing death, or who are actively dying, it was expected that they would be willing to discuss their experience and truthfully discuss their experience in the clinical setting in their interviews.

Significance of the Study

Understanding student nurses' experiences and perceptions of death and working with dying patients is important for educators and clinical faculty. Nursing theory (what is learned in the classroom) needs to be incorporated into real world experiences in the clinical setting. The physical process of death can be taught, but the emotional and

spiritual aspects of death and dying are much more difficult to teach students. According to Loftus (1998), “developing an understanding of the meaning of student nurses’ experience when caring for dying patients will help both teachers and clinical staff by (influencing) both nursing theory and practice” (p. 641). This understanding may help educators incorporate different teaching methods like role play, guest speakers from hospice or palliative care and religious groups to explain their beliefs and rituals associated with death and dying.

Limitations

There are several limitations to this study. First, this study was conducted at only one university. Second, the study was only done with one cohort of students. The mix of students changes slightly from year to year. Third, the study was completed with only basic level nursing students. This university has an accelerated program with students who have a minimum of a baccalaureate degree with most in fields other than medical areas. The accelerated students will not be involved in this study. The group that was in the study was the undergraduate students in the basic nursing program.

CHAPTER II

LITERATURE REVIEW

The review of the literature is divided into two main sections with subdivisions in each. The first section of the literature review looks at the prevailing themes about death in the United States. This section reviews some history about death and dying and the changes over time including the current thinking and barriers regarding this topic. In addition, this section reviews the religious and cultural variations about death and dying. The second section is a literature review of the current research on death and dying. There are four subsections in this area. The literature review includes research of nursing students, nurses in various areas of nursing, medical students and doctors. The first part of this section focuses on research on thoughts about dying. The second part focuses on research on feelings about death and dying. The third part focuses on research related to communication with patients and families who are faced with death and the fourth part focuses on research about education of nursing students, nurses and medical students about death and dying.

Prevailing Themes about Death in the US

In the early 1900's, most people died at home, with family present. In the past

century, there have been medical and public health advances which have increased life expectancy. People today tend to die in old age, and have a period of functional decline before death. With our medical technology, we have moved death out of the home and into institutions (Cassel & Demel, 2001).

In 1965, Medicare was enacted to help with the financial burden of acute hospital stays. In 1983, Medicare established a hospice benefit to help reduce the costly inpatient hospital end-of-life care (Cassel et al, 2001). However, this benefit only recognizes certain types of deaths and the patient expected life expectancy needs to be six months or less.

The word “hospice” comes from the Latin word “hospitium” which means guesthouse (What is Hospice, 2006). It was originally used to describe a place for shelter for tired and sick travelers returning from religious pilgrimages (What is Hospice). Hospice was originally started in London in the 1960’s. The philosophy of hospice is to provide comfort and support to patients and their families when they have been diagnosed with a terminal illness. The goal of hospice is to improve the quality of patients’ last days. Hospice offers comfort and dignity to the dying patient and their families. Hospice assists with controlling physical symptoms, especially pain, but also deals with the emotional, social, and spiritual aspects of the disease for both the patient and their family. Hospice also offers bereavement and counseling services to families before and after death.

The first hospice opened in the US in the 1970's. Hospice attempts to recognize and address quality of life issues at the patient’s end-of-life (Forbes & Rosdahl, 2003). In a study of trends in the US, the percentage of persons who died as hospitalized patients

has had a fairly consistent decline from about 54% in 1983 to 41 % in 1998 (Flory, Young-Xu, Gurol & Levinsky, 2004). It was also found that home deaths rose from 17 % to 22 % and nursing home deaths rose from 16 % to 22 % (Flory et al, 2004).

The hospice program has grown dramatically since 1974 (What is Hospice). In 2005, there were 4,160 hospice programs throughout the US (NHPCO, 2006) and according to NHPCO (2006) data, in 2005 approximately one-third of all deaths in the US were under hospice care. There were 1.2 million hospice patients' during 2005. This continued increase in hospice programs and patients using their service shows a shift in thinking about death in the US.

One major problem in Western culture since the 1960's is the debate about communication and awareness about dying (Field & Copp, 1999, Roose, 1974). There has been a shift in policy from 'withholding' information to a policy of 'revealing' information to patients with a terminal prognosis (Darr, 2002). In an analysis of research by Field and Copp (1999), it was found that in a 1961 survey, US physicians' attitudes revealed that 88% of respondents' reported that they would not tell a cancer patient of their diagnosis compared to 98% of respondents' who would tell a patient of a cancer diagnosis in a 1979 replica of the same study. However, Fields and Copp also found that even though there is an open policy of disclosure of a diagnosis, "in the day-to-day encounters with the dying patients, health workers moderate and back away from automatic disclosure of a terminal prognosis" (p. 463). There seems to be a lack of continued discussion about death and dying with the patient or the family after a diagnosis is given.

In the 1990's, Jack Kevorkian sparked a debate about dying with dignity and

physician assisted suicide. Oregon became the first state to legalize assisted suicides as a result of the debate. It has been found that there have been a small number of suicides committed under Oregon's assisted suicide law (Cassel & Demel, 2001, p. 434). However, it did bring to the attention of the medical field the need to provide better end-of-life care to patients.

There are barriers that affect optimal end-of-life care. Mass media plays a large role in society's perceptions of death and dying and may feed the general public's fear of painful death or developing certain diseases like cancer (Yarbroff, Madelblatt & Ingham, 2004). Physician assisted suicide has also been in the media and fueled debates about end-of-life care and the idea of pain. According to Yarbroff et al (2004), these influences can set expectations for quality of life at a low level causing barriers on in the health care system.

There are also barriers within the healthcare system itself. We have had rapid changes in the healthcare delivery system and technology over the last 10-15 years (Bramstedt, 2001; Baldwin, 2003). Insurance coverage is not available to everyone and some have large out of pocket expenses associated with medical care (Tilden, Tolle, Crach & Perrin, 2004). This leaves patients who may not be able to get end-of-life care because they have no coverage and can't afford it. There is also fragmented end-of-life care. There are shorter hospital stays and more and more care is being shifted to families and friends who have little or no training (Yarbroff & Mandelblatt, 2004). Patients can also be shifted from place to place like hospital to nursing home to home. With every shift in place, a new routine and care plan need to be developed.

The last place where there are barriers to end-of -life care is at the provider level.

There is much research about lack of education in palliative care issues with nurses (Ersek, Kraybill & Hansberry, 1999). One study of oncology nurses reviewed core end-of-life competencies. Nearly all the respondents' reported end-of-life care was part of their practice, yet one-third of respondents' had less than two hours of continuing education in two years (White, Coyne & Patel, 2003). A study of emergency room nurses and end-of-life care also identified a need for more education in end-of-life care and communication. This same article identified physician's trying to treat patients with advanced treatment that were not going to save the patient but provides financial benefits to the hospital (Beckstrand, Bond & Palmer, 2006).

Physicians also have a gap in training related to end-of-life care. Medical textbooks have limited information discussing end-of-life issues (Rabow, Hardie, Fair & McPhee, 2000) and residency programs have limited opportunities for residency training in end-of-life care or palliative care (Dunn & Miller, 1997). This lack of education and exposure can cause fragmented care.

When patients and families hear the diagnosis and end results, it can be devastating. Each individual handles the news in different ways. Each person, however, appears to pass through the stages of grief. Some know what to do from experience, education or religious experience. Others are lost, feeling helpless or powerless and they handle grief poorly and with fear.

Because the diagnosis of a terminal illness takes time to be fulfilled, patients and families suffer anticipatory grief. This grief occurs before the actual loss. When dealing with terminal illness, there are two groups of people who suffer. The person who is diagnosed with the terminal illness is one; the other is the family/loved ones. They all

move through the grief process. According to Kubler-Ross (1970), the grieving process has the following five steps:

1. Denial and isolation. In this stage, the person does not acknowledging the loss in effort to avoid pain. Denial acts as a buffer. It allows the patient to pull himself together and utilize other defenses (p. 35).
2. Anger. In this stage, there is resentment at the loss or experience. The question is 'why me'? This is a difficult stage to deal with for the family and staff. The patient's anger is displaced in all directions and at all those around at random (p. 44).
3. Bargaining. In this stage, the patient tries to postpone the inevitable from happening (p. 73).
4. Depression. In this stage, the patient has a deep sadness or hopelessness. There are actually two types of depression identified by Kubler-Ross (1970). The first is the depression a person may get from declining health, financial problems, loss of job etc. The second is a preparatory depression as a patient undergoes in order to prepare for the "final separation from this world" (p. 76).
5. Acceptance. In the stage, the patient accepts the loss, learning and growing through the experience, and moving on (p. 99).

Most students are taught Kubler-Ross's grieving process and some of the students may go through this process when working with dying patients. However, the experience of grieving is influenced by religion and culture and these issues are considered in the next section.

Religious and Cultural Variations in beliefs about Death and Dying

The United States has become a nation of diversity. Many different cultures are represented within the population. In the 1960's, Madeleine Leininger founded the field of transcultural nursing (Giger & Davidhizar, 1999; Andrews & Boyle, 2003). Cultural sensitivity has become increasingly important in nursing. Not only is the patient population diverse, but more and more nurses are being hired from other countries to fill needed nurse positions.

Culture is shaped by beliefs and practices of members from the same cultural group (Huff & Kline, 1999; Rawlings-Anderson, 2004). Culture affects our "thinking and doing, and becomes patterned expressions of who we are" (Giger & Davidhizar, 1999, p. 3). Culture affects how illness is perceived and experienced. It also affects what health information a patient may report, what medical remedies they choose to use and who the patient consults for help (Srivastava, 2007). Diversity refers to differences in "race, ethnicity, national origin, religion, age, gender, sexual orientation, ability/disability, social and economic status or class, education and related attributes of groups of people in society" (Andrews & Boyle, 2003, p. 5). Cultural competence is the goal for nurses. This term means that healthcare providers are able to apply knowledge and skill appropriately in interactions with their clients (Srivastava, 2007; Boyer, 2006; Collins, 2006; Campinha-Bacote, 2003, Jenko & Moffitt, 2006). According to Collins (2006), "providing culturally competent care means recognizing and appreciating that each individual is a part of a cultural group that will color the individual's response to illness" (p. 5).

There are many religious and cultural beliefs that affect a person in the dying

process. In some places, culture and religion are intertwined and the religious beliefs are also the prevailing way of life. In the US, some families are a mixture of cultures and religions, so it becomes important for nurses to understand which practices are being followed. Understanding these cultural and religious differences can help provide quality care to the patient and their family.

In some religions, dietary habits affect the patient's view of health. Many religious and cultural groups have certain foods that are forbidden or have strict requirements as to how the food is to be prepared. For some culture/religious groups, if a patient violates a dietary requirement, it can be perceived as an actual challenge to the supreme authority and can have a negative impact on their recovery (ElGindy, 2005).

Many Muslims believe that their health is a religious matter and nutrition is an important way to maintain good health. The Muslim religion prohibits alcohol and any mind-altering substances. Pork and pork products are also forbidden as are foods with animal shortening. Raw meats are typically forbidden and meat has to be soaked in water to drain out the blood before cooking. The meat has to be well-done with no trace of blood. No dishes can be used for cooking that contained foods that had alcohol or pork in them (ElGindy, 2005).

The Jewish faith also has restrictions with their diet for those who follow the kosher rules. There is the same pork prohibition as Muslims, and all blood must be drained before cooking. They also believe that no dairy products and no meat products can be eaten together. Animals must be slaughtered a certain way according to Jewish law. Certain fish and birds are not allowed (ElGindy, 2005).

Those of the Buddhist faith are typically vegetarian. It is believed that no living

thing should be killed or harmed. They believe that what they eat affects health. They also believe that what they eat can affect them in the afterlife. Strict Buddhists are forbidden to eat onions, scallions, chives and garlic. If these are eaten, they believe that they will be rejected by the gods and saints (ElGindy, 2005). Other religions/cultures have restrictions on the types of foods they can eat. Nurses need to be culturally aware of what the client believes and help meet their dietary needs based on those beliefs.

There are various religious/cultural beliefs about death and dying. Overall, people want to die with dignity (Andrews & Boyle, 2003). Home death used to be the norm, but today about half of the population in the US dies in institutions outside the home. Because of cultural and religious differences, it becomes more and more important to understand client's beliefs and wishes regarding end-of-life care.

In some cultures, like American Indian or Iranian, death is a subject that is avoided (Baltaglia, 1997). For some, talking about death may bring a feeling that the family has lost hope. Some clients/families do not want anyone to die in the home. For example, many African Americans believe that this may bring bad luck and some American Indians may believe this will pollute the home with troublesome spirits (Baltaglia, 1997). Others, such as many Hispanic Americans prefer to die at home because of a fear that their soul will get lost (Baltaglia). Muslims also typically prefer to die at home (Cheraghi, Payne & Salsali, 2005).

There also is controversy about giving patients bad news about a terminal illness. In western culture, there is a belief that the patient has a right to know their diagnosis in order to make an informed decision about their care. This "truth telling" may be in conflict with other cultures who believe that it is in the best interest of the patient not to

“burden them” and destroy their feelings of hope (Srivastava, 2007, p. 236). Several non-Western cultures prefer not to have the diagnosis disclosed. These include: Asian, Japanese, African, Bosnian and Italian. These cultures perceive direct disclosure of a terminal diagnosis as inhumane (Srivastava, 2007).

Another problem encountered by nursing is the use of other remedies by other cultures. Not all cultures or religions for that matter, believe in Western medicine as the only way to cure or comfort someone. Many cultures practice other types of cures/comfort measures for their particular population. Acupuncture (Chinese, Japanese) is using needles at specific body points to allow the qi (concept of energy and vitality) to flow and therefore improve health (Srivastava, 2007). Herbs are also a source of healing or comfort for many cultures (Chinese, Hispanic, Japanese, Appalachian, Amish) (Giger & Davidhizar, 1999; Lemon, 2002; Donnermeyer & Friedrich, 2002). Folk medicine and use of folk healers is passed down from generation to generation can also be used (African American, Appalachian, Russian Americans, Filipino Americans) (Giger & Davidhizar, 1999). When nurses are working with clients, families may want to continue the use of these remedies. Nurses will need to be sensitive and understand how these work in relation to other medical treatments being done.

Some cultures believe in religious or spiritual objects that they feel need to remain with the patient. Understanding how these objects fit into the beliefs of the family and patient is important for the nurse. Removal of the objects can be seen as causing the patient harm (Andrews & Boyle, 2003).

Different religions/cultures vary on their practices towards the end-of-life. Catholics practice anointing of the sick by a priest which is performed close to a patient's

death. The ability for Sacrament of Reconciliation (confession) where a priest grants forgiveness from God is also practiced in the Catholic faith (Zerwekh, 2006). In some faiths, there is use of prayer, scripture reading or hymns as a comfort to the dying patient (Protestant, Jewish, Baptist) (Zerwekh, 2006). Hindu's and Buddhist's may use chanting, incense and rituals to help comfort the dying patient (Zerwekh, 2006). Cultures/religions differ on their view of death. Some believe that this life is a preparatory state for something better (Christian, Jewish, Protestant, Muslim) (Zerwekh, 2006). Others believe in reincarnation (Buddhist, Hindu) (Zerwekh, 2006).

There are many things that the nurse needs to consider when working with diverse populations. Being culturally competent becomes extremely important when working with those who are ill or who are dying. In the US, the population will continue to become more diverse in the future. This affects the care given to patients.

RESEARCH ON DEATH AND DYING

There were only eight articles that addressed nursing students' perception of death and dying or their experience with death and dying found in the literature. For this reason, the literature review was expanded to include the experience and perceptions of nurses, medical students and physicians as well as selected articles involving patients and family perceptions of care received. There are several areas that will be discussed in this literature review which are: thoughts about dying, feelings about dying, communication and education.

Thoughts About Dying

A qualitative research study was done using a phenomenology design to better understand the nursing students' experiences providing care to dying patients. Twenty-

six nursing students were asked to write their experience of taking care of caring for a dying patient. Students' became aware of the need to work with both the patient and the family and at times, found this emotionally draining. Students' also realized their role as patient advocate and they were frustrated at times because they felt they could not fulfill this role. Students' also felt that a large portion of their time was spent in caring for the dying patient physically, mentally and spiritually. Through their experiences, students' felt their experiences with the dying patient taught them something about themselves. Students' were able to identify strengths they did not know they had (Beck, 1997).

Consistent findings were reported in another study conducted with nursing students (Loftus,1998). Students identified several areas that they felt needed to be discussed in the theory part of the courses. These included nurse-patient relationships, communication difficulties, ethical dilemmas related to sudden death situations, sudden deterioration, and mechanistic care and resuscitation policies.

Part of the student nurse's educational experience takes place in the clinical setting. Several research articles look at the experience of the nursing students. One study examined nursing students' attitudes after education and experience as companions with palliative care patients and nursing students. The nursing students were assigned to be companions and a comfort to patients at the end of life who have no family present or who have limited family available. This program was on a volunteer basis and students were given independent study credit. There were two meeting sessions before students were placed with patients. At the end of the semester, there were significant differences between the study group and the control group in knowledge and attitudes toward end of life care with Palliative care companions reporting more positive attitudes. Also,

companions reported fewer concerns of nursing the dying patients (Kwekkeboom, Vahl & Eland, 2005).

In another comparison study, researchers found that emergency room nurses were more likely to avoid thinking about death than hospice nurses. Emergency room nurses also showed a greater fear of death and less acceptance of death than hospice nurses (Payne, Dean and Kalus, 1998). The hospice nurses continually took training and development courses to help them work with the dying population. This suggests that student nurse's perceptions and attitudes about death and dying may be influenced by their experiences in clinical settings as well as coursework.

Life experiences can have an influence on how students' perceive death and dying. Events such as death of family or friend, religious upbringing, near-death experiences and personal meditation can all have an influence on a students' perception of death and dying. Franke and Durlak (1990) investigated the impact of life factors on college students' feelings about death. Subjects completed a self-report scale and then were individually interviewed regarding their life experiences related to death. Subjects identified important life events that affected how they looked at death and dying. Researchers also found that "modeling effects were important for participants influenced by the reactions of significant others to a particular death" (p. 46). How others react to these life events also help form perceptions about death and dying.

Comfort is an important component to the dying patient and their family. The medical profession has come a long way in being able to make patients comfortable during the dying process. In a questionnaire study that asked Korean nurses' their perceptions of the elements of good or bad death, it was found that comfort was identified

as an important element in a good death. Other qualities were: pain management, not being a burden to the family, a good relationship with the family, preparation for death and belief in perpetuity (Kim & Lee, 2003). Kim and Lee argued that nurses were qualified to discuss death, dying and treatment preferences with patients as nurses, not the doctor, are at the bedside. Nurses are usually the ones that talk with the patient, provide emotional support and comfort measures for patients and their families. Another study, this time with intensive care nurses, also found that comfort of the patient was a major concern (McClement & Degner, 1995). Researchers also identified encouraging family participation with the patient as being important. Respect for the body after death was also listed among expert nursing behaviors. According to Benner, Kerchner, Corless and Davies (2003), the passage from life to death is “reflective not only of the person and significant others but of the caregivers and their respect of dying as a human passage” (p.558).

Feelings About Dying

Sharma, Monsen and Gary (1996-1997) described a study comparing attitudes of nursing majors with those of other college students regarding death and dying. Nursing students showed significant attitudinal differences as compared to other students studied. Nursing students described positive attitudes in that they saw the caring experience of death and dying patients as both valuable and satisfying where as students had negative attitudes in that the thought of giving physical care to a dying patient and relating to families were difficult and made them uncomfortable. This study also compared attitudes between nursing students by class rank (freshmen, sophomores, juniors and seniors). There were no significant differences between sophomores, juniors and seniors but there

were attitudinal differences with the freshmen class. This may be due to the fact that at this level, the students have not yet had experience in a clinical setting where they actually work with death and dying patients.

It is thought that any experience with death and dying will have an influence on a person's fear of death and dying. One study found that actual involvement with another person while that person is dying can influence the student's fear about death; however, the change direction was not identified. It was only noted that those nursing students who cared for someone who was dying had a change in their level of fear (Schrock & Swanson, 1981). Another study found that an experiential program was more effective than a didactic type approach in helping students without a personal death experience to face their thoughts and feelings about death (Hurtig & Stewin, 1990).

In a qualitative research study, a phenomenology design was used to better understand the nursing students' experiences providing care to dying patients. Twenty-six nursing students were asked to write their experience of taking care of caring for a dying patient and six themes were identified. The range of emotions identified by the students included fear, helplessness, anxiety, anger, and frustration. Students' also became aware of the need to work with both the patient and the family and found that at times, this was emotionally draining (Beck, 1997). Another study also found that new nurses feel overwhelmed by the emotional strain of dealing with death and dying patients (Hopkinson, Hallett & Luker, 2003).

In a questionnaire study looking at demographic variables and nurses' attitudes toward death and caring for dying patients, it was found that nurses with more education and actual experience working with dying patients viewed death as an opportunity to

escape from a painful existence. They also accepted death as a reality and had lower negative thoughts and feelings about death (Dunn, Otten, & Stephens, 2005).

There were only four articles found that actually dealt with the student nurses' experience with death and dying. In two of the studies, researchers reported that student nurses felt the experience with death and dying to be emotionally draining. Both studies identify a need to help students deal with the emotional issues related to the death and dying client (Kiger, 1994 & Loftus, 1998). Another study completed in the UK looked at the cause of student anxiety when working with the dying patient. Data collection was done using reflective diaries and two group focus meetings. Research findings suggest that student anxiety stems more from aspects of the caring role than personal fear of death (Cooper, J. & Barnett, M., 2005).

Attitudes of entering classes of nursing and medical students toward care of the dying patient were reviewed (Gates, Kaul, Speece & Brent, 1992). It was found that talking about death elicited the most negative scores among both groups. Other researchers used reflection groups to help medical students look at their own personal and professional development (Pololi, Frankel, Clay & Jobe, 2001). One of the three sources of stress identified was issues related to death and dying.

Communication

There were a number of articles found related to the nursing profession and the topic of death and dying that focused on communication. A phenomenological study of new nurses' experiences was completed in Hong Kong. In this study it was found that nurses were not adequately equipped to communicate with the dying and grieving relatives. Subjects often expressed a sense of helplessness, frustration, uselessness and

even guilt when working with patients and families in death and dying situations (Wong & Lee, 2000). In two other studies, communication was also identified as difficult when working with dying patients (Sasahara, Miyashita, Kawa & Kazuma, 2003; Johnston & Smith, 2006).

As student's work with dying patients, it would be expected to find a shift in attitudes related to working with death and dying. One group of researchers conducted a study using a 2 section questionnaire that dealt with attitudes and experiences. They found that hours of death and dying coursework and general life experience had a significant influence on attitudes toward talking to dying patients about death and dying (Brent, Speece, Gates & Kaul, 1992-1993).

In a study with oncology nurses, subjects identified communication skills as an area that they were lacking in (Sivesind, et al., 2003). The evidence suggests that nurses believe more education needs to focus on communication skills, especially in dealing with death and dying patients and their families. Costello (2001) found that there was a lack of effective, open communication about death with patients. Researchers conducted an exploratory study of oncologists. It was found that respondents believed that 97 % of patients who are dying realize that they are dying but stated only 40% of these patients initiate conversations about end-of-life issues. It was also noted that more than half of oncologists have a difficult time talking to patients about their terminal diagnosis (Ramondetta, et al., 2004). Other researchers identified communication among healthcare providers, patients and families as areas that need improvement (Ciccarello, 2003; Wenrich, Curtis, Shannon, Carline, Ambrozy & Ramsey, 2001; McCabe, 2004).

Physicians also have difficulty with death and dying when dealing with clients. In

one study, physicians identified communication in many aspects of the death and dying process with clients as areas where physicians had difficulties (Levetown, Hayslip & Peel, 1999-2000).

A research study was conducted using a cross-sectional study of 180 randomly selected nurses from six randomly selected hospitals in Connecticut. A questionnaire was used looking at hospice-related training, knowledge and attitudes and personal experience with hospice. It was found that those nurses who felt knowledgeable about hospice and rated themselves comfortable discussing death related topics were more likely to initiate a discussion about hospice with terminally ill patients and their families (Cramer, McCorkle, Cherlin, Johnson-Hurzeler, & Bradley, 2003).

Faas (2004) wrote about her personal experience in dealing with dying patients and their families. She identified several skills that were important. Nurses should have expert ethical practice, skillful interactions and respectful relationships with patients, families and co-workers, and they should have the ability to respond to a situation in a timely manner. Again, communication appears to be a key factor in her experience. Other researchers also identified communication as an important nursing skill (de Araujo & de Silva, 2003, 2004). An ethnographic research study was conducted of patients, nurses and physicians. The design included participant observation and semi-structured interviews for gathering data. Researchers found that there was a lack of emotional interaction with the patient and the institutionalized nondisclosure of information about death and dying. It was found that both nurses and doctors were reluctant to have open communication with the patients about death and dying (Costello, 2001). Communication and respect were areas identified where student nurses and new graduate nurses needed

more skill development (Degner, Gow & Thompson, 1991).

In a survey of physicians and nurses regarding palliative care education needs, communication skills were identified as being the most important. Also, most physicians/nurses said that they were uncomfortable when patients or family were having discomfort related to the emotional aspects of dying (Samaroo, 1996).

A group of researchers conducted a focus group about the influence of culture on communication preferences in end-of-life care. Six focus groups were conducted with patients from a University hospital. There were thirty-six non-Hispanic white participants and 34 African-American participants. Researchers found that the groups differed broadly in their preferences for both content and structure of end-of-life discussions and on the values that influence those preferences (Shrank, et al., 2005).

There has been research conducted with patients and family members asking for their suggestions about good care during the death and dying phase. One researcher found that communication between caregivers and patients was an area of concern (Pierce, 1999). The research showed that caregivers did not take the time to explain procedures or to sit and listen to the patient. Family members were not always told what to expect during the dying process. This was frustrating and anxiety producing for the patient and the family. Also, patients wanted to be treated as a person and with respect.

A phenomenological study of 110 palliative care patients and 15 nurses working on the palliative unit in a Chinese setting was conducted. Researchers found four major themes emerged from the research. The patients identified the building of a trusting relationship through communication and caring, as two themes that were important (Mok & Chiu, 2004).

For many clients, the death and dying process brings about a reflection on spiritual matters. According to Kaut (2002), death is an “ever present reminder of our mortality and vulnerability to senescence and physical decline” (p.220) and the neglect of spiritual issues may “contribute to emotional, cognitive, and physical difficulties experienced at the end of life” (p.220). These issues fall under the communication area where students’ and nurses’ already feel a need for improvement. Spirituality and “meaning making” are important resources for clients for coping with the emotional and physical suffering of death (Breitbart, Gibson, Poppito & Berg, 2004, p.366). Moraglia (2004) states that the “acknowledgment of one’s mortality is associated with fears and anxieties and that in such an undertaking one can draw support from beliefs” (p. 337). Clients need the opportunity to explore and work through their spiritual beliefs. Nurses (including student nurses) need to be able to help address these spiritual areas with their clients.

Education

Death education is an important component in the nursing students curriculum. Nurses have verified the need for nurses to be educated about end-of-life care (Pimple, Schmidt & Tidwell, 2003). One study looked at the transition of new graduate nurses’ into the nursing field. In this study, it was found that new nurses did not feel ready to deal with death and dying patients (Delaney, 2003).

A case study was conducted using baccalaureate students who designed their own death and dying course curriculum. These students identified learning topics and learning experiences that would help them learn about death and dying in different areas. Students had a psychologist come in who worked with dying patients and their families

and discuss communication and emotional needs, a nurse psychotherapist came in to talk about grief and bereavement for families, and different religious groups came in and discussed cultural differences and spiritual needs. Students also planned community experiences to help reinforce those classroom experiences that they had. They went to a hospice orientation to learn about eligibility requirements, they went on a home visit with a hospice nurse, and they completed an advance directive form and discussed end-of-life requests with families. They also went to a mortuary to learn about procedures involved in preparing the body for burial (Birkholz, Clements, Cox & Gaume, 2004). Through all these experiences, Birkholz et al found that students felt it was important to communicate effectively with dying patients and their families.

Research was conducted on an oncology unit using questionnaires given to nurses. Researchers found eight underlying domains identified by participants. These domains were: communication with patients and families, knowledge and skill of nurses, treatment and informed consent, personal issues, collaboration as a team including patients and families, environment and system, and collaboration among nurses. These were areas identified by the nurses as being difficult areas to deal with when working with the dying population and areas where more education is needed (Sasahara, Miyashita, Kawa & Kazuma, 2003).

In most nursing schools, topics on death and dying are mingled with other areas of the curriculum. Researchers conducted a survey of 206 baccalaureate nursing education programs looking at the education that they provide in the area of death and dying (Coolican, Stark, Doka, & Corr, 1994). They found that “99% reported that their programs offered some sort of education about death, dying and bereavement; however,

only 16% indicated that this education existed as a separate course” (p. 36). Ferrell, Virani and Grant (1999) reviewed 50 text books on topics in various areas of nursing.

They found the following results:

1. Of the 45,683 pages of text reviewed, 902 pages were related to end of life content, representing only 2 % of the total content.
2. Of 1,750 chapters included in the texts, 24 were related to end of life, representing 1.4% of all chapters.
3. Overall, 74% of the content in the framework was found to be absent from the texts, 15% was present, and 11% was present and commendable (p.873).

Robinson (2004) discusses the necessity of end of life education in undergraduate nursing curricula. She states that there should be “mandatory inclusion of key elements of end of life care into undergraduate nursing education in the United States. Being able to provide optimum care is based on adequate knowledge and education” (p.89).

Education on death and dying issues to medical students has also been identified as an area that may need improvement. Results from a questionnaire received back from 23 United Kingdom medical schools were reviewed (Field & Wee, 2002). To the question “what is the greatest extent to which the topic of dying, death and bereavement is represented in your curriculum?” the following data was found:

On 3 programmes (13%) this material was covered in one or 2 lectures only, in 6 programmes it formed a module of a larger course, and in 3 it was covered in a separate course. In the remaining 11 programmes (46%), such material was integrated across the curriculum in various ways: as part of other teaching areas, as part of problem-bases learning, in special subject modules and/or in clinical placements. (p.562).

Coursework on death and dying topics is limited in many medical schools in both

the United States and in the United Kingdom. According to a study by Dickinson and Field (2002), the following information was found related to medical schools in the United States and the United Kingdom:

Hospice exposure was found in all United Kingdom medical schools, only 50 percent of students in the United States medical schools had hospice exposure. Of the 19 end-of-life topics listed in a survey, only eight were covered in at least 70 percent of the medical schools in both the United Kingdom and the United States while 13 were covered in at least 75 percent of the United Kingdom schools. Separate courses on dying, death, bereavement and palliative care did not seem to be the direction that medical schools wish to go. (p.184-185)

Sullivan, Lakoma, and Block (2003) conducted a survey of 1,455 students, 296 residents, and 287 faculty throughout the United States. The survey focused on the amount of education students received in school about death and dying. They found the following data:

Fewer than 18% of students and residents received formal end-of-life care education, 39% of students reported being unprepared to address patients' fears and nearly half felt unprepared to manage their feelings about patients' deaths or help bereaved families. More than 40% of residents felt unprepared to teach end-of-life care. More than 40% of respondents reported that dying patients were not considered good teaching cases, and that meeting psychosocial needs of dying patients was not considered a core competency. (p.685)

Education is an important piece of the process of students and nurses learning how to deal with death and dying clients. "Supervised clinical experiences with dying patients may be the most important part of a relevant death education program. Therefore, the death education module should be made available at the same time nursing students are having their first supervised clinical experiences with dying patients" (Johansson & Lally, 1991, p. 31). According to Norton and Thacker (2004) "a significant amount of learning can occur when an end-of-life experience takes place

under the direction of a faculty member. Faculty members can function as role models and facilitators who help students understand their feelings about the dying experience” (p.67).

It may be that even a short course may influence nurses’ attitudes. It was found that nursing students in the one week intervention group had a significant positive increase in their attitudes toward care of the dying after the class (Mallory, 2003). Kaye, Gracely and Loscalzo (1994) also saw improvement in students’ attitudes toward dealing with death by participation in a course on death and dying. Other researchers found that educational programs for nursing should focus on the “consequences of specific behaviors of the nurse rather than on death anxiety in nurses” (Waltman, 1990, p.55). Rooda, Clements and Jordan (1999) suggested that nurse educators should include an assessment of “death attitudes and interventions aimed at decreasing negative attitudes and increasing positive attitudes toward death in such programs” (p.1683).

The research literature shows that there is very limited time spent on the topic of death and dying in the classroom setting (Coolican, Stark, Doka, & Corr, 1994; Ferrell, Virani and Grant, 1999; Robinson, 2004, Yabroff & Mandelblatt, 2004). The literature also states that nurses working in areas where they take care of dying patients have limited education on topics related to death and dying (Wong & Lee, 2000).

In addition to lack of education on the topic of death and dying, research shows that there is a lack of knowledge in the area of diverse cultural groups. One study explored the views of one group of healthcare professionals on the importance of cultural awareness in healthcare practices. Ten nurses of varying age from two counties in Scotland who worked in a variety of clinical settings were interviewed. Researchers

found that there was a lack of knowledge and understanding in relation to the diverse cultural groups who were members of the country. They also found a gap in nursing education and training across a range of healthcare areas (Leishman, 2004). Mazanec and Tyler (2003) also discuss the lack of cultural knowledge with patients at end-of-life and the need to be culturally competent.

There is research that demonstrates ways to help students learn about other cultures successfully. One researcher discussed a service-learning program for freshmen at Indiana University Purdue University at Indianapolis. The program was used to promote cultural awareness in a course for prenursing students. Community nonprofit agencies servicing diverse populations across the life span were used as places students could volunteer. Students were given assignments to go along with their experiences. Students reported personal transformations as a result of the service-learning experience with diverse populations.

The medical community has also seen the need to educate future physicians in cultural competence. One of the areas identified as a way to improve skills and knowledge was the use of clinical education experiences rather than isolated workshops. Reinforcing culturally relevant knowledge and skills can be done in the clinical setting and cultural issues can be discussed with students (Kripalani, Bussey-Jones, Katz & Genao, 2006). Another article discussed the need to have a comprehensive curriculum for continuing cultural experiences and assessment within the undergraduate medical education programs. The End of Life Nursing Education Consortium has developed an educational program that teaches culture, ethnic identity, religion and spirituality. Comprehensive education for nurses in regards to culture and end-of-life issues is

identified as being important (Matzo, Sherman, Mazanec, Barber, Virani & McLaughlin, 2002).

Summary

Attitudes about death and dying have changed during the last 100 years. Religious and cultural beliefs affect a person's perception and attitudes towards death and are important for student nurses to understand and be aware of when working with dying patients and their families. Nurses' thoughts and feelings while working with dying patients need to be considered by educators in an effort to help them better work with and support the patients and families with whom they are working. Communication skills are also important when working with patients. Being able to help patients discuss their thoughts and fears is important in nursing.

From the literature review, it can be seen that death and dying is an important component of nursing education. Because clients are living longer and are more critically ill than in the past, it becomes necessary for nurses to be able to discuss this topic with both patients and families.

CHAPTER III

METHODS

Participants

A purposeful sampling approach was used for this study. The subjects were junior level nursing students in a basic 4 year nursing program at a large metropolitan area university. The courses were in an undergraduate program leading to a baccalaureate degree in nursing. The sample consisted of 13 basic nursing students' ages 20-42 enrolled in a nursing program at a Midwest urban university. The hospital settings used for the clinical sites were several small to medium size urban hospitals within a large metropolitan area. Some of the participants did have some medical background in a healthcare related area. Participants had completed a Tertiary Strategies Clinical training experience at several urban hospitals. Each participant was in a clinical rotation on a medical floor with patients who were diagnosed with a variety of illnesses. The nursing students had completed their first two semesters in a medical clinical setting with patients who had chronic illnesses.

Students had courses where some theoretical knowledge had been taught related to death and dying. Students also had a class in which therapeutic communication

techniques were discussed and students had practice using the skills in the clinical area. Participants had anywhere from one patient who fit the criteria to up to six patients who fit the criteria. Some students work as a nursing assistant where they have worked with death and dying patients and their families and this data was included in the collected data. The researcher did not teach any of the students in this study in a clinical rotation. All 13 participants in the study met the inclusion criteria in which the students cared for at least one patient in at least one of the following three situations:

1. the patient was actively dying
2. the patient was diagnosed with a terminal illness during the time the student was with them or
3. the patient went into cardiac or respiratory arrest and died during the student's care.

Students were on adult medical floors with patients ranging in age from 20-100. The majority of patients on the medical floors were age 40 and above.

The make-up of the class changes from semester to semester. The makeup of the student population of the class used in this study was: 82 % female, 18 % male, 88% Caucasian, 6% Hispanic, 2% African American and 4% Eastern European. The aim for the research study was to solicit participants who are representative of the student population for this class.

For this study, exactly 13 students from the class of 48 students met the criteria and all 13 volunteered to participate. The participants did not match the make-up of the class as hoped but were close. Participants ranged in age from 20 years old to 42 years old. There was 1- 20 year old, 5- 21 year olds, 2- 22 year olds and one of each who was

24, 26, 31, 38 and 42 years of age. There were 3 (23 %) males and 10 (77%) females. Of those participants in the study, one was African American, one was Hispanic and the other 11 were Caucasian. Two of the students had degrees' in other disciplines. One student had a bachelor's degree in biology; the other participant had a two year technical degree and bachelors in Biblical studies. One of the students had spent time with the military in Iraq.

Twelve of the participants reported working in the medical area. Five of the students had worked in the medical area for less than eight months at the time of the study. The other seven participants had worked in the medical field in some capacity from eight months to almost six years. The medical settings and jobs varied. Some of the students reported working in areas where they did not have any hands on contact and then changing jobs later to become nursing assistants. The areas where participants reported working included oncology, medical-surgical, cardiac, float pool and one student was an emergency medical tech (EMT). One participant had never worked in a medical area. Participant data is summarized in Table 1.

Researcher

The researcher for this study is a Caucasian female in her mid-forties, with a master's degree in nursing education/geriatrics. She is currently a doctoral student in urban education where she completed a doctoral course in qualitative research. In this course, a small research study using qualitative methods was completed. She also has had several courses on quantitative research methods. She has been a nurse for twelve and a half years at a large urban hospital. Approximately eleven years of this experience was on medical floors, nine and a half years were as a staff nurse working with acutely ill

Table 1

Participants Demographics

Gender	Age	Race	Previous Medical Experience	Other Degree
F	20	European American	8 months	none
F	21	European American	5 years 8 months	none
F	21	European American	7 months	none
F	21	European American	1 month	none
F	21	European American	7 months	none
F	21	European American	7 months	none
F	22	Other	8 months	none
F	22	European American	4 years 6 months	none
F	24	European American	1 year 1 month	none
M	26	European American	1 month	Baccalaureate
M	31	Hispanic	5 years 0 months	none
F	38	European American	0	none
M	42	African American	1 year 5 months	Baccalaureate

Note. Number of participants=13

patients with chronic, progressive disease processes. She has worked with many patients who were actively dying or who were diagnosed with a terminal illness during her care, and has worked with many family members of patients who were in the dying process.

For the past three years, the researcher has been working in the float pool at the same hospital going to various floors that were short of staff. The floors that she has worked on included cardiac, medical, surgical, palliative care, and cancer floors. She has continued to work with patients who were actively dying or diagnosed with a terminal illness during her care. In addition to being a staff nurse, this researcher has been engaged in didactic and clinical teaching in the nursing department at a Midwest urban university for over 7 years. She has taught clinical rotations in the medical, surgical, and advanced medical areas. Students are exposed to death and dying patients in these areas. This researcher has biases coming into this research project. She has experienced a wide range of emotions when dealing with dying patients and their families. Her thoughts, feelings, and communication skills have changed over her 15 year nursing career. Feelings of sadness are still present when working with dying patients; however, she is able to separate work and home. The feelings of sadness do not affect her home life. Her spiritual beliefs about death and dying have strengthened, and she no longer has a fear of dying or working with dying patients. She is no longer afraid to talk about death and dying with patients or their families, but realizes that the choices made have to come from the patient and the family. Her role when working with patients and families is that of support and giving information. As an educator, she has worked with students in the clinical setting and has had discussions with them about their patients and how to approach the topic of death and dying. She has seen how different students are affected

by these patients and their families and how they handle the different situations that arise. She had some preconceived notions before starting this project.

Based on literature reviews and her experience, the researcher expects students to identify a wide range of emotions when dealing with death and dying. It is believed that they will identify fear, frustration, and anger as emotions that they experience. Given the literature suggesting that nursing students lack the communication skills needed to talk to patients who are diagnosed with a terminal illness or who are actively dying and their families (Sasahara, Miyashita, Kawa & Kazuma, 2003; Sivesind et al., 2003; Delaney, 2002), she expects students to be uncomfortable communicating with patients and their families and identify communication skills as something they are lacking. In addition, it is expected that students also will identify physiological symptoms (e.g. nausea, headache, anxiety) that they have when working with this group of patients. The researcher also expects that students will probably state that they do not feel prepared to work with dying patients.

Measures

Demographic questionnaire. A demographic questionnaire designed for this study was given to all participants. The participants were asked their age, gender, ethnic background, education background, current education program, and experience working in the medical field. The demographic questionnaire is available in Appendix A.

Interview Questionnaire. The purpose of this semi structured interview was to examine the participants' perceptions of death and dying. The interview questionnaire was based on a review of the literature on student nurses perceptions of death and dying (as well as nurses working in areas where death and dying occur on a regular basis). The

interview questionnaire is available in Appendix B.

The interview began with warm-up questions that address the type of floor the student was on, their education background, and experience in the medical field prior to becoming a nursing student. Next, participants were asked to describe an experience working with a dying patient and their family. Specific questions were asked regarding thoughts and feelings the student had while working with a dying patient and their family. Questions also focused on communication with the patient and family. Questions to encourage clarification and elaboration were used throughout the interview. Interviews were approximately 1 hour in length. They were audio taped, professionally transcribed, and checked for accuracy. There was only one interviewer for all participants. The interview questions that used can be found in Appendix B.

Procedures

Participants were solicited by attending a lecture class and identifying which students met the inclusion criteria. The interview took place on the university campus. The interview was done using a semi-structured format. Each participant was asked a set of questions via a one hour interview.

During the course of the interview, follow-up questions were asked to clarify and expand upon the information provided by the participant. Each interview was audio taped, transcribed verbatim, and checked for accuracy. The hard copy was used for coding. Participants' identities were kept confidential using a number to identify each one.

Permission was obtained through the university Institutional Review Board (IRB). A written, informed consent form (Appendix C) was given to each participant explaining

the purpose of the study, its risks, and benefits. The study and consent form were reviewed with each participant, and the purpose and procedures of the study was explained. Each participant was informed that they can withdraw from the study at any time. The participants signed the consent form prior to the start of the interview.

All consent forms are being kept separate for the audiotapes and transcripts. All study related materials are being kept in the researcher's office under lock and key.

Research Questions

The overall research question for this study are how do beginning nursing students experience death and dying in the clinical setting. The three associated questions are:

1. What are the thoughts that nursing students experience when working with dying patients and their families?
2. What are the feelings that nursing students experience when working with dying patients and their families?
3. How do nursing students report communicating with dying patients and their families?

In addition to the above three research questions, participants were asked how world views and cultural backgrounds affected them in regards to their thoughts, feelings and communication with dying patients and their families.

Research Paradigm

A social phenomenological paradigm was used for this study. A phenomenological study seeks to study the person's everyday experiences in relation to a particular group of people, in this case, nursing students. This method seeks to describe

the essence of the experience from those who have lived it (Merriam, 2002). Munhill (2001) states it well when she writes “I do not know you. I do not know your subjective world” (p. 143). Each subject sees the world differently. The researcher using phenomenology tries to capture the meaning that an experience has for each individual participant. Human involvement in the world is the main focus of qualitative researchers.

Phenomenology is a method used to gather descriptions of a phenomenon of everyday experience (Priest, 2002; Annells, 1999). Researchers need to understand that a person’s experience is subjective. Phenomenology seeks to look at the subjects’ experience and the relation it has with the experiencing person. The researcher attempts to understand the lived experience of the research subjects. The researcher puts meaning into their experience. This method insists on “careful description of ordinary conscious experience of everyday life (the life-world) - a description of things (the essential structures of consciousness) as one experiences them” (Schwandt, 2001, p.191). The things referred to include “perception, believing, remembering, deciding, feeling, judging, evaluating, and all experiences of bodily action” (p. 191).

In order for the researcher to be objective, they must let go of their preconceived ideas and notions about the topic being researched and focus on identifying the subjects lived experience. Phenomenological research is used to describe and understand the “essence of a concept” (Priest, 2002, p. 61). Phenomenology is not a research method but “rather a set of assumptions about humans, about science and about how we can acquire knowledge about other people’s ways of experiencing the world” (Sjostrum & Dahlgren, 2002, p. 339).

The aim of phenomenology research is to identify and describe the subjective

experiences of the research subjects (Giorgi, 2005). The data is reviewed looking for common themes and experiences. The categories developed from the collected data “are people’s various ways of thinking about their experience” (Sjostrum & Dahlgren, p. 342). The overall purpose is to understand how people make sense of their experiences (Merriam, 2002).

Research Method and Data Analysis

The aim of data analysis is to identify commonalities and differences in the individual experiences of participants. The goal is to keep the richness of the experience that each participant has with the patients that they cared for. The data analysis took place based on an eight-phase model developed by Denzin (1989), King (1994) and Sheehan (2004). Two additional phases were added at the end to verify information with the participants and categorizing the results based on number of participants who expressed the same idea within a domain. The analysis phase of the data was a series of overlapping activities that focused on a review of the transcripts and identification of the themes that emerged within the data. Each phase is explained in further detail below.

Contextualizing. Each transcript was reviewed with a read through to get a feel for each participant’s experience. The researcher looked for contextual information relating to the students’ experience in the clinical setting. The researcher specifically looked for information related to the students’ experience dealing with dying patients. No formal analysis was done at that time. This was a read-through only (Sheehan, 2004).

Bracketing. A bracketing technique was used for data analysis. Bracketing is a method of reviewing qualitative data. Bracketing is used by a researcher to set aside their own judgment and focus on the experience of the subjects. Bracketing is a way to focus

on the experience of everyday life (Schwandt, 2001). The goal is to understand how subjects experience their world in nursing when working with the dying patient. Each transcript was reviewed looking for key phrases and statements related to the participants' experiences in working with dying patients (Denzin, 1989).

Each transcript was concurrently read while listening to the audiotape. Listening to the audiotape helped the researcher take into account the participant's speech, tone of voice, pauses, word articulations, and other non-verbal communication that might be perceived on the audiotape (King, 1994). The transcripts were re-read at least three times or more during the analytical process to identify shared experiences of the participants (Denzin, 1989).

Theming. During this phase, the researcher arranged the data into themes that followed the three main research topics of thoughts, feelings, and communication. During this phase, the researcher re-read the transcripts to make sure that all themes were identified. A matrix was developed for the themes identified by each participant. This made it easier to see the common/shared themes and the more individual experiences of the participants. The list of themes was collapsed to a workable and more refined list. The final number of themes identified was twelve based on the data gathered and the ability to collapse the data without losing the meaning of the experience expressed by the participants (Denzin, 1989 & Sheehan, 2004).

Conceptualizing. During this phase of analysis, the aim was to find recurring experiences that are identified by the participants (Denzin, 1989; King, 1994). Transcripts were reviewed looking for the narrative excerpts from the interviews that best fit with the identified themes. These excerpts were written with the appropriate theme.

The interview number and page number of the transcript were listed with the narrative for easy identification and location. The themes represented the major, emerging concepts in the transcripts.

Refining. From the data, shared words, phrases and statements emerged into patterns that are common for several participants. Again, locating extracts of data that fit into the themes continued. During this phase, rereading of the transcripts was necessary to again make sure all data was accounted for. The number of themes was collapsed again in this phase with the final number being eight. The goal was to fit like data into a common theme (Sheehan, 2004).

Renaming. In this stage, identified themes were reviewed. Renaming of the themes was necessary for clarity and to help the reader better understand the events being described. Denzin (1989) uses the term “verisimilitude” to describe his approach.

Categorizing. In this phase, themes were reviewed for the purpose of placing them into categories. The goal was to cluster themes and to “present them as the logical representation of the stories of the participants” (Denzin, 1989; Sheehan, 2004). The initial categories were cognitive, affective and communication experiences. When it came time to go to this phase, the categories were reviewed to make sure they did not need to be changed. One additional major category was added which was world views.

Reassembling. During this phase, the data was put into a meaningful context. The lived experience of the participants in relation to taking care of dying patients was put into a narrative format. Denzin (1989) suggests using thick description in writing about the experiences of the participants. The identified categories were the guide for writing the narrative.

Confirming. After all data has been analyzed and categorized, the researcher confirmed the data with each of the participants. This phase was done to make sure that nothing was missed and that participants agreed with the interpretation of the data collected.

Categorizing the representativeness of the results. According to Hill, Thompson & Williams (1997), there is a way to categorize the representativeness of the results into categories. The categories were general if it applied to all 13 cases, typical if it applied to 7 to 12 cases (i.e., at least 50% of the cases), and variant (occasional, a few, 25%-49% of the cases) if it applied to 3 to 6 cases. The number of cases assigned to each category were placed in a table form for easy review.

Validation of results. Once the data has been analyzed and categorized, the participants were given the opportunity to review the data and validate the findings. This was done by providing participants with the table of findings and a copy of chapter four. Participants were given the opportunity to respond in person or via email about the results and verify that the results captured their thoughts and feelings about death and dying.

CHAPTER IV

RESULTS

The data was organized into six primary domains based on a review of the data and the research questions. These themes emerged from the interviews of 13 participants. The six domains were thoughts, feelings, communication, multicultural diversity, training and education and coping mechanisms. According to Hill, Thompson & Williams (1997), there is a way to categorize the representativeness of the results into categories. The categories were general if it applied to all 13 cases, typical if it applied to 7 to 12 cases (i.e., at least 50% of the cases), and variant (occasional, a few, 25%-49% of the cases) if it applied to 3 to 6 cases. The number of cases that was assigned to each category was placed in a table form for easy review. A summary of the domains, categories and number of cases per category are displayed in Table 2.

THOUGHTS

Everyone has thoughts about their work, who they are working with, their social contacts etc. Students are no exception. There are many thoughts that go through their heads as they learn new things, work with different instructors, and encounter new situations. Working with dying patients and their families can cause students to have a

Table 2

Conceptual Domains Emerging from Interviews

<u>Domain</u>	<u>Number of Occurrences</u>	<u>Representativeness</u>
Thoughts		
Physical, emotional, spiritual care	10	Typical
Family	8	Typical
Own Beliefs	8	Typical
They won't suffer anymore	6	Variant
It's Part of Life	5	Variant
Aggressive care	3	Variant
Was something Missed	3	Variant
Privilege	3	Variant
Feelings		
Fear	12	Typical
Sadness	11	Typical
Compassion	8	Typical
Physiological Manifestations	7	Typical
Upset	7	Typical
Nervous/anxious	6	Variant
Awkward	4	Variant
Frustration	3	Variant
Communication		
Not knowing what to say	10	Typical
Topic of death	10	Typical
Therapeutic communication	10	Typical
Unresponsive patient or nonverbal patient	7	Typical
Language barrier	6	Typical
Difficult patient and/or family member	5	Variant
Emotions	4	Variant
Dying process	3	Variant

Table 2 (continued).

Domain	Number of Occurrences	Representiveness
Multicultural Diversity		
Patient beliefs and values	7	Typical
Emotional expression	5	Variant
Role of the family	4	Variant
Training and Educational Preparation		
Lack of education/preparation	11	Typical
Novice to Expert	9	Typical
Coping Mechanisms		
Talking about the experience	12	Typical
Crying	4	Variant

Note. Total participants=13. General=applied to all 13 cases, Typical= applied to at least 50% of the cases (7-12), and Variant= applied to 25%-49% of the cases (3-6) Hill, Thompson & Williams (1997).

lot of thoughts that cause them to think of things that they may not have thought about before.

In this domain, students identified the thoughts they had while working with dying patients and their families. Participants had a range of thoughts when working with death and dying patients and their families. Some thoughts related to tasks that needed to be completed, some related to the decisions being made in regards to the patients' long term care and some related to thoughts about the patient. Within the domain of thoughts, there were eight categories. The categories included: physical, emotional and spiritual care (*typical*), family (*typical*) own beliefs (*typical*), they won't suffer anymore (*variant*), it's a part of life (*variant*), aggressive care (*variant*), was something missed (*variant*), and privilege (*variant*).

Physical, Emotional and Spiritual Care

One aspect of nursing is the care that is given to the patient including physical, emotional and spiritual. Students feel it is important to be attentive to patients in general but are concerned when it comes to those who are in the dying process. Several participants discussed their thoughts regarding the care given to patients who were dying.

At first I didn't even realize she was dying, I just thought she was like change in mental status or something. But when I did realize that I had to take extra special care with her, and she was kind of responding. You don't know if they can understand you, so I like was trying to talk to her, you know. I wanted to do everything I could, make her as comfortable as you can. Participant #3

This participant saw some physical changes in the patient and realized the patient was in the dying process. She took extra time with her to give her extra special care.

Another participant talked about giving good care not only to the patient, but to the family as well. Students understand that the family is part of those nurses take care of in their work. One participant stated:

I always give good care. I give good care all the time, just taking some special time with them. I definitely do that, especially with their family.
Participant #13

This participant recognized that the patient is not the only one who needs extra care. She sees the family as needing extra time and care when they are dealing with a loved one dying.

The family is an important part of the care provided to the patient. The students understand that we provide care for the family, too. Care of the patient can be a way of caring for the family. Another student talked about the need to give good care and take time to show the patient and family that they care.

When I come into the room as a nursing assistant, you want to communicate to them that we are here to do what we can to comfort them. Like the first man was dying, the nurse I was working with wanted me to get this device; it was like a little pad to put around the elbow. Here he was probably expected to die. They probably expected him to die the day before, yet still the nurse suggested getting these things to protect his elbow. I think that communicated to the family that the staff cares. Even the idea of turning, I don't think a lot of families know the importance of turning, so when you come in to turn a patient you may have to explain to them why you want to turn them. I want to turn them because we don't want them getting any bed sores while they are dying. It may not seem that important, but I think that's still important to communicate to them because you are trying to care and give the best of care to the patient. Even though on one hand it may not mean anything, if the patient is just hours away, but on the other hand it is saying that people care. It's about the living, so if you communicate that there are people that care, which may be a sense of comfort. Participant #9

This participant identified demonstrating caring as a way to communicate to the family that the nurse is there for them and that they care about that person. He felt that it is comforting to the family to know that someone is concerned for their loved one.

Students take care of the body after death. This can be an emotional experience for them especially if they never have been around a dead body. Students identify the need to take special care with the preparation for the body. One participant talked about the care he gives to those who have died.

Because there is such a degree of dignity and respect that I think we all are obligated to give to another human being, regardless of who they are. When a person dies, I believe that the real person is no longer there. You don't just throw a corpse away. You have a degree of respect for it. It's unlawful to abuse a corpse. I think that is just ingrained within us throughout the years that we are to give respect to the remains of the departed. Participant #9

Students who have little experience can have strong feelings when working with dying patients and their families. Morgue care is something students may come in contact with in the clinical setting. Morgue care is when the student has to get the body cleaned up and ready for the family to visit and then to go to the morgue or funeral home. This participant felt it was important to give good care to those who have passed on.

Sometimes students have patients who want to have someone pray with them or perform some type of religious ritual like reading the scriptures or listening to music. One participant talked about a patient who she spent time with.

We had two patients that day. She was already working with the therapy aides when I got there so I was more concentrated on the other patient but I was able to spend some time with her. Actually I prayed with her, I remember because she was upset. She kept coughing all this stuff and was having a hard time, and I named one of my fish after her. Participant #1

Prayer can be helpful to the student and to the patient. It can bring comfort to both.

Another participant talked about his experience with his patient.

She was in denial; we were talking about a diagnosis. She was dying and she was still in denial, so much denial that she was refusing any treatments or anything. So we were talking and a lot of the nurses were frustrated with her so I decided that I was going to, you know, go in there and do the best I can to help her get through this situation. So we sat there and we talked and we had a common bond in religion. I'm Catholic and she was another form of Christian. I think she was Baptist. So we had talked and I tried to help her understand that, you know that you need to make a decision of what you're going to do. Now God's not going to fault your decision, any decision you make, but this is, you know, I'm trying to explain to her that this is real and if you want treatment, you can approve the treatment. If you do not want treatment, you don't have to. We sat there and we prayed. She actually made no decisions, but I helped her try to get past that denial phase and start going into bargaining, which she did do some bargaining in there actually, not just straight denial any more. She did verbalize to me that if she prayed more, God may take this away from her. Participant #7

This participant recognized that for some people, praying is comforting. Even though a decision was not reached with this patient and her treatment, the participant could see that the patient was able to start moving forward in the Kubler-Ross stages of grief. She was able to use her religious beliefs to start moving forward.

Family

Some patients are alone in life. They have no family or friends to help support them through the trying times, especially in the dying process. One student spoke about a homeless, orphaned man who had spent his life traveling from state to state and had no family or friends. The patient was diagnosed with terminal cancer and had no support system. This student commented:

I went home and thought about it and was talking to my husband. I'm so glad that we have family. I can't even imagine, for this poor guy to have to go through this by himself. Participant #13

This student felt a sense of sadness that the patient had to face death all alone. There was no one who would be with him. She was then grateful for her family and realized how important family was to her. Another student talked about another patient who was alone.

His family was actually in Florida, his parents. He had a care person here but I never saw her. He was twenty-six years old and he was mentally retarded, had cerebral palsy, a peg tub, he had everything. There was no family. He just had a sign, like all about him. When he makes this face it means this and when he makes this noise it means that. He was just coming back in and out of the nursing home and kept coming back to that floor. He got switched to hospice. Participant #6

This patient was alone here in Cleveland and his family was in Florida. The student never saw anyone that the patient might know in the room with him. This can cause some reflection by students about family. It can also bring up feelings of sadness for the patient.

Own Beliefs

Not all students have come to terms with their own beliefs about death and dying. When faced with patients who are dying or have terminal illnesses, it causes the student to have to do some reflection about themselves. One student stated:

I believe the first time I saw someone die, the first thing I thought is, oh my gosh, where does it go? I know it sounds really dumb. I guess it is like a thought that a three year old would have, but I never had seen a dead body before, and I was just like wow! It was like something really leaves. That was my first thought and then it just has made me think about what I think in terms of like after, or as to what happens when you die. That really made me think about that a lot. Participant #13

This participant had never really faced death and in nursing school is forced to face the idea of death and think about it. Another participant, who was in Iraq, was forced to face the idea of death before nursing school. He stated:

At thirty years old, not a lot of people have to sit there and come to their own terms that they might die. I've already gone to Iraq, already had that discussion with myself, I've already prayed on it. I've already done all the things that I need to, so right now I live my life in a way that if I die tomorrow, I wouldn't have that many regrets. I want the people that I love to know that I love them. There's only two ways to come out of an experience like that, better or worse. I chose to come out better and it's a choice. Participant #7

This participant had to face death in a very different way than most nursing students do.

He had made a decision and choice about what death meant to him and how he was going to handle it. It did affect his thought process when working with dying patients and their families.

They won't suffer anymore

Students spend time caring for patients in the acute care area or in a nursing facility. They may spend days or weeks watching and caring for a patient who is critically ill and not expected to get better. A few students talked about the patient's release from suffering as something that they thought about. One participant stated:

She was sick. I don't know what she was sick with but her husband said that she was sick for awhile and I don't think in situations like that, you know, they are not suffering anymore. When somebody has been suffering for a long time, I feel like it's a release for them, like its better that way. Participant #6

This participant identifies death as a relief from suffering. It was hard for her to see the patient suffer and there was a relief felt for the patient when they are no longer dealing with the illness or pain.

Another participant spoke about death and situations where it is not so sad when someone passes away when she stated:

I think depending on the circumstances, I am a little bit more accepting of it. It is sad, but it's like okay, they are in a better place. That's how I feel about it. Participant # 10

This participant felt that the circumstances can play a role in how she perceives a patient's death. If the patient is suffering, it may be easier for her to accept the patient's passing.

Another participant talked about a patient who had her family with her. The participant stated:

She was an elderly lady in her eighties and she had lived a good life. She did tell me that and you know, she had lots of family and they were all around her. It made me feel like she was going in peace and she had been well taken care of. Participant #5

This participant had spoken with the patient who had stated she had lived a good life. The participant felt like the patient was going in peace and it provided some comfort.

It's part of life

When nurses work with patients who are terminally ill or dying, it makes them aware of life and death. It puts it at the forefront where it has to be thought about.

Students express their thoughts about having to think about death in relation to themselves. One participant talked about a younger patient and stated:

It makes you think how it could affect anyone really, given the age of the patient. Something like that could happen to almost anyone and it is hard to prepare. Participant #8

This participant felt that it made her think about death and dying when she worked with those patients. She realized that it could happen to anyone and that it was difficult to prepare for death. Some participants have come to a realization that death is a part of life and some have come to accept it. One participant stated:

There was not any sadness, just reality. I guess it was like a point in life where this is what's going to happen and so you accept it. That is where I am at in life now. I don't like people dying, but you know it's something that we all have to come to accept. Participant #9

This student has identified the point in life where he accepts death as a reality.

Having to work with dying patient's made this student look at this part of life and confront it and come to some idea about what death is for them. This same participant stated the following about a patient who died:

I wouldn't say it was intense because death happens every day. Because of my own spiritual thinking, if you will. For me it is like just something I use to keep me centered, kind of put things into perspective. Participant #9

For this student death is a part of life. Death helps keep this student focused on important things in life. He realizes that death happens every day and this realization helps him to put things into perspective.

One participant talked about their experience in caring for an elderly patient. The patient was in hospice but was in a subacute unit. In this type of facility, the patient gets physical therapy to gain strength. She expressed her view about death and dying. She states:

She was an eighty year old lady. It was kind of a while ago but I do remember thinking, like why was the situation the way it was. She was on the subacute floor and it just didn't seem like it was the right place for her. I don't know, the only thing that I could think of was that around society death is kind of taboo, like people try to avoid it like the plague, but I think you know, it's a natural part of life. Maybe they are just trying to avoid it or something, I'm not sure. Participant # 11

This participant did not understand why the patient was in subacute since they were in hospice and were not expected to live much longer. This did not make sense to her. She expressed the idea that perhaps the patient or family were not talking about death and the patient's prognosis.

Aggressive Care

The category, aggressive care, illustrated the idea that students did not always agree with the aggressive treatment given to patients especially if they were terminal or had little hope of surviving, or were frail and elderly with not much chance of an improvement in their quality of life. One participant talked about her experience with an elderly woman who was unresponsive and her son, who was the primary caregiver. The patient had been in and out of the hospital for a long time and was not getting any better. The son wanted everything done for the patient to keep her alive.

She was not really responsive, like she would look at you but with wide eyes, they were probably like stop doing this to me. So finally one day I came in and I had just seen her the day before and I asked where she went because I figured she would still be there. She had passed away during the night. He finally signed the DNR (do not resuscitate). I think 'finally she's free.' Participant #1

This participant felt that doing things to prolong someone's life may not be in the best interest of the patient. She had been able to work with this patient over a long period of time and see the negative effects of aggressive care for the patient.

This same participant talked about another patient who was unresponsive. With this patient, the participant did not see the negative effect of aggressive care until after the patient had passed on. She stated:

After the fact I thought, I was kind of mad that they had removed the feeding tube, I thought, like are you just going to let him die. But when I began to see afterwards, like in all the other clinicals, how you can keep someone alive but they are really not alive on the inside, I was kind of happy that he was finally able to pass, because he had been like that for awhile. A lot of time it (aggressive care) is for the families benefit, not for the patient. Participant #1

This participant reflected back on her experience and was able to see that maybe the quality of life may not have been good and aggressive care was prolonging the patient's life but not improving the quality of life.

Another participant also talked about the use of aggressive care in her patient.

The patient was burned over 92% of the body. Aggressive care was given to the patient to save him. Participant 2 stated:

He came in and there was pretty much no chance for him, but he was a younger guy, you know. It was very aggressive dressing changes and surgeries and stuff and I remember, like thinking, all that he went through and he died. Why did he have to go through all these issues instead of passing in the first place? Why would you put him through that? I think it's almost like a thing between the doctors too. They need to not give the family such hope. Participant #2

This participant felt that the aggressive care was not really for the patient and the patient had to suffer with the treatments of burns which are painful. She thought about why the doctors were doing all this aggressive care when it was not going to help. This same participant also talked about another family and the choices they made in regards to the patient.

Some of the thoughts I get are like they are being selfish. Why are they holding on to them for so long? But then I realize, you know, I see what goes on behind the curtains and they don't and they just see their family member and their loved one and their life. As a nurse you have to stay focused. It's just questioning the family's decision when it's really not your (the nurse) decision to make, you know. Participant #2

This participant had difficulty trying to make sense of the family's decision to continue with aggressive care of the patient. Although she recognized the fact that it is not her decision to make, it was still something she thought about.

Was something missed?

One of the things student nurses may deal with and think about is whether or not they missed something. Depending on the situation, some students express a concern about missing a clue that might have alerted someone to a potential problem. Students are new in the area of nursing and are learning. They become concerned that due to their lack of knowledge, they may not see something that was important. One participant discussed this fear in relation to her patient who died suddenly.

I think that every time I encounter a dying person I'm still going to feel the sadness, the anxiety that they are going to die while I'm there and that I didn't do enough for them. That was one thought that did go through my head a lot, was did I miss something. Was I, and it's not that I wasn't thorough; it was just, you know, could I have prevented it somehow.
Participant #5

This student was concerned that maybe she missed something that might have been a clue that the patient wasn't doing well. The idea that maybe something was missed in an assessment or in what the patient said was a source of stress for this student.

Another participant made a statement related to this idea of missing something. His idea ties into the novice to expert theory. He stated:

I'm building on what I've learned and therefore hopefully I'll make less mistakes and be more efficient, effective and become a more honed instrument. Participant #9

This student felt that experience can help him become more aware of what is going on with the patient and hopefully be able to recognize problems early where they can be addressed before the patient arrests.

Another participant talked about signs and symptoms of one of her patients that may not have been taken seriously until it was too late. Her patient had complained of a

headache that was pretty bad. The participant had told the nurse several times because it did not get better with medication. She stated:

There was one time a younger man, it was sad, he was in his fifties and he had hemorrhagic stroke while he was there. I remember it was like a really, really busy day and I went in there and he kept telling me like I have a really bad headache and I told his nurse but it was kind of awful. But the headache, he just said I have a headache, it was kind of not taken, I don't think as seriously as it really was. He was just given maybe like Tylenol. The headache got worse and worse and then his vision started going. So then they knew that it was serious and they like rushed him down to the CT scan and found that his brain was like completely filled with blood. I was there when they called a code. He died shortly after that. Participant #4

This student felt like the patient complaints were not being taken seriously and that this may have been a sign of a problem that the patient was having. This student looked back at the experience and saw that the patient was having problems when he complained of a headache.

Privilege

One student talked about being able to care for dying patients as a privilege.

Death is a part of life and some students see it as an opportunity to work with those who are going through the dying process. One participant stated:

There may be a sense of, I can't find the right word, of privilege, I think, whenever you are able to help another person. I personally think we were made to serve and whenever you have opportunities to serve and to do good for somebody else, to comfort, or help them, there is like a sense of doing something worthwhile and meaningful. Participant #9

This participant looks at the nursing art of caring and sees it as worthwhile and meaningful to care for someone. This is a concept that this participant identifies as being important.

Another student also talked about her feelings of taking care of the terminally ill patients and their families. She stated:

Dealing with the family, I guess is like being rewarded or feeling almost blessed you were able to be there for them. If you have worked with them for a long time and then you are there at that moment, you almost feel that is the rewarding part of it, it is being able to be supportive for the family.
Participant #2

This participant was glad to be there for the patient and the family. It was a rewarding experience for her to be able to care for the patient and their family during the dying process.

FEELINGS

This domain focused on the feelings participants had while caring for dying patients and their families. Within the domain of feelings there were eight categories which included: fear/scary (*typical*), sadness (*typical*), compassion (*typical*), physical manifestations (*typical*), upset (*typical*), nervous/anxious (*variant*), awkward (*variant*), and frustration (*variant*).

Fear/scary

Another feeling expressed is that of fear. Students can have fear when working with dying patients, fear that they (the student) will get a disease or fear when having to do certain procedures with the patient. One participant commented:

Sometimes it is fear. You see what they go through. Oh my God, even if it's like a disease process. Like going to nursing school, you learn about a lot of stuff. What if I get that, what if I get this? It is hard to separate that fear from taking care of the patient. Participant #2

This participant was connecting diseases she had learned about in school and her fear of possibly getting these illnesses.

One participant talked about his experience in a code situation when the patient was having difficulty breathing. She stated:

I was just taking care of another patient and I heard someone call a code. I guess a doctor was in the room taking care of another patient in there and she heard like gurgling noises and so she felt like that other patient in the bed was aspirating. So she called the code and all the nurses came and were doing like CPR and stuff on her and they ended up taking her to the unit. That was my first experience. It kind of makes me wonder when I'm a nurse, I just hope I know what to do, if it ever happened to me. I just don't want to be fumbling around. I just kind of watched the nurses. It was scary, I was just more worried for her and her roommate was coming out and she said 'oh my God, I was talking to her sister and she told me to look out for her.' So I was kind of dealing with her roommate too. But it was scary. Participant #10

This participant was scared by the code. She stated that she has a fear of not knowing what to do in a code situation when she is a nurse. She also talked about this being her first experience and that it was scary to watch what was happening.

Students may be afraid to work with dying patients and their families. One participant talked about her experience. She stated:

First I was scared. I was going to run in, be nice, smile and leave and then I realized like they kind of want to talk to you even though I don't really have much to say. I don't have any information for them so they are like, 'oh do you think he's comfortable like that.' I don't know much but I know a little more than them so they kind of look to you. I'm just an aide. I don't really know anything compared to the nurse or the doctor that would help them, but they still look to you. They just want to know anything they can. Participant #3

This participant was scared to go into the room. She wanted to go in quickly and leave but she realized that the family wanted to talk and get information. She saw that they need to be able to talk and ask questions. Even though this participant did not feel like she had a lot to offer, she still took to time to be with them.

One of the fears that some students have is actually having the patient die while in the student's care. This can be a very scary thought for some students. One participant talked about her fear of death and dying. She stated:

I was scared that she was going to die while I was there and I was going to have to do the morgue care. I had never done that and didn't want to have to do it. The whole touching a dead person just freaks me out. Participant #5

This participant was afraid that the patient would die while under her care and then she would have to do morgue care. The participant had a fear of touching a dead body.

A number of emotions were expressed in relation to morgue care. Morgue care (preparing the body after death) can be something that causes strong emotions in participants. This participant talked about her experience with morgue care. It was the first time she had touched and cared for a dead body. She stated:

She (the practitioner) listened to her heart and all that and then after that me and Professor and the patient's nurse went in and cleaned her up and got her ready and crossed her arms and everything that they would do. She was kind of a mess so it took us kind of a while. It was scary. Kind of, like she was completely white, like white as a ghost, like I didn't know that that would happen but she had absolutely no color in her body, her jaw was open; we were trying to like tie it which is a little bit scary too. Her nurse was really nervous so that's kind of why Professor came in with us. She did it with both of us. Participant #4

This participant identified a teaching opportunity that her instructor took for her and the nurse caring for the patient. It was scary for both of them and having someone more experienced was helpful to the participant.

Participant # 10 also talked about her experience with morgue care. She was able to work with another nurse in the preparation of the body. She states:

I did help a nurse get them prepared for that (morgue care). I had to clean them up and close the mouth, close the eyes, take out things like IVs if they wanted to, I don't remember if they were doing an autopsy. We just

got him cleaned up and when the family left, actually we put him in a bag and all that stuff. It was a little creepy. I don't know, it just was like a little creepy and I don't know if I could like deal. I know that working in medicine you are going to have to deal with that all the time, but I don't think I could work like on an older geriatric floor where it happened all the time. I think actually I would get used to it and go like "oh yea, it happens, it's like a natural process of life", but its creepy doing all that and putting them in the bag and putting them in the metal contraption thing.
Participant #10

This participant described in some detail what goes on with morgue care. It seems to have had an impact on her. She mentioned that it is a natural process of life, but what we do with the body after death is uncomfortable for her.

It can be very scary to work with a dying patient especially if it is a new experience. One participant talked about how scared she was to be working with a dying patient. She stated:

I didn't want them to know this could really be like, hey, this is my first death. I'm scared. I'm scared; I think I'm going to die with him.
Participant # 5

This participant was scared. It was their first experience with caring for a dying patient and she did not want the patient or family to know.

Sadness

One of the most common feelings expressed by participants was sadness. One participant stated:

Like sad, obviously, I just felt like I, I thought about what the family thinks cause they were talking about him. Then I always turn it to myself, like that would be so sad if it was my family. Emotions like sad.
Participant #3

Another participant stated:

Mainly sadness. The patient was told that he had this diagnosis and had no one to comfort him or to be there with him when he was going to start getting worse. He would not have any support. Participant #12

This participant felt sadness not only about the patient diagnosis, but also that the patient had no family to be with them as they went through the dying process. This made the participant sad.

Age did play a part in the intensity of the feelings that a participant had. Younger patients had a stronger impact on participants. One student discussed her patient who was a young gentleman with a young wife who was pregnant. She stated:

Yea, it was just emotional, like I don't know, he was so not responsive. You could pick his hand up and it would just drop. It was almost like he was dead already when I got him as a patient. So it was like feeling really sad and emotional and asking why would I get assigned on my first clinical day to someone so bad. But, it was a good experience. Participant #1

This participant had stronger emotions because the patient was young and his wife was pregnant. It was also her first clinical experience where she was trying to get used to the clinical area and now having to deal with strong emotions made it more difficult for her.

Participants work with patients of all ages during their nursing clinical time as a student. Most participants stated that they had more difficulty caring for younger patients who were dying than for older patients. When asked if their thoughts and feeling were different if the patient is younger, one participant stated:

I do think so. It's kind of hard to see the patients who are very much younger, who are sick. I don't know, we learned a lot that they don't process it as well because they are younger and they don't understand or have concrete thoughts, but it's hard to see the parents, because the parents are often thinking, did I do something wrong, or what could I do different. I don't know, I think it's just really hard because they are such an innocent population; they haven't done anything wrong in their life. It is harder, I think, with younger kids. Participant # 11

This participant felt that if the patient were younger it would be harder for her to deal with. She also identified that it was hard to watch the parents who may be doing some self blame. That can be hard.

Another participant talked about her feeling of working with younger patients. She stated:

They are so young and haven't had a chance to live their life verses someone that's seventy-eight years old, they've been around for a long time and we know we have to die eventually, but when someone is so young, just coming into the world and you don't expect it, and as a parent myself, you don't expect to have to bury your own kids. So yes, that would be really hard. Participant #12

This participant felt that it would be much harder to care for someone who was young and dying than someone older. Participant #10 also talked about this when she stated:

I think maybe I might feel a little bit more sad because I actually floated on the peds (pediatric) floor before and there were a couple of kids with trachs (tracheostomies). It's just sad because they are so young and they haven't lived life yet and they are not going to. I think it would be a little more sad then dealing with adults. Participant #10

This participant had the opportunity to work with the younger patients and felt it was much more difficult and sad.

Compassion

Students feel a connection with some patients and their families. They feel bad for what the patient and the family is going through. They can put themselves into the situation. One participant stated what some students might think is a diagnosis of a terminal illness for one of their patients.

My first thought is 'that really sucks for you.' Then I focus on my work and I try to focus on being sympathetic and showing them I care. I think about how I would handle this situation. I try to be compassionate and empathetic. I show them that I care. Participant #7

This participant stated what really goes through their mind but then puts himself in the patient's situation and tries to show compassion. Showing the patient that they care was important to this participant.

Another participant talks about her patient who was young and dying of cancer. His wife was pregnant with their first child and having to care for her husband who was dying. She stated:

With the wife and her husband I was really compassionate. I couldn't imagine having a child and knowing that my husband was dying at the same time. It's like a rise of feelings and then a fall at the same time, so that was tough, but I just tried to be supportive with them. Participant #1

Students see patients of all ages and family situations. This participant wanted to be supportive, but found it more difficult because of the young age. This participant also mentioned that she felt a number of feelings at the same time.

Another participant talked about her feeling when working with patients and their families. She states:

I think I just feel sympathy for the family. I just tried to do whatever I can do to make them feel better, but I think it's just a sad situation altogether to see the person dying and the family is with them but there is not really much they can do. I just feel sad for them. But then again, I do know that death is inevitable, it does happen. Participant #10

This participant identifies sympathy for the family and what they are going through as a feeling that she has. This participant states that she tries to do all she can for the family and patient to make them feel better.

Physiological Manifestations

Most of the students stated that they did not have any physiological manifestations when working with death and dying patients or their families. However,

there were a few students who stated they felt or displayed something physical when working with dying patients.

Some participants had manifestations that only they knew about. There were several manifestations identified. One student mentioned that she gets headaches. She stated:

I can get headaches sometimes when I've taken care of patients. Actually I think that one day, that I took care of a patient in the hospital in clinical that was actually dying, I think I really had a bad headache after that.
Participant #13

This student reacts to the stress with getting headaches. There is a lot of emotional energy that goes with caring for dying patients especially when students haven't had a lot of experience in that area.

Some patients have small children that come in to see the patients. It can be difficult working with the children in the family when the student may not know how much the child already knows and how to work with them in regards to the dying family member. One participant said:

There was one who had children came in. When I knew I had to face them, I was a little nervous about what they might think of the situation.-
participant #8

Students state that not knowing what to say to the patient or family can be stressful. This participant got nervous with the thought of having to say something to the children of this family. Children can be inquisitive and not knowing how to answer a question can make a student nervous.

The thought of death itself and having the patient die while in the students care can be emotional. One student talked about her experience with a patient who was actively dying. She stated:

I think I had a little bit of an upset stomach at the thought of possibly having a patient die on me. Participant #5

This participant was afraid the patient may die while she was there. This caused her to have an upset stomach.

Another student talked about having several physiological manifestations when working with death and dying patients. She talked about having to give mouth care and suction the patient.

I got shaky and I got overall itchy. You get nervous, kind of, to go in there, like everything I did, I didn't want to do it wrong. Participant #3

This participant talked about being nervous. Some of the procedures that students are required to do with the patient can cause them to be nervous. This participant didn't want to do the procedure wrong.

One participant reported a physiological sign that could be seen by the patient or family. This participant talked about a noticeable sign that she gets when she feels stressed that others can see. She stated:

Well, it is like I know I've got two ways stress comes out of my body. I get muscle spasms in my neck, but like in clinical, or even at work, just the frustration of sometimes dealing with patients, my eye will twitch. Most of the time it is my neck, but if I don't have a relief, I think, my eye will start twitching because I've got that all bottled up. I don't know how much really is bottled up emotions or more stress. Participant #1

This student knows when she is frustrated or stressed by how her body reacts. Not many participants in this study reported actual visual signs of this stress.

Upset

Some participants voiced feelings of being upset. It can be quite an emotional experience for students when working with dying patients and their families. One participant stated:

I took a lot home, I get very upset, sometimes it's like depressing, you know. You think about it. I still think about people that have passed. Like I thought of patients that have died, or you see them in the obituaries. It just brings up like a bad, you know, depressed feeling. Some of it is almost, sometimes you feel relieved like oh my gosh, thank God. They are not suffering anymore when they are chronically ill and are really suffering. So I would feel like depression and sometimes you're relieved. It's just like mixed emotions.-participant #2

This student had that problem at the beginning of her work in the healthcare area but has since been able to separate her work from her home life. She sometimes thinks about those patients she has had who have died and feels sad.

Students may spend a lot of time with a patient and get attached to them. One participant talked about one of her patients who died sometime after she took care of her. She stated:

She actually was down there and coded and died while we were there. I wasn't assigned to her or anything, but I saw her name on the patient list. It is tough, really tough for me to see what was going on during clinical, that a patient I had taken care of and got attached to her a little bit was dying.-participant #1

This participant had developed an attachment to her patient. This seemed to make it more difficult for the student emotionally.

Some patients have many medical problems and are unable to communicate. They may not have any family. One participant discussed how she felt about her patient who was in his twenties, was nonverbal and had no family in the area when she stated:

There he was by himself. I felt so bad because his family wasn't there. Everybody on that floor really liked him and they took really good care of him. We were all really upset, but I thought about it afterwards. It was just, I felt really bad. He was so young and had so many problems.-participant #6

This participant was upset that the patient was so young and no family was with him

This participant was frustrated by several things. The idea of death itself was frustrating and she mentioned that watching someone in pain was also frustrating.

Another participant talked about their experience with caring for a patient. This patient was elderly but the experience was upsetting to the participant. She stated:

With the ninety-five year old I was upset. She was really sweet and she kept telling me that she loved me, so that was sad because I really liked her. One of my patient's did die. I didn't know her before then so I was scared because I didn't really know what to do and that part where she was breathing and that she turned really white, which was kind of scary. But I think I was more upset because of her family. I felt so bad for her family and her daughter was there and she was really upset. So I think I was just of overwhelmed and that's what made me so upset. And then cleaning her up was kind of scary too, but I'm really emotional myself. Participant #4

This participant talked about two separate patients. One patient she had gotten close to and it was upsetting for her to see this patient die. The participant was upset because the family was emotional and that was overwhelming for her.

Nervous/Anxious

Being in the clinical area can cause students to be nervous. One participant talked about how they felt during their clinical experience.

I think that whole clinical time I was nervous because I didn't know what was going to happen. I had never dealt with that before (death) so I was unsure what to say to them. I still might be a little bit unsure what I would say to them but I just tried to make them feel better in any way that I could. Participant #4

This participant was nervous the whole time they were in clinical. They had not worked with a dying patient before. The participant did not know what to say to the family.

Having to provide morgue care to a deceased patient produces a number of emotions. One participant discussed her feelings about her first experience with morgue care. She stated:

I was upset that he was dying because everyone else had patients that were walking and talking and could answer their head to toe questions. I burst into tears when it came to cleaning him, so pretty much I couldn't get over that. I was like upset the whole time so I stepped back and went to the break room. My classmates washed my patient for me. It was pretty tough because I had never seen somebody dead. Participant #1

This participant was very overwhelmed by having to do morgue care. It produced anxiety in such a way that she was unable to fulfill this nursing role at this time.

Another participant commented on morgue care. It was her very first day in the clinical setting. She states:

It was my first day ever, like taking care of patients by myself and I didn't know what to do. But I gave her post mortem care and got her cleaned up and ready for the family. It was a difficult experience. I never really saw a body before, but I never touched one and cleaned them up. It was definitely something else. Participant #2

This participant mentions how difficult it was for her to do the morgue care. It was a difficult experience because she had never worked with a dead body before.

Awkward

Some students found it hard to work with unresponsive patients. It is reported that hearing is the last sense to go and students are told to talk to the patient in their care.

Some students feel uncomfortable in this situation. One participant stated:

I felt really awkward because I was like okay; I am going to clean your arm now. He was not listening to me, well that was my thinking. He could have been aware of everything, and unknown things may bother him some too. Participant #1

This student found it awkward to talk to someone who was not able to respond back to her. She found it uncomfortable working with an unresponsive patient.

Sometimes the awkward feeling comes from not knowing what to say. One participant talked about her experience with a patient she had known for awhile. She states:

It seems like the one time when the one lady that died on my birthday, we were so close. It was a couple of months before she died. I think she kind of knew that she was going to die and I would work there- twelve's and was working in a row. I would be off for four days and then come back and usually I would go and visit her in between. But I couldn't for some reason. I was real busy and I came back to work and I went to her room and she started crying and said "Where have you been" and she was angry and then her husband had died. She said "I just want to be with Oliver" her husband and I hugged her and stuff cause I didn't know what to say. It was kind of negative in that I wished I had something to say. I wished that there was something I could do, but there was nothing. Participant #13

This participant felt this was a negative experience. She had known this patient for awhile and was unable, in her mind, to provide the patient with any comforting words.

This left an impression on this participant.

Sometimes this can be difficult for the student to manage and may make them feel uncomfortable. Some students get nervous and may manifest it inappropriately with patients and their families. One participant stated:

Sometimes you may feel like laughing at something and it may not, not that you are laughing, or you may want to smile or whatever, something that may not be appropriate for the time, those are things I may guard against, not showing or communicating the wrong things with body language. Participant #9

This participant didn't want to send the wrong messages to family and the patient with his nonverbal communication.

Frustration

One participant mentioned how frustrated they are about the whole situation of death. There are a lot of thoughts and emotions that the student may have about the topic

of death. Students may feel frustrated about death because they don't understand it. One participant stated:

I think frustrated, definitely, because I don't really know what to think about it. I know that we all have to die sometime, but it is sad when you see someone who has a lot of pain and is very uncomfortable. The hospital is not a comfortable place, I would think, to die. I wouldn't want to die in a hospital. Honestly, I don't know. It is kind of hard to digest it all. Participant #11

This participant was frustrated by seeing a patient suffer. She didn't want to see the patient suffer or be uncomfortable.

Sometimes students are frustrated by the lack of medical response by the physicians and nurses. One participant talked about this experience.

One patient (I had), my second semester of my sophomore year, was being released to hospice. While I was there, she started to have all sorts of chest pains and I had met with the hospice nurse and she kindly explained to me what was going on but it was really hard for me because she was having the chest pain and the doctors were just ignoring it, cause she was a DNRCC (do not resuscitate, comfort care). It was driving me nuts because it was like so bad, but she died the next day with another student in our clinical. I was really sad because in my job I see people get better. It was hard because you knew she wasn't getting better and it was ... the hardest part for me was she was having the chest pains and to me, the doctors and the nurses should be rushing around doing an EKG, doing all sorts of stats (immediately) instead they just give her more pain medications. Participant # 5

This participant was frustrated by the fact that the doctors did not seem to be doing anything for the patient's chest pain. She felt like the patient was not getting worked up for the chest pain because she was comfort care. This was frustrating to her.

COMMUNICATION

Communication is the third domain identified from the research. In this domain participants talk about communication with patients and their families. In this domain, there were eight categories identified which include: not knowing what to say (*typical*),

topic of death (*typical*), therapeutic communication (*typical*), unresponsive patient or nonverbal patient (*typical*), language barrier (*variant*), difficult patient and/or family member (*variant*), emotions (*variant*), and dying process (*variant*).

Not knowing What to Say

Some students will make an effort to talk about the patient's diagnosis and about death. It may be difficult because the student may not know how to talk about death.

One participant stated:

I didn't want to keep pressuring him into talking about it; I didn't want to say the wrong thing too. It's kind of hard talking to a patient like that when they have a roommate, so I didn't want to say too much just in case the roommate might of heard. I was always kind of hesitant as to what to ask him. Also, I never had dealt with patients like that a lot, so I don't really know the right things to say. What makes them feel better or to know what the right questions to ask, it's just something I just have to learn with practice, I guess, but when that guy was HIV and the cancer and stuff, it was kind of hard for me to talk to him 'cause I didn't know what to say and he wasn't really like as talkative as I was. Participant #10

This participant made a good point about roommates and what is appropriate to ask a patient when someone else is in the room. A student may not feel it is the right time to discuss the patient's feelings when others are present.

Saying the wrong thing is of concern to students. They don't want to say something that is not helpful. One participant talked about this idea.

I don't want to say something stupid. The only time I ever felt like that was with the one family that was really sad, emotional and everything. It was the woman dying with cancer. I guess that was why I left. If I don't have anything that I think is appropriate to say, I had just better leave before I say the wrong dumb thing. Participant #13

This participant was afraid to say the wrong thing to the patient and family. She felt safer leaving the room.

The Topic of Death

Talking about death can be extremely difficult for students. It is usually not an everyday topic that they encounter with friends and family. Becoming comfortable with the topic of death and dying can take a long time. When asked about having conversations about death and dying with her clients the participant said:

I think if anything ever got brought up the subject was changed right away. I guess I try to avoid it, because you want to keep them happy. That's not a happy subject. Participant #1

This participant made a conscious effort to avoid the topic of death and dying. It was not a comfortable topic for her. Another participant talked about his experience talking to his patient. He stated:

At first I didn't know what to expect because a lot of the stuff like cancer, she just got the diagnosis literally hours before I got there and I tried not to, you know, actually I tried not to act like anything, like I knew. I didn't want to bring it up because I thought maybe she would be very sensitive about it. Participant #8

This participant was not comfortable bringing up the topic of death and dying with his patient. He was told that the patient knew but he was afraid that she would be sensitive about it.

Another participant talked about her thoughts about being able to talk to her patients about death and dying. When asked if the topic of death and dying was brought up, would she be comfortable talking about it, participant #11 said:

I think so, I honestly think it would have caught me off guard, but I think I would have been comfortable talking about it. I don't know, I think it would have been interesting to hear their thoughts on it. What they are thinking and what they were feeling. I don't know, I'm not the most outgoing person. I don't think I would be the one to bring it up. Participant #11

This participant felt that she would be able to talk about death and dying with a patient but only if the patient brought it up. The participant would not feel comfortable bringing up the topic herself.

Another participant talked about her experience talking about death and dying with her client. She stated:

In the beginning it was difficult but then when he pretty much was like 'what's going to happen?' and he wasn't super sad about it, I think it became more easy for me to talk to him about it. If it was somebody that was really upset and crying, with family members who were crying, then I think it would be more difficulty and I'm not sure how I would handle that situation. The doctors had just told him earlier that day, that it (the cancer) had spread, and he knew he was going to this facility and that was going to be the end for him. I think that since he had lived on the streets and just had an itty-bitty apartment, didn't have much money coming in, struggled with paying bills, not knowing where his next meals were coming from, that it was almost like he was peaceful with the fact that his time had come. Participant #12

This participant was able to talk to her patient about death and dying because they weren't sad about the diagnosis or at least weren't displaying any outward signs of grief.

The participant felt that emotional patients or family members would make it more difficult to communicate with on this topic.

Sometimes the patient is aware of their impending death. This may be difficult for students to handle. One participant talked about this experience with her patient.

It was hard because I said "you're going home with your family" and she kind of looked at me like she knew she wasn't even going to make it that far and she shook her head no. I said "be optimistic," and she just shook her head no. I said to her because she wasn't going home until the weekend and I said to her "well I'll be your nurse on Thursday" and she looked at me and she said "no you won't". I was, I was really freaked out and the hospice nurse was like, sometimes they know, and they are like but we're setting up for her to go home anyway. She had kind of resigned herself... I don't want to say given up, but resigned herself to the fact that death was near, it really brought me down because by nature I am someone that's "hope I'll see you next week," or "you know, the next time I see you,

you'll be a lot stronger, you'll be getting better''. To know that she wasn't going to get stronger or better was just really hard for me. Participant # 5

This participant had a hard time with the fact that her patient knew her time was near.

This was scary to have a patient tell her that she won't be here the next time the student comes in.

Therapeutic Communication

Students are taught about using therapeutic communication when working with patients and their families. They are taught this technique in their first semester of nursing school and are required to complete a conversation form each clinical rotation.

When asked about her therapeutic communication experience with her patients, participant #1 stated:

The first guy, when I was in that first clinical, he did not talk, and I had no experience with therapeutic communication. In the second, the lady with cancer was pretty early into the clinical. I think I'm trying to do that more, especially after my psych clinical. We used that all of the time. 'Tell me how you feel about that?' so it is getting into my mind set now. So every time I use it, I learn a little bit of how to ask things to get more depth. Participant #1

This participant recognized that experience would help her become better at therapeutic communication but had not had that much practice with it in the clinical setting.

Another participant talked about an experience she had with therapeutic communication that she felt was a positive experience. This happened in a pediatric rotation and the therapeutic communication took place with the mother. She stated:

In pediatrics now, there is a little boy who is six years old and he led a normal life and then was hit by a truck and now he's just had so much of his brain removed and he's a spastic quadriplegic and in talking with his mom, I think we have had therapeutic conversations. I think that it did go well because now every time, I don't have her son now, he's in a long term type facility, and every time I see her, she comes up to me and we have a nice conversation. She's like, oh I missed you on this day, so it's

like I almost feel like I have a bond with her now and it's going to be sad when her son gets discharged because I always go into her to see the two of them. Participant # 12

This participant picked up a little on how her communication was therapeutic with this mother. The fact that the mother missed the participant and looked forward to seeing her meant that the participant had formed a bond with this mother and this is therapeutic communication.

Students are taught therapeutic communication skills in the sophomore year of nursing courses. They don't always have an opportunity to use them as often as they would like. One participant talked about how learning about therapeutic communication has helped her. When asked if she thought learning therapeutic communication will be helpful to her in the future she stated:

Yea, kind of. It sets up like structure for how to ask and what not to ask and what's okay to say and what's not okay to say, aren't like verbatim for therapeutic techniques, but you know what you're trying to deal with.
Participant #6

This participant felt that learning how to do therapeutic communication was important and that it would be helpful in future interactions with other patients.

Unresponsive Patient or Nonverbal Patient.

Patients who are not able to communicate due to brain type injury or brain involvement or who are at the end of life and systems are shutting down; make it difficult for students to work with. When they have to talk to them, and they don't respond back, it makes students feel uncomfortable. One participant talked about her experience with an unresponsive patient.

I felt really awkward because I was like okay, I'm going to clean your arm now, and he was not listening to me, he was just, well, that was my

thinking, he could have been aware of everything, and unknown things bother him some too. Participant #1

This participant did not feel comfortable talking to a patient who did not talk back to her.

It made her feel uncomfortable. Another participant talked about her experience.

I took care of a lady who was unresponsive. Professor told me to talk to her that maybe she could still hear, so I think I just told her what I was doing, that I was taking her temperature. I took her temperature pretty frequently, she had a really high fever, so I decided to just talk to her and tell her who I was and what I was doing. It was sad. I didn't know if she heard me or not. I was uncomfortable. Participant #4

This participant was uncomfortable talking to the patient. She was not sure if the patient heard her or not. But, the instructor told her to talk to the patient and tell her what she was doing.

Another participant talked about her experience working with a nonverbal patient. She stated:

No, he could not talk at all, but he would cry and make sad noises or he would have like big smiley faces or he would blow raspberries when he was mad. You knew by the chart some sounds that he made. You knew when he was crying. I asked him once, "What's wrong JB?" He can't really answer you. Participant #6

This participant would try and use the information given by the family about the patient and his sounds as to what was wrong with him but it made it difficult to actually know what the patient needed. It was a guessing game by the student and nurses.

Sometimes when a student is taking care of a nonverbal patient, they forget that they should be trying to communicate with them. One participant stated:

That's the thing, I think when they are dying, most of them that I have dealt with have been nonverbal, or intubated and you have, I think partly I forget that I should still talk to them you know. Like that they probably still can hear me, but I think, someone once told me that it is the last sense to go. So that's probably something else that should probably be brought up through, you know, lecture or something because I think you're so

wrapped up in just, you're afraid to turn them over, because they might take their last breath on you or something like that. So I think I need to learn to be more, you know, I need to learn to talk to them more and let them know what I'm doing instead of just doing it, you know, that kind of thing. Participant #2

This participant recognized that she did not always talk to the nonresponsive patients when she cared for them. She knew that it was important to interact with the patient even when the patient was unable to respond.

Working with unresponsive patients is new to many students in nursing school. It can be uncomfortable. One participant talked about her experience.

I was actually kind of uncomfortable at first, but then my instructor came in the room and she was like hi, he opened his eyes. She said "hi" and he opened his eyes so that made me comfortable. Then I was okay. Then I was talking to him and stuff and he couldn't talk back but he could open his eyes and he would look. Participant #13

This participant had an instructor who was willing to come in with the student and help her feel comfortable with the patient. The participant was then able to work with the patient and talk to him as she provided care.

Disease processes can cause the patient to have problems with body functions, wounds that are large, have an odor or that may be difficult to look at. One participant talked about one of the patients she took care of.

Well, the lady with cancer, it was hard to understand her, she was very raspy and whispery and was coughing up a lot of stuff that was gross to look at. So it was hard to not gag and talk to her at the same time. Participant # 1

This participant talked about some of the changes in a patient's body that can make it difficult to communicate. Not being able to understand the patient is frustrating to the patient and the student.

Language barrier

Language barriers can be a problem when working with other cultures. It can be frustrating to the nurse and to the patient. There may be a lack of effective care and misunderstandings due to the difficulty in communication. One participant mentioned the difficulty in working with a patient of Romanian decent.

The Romanian patient is very upset that there is a little bit of a communication barrier. He doesn't want to use the communication phone and refuses to take his medications. He is not communicative, the communication barrier is there, and he just goes through the motions.
Participant #5

This patient seemed to be uncooperative and it may have been because he can't understand what is going on around him. The participant was frustrated because the patient would not use the communication phone to talk with a translator. Another participant talked about the problems caring for her patient who was Egyptian.

There was no interrupter. There were Egyptian people and one doctor, I guess who spoke Egyptian but there was no translator available. It was pretty weird. I really couldn't talk to them at all, so I couldn't find out there resources or stressors or anything. Basically I could tell he was in pain just by looking a little bit, but otherwise in the basics' I couldn't find anything else out. They were breathing. I couldn't offer any special support. Participant #13

This participant was frustrated because she could not communicate with the patient or the family. This participant was having difficulty finding out what the patient actually needed due to the communication barrier. It was more difficult for her because there was no translator available. She has to look for nonverbal signs of what the patient needed.

Trying to give clients good care can be difficult. When there is a problem understanding them or them understanding the nurse, it can become frustrating. One participant talked about her patient who was Hungarian. She stated:

I did have a guy, he was Hungarian and I was trying to find a translator. He was very confused, he had to drink his ups of contrast, and he didn't know why he had to drink this yucky stuff. And you can't explain, because I've never met someone who was Hungarian. So I was trying to use German, I printed out a sign; you must drink this for your test tomorrow. He had no idea. Participant #1

This participant was trying to get the patient to take in the medication that he needed for a test that was to be done. It made it more difficult because the patient was confused and the medication tasted bad.

Another participant talked about her experience with a patient from India. She stated:

Yea, it's difficult because they try to talk to you and you don't know what they are talking about and all I could do was smile and nod and say okay. The lady that I had, I think it was last weekend, she kept pointing to her head and I was like, "ow, ow" and she was like shaking her head. I needed to go tell the nurse she wanted pain medicine for her head, but it is difficult trying to communicate with someone who doesn't speak English. It's so hard, because you don't know what they want. Participant #10

Trying to identify what the patient really needs was frustrating to this student especially because of the pain issue. This participant seemed to be able to understand the patient was in pain but not able to understand much else. The participant could not ask questions about the type of pain or how bad it was.

Difficult Patient and/or Family Members

Because nursing involves the patient and the family, students need to be able to communicate to everyone. Communication can become strained when the family member is angry or is very demanding. Participant #1 talked about the son of one of the patients and one reason for the lack of conversation. She stated:

There wasn't a lot of conversation with the son because he was Mr. Know-it-all. I felt like am I going to wipe her right. Is he going to yell at me? He wouldn't leave the room unless it was like ordered for him to leave the room. Every time I saw him it was annoying. I thought, I know you were

taking care of her, but right now she is in our care. It was just a weird situation. He was so snooty and it's hard to deal with. I don't have much experience dealing with snooty people. It might have affected how I cared for her because I wanted to get in and get out as fast as I could.

Participant #1

This participant found it difficult to care for the patient because of the family member. It can be uncomfortable for the student when they feel like they will be criticized for everything that they do. This participant did not want to engage in much conversation with the family. This can keep the student from having meaningful conversations with the patient or family. Another participant talked about her experience with a difficult patient. She stated:

Well, the one patient kept saying like, boy, I'm in really bad shape and you don't know what to say because like they are in really bad shape and he actually had pressure ulcers because he didn't move and he wouldn't move and he had amputated legs and he couldn't get around much to begin with. He would just grunt and moan was in very bad shape and he needed encouragement but it felt wrong to say "oh you can do it, you can get over to the bedside, and you know you can" and he can't. He was just sitting there and he was in very bad shape. The whole family was crying and they were like crying in his room and I was like "why don't you leave?" You don't know what to say to him. You learn to say a couple of things, but there's nothing you can say to make it better. Participant #3

This participant had difficulty knowing what to say to the patient. She knew that the patient was not doing well but she still wanted to encourage him but felt bad about doing that. This participant also identified another patient that she worked with.

One was really cold towards everybody, he didn't want anybody to touch him, so many people ran out of his room because they wouldn't help him, and he got really offensive to a lot of people and the family understood. At that point, this guy had brain mets (metastasis) too, he didn't really know what he was saying, but you would go to take his vital signs and he would swear at you and call you all kinds of nasty names and you would just have to do it anyway. It's a challenge because some of them are really bitter still, some like that man hadn't accepted it, he just was angry at everybody. That I find challenging and the other is not knowing what to

say and feeling bad, trying not to cry because the whole family's crying and you can't cry in front of the patient. Participant #3

This participant found the patient challenging because he was so angry and mean to those who were trying to care for him. This participant identified this patient as one where caregivers were in and out of the room very quickly.

Emotions

Patients and families can experience many emotions due to the diagnosis itself, the stress of the changes occurring within the body, the thought of death, the stress of the illness or carrying for a loved one or a mixture of these things. Participant #2 talked about this and stated:

I think the biggest challenge is when the family is really upset, you don't know what to say sometimes and it makes you feel like an idiot. You are like uh-huh, you know. I don't want to say the wrong thing. I don't want to tell them I know how you feel, because I don't really. So my biggest challenge is what do I say, how do I comfort them and I think that nursing school kind of helped. Participant #2

For this participant, the difficulty of trying to work with families and patients came with knowing what to say to them. She was looking for words that would comfort them. Being afraid that she will say something wrong is a big fear with this participant when it comes to communication.

Another participant talked about a family member who was unable to accept her mother's impending death. She kept calling the ambulance to pick up her mother and take her to the hospital. The participant stated:

I didn't realize that she was even dying until the nurses said that her daughter just needs to learn how to deal with the end. I guess she just kept calling like the ER (emergency room) and kept sending her an ambulance when she was supposed to die in the nursing home. That was the plan, so anyway, but I just cared for her, I did like morning care and everything.

That was the first time I did mouth care too. She was completely unresponsive, drooling on herself. Participant #3

This participant saw that not everyone is able to accept death and there are family members who have a hard time watching the patient pass on. This participant was focused on giving care to the patient.

Dying process

One of the hardest areas for nurses to deal with especially when the patient is dying is that of communication. Participants were asked if they would talk to the patient about the topic of death and dying. Most students felt that they should not bring up the topic to the patient. One participant was asked if she would feel comfortable talking about death and she stated:

Probably not. I still don't know enough about it. I don't know how it will happen for him or how things are going to start going down. I don't know, we haven't studied that much into it. I guess I try to avoid it because you want to keep them happy. Death is not a happy subject.
Participant #1

This participant expressed her concern of not knowing enough about death and dying to be able to talk to the patient. She also stated that death is not a happy subject and so would try to avoid the topic.

This same participant talked about another patient who knew she wasn't doing well. When asked if it was easier to talk to the patient because the patient knew her diagnosis the participant said:

It was still awkward because at that point we hadn't even gone over lung cancer so I had to go look it up as quick as I could and see what danger or what part she was in. She was crying and it was hard for her to cry because she couldn't breathe very well and that was making me a little upset. But I had to try to stay strong, so she won't really, really break down. The other nurses were working with her and there was someone else who came in just to talk with her. She was hard to understand. She

was very raspy and whispery and was coughing up a lot of stuff that was gross to look at, so it was hard to not gag and talk to her at the same time.
Participant #1

This participant was frustrated because she felt she lacked the knowledge about the disease process and the dying process to be able to discuss this proficiently with the patient or the family. She also was having difficulty understanding the patient. The body secretions that the patient was coughing up also made it difficult to talk with the patient.

MULTICULTURAL DIVERSITY

In this domain, students identified their experiences caring for patients from other cultures or religious backgrounds. Within the multicultural diversity domain, there were three categories identified. These were: patient beliefs and values (*typical*), emotional expression (*variant*), and family (*variant*). In this domain participants discussed their experiences with patients and families of different cultures and beliefs.

This group of students stated that they did not have a lot of experience with other cultures. Participants in this group were in small suburban hospitals and not the large metropolitan hospitals in the area. This may have been a factor in their experiences. The majority of patients' identified by students were of European American decent. However, several students had Hispanic and African American patients and one student had an Eastern European patient from Romania. One student reported having a patients who identified himself as an atheist.

Patient Beliefs and Values

Patient beliefs have an effect on the type of care they may want. It also has an effect on how nurses may communicate with them. One participant talked about the African American patient that he had. He stated:

The patient had a different view of the world than I did. He had a view that there was somebody holding him down and he would have better healthcare and he wouldn't be in this situation if he wasn't black.

Participant #7

This participant recognized a belief system that was different than his own. It can be difficult to talk with someone about their belief when it is so different.

This same participant also talked about other members of the team and how they deal with patients of different cultures and religions and the need to be aware of the cultural differences that may be present in an interaction.

I remember sending the priest in to her. He went to talk with her and came out smiling at me. I'm like you missed the point because she had just gotten a horrible diagnosis, she needed emotional support and I think he missed the point because he was a Catholic priest and the patient was not Catholic. He (the priest) was also from a different country. So the priest was not attuned to how she was relating to him. I've seen and I've experienced a lot of different cultures so I know that not everybody expresses themselves the same way. I try to pick up on what their views are. So dealing with their culture is completely different than trying to do it here. Participant #7

This participant felt that the priest was not in tune to what the patient needed. He felt that the patient had received a bad diagnosis and did not understand that the patient needed emotional support that this student did not feel was given effectively.

This participant also talked about knowing who you are personally and being comfortable with yourself as being important when working with other cultures.

You have to be culturally sensitive, this is something you really have to do and different perceptions reflect different people and their cultures. Different perspectives reflect different people and their different cultures and things like that. So you're the health care provider, you have to be comfortable in yourself. I understand your culture, and I understand where you are at and still be able to provide good care. So you have to adapt slowly and you know, make the changes that you are comfortable making so that you can work this out. Not everybody receives the same, you can tell different people the same message and everybody is going to hear a different message. Participant #7

This participant felt that knowing and understanding yourself and your own beliefs is important when caring for patients especially of different cultures. He felt that nurses need to understand their patient's culture and implement care based on that culture.

Varying religious views can have a profound effect on how care is given and in working with dying patients. One participant had a patient who indicated that he was an atheist. He stated:

With one person he was an atheist. It was when I die, it's over. The patient had colon cancer. We didn't have lots of conversations about death because I didn't know what to say to him, when I die it's over. We were just kind of talking about, you know, how to take care of him and stuff because I don't understand that view, how do you believe when you die, it's over. Participant #7

This student had a difficult time talking about death and dying because the patient has no belief about what happens to them after death. This participant was having difficulty talking with the patient because of his beliefs that death was the end.

Male nurses are fairly new to nursing. Some female patients may be uncomfortable in allowing male nurses to take care of them or examine certain areas of the body. One participant talks about his experience with a patient from Eastern Europe.

The one patient was from Eastern Europe. Her and her husband were recent immigrants here. I am pretty sure her husband spoke more than one language. She may have spoken more than one language herself. That may have had something to do with her way of thinking and so forth. I think when I came in and when I wanted to do the head-to-toe assessment, she is like is this necessary? Because I was a male, I think that played a part in it. Yea, I think it depends on what cultural background a person has. I think she was younger than I was, too. Also being young and female, she may look at me and that may have played a part in it. Now that I think about it, I think that had a lot to do with it because in medical-surgical, when you do the head-to-toe and you may have to touch in areas that maybe somewhat sensitive, if it wasn't necessary, you are not the doctor, so things come up and she refused that. So we got off to a bad start. Participant #9

This participant recognized that the age of the patient and her cultural background made it difficult for him to complete his full assessment of the patient. Though the participant did not take it personally, he did recognize that there were some patients who may have concerns with the gender of the nurse. This can be frustrating for nurses both male and female depending on the culture of the patient.

Emotional Expression

Emotional reactions vary depending on cultural backgrounds and experiences. One participant noted the emotional reactions of an African American family after the unexpected death of their family member.

The lady that coded was African-American. I was kind of surprised at the way that the family was reacting. I understand it's really sad and stuff but you could hear them like all the way down the hallway, down to the trach (tracheostomy) sensors. They were very emotional in there. I was a little shocked to see that, only because I do know that's how African-Americans are, they are more emotional. I go to an African-American church. Participant #10

This participant was surprised by the reaction of this cultural group with the death of a loved one. Even though she had participated in an African American church, she was still surprised to see the reaction.

Another participant talked about her experience with a Caucasian family. The experience was a positive one even though the family was upset and crying. She states:

I think that the only patient I had was a very positive one with the lady that had cancer in her mouth. When she died, she had a pretty large family that would come in quite often and they were more so a happy type. They were upset, obviously, and they were crying and they were grieving but they just focused on positives, like her life, what a good mother she was and they would sit there and reminisce about things. So I thought that was really nice and I got kind of emotionally involved in that. I would talk to them and I'd tell them funny things she would say or do, like when I was taking care of her. Participant #13

This participant states she was able to see a family spend time remembering their loved one. Talking about the patient made the student feel good even though she felt sad about the patient's death. The family showed grief but the participant was able to stay in the room with the family and join in the conversation.

Family

Students who had patients from the Hispanic and African American decent noted that they tended to have a lot of family who come to see the patient. One participant noted the following about her Hispanic patient, the family and care given.

One patient was critically ill. I had seen her a couple of times. She was of a Spanish culture but I still think she was Christian. I think everybody and their mothers were there. That's one of the big cultural family groups. It was something private so you had to shuffle them all out of the room. It's not like they stopped you from cleaning her up. I think they were even happy to help you sometimes. Participant #1

The participant recognized that for this culture, family is important and the family spends a lot of time with the hospitalized patient. It is important for students to understand the family role in the patient's recovery.

Another participant talked about her Hispanic patient and several things she noted about the patient and the family.

I had this Spanish lady; she was actually Mexican, Spanish speaking. The family were spending the night, they would sleep in the lobby, they like didn't leave ever. They tried to stay in the room all the time too and I couldn't make them leave at night. She had a rosary. I see a lot of that in Hispanic women saying their rosaries. Participant #3

This participant noticed that family was important to her patient also. She also saw that religion must have some meaning in the patient's life.

The same participant also talked about what she noticed with her African American patient. She stated:

I had one lady who came in; she didn't even know she had cancer. She came in and it was too late to do anything and she was an African-American. Her whole family was there, all the time. It was like you couldn't even get in her room most of the time. There was a new born in the corner of the room and I was like you can't do that. Everyone's whole family comes but they just wanted to stay there.- Participant #3

This participant saw how important family was to this patient. The room can be very crowded with all the family members who want to show support for the hospitalized patient. This participant was also concerned about the family bringing a baby into the hospital.

TRAINING AND EDUCATIONAL PREPARATION

In the domain of training and education, participants identified how their training and education affected their ability to care for dying patients and their families. In this domain, two categories were identified. These two categories were: lack of education (*typical*) and novice to expert (*typical*).

Lack of Education

One area students felt they were lacking in was education about working with dying patients and their families. They felt they were prepared better for the physiological changes that occur with the dying process but not prepared emotionally or with communication skills needed to work with patients and their families. They also felt unprepared for morgue care and working with a dead body. One participant stated:

We talked about diseases and what will happen. There is like different stressors that are happening to everyone else, but not specific issues on dying itself, or how to deal with patients. Participant #1

This participant felt that there was not information on death and dying in the nursing program. The first lecture is in their first semester didactic course. Another participant stated:

We did a short little chapter on death and dying, but we don't get into it very much, at least as far as I am in the program. I think that we could get into it a little more, because you really don't know what to expect.
Participant #5

This participant could remember short chapters but nothing in depth. She stated that she did not know what to expect when working with dying patients. Another participant stated:

I don't really feel like as far as what you learn at school, I honestly don't feel like we have been given enough education on it. We had one class I think. I honestly don't feel I really got anything out of it. I can't recall anything from that lecture. I think that we definitely could improve the education and maybe, you know, a couple of lectures on it and not just one lecture, and bring it throughout all of the semesters, not just one. Like your very first one where you're going to forget it because you're too worried. I don't think it helped at all because I don't remember it.
Participant #2

This participant felt they lacked the knowledge necessary to care for dying patients. Also, this participant stated that there was only one lecture they could remember having.

Knowledge about death is important for students to have. But, even when students have knowledge about aspects of death, they still may not feel prepared.

Participant 11 addressed this.

It is certainly interesting to know physiology and what goes on when someone has cancer or other disease process, to understand what to expect and also a certain time frame. It all makes sense, but I don't think it makes it any easier. Participant #11

This participant acknowledges that it is important to know about the disease process and what to expect. However, the participant states that knowing does not mean being able to

handle it any better. One student remembered talking about different cultures in class.

Participant 3 stated:

We have learned about different cultures and how they view sickness and health but it doesn't really go deep into death. Participant #3

Cultural competence has become an important topic in nursing. This participant didn't feel they got a lot of information about different cultures especially in the area of death and dying.

One student talked about being confronted with death and dying. This student was an older student and has had some experience and time to think about death and dying. Participant #7 stated:

We talk about death and dying when most of it is common sense, the stuff I do. I came into this program a little bit older and I knew a little, but had also more world experience than everybody else. Some of the people I'm in clinical with really need a lot more teaching about this. One of the things about this course, it never asks you the question of how do you view death and dying. They never confront you and have you deal with this issue. I think that should be at least part of the protocol so if you can deal with it, then you would be a much better person. Participant #7

This student feels that it is important for students to confront their own beliefs about death and dying. He feels that we should be looking at this in the classroom before students go into the clinical setting.

Novice to Expert

The framework used in this study was Benner's Novice to Expert (1984). Students mentioned several times about this idea of improving over time their ability to care for, communicate with and deal with their feelings when working with death and dying patients and their families. Several participants brought up Benner's framework when discussing how they will handle death and dying situations in the future. Most

subjects felt they would do things differently in the future and stated it in terms of Benner's theory of Novice to Expert. They felt that with experience over time, they would improve in nursing care, knowing what to do in given situations and in their communication skills. One participant stated:

Given the mode, in any area of endeavor, is getting to the point where it becomes second nature. So, I know I'm a student, but I know I am very much a novice and I know I have a lot to learn. So getting to the point where I don't have to think about it, that, I would say, is the area of challenge I'm facing now. I think the more experience I get; the easier it is for me. It is just like the first time, going to a funeral or touching a dead person, you know, it is like the unknown is what's fearful, once you do it, it is just okay, I've done this before, I know how it feels or how things are going to be. Or it is less fearful. I take this as a job. I can do it, you know and do it professionally. I am building on what I've learned and therefore hopefully I'll make less mistakes and be more efficient, effective and become a more honed instrument if you will. Participant #9

This participant sees the nurse as continuously learning and building on past experience. He felt that experience helps the nurse go from the unknown to the known and feel more comfortable in the role as a nurse. Another participant also talked about learning and experience. She stated:

I think as we learn more skills and we learn how to do certain things that could help the patient be more comfortable and you kind of build an immunity or resistance to those emotions, but you still have to learn how important they are and how that made you feel, you have to use that. Participant #3

This participant recognizes the need to remember past experiences and not forget the feelings that may have been experienced. Time may make it easier to deal with dying patients but the participant states that those feelings help the nurse understand the importance of the patient. Another participant also talked about changes in her emotions over time. She stated:

Starting off originally and going into the process and seeing, you know, the dead body and caring for a dead body to now, being able to get past that part and look at the big picture of things and realize the families are going to need your support at the last minute, you know. Things they need are taken care of and really realizing your position and what your role is in it. I think it does change how you look at it, you know, because it's almost like a level of maturity, like I should go through and I think it's great because some people haven't dealt with it yet as nursing students. Things have changed in only like three years and how I felt about it.
Participant #2

This student can see changes in herself over the time she has been a nursing student and a nursing assistant. There are changes in both skills and emotions over time in nursing students. This is expected with the theory of Novice to Expert. Students build on past experiences.

COPING MECHANISMS

The coping mechanisms domain concerns the ways students cope with their thoughts, feelings and experiences while working with dying patients and their families. This domain was broken down into two categories which were: talking about the experience (*typical*) and crying (*variant*).

Talking About the Experience

Because nursing can be an emotional experience it becomes important for students to identify ways to cope with their feelings while working with dying patients and their families. Participants identified several ways in which they cope with the stress, thoughts and feelings when working with dying patients and their families. Students are in the clinical area with an instructor and the clinical groups meet together for pre conference, post conference or both. One of the things identified was talking about the experience. The student's identified talking to their clinical group, talking to the

instructor, the patient or patient family and talking to a personal family member as ways to deal with their experience. One participant stated:

I just talk about it, especially in post conference; there are people there who have had a chance to meet the patient. I talked about it with my husband to. He's seen people you know, in similar situations. I talked about it; I probably talk mostly to my husband. He recently had a mom who died too. Participant #11

This student identified post conference as a time for her to discuss her patients and discuss her thoughts and feelings about what is going on with her patients. One participant stated:

We usually talk in post conference. We always share our feelings and talk about the patients. Participant #12

Another participant also talked about using the clinical group as a time to discuss thoughts and feelings about the clinical day and patients that the students had. She stated:

We talked about him in clinical post conference a lot. And since everybody had him, we had all helped him and got in there and helped somebody change him or change his bed or do something. We talked about it a lot; it was a good learning experience. Participant #13

This participant stated that the experience with this patient as a good learning experience. The participant noted that other students already knew this patient.

The student may be able to discuss issues regarding death and dying with the clinical instructor. Another participant talked about expressing her feelings to the instructor. Clinical instructors can be a big source of strength for students. One participant stated:

I expressed some to my instructor and she told me, 'it's part of the job, you are going to deal with it. She was very supportive, can't say enough about her. She told me that if something happened, one of the other students or the nurse would come in and help me with the morgue care. We also talked about it a little bit in post-conference. We talked about my visit with the nurse and the hospice nurse and everything a hospice nurse

can do. We talked a little bit about how I felt about it and that, you know, it was depressing that she had passed. Participant #5

Students need to feel comfortable talking about their emotions. This participant was comfortable talking with her clinical instructor about her emotions and feelings.

Sometimes, the clinical instructor is the one students feel able to talk to. This participant also mentioned post conference as a place where she could discuss her feelings about her experience where she was among the other nursing students in her group.

The nurses on the floor where students are having clinical can be another source of emotional strength for students. Family can be a listening ear for students also. One participant talked about the floor nurse and her mom as people she could talk to about her experiences.

The nurse I was with that day, her and I just talked about it a little bit. I told my mom. It was my first time dealing with somebody, like the older lady, who was dying. Then at school I found out like a month afterwards, that she had passed so I just talked to my mom. I mean it was my first experience so it was kind of different, but I was kind of relieved she didn't die on our floor because I didn't know if I'd be able to bag her.
Participant #6

The participant was able to continue to talk to her mom about this patient. It was helpful for this student to be able to talk to her mom about the death of this patient especially since it did not happen while the student was taking care of her but happened later.

This participant also mentioned the nurse on the floor as a source that she talked to about the events in the clinical area.

Some students will spend time with the family and talk about the patient and things they said or did. This can be a very positive experience for the student.

Participant #13 talked about her experience with the family.

I think that the only one I had was a very positive one with the lady that had cancer in her mouth. She had a pretty large family that would come in quite often and they were more so a happy type, and they were upset, obviously, when she died. They were crying and they were grieving but they just focused on positives, like her life, what a good mother she was and they would sit there and reminisce about things. So I thought that was really nice and I got kind of emotionally involved in that , and I would talk to them and I'd tell them funny things she would say or do, like when I was taking care of her. Participant #13

Being able to talk about the patient with the family gave some comfort to this participant.

The sharing of experiences was a way to help remember the person and help form a bond with those who also knew her.

Crying

There are some students who have a difficult time with death and dying. Several participants mentioned that they spent some time crying about their patients. One participant mentioned crying as an outlet for her emotions besides talking to family. She stated:

Sometimes I'll mention them to my boss; she's a good resource person. I'll go to somebody that I know I can trust and that kind of thing. Usually my mom asks to hear about everything, you know. The poor woman, she's been through a lot since I was in nursing school. I usually just go to the resource person and you know, will cry by myself or something.
Participant #2

Sometimes people need to be alone in order to work through their emotions. This participant mentioned crying as a way for her to deal with the emotions. This participant also mentioned having people to talk to about her emotions.

There are students who become extremely overwhelmed with things that happen in clinical. One participant talked about her first clinical day experience where she was taking care of a dying patient.

It was a male patient and I never had a male patient before and he was in a coma. They had just taken out his feeding tube; they were going to let him go on his own. I didn't meet any of the family, but it was my first day and I came in to give him a bath and I had never seen a male before. So I was upset that he was dying 'cause everyone else had patients that were walking and talking and could answer their head to toe questions, so I burst into tear when it came to cleaning him. So pretty much I couldn't get over that. I was like upset the whole time so I stepped back and went to the break room and my classmates washed my patient for me. It was just tough. Participant #1

This participant was in clinical for the first time, was taking care of a dying patient for the first time and she was taking care of her first male patient. All this was extremely overwhelming to this student. Sometimes the only outlet is crying.

Another participant talked about her patient who passed away and the emotions that she felt. She stated:

The hospice nurse was in and out also, and she wanted to talk to me so she gave me a whole bunch of information. I met with her afterwards and I know she met with the rest of my clinical group like as a group and then with me separately. She would talk to me about what hospice does and that's the point when I was upset and I was crying. She told me it was okay. I can't completely remember what she said. I told her like "oh, you know, I shouldn't be crying" and she said the day you stop crying is the day you should stop being a nurse. Then she told me that was okay and she talked about how she liked like the process of dying, that she thought that it was not a scary thing, like a spiritual thing. She talked to me about that, and then that was really it. Participant # 4

This participant was emotional about the whole situation. The hospice nurse told her that it was alright to cry for her patient. This participant needed to hear from another nurse that it is ok to show their emotions. It is ok to be sad.

VALIDATION OF RESEARCH

All participants were given research findings table and a copy of chapter four. There was a face-to-face meeting and a follow-up email asking participants to look over the data and review chapter four to see if the findings matched the thoughts and feelings

they were trying to express. Of the 13 participants, 12 responded back either by email or in person and stated that the findings did capture their thoughts and feelings about death and dying.

CHAPTER V

DISCUSSION

The purpose of this study was to investigate the participants' experience of working with dying patients and their families. The three research questions were: (1) understand the nursing student's thoughts they experience in caring for the dying patient and their family, (2) understand the nursing student's feelings about caring for the dying patient and their family, and (3) understand how the nursing student's communicate with the dying patients and their family. Two other areas that were addressed in the study were multicultural issues and education that students received in preparing to care for patients in the clinical area. The study provides a phenomenological focus using interviews with each respondent to identify common themes.

A purposeful sampling approach was used for this study. The subjects were junior level nursing students in a basic 4 year nursing program at a large metropolitan area university. The courses were in an undergraduate program leading to a baccalaureate degree in nursing. The sample consisted of 13 basic nursing students age 20-42 enrolled in a nursing program at a Midwest urban university. The hospital settings used for the clinical sites were several small to medium size urban hospitals within a large metropolitan area.

Students had courses where some theoretical knowledge had been taught related to death and dying. Students also had a class in which therapeutic communication techniques were discussed and students had practice using the skills in the clinical area. These students were in their first semester of their junior year in a 4 year nursing program. Participants had anywhere from one patient who fit the criteria to up to six patients who fit the criteria. The researcher did not teach any of the students in this study in a clinical rotation. All 13 participants in the study met the inclusion criteria in which the students cared for at least one patient in at least one of the following three situations:

1. the patient was actively dying
2. the patient was diagnosed with a terminal illness during the time the student was with them or
3. the patient went into cardiac or respiratory arrest and died during the student's care.

Each participant came in for a 45-60 minute structured interview. A question outline was used for each participant. The aim of data analysis was to identify commonalities and differences in the individual experiences of participants. The goal was to keep the richness of the experience that each participant had with the patients that they cared for. The data analysis took place based on an eight-phase model developed by Denzin (1989), King (1994) and Sheehan (2004). Two additional phases were added. One phase was used to verify information with the participants and the second was a method used to categorize the results based on the number of participants who expressed the same idea within a domain. The analysis phase of the data was a series of overlapping activities that focused on a review of the transcripts and identification of the themes that emerge within the data.

Based on data analysis, there were 6 domains that emerged from the data. These

included thoughts, feelings, communication, multicultural diversity, training and education, and coping mechanisms.

In the thoughts domain, there were 8 categories identified. In this domain, students identified the thoughts they had while working with dying patients and their families. The categories were: aggressive care, physical, emotional and spiritual care, was something missed, they won't suffer anymore, it's part of life, privilege, family and own beliefs. The research indicated that nursing students had various thoughts about working with dying patients and their families including that it is frustrating and emotionally draining (Beck, 1997). Working with dying patients and their families included communication difficulties and ethical dilemmas (Loftus, 1998). Providing good comfort care (Kim & Lee, 2003; McClement & Degner, 1995) was an important aspect of providing care for the patient and their family.

Feelings were the next domain. This domain focused on the feelings participants had while caring for dying patients and their families. There were 8 categories identified which included: compassion, sadness, fear, upset, nervous/anxious, awkward, frustration and physical manifestations. The research indicated that students had many feelings when working with dying patients and their families including feeling overwhelmed (Hopkinson, Hallett & Luker, 2003), relief for the patient who was in pain and passed (Dunn, Otten & Stephens, 2005), feelings of anxiety (Cooper & Barnett, 2005) and positive feelings of the caring experience when working with dying patients and their families (Sharma, 1996-1997). Participants also identified some physical manifestations that they had in relation to these feelings. These included nausea, butterflies in the stomach, headache and being itchy. One student identified muscle twitching/eye

twitching as something she got when nervous and that was apparent to others around her.

The next domain was communication. In this domain participants talk about communication with patients and their families. There were 8 categories identified which included: dying process, difficult patient and/or family, unresponsive patient or nonverbal patient, emotions, not knowing what to say, language barrier, topic of death and therapeutic communication. Students in the study indicated that they had difficulty talking about death with their patient or the patient's family (Costello, 2001; Ramondetta et al, 2004; Levetown et al, 1999-2000). Several of the participants indicated that they had difficulty talking to patients who were unresponsive or nonverbal. Not knowing what to say seemed to be one of the most common things students mentioned having difficulty with when working with dying patients and their families (Sasahara, Miyashita, Kawa & Kazuma, 2003; Johnston & Smith, 2006). The language barrier presented the problem of the inability to communicate with the patient in general about their needs and the students were unable to assess other needs in regards to death and dying. Several factors made it more difficult with communication including language barriers, emotional patients or families and the students not knowing what to say in the situation (Sasahara et al., Johnston et al.). Also, age of the patient played a role in how the participant felt and how they communicated with the patients or family. The research did indicate that students were glad they had discussed therapeutic communication skills in class but many indicated that they needed more practice using it in the clinical area. Several participants stated that they would just avoid the topic of death and dying when working with their patients (Costello, 2001).

The next domain was multicultural diversity. In this domain, students identified

their experiences caring for patients from other cultures or religious backgrounds. The 3 categories identified were: role of the family, patient beliefs and values, and emotional expression. Participants identified family role as important to certain family groups. Some families were much more involved in the patient's care and decision making. Certain cultures/families had personal beliefs about who should and could take care of their family member. Gender of the nurse affected patient care in some instances and emotional expression of patient or family affected the students' ability to care for the patient. Students also stated that they felt there was a lack of education both in cultural diversity issues and in how to work with dying patients and their families (Sasahara, Miyashita, Kawa & Kazuma, 2003).

Training and educational preparation was the next domain. In this domain, participants identified how their training and education affected their ability to care for dying patients and their families. The major issue identified by students was the lack of educational preparation in working with dying patients and their families, lack of preparation in dealing with body preparation after death and lack of knowledge about cultural (Srivastava, 2007; Baltaglia, 1997) and religious (Collins 2006), issues when working with dying patients and their families. Participants stated that multicultural diversity patients were difficult because the students felt unprepared to care for them. Lack of education was the main issue that participants identified. They felt that not enough time was spent in the nursing program talking about diversity issues nor was enough time spent on the topic of death and dying and the care they needed to provide for the patients and the families.

The last domain is coping mechanisms. This domain concerns the ways students cope with their thoughts, feelings and experiences while working with dying patients and their families. This domain was broken down into two categories which were: talking about the experience and crying. Participants identified talking to fellow students, their instructor, family members and nurses on the floor as a way to deal with their thoughts and feelings while caring for dying patients and their families. The other coping mechanism identified was that of crying as a way to deal with their thoughts and feelings.

There are three ways this study can be viewed. First, this study can be viewed by self reflection of the student and their experience when working with dying patients and their families. The second by what needs students identified that they needed to help them be better prepared to work with dying patients and their families. The third way is by comparing findings from this study with those of previous studies of nurses and death and dying. All three areas are important in getting a complete picture of this study.

Research Questions

What thoughts do students experience when working with dying patients and their families?

The findings from this study indicated that students have a variety of thoughts when working with dying patients and their families. A major area that was identified by students was the idea of care and the need to give good care or extra care for both the patient and their family. The care was physical, emotional and spiritual in nature. Students stated that it was important to be attentive to patients especially those going through the dying process. Participants felt that when they couldn't do anything to save the patient, they needed to spend extra time to show them their concern. They want to

make the patient as comfortable as possible (McClement & Degner, 1995; Kim and Lee, 2003). When students know that they cannot do much for the patient to save them, they look for something that they can do to show their concern. Students also understand that the family is important too and needs to be taken care of (McClement & Degner, 1995). By showing care for the patient, it is a way to show care for the family as well. It can provide comfort to the family to know that someone is concerned for their loved one. Two students talked about taking care of a dying patient as a privilege. These students saw it as an opportunity to help someone and try to make them comfortable- it was meaningful to be able to do this for them. When students know they cannot fix things and that the patient is at that stage of life where they are not going to get better, they want to help them make their last days on earth as comfortable as possible. They feel a sense of happiness that they were able to help the patient and their family in some way. Sometimes giving care to the patient is the only thing that they can do. This idea of being able to care for someone who is dying as a privilege was not found in the literature.

Another aspect of care that one student in particular expressed was that of respect for the body after death. The participant felt that it was important to provide the best care for the patient's body with morgue care. This idea was also mentioned in the literature (Benner, Kerchner, Corless & Davies, 2003).

Participants identified thoughts about the family. Family was identified as important in the patients experience with death and dying (McClement & Degner, 1995). Some patients have no family at all due to life situations (one patient was homeless) or the family doesn't live near the patient. Students reflected on how sad it was to see the patient going through the dying process alone with no family to support them.

Aggressive care was a concern for several students. They found it difficult to watch a patient suffer especially if the student knew that there wasn't anything that could be done for the patient. Aggressive care includes medical procedures that won't improve the patient's quality of life or relieve their pain and suffering. Technology has allowed doctors to keep patients alive longer (Beckstrand & Kirchoff, 2005). Sometimes the care seems excessive. Patients or their families may be reluctant to let go and request that everything medically possible be done for the patient even if it is not going to prolong the patient's life or not improve the patient's quality of life. Those not in the health care area may not see or understand how this can affect the patient over time. Students may find it difficult to let the patient and family make these decisions when it is known that it will not improve the patient's quality of life. Participants talked about aggressive care given to patients when it appears that the patient will not recover (Bramstedt, 2001; Baldwin, 2003). This can become a conflict for students as they provide care to patients who don't get better but the family or even perhaps the patient is not ready to let go. Students see what decisions are made for the patient in relation to their care. For example, we may keep patients alive with a ventilator to breathe for the patient, but the patient may develop bed sores or pneumonia from lack of mobility. Patients may be kept alive via other means but may continue to experience pain that decreases the quality of the patient's life. Sometimes students can be overwhelmed with the decisions that need to be made in the care of a patient, not only by the doctors, but also the patient and family. It can be difficult for a student to see the patient suffer.

Several students realized that death is part of life (Dunn, Otten & Stephens, 2005). As students work with dying patients, it forces them to think about death (Moraglia,

2004). Many in our society do not talk about (Field & Copp, 1979), think about, or plan for death. It is a difficult topic and many are fearful of death. Many nurses are put in a position where they have to think about death when, if working in a different job, they may not have focused on this topic (Payne, Dean & Kalus, 1998). Having to think about death and how a student feels about it can be scary and difficult. Many nurses are forced to think about death when they are in a nursing position. Students may not be comfortable with their own idea of death. This can cause strong emotions when working with dying patients and their families. By working with dying patients, students realize it is part of life and can help them focus on the important things in life, things they might not realize until they really look at the big picture. Experiences with death can influence how they perceive death (Franke & Durlak, 1990; Schrock & Swanson, 1981). Students may be able to focus on what is most important to them when they see patients who are ill and dying. It can help redirect goals that they may have.

Along with the idea of death being part of life, students also realized that the patient won't suffer anymore (Kim & Lee, 2003). Students feel that it was a release from suffering for the patient and identified this as something they thought about (Dunn, Otten & Stephens, 2005). Because students may spend weeks with a patient in the clinical area, they may see that the patient is not getting better and is deteriorating. Students watch the patient suffer through the pain of their illness and even with the advancement of medical technology; it is not always possible to take away the pain or discomfort of an illness. Families will talk about how the patient has been suffering for a long time. The death of the patient may still affect the student with grief and loss, but they may find some relief from these feelings knowing that the patient is not suffering anymore.

One of the thoughts identified by students was did I miss something that may have signaled a problem with the patient that should have been identified and if it had been identified, would the patient still be alive (Loftus, 1998). This is especially true with those who are recovering as expected and then have a sudden arrest either cardiac (heart stops) or pulmonary (stops breathing). Students reflected on several patient experiences looking for something that may have indicated that the patient was in trouble. It is good for students to be able to reflect back on an event and review what was said, what was done and what the outcome was. It can help them in their learning process. It can also be frustrating to them when they think something should have been done sooner. Sometimes, however, when patient symptoms are somewhat common, like a headache, it can be difficult to see that there may be something else going on with the patient that is new. Students know that they are new to nursing and trying to hone their assessment skill-which takes time and practice. Reflection is part of the learning process even for experienced nurses. However, it can cause some self doubt about skills and abilities. Research literature talked about the need for more education in recognizing symptoms with sudden deterioration in hospitalized patients (Loftus).

All participants had some thoughts about death and dying or about working with patients and their families. There was a mixture of thoughts that participants had. Some thoughts were based on the participants past experiences but a lot of the thoughts were new because of the situation the participant found themselves in working in the hospital with dying patients and their families.

What are the feelings that nursing students experience when working with dying patients and their families?

There is a lot of emotion involved when thinking about the topic of death. The findings in this study revealed a number of emotions that students had when working with dying patients and their families. The most common feeling identified was that of sadness (Payne, Dean and Kalus, 1998). The feeling of sadness wasn't usually intense but death did have an impact on the participant in some way. Participants discussed intensity of feelings in regards to feeling sad in relation to taking care of younger patients verses older adults. Students stated that they would have a more intense feeling of sadness when caring for a child or young adult who was dying verses an older adult. The feeling that one has not had the opportunity to fully live when it is a younger child or younger adult makes the sadness more intense. Participants stated that it was much more difficult to work with the younger patients because of these feelings. In the literature reviewed, there was no mention of intensity of feelings in relation to age of the patient. The other part of feeling sad was watching the family as they watched their loved one (Hopkinson, Hallett & Luker, 2002). Participants stated that it was sad to watch the emotions of the family as they watch their loved one suffer and die.

Another feeling identified by participants was that of compassion. Showing compassion is considered a nursing trait. Trying to understand where the patient and family are coming from is important. It can be emotional to work with dying patients (Hopkinson, Hallett & Luker, 2003). Students can sometimes put themselves in their patient's situation and identify with what their feelings and frustrations may be. It can be hard when the patient and family are the student's age. The focus must be on the care of

the patient and their family. Students put themselves in the family or even the patient's situation and try to understand what they may be going through. Along with compassion is the idea of care and giving good care not only physical care, but also emotional and spiritual care. Participants talked about giving extra care or special care to the patient or family. It was important for them to show the family that they cared and were there for them and the patient. Providing comfort to the patient was part of giving care (Mc Clement & Degner, 1995).

Several other feelings that were identified by students included fear, being upset and being frustrated (Payne, Dean & Kalus, 1998; Beck, 1997). Students had negative feelings and although these feelings did not keep them from performing their duties as a student nurse, it did affect them in some way. The attachment students may develop with patients can make death harder for them to handle. They may have deeper emotions with those whom they feel a stronger bond. In nursing areas where patients may be living for a long time, nurses may form deep attachments to the patient and the family. One participant stated that her attachment made her more upset when her patient was actually going through the dying process. One participant talked about taking the feelings home every day. Some students are not able to separate out the nursing job from home life. They may take a lot of emotions home with them and have to learn to separate out these emotions so it doesn't affect their home life. The literature does talk about these strong emotions especially for newer nurses (Hopkinson et al, 2003).

All three emotions (fear, being upset and being frustrated) can affect communication or providing care to the patient or family. Several students would avoid some situations that made them uncomfortable or limited their time in the room. This can

cause the patient or family to feel isolated at a time when they may need emotional support. This can also leave students emotionally drained (Beck, 1997; Hopkinson, Hallett & Luker, 2003).

Students learn a lot of the body and disease processes that affect the body. Participants identified that there is a fear of knowing too much. It is hard to learn about all the things that can happen to the human body, all the things that can go wrong and not worry that you will get one of these diseases. This concept was not found in the literature review.

Participants mentioned feeling frustrated (Beck, 1997; Wong & Lee, 2000). Frustration can come from things they see like no family with the patient and the patient having to go through the dying process alone, to being frustrated by working with difficult patients or family members. Being frustrated can cause the student not to participate in meaningful conversations with the family or patient or the student avoiding the family or patient. Several participants mentioned these different situations and that it was difficult to complete tasks and stay focused.

Another feeling participants identified was feeling scared (Beck, 1997). It was usually tied to morgue care or the patient dying while the student was there. The data from this study revealed that for some participants, touching a dead body brought up very strong emotions that were sometimes overpowering in such a way that the participant could not complete the needed morgue care tasks with the patient and someone else had to do them. Students can feel overwhelmed by this emotion and it makes it difficult for them to care for the patient or provide post mortem care. Being afraid of providing morgue care was mentioned by several students. Students stated that having to touch a

lifeless body that may be cold and stiff can bring up a lot of emotions. Although they know it may be part of nursing duties, there is something scary about touching a dead body and one student mentioned the finality of zipping up the body in a body bag. The literature review did not reveal data on this topic.

Being nervous or anxious was another feeling that was mentioned (Beck, 1997). This feeling was mentioned in relation to caring for the dying patient (Cooper & Barnett, 2005), with morgue care, talking to the patient or family, or having a patient die while the student was there. The not knowing what to expect in the dying process or the disease process was also a source of anxiety for one participant in this study.

Three students talked about feeling awkward when working with dying patients and their families. The comments were related to nonverbal patients and feeling awkward in talking to someone who wasn't going to respond back and in talking with a patient or family member and not knowing what to say. Another aspect of feeling awkward was that of body language. One participant talked about body language communication that takes place in any situation. Sometimes someone may use body language that is inappropriate for the situation due to being nervous. It can become a barrier between the caregiver and the patient/family. It can be upsetting to both parties when this happens. Body language can send the message of I am not interested or I don't care. Students don't want to do this and need to be aware of their nonverbal communication. One participant recognized that this can be a problem for him. Talking about death (Gates, Kaul, Speece & Brent, 1992) felt awkward for some students. They had a fear of saying something wrong. This idea of feeling awkward was not found in the literature review.

Along with feelings that students had when working with dying patients and their families, students reported having physiological responses to these feelings. Although students didn't identify the same physiological response, eight students identified some type of physiological response they had when working with dying patients and their families. There were two categories of responses; those that were felt by the student and the other were those that could be seen by others. Responses that could be felt by the students included headaches, butterflies, upset stomach and feeling itchy. Those physiological responses that could be seen included shaking muscle/eye twitching and responding inappropriately like laughing. Families and patients may notice the visible signs and that may affect patient or family response to the nurse caring for them. If the patient is unconscious, the student doesn't want to look like they don't know what they are doing in front of the family which can also be emotionally draining (Beck, 1997; Cooper & Barnett, 2005). If the caregiver looks nervous or upset, it can affect the confidence the family may have in the person giving care. Physiological manifestations were not found in the literature review.

Everyone reacts to stress differently. Some reactions may cause problems for the student in giving care to the patient or the family. It is important for students to know how they react to stress, however, some manifestations may not actually happen until the student is placed in the situation and the response happens. Although the participants had varying physiological manifestations, none of them felt that these interfered with the care they gave their patients nor did it interfere with their work on the clinical unit. They were still able to cope with the tasks they had to complete and they were able to work with the

patients and their families. They also stated their physiological manifestations did not interfere with their daily life or activities.

There were a number of feelings identified by participants that they experienced when working with dying patients and their families. Feelings can be affected by age of the participant, past experiences, spiritual beliefs and their environment as they grew up (Franke & durlak, 1990). It is hard to predict how someone will feel when caring for dying patients but it is important to know and acknowledge the students feelings and help them work through them.

How do nursing students report communicating with dying patients and their families?

The research indicated that communication was a major concern for participants in this study. One of the hardest areas of communication for students was talking about death and dying with the patient or the family (Ciccarello, 2003; Mc Cabe, 2004; Pierce, 1999; Wenrich et al, 2001). Avoiding the topic of death and dying seems to be how some participants in the study felt they would handle this situation (Costello, 2001; Levetown, Hayslip & Peel, 1999-2000). Most said they would not bring up the topic of death and dying on their own. A few felt that if the patient did not bring it up, they probably did not want to talk about it (Costello, 2001). Death and dying is usually not an everyday topic of conversation that students have with family and friends so it is difficult for them to talk to patients and family members about death. Students stated they try to avoid the topic or may try and change the subject. One student did talk to the patient a little bit about their diagnosis and dying but stated that the patient brought it up, did not seem sad about it and was not emotional about it. This made it easier for the student to talk about death with

the patient. The literature did mention that if the patient or family were emotional, it made it more difficult for physicians/nurses to discuss death with them (Samaroo, 1996).

Another part of communication that students found difficult was trying to have conversations with difficult patients or family members, unresponsive patients or emotional patients or family members. All three of these types of patients or situations made communication difficult. When the patients or family member is angry or demanding, it can strain the caregiver role of the student (Samaroo, 1996). Participants stated they would try to avoid the room as much as possible. If it is a difficult family member, it can keep the student from having a meaningful conversation with the patient or family. It is difficult to try and have a meaningful conversation with a patient who is angry or bitter.

Unresponsive patients are difficult because students feel uncomfortable talking to someone who can't respond back to them. If the patient is making noises, sometimes the student is unsure what is needed. Is the patient in pain, in an uncomfortable position or hungry? It becomes a guessing game. If the patient is totally unresponsive, the student may feel like they are talking to themselves and several students stated that it was awkward for them. The emotional patient or family is also hard to deal with. Trying to be there for a patient or family who is crying or upset can strain the communication (Samaroo, 1996). Again, students said that not knowing what to say was a challenge in these situations (Wong & Lee, 2000).

Another communication issue that was brought out in the study was that of the language barrier. Students found it difficult to try and communicate with those who did not speak English. Participants also found it difficult to hold any meaningful

conversation with the patient or family including anything about death and dying.

Patients may be afraid to take medications that may look different than the ones from home or may be afraid of the tests and procedures that the doctors want to do (Andrews & Boyle, 2003; Huff & Kline, 1999). One problem was that students could not always figure out what the patient or family needed, so they felt this affected the care they were able to give. Nurses may feel like they are not giving the best care when they are unable to communicate with the client or their family. Language barriers can be very difficult to work with especially if the family is unable to help translate and the nurse is in a hospital with limited translation help or on a shift where help may not be available. One of the biggest problems is that the patient may not get the necessary care that they need and the nurse becomes frustrated because he or she cannot understand what the patient is asking for (Beck, 1997).

One challenge that was identified by most participants in the research data was that of not knowing what to say. This was one of the most often identified problem that participants said they have is knowing what to say in a given situation. This made it difficult for participants to talk about death and dying with patients and family members. It can be frustrating for the student as well as the patient. Sometimes the topic of death and dying is avoided because the student doesn't know what to say or is afraid that the patient won't want to talk about it (Levetown, Hayslip & Peel, 1999-2000). Sometimes however, if the student would listen or ask one simple question of 'do you want to talk' they may find that the patient is just waiting for someone to ask so they can express their thoughts, feelings and fears (Breitbart, Gibson, Poppito & Berg, 2004).

Several participants had the opportunity to use therapeutic communication skills that were taught in their fundamentals courses in nursing school. Those who were able to use therapeutic communication were grateful that they had learned it in school because it helped to guide them in their conversations with the patients or family members. One participant mentioned how a parent of a young child would come find her to talk to her even though she was no longer assigned to the patient. There had been a bond formed between her and the mother. Several participants stated that even though they did not have the opportunity to use therapeutic communication in the clinical setting, they felt it was good information to know so they would know what to ask and what not to ask patients in the future. Not many participants actually had a therapeutic conversation with a patient or family member in this study. Some participants stated that they had avoided the topic of death and dying and did not pursue any other topics with a therapeutic conversation in mind. Although the literature did not mention therapeutic communication by name, several articles addressed the need to allow the patient and family to discuss their thoughts and feelings about death and dying (Breitbart, Gibson, Poppito & Berg, 2004; Kaut, 2002).

Communication is an important skill that students need to develop. As can be seen in this section, there are many areas that were identified by students that show a lack of effective communication skills when working with dying patients and their families. It can be emotional for the students to talk about death but the patient's needs should be the priority and some patients may need to be able to express their feelings or may need help moving through the dying process. Being prepared for this kind of interaction takes education and practice.

There were three other areas that were discussed in the interviews with participants. One was multicultural diversity and the second one was education and training that was received in the nursing program and the third was coping mechanisms. Both topics produced important research data that needs to be reviewed. The next section is a discussion of the research data from this study.

Multicultural Diversity

One aspect of nursing care that has changed over the last 50 or so years is that of working with patients and families of varying cultural backgrounds. In a large metropolitan area, it would be expected that students would have patients with a variety of cultural backgrounds/ worldviews. Multicultural diversity is an important topic in relation to nursing in general and specifically to the topic of death and dying. In today's society, there are multiple cultural and religious groups that nurses come in contact with (Huff & Kline 1999, Rawlings-Anderson, 2004). It is important for students to have some understanding of other cultures and religions especially when working with dying patients and their families (Srivastava, 2007; Andrews & Boyle, 2003; Campinha-Bacote, 2003). There may be important cultural or religious rituals that the patient or family wants to have done and nurses need to be culturally aware of those rituals in order to provide the best care for their patients (ElGindy, 2005, Giger & Davidhizar, 1999, Lemon, 2002, Donnermeyer & Freidrich, 2002). Because of the small number of patients from other cultures, most students reported that they did not have varying world views that were much different than those of the patients they took care of. This has a profound effect on this part of the research since there is not much data that was collected in this area.

In this study, participants stated that there were not many opportunities to work with different cultures. One reason this may be is that participants were at smaller hospitals in the city and suburban areas and not in the several very large hospitals where there may have been more of an opportunity to be exposed to more diverse populations. The second reason may be the types of floors that participants were on. Some areas of nursing have higher incidences of having more diverse populations than others. For instance, on rehabilitation type floors, many patients will try to find locations close to home since the rehabilitation phase can take up to six weeks or more. This may limit the culturally diverse population that might be seen elsewhere.

One aspect of multicultural diversity brought out in the research data was that of family. For some cultures, family is very important not only for support but for decision making. Participants found that depending on the culture, family may be extremely involved or not involved much at all (Andrews & Boyle, 2003). One way family was involved was in the number of family members who came to stay with the patient while they were in the hospital. With some cultures there are a lot of family members in the room at one time. Participants were surprised not only by how many family members were in the room, but that some families would bring small babies or small children. Several participants talked about their experiences with the African American culture and the Hispanic culture. Both of these cultures seem to value family and many of the family will be in the room with the patient at the same time. Participants mentioned that it was difficult to have that many people in the room and that at times it was hard to get everyone out of the room in order to provide care. Some families would not leave at night and would sleep in the lounge in order to be close to the patient. Nurses need to

understand that some cultures bring everyone with them to the hospital. It is important to allow family to be involved with the patient especially if the patient is in the dying process (McClement & Degner, 1995). This may be the last bit of time the family has to spend with them. Family is an important aspect of patients' lives. Family is often present when the patient is in the hospital and is often involved in their care. It is important for nurses to be able to work with the patient and their family in order to provide good care (Kim & Lee, 2003).

Participants also talked about patient beliefs and how they affected care and conversations between the participants and the patient (Huff & Kline, 1999; Rawlings-Anderson, 2004). One participant had an atheist and found it very difficult to talk to this patient about this particular belief system because it was so different from his own. However, being open to discuss the beliefs of the patient is something nurses need to be able to do. Being culturally competent is discussed in the literature (Collins, 2006; Campinha-Bacote, 2003). Nurses need to understand the patient's belief system and religion and be able to talk about these beliefs with the patient even when they don't match the nurses (Zerwekh, 2006). Nurses need to be able to hold meaningful conversations with patients about the patient's beliefs even when they are very different from what the nurse may believe. This is where cultural competence comes in. Nurses need to be able to set aside their own beliefs and let the patient talk about what they are feeling and what they are experiencing in relation to their beliefs (Srivastava, 2007; Boyer, 2006; Collins, 2006; Campinha-Bacote, 2003). The data revealed that participants had a difficult time being able to do this. Nurses need to try and understand the patient's

view of life and the world. The patient's view can affect how they take care of themselves and how they view the healthcare system (Collins, 2006).

One participant pointed out his experience with a patient of one culture and a priest of another culture. The participant felt like the priest missed the point of the participant asking him to go and speak with the patient. Sometimes other members of the team are not focused on what the patient's needs may be. When two different cultures interact together, the true needs of the patient may be missed because one person is not viewing things from the patients view point. Nurses need to be aware of what is going on with their patient when others come to talk with them from other disciplines. Opportunities for comfort and good care may be missed when someone does not understand the needs of the patient or family (Zerwekh, 2006; Campinha-Bacote, 2003).

The research also revealed data related to patient values and beliefs. There were three men in the study and only one of them mentioned the gender issue but it is important for nurses to be aware of this potential problem and be able to accommodate patients based on their needs whether due to cultural or religious beliefs. There are several cultures who do not allow the opposite sex to care for them. There are also patients in general who do not feel comfortable with someone of the opposite sex taking care of them. This may not always be culturally or religiously influenced but needs to be addressed.

Different cultures and different age groups of people react differently to those giving care. Men in nursing may have trouble breaking that barrier with women of other cultures or with women in general even in the American culture. Sometimes it is necessary to change the nurse in order for care to be given. This problem has also been

seen with men of certain cultures with female nurses who may encounter this same issue of no opposite sex contact. This may cause problems especially if there is no one who can fill in from the other nursing staff available. Nurses need to be culturally sensitive to the needs of the patients and make accommodations when possible. Although the literature reviewed did not specifically mention the gender issue, being aware of cultural needs was talked about (Huff & Kline, 1999; Giger & Davidhizar, 2004).

Emotions are different among family groups and among cultures (Wong & Lee, 2000). One aspect of caring for the patient that participants found difficult was when the patient or family was emotional. Nurses need to allow the family to grieve but it can be difficult and uncomfortable for the student when the family is displaying overwhelming grief and the student is not used to that type of reaction. Understanding how cultural groups show grief may be helpful for students to be somewhat prepared to work with the different cultures (Huff & Kline, 1999; Geiger & Davidhizar, 2004).

Training and Educational Preparation

Another important topic that was revealed in the research data was that of education. Many students felt unprepared to go into the clinical setting. The areas that participants addressed as not being prepared in were talking to patients about death and dying, cultural needs of patients, and how to work with dying patients and their families. Knowledge of the dying process was something else participants felt weak in.

Participants stated that they felt there was not continuous learning about death and dying or with cultural diversity throughout the nursing program (Ferrell, Virani & Grant, 1999; Field & Wee, 2002). They stated that there were several classes in the beginning of their program that addressed culture and dying but they felt it was not enough to

prepare them to work with dying patients and their families (Sullivan, Lakoma & Block, 2002; Loftus, 1998). One participant mentioned that in the nursing program students were not given the opportunity to think about what they personally thought about death and dying (Rooda, Clements & Jordan, 1999). This participant felt that it would help students when working in clinical if they had already thought about their own personal beliefs. Participants stated that there was very little class time devoted to the topic of death and dying including how to communicate with the patients and the family members (Wong & Lee, 2000; Sasahara, Miyashita, Kawa & Kazuma, 2003). Participants stated that they did not know what to say to patients or to family members. Many would avoid the topic of death and dying all together. Feeling unprepared to work with dying patients and their families sometimes increased the stress that participants felt in the clinical setting. Also with feeling unprepared, participants identified the lack of preparation with understanding and working with different cultures (Campinha-Bacote, 2003). In this particular study, there was not a lot of interaction with other cultures by many of the participants.

One of the problems with nursing and nursing education is that there is so much information that needs to be taught. There seems to be little extra time to add things into the curriculum. This had students frustrated when they were in the clinical setting and having to do morgue care, talk to patients about death and having to determine what cultural rituals were needed for their particular patient. Participants felt emotionally unprepared to work in the clinical area and there was increased anxiety when having to work with a dying patient (Cooper & Barnett, 2005; Delaney, 2002). They also stated that it was even harder when it was their first clinical setting and they were trying to get

used to the setting. Now they had something additional that they had to think about with the patient who was dying or having to do morgue care.

Understanding cultures and providing cultural competent care has become an important aspect of nursing within the last 30 years (Giger & Davidhizar, 2004). It is only recently that culturally oriented questions have been added to the Nursing Licensure exam. Multicultural diversity is an important area that students need to be aware of and have some understanding of. It is important for students to understand their patient's beliefs. It can affect how nurses provide care and how nurses advocate for the patient in meeting their desires in regards to death and dying. It can also be very difficult for students to talk about death and dying especially if the beliefs of the patients are different than that of the students. Students need to have some education on culture and multicultural diversity in order to provide good care to patients (Srivastava, 2007; Boyer, 2006; Campinha-Bacote, 2003; Worrell-Carlisle, 2005). Research also indicates that there is a lack of cultural understanding in many areas including religious beliefs (El Gindy, 2005; Andrews & Boyce, 2003; Baltaglia, 1997), use of healers and alternative healing methods among other cultures (Srivastava, 2007; Giger & Davidhizar, 1999; Lemon, 2002) and practices at the time of death (Zerwekh, 2006). The research also indicated that there was an overall lack of education in the area of death and dying (Deleaney, 2002; Pimple et al, 2003; Sasahara et al, 2003; Coolican et al, 1994).

The second part of education that participants mentioned was the idea of novice to expert (Benner, 1984). Novice to expert is an important framework for students in explaining their learning and development in the nursing area. It affects all areas of nursing. Some participants recognized that they were in the beginning phase of learning

and developing their nursing skills in assessment and communication and were very inexperienced at this point of their nursing career (Benner, 1984; Haag-Heitman, 1999). This can affect their thoughts and feelings about what is happening in the clinical setting because they don't have any past experience to work with, this is all new. Participants stated that they felt as they got more experience and opportunities to practice their skills and gain knowledge that it would become easier to work with dying patients and their families and it would be easier to communicate with them.

Coping Mechanisms

One additional piece of data that came out of the research was that of coping mechanisms. Participants were asked how they dealt with their thoughts and feelings when working with dying patients and their families. The most common response was talking to someone about their thoughts, feelings and experiences. Post conference time seemed to be the most common place for this to occur. Post conference is at the end of the clinical day when the students can discuss things that happened on the floor, talk about patients and discuss their feelings about nursing and nursing care. Post conference usually lasts about 45 minutes. Post conference also provides students with an opportunity to bond since the patients were usually familiar to the rest of the group. When students have all participated in a patient's care at some point during the clinical rotation, it can form a bond between the students and the patient. This bond can help students deal with the death of the patient and talking in post conference, the students are able to work through their emotions. Students don't feel alone in their thoughts and feelings and can see and hear that others feel the same way. Talking is a way for students to deal with the emotional issues of death and dying (Kiger, 1994; Loftus, 1998). Other

research showed that clinical education with a faculty member can have a significant effect on helping students understand their feelings about the dying experience (Johannsson & Lally, 1991). Other students identified someone they could talk to about their thoughts and feelings, about their death and dying experience that they had in clinical and included family members, clinical instructors, and other nurses on the floor.

There was one other coping mechanism identified as a way to deal with the emotions of working with dying patients and their families. Several students stated that they would use crying as an emotional release to their feelings. Usually their crying took place outside of the clinical area but one student stated that she had a crying episode at the clinical site due to the overwhelming emotions she had. Since the other students knew who her patient was, this student also used post conference to talk about the experience as a way to deal with the emotions. Although the literature did not specifically mention coping mechanisms, anxiety and emotional distress was mentioned in the literature (Beck, 1997).

RECOMMENDATIONS FOR FURTHER RESEARCH

The implications of this study for research are far reaching. There are many areas of this study that could be a study by itself. More research in communication issues, education and multicultural diversity would all be important studies that could be studied in more depth. Each area could be a study by itself. There is a lot of research about students/nurses feeling they lack knowledge and skill in the communication area especially when working with dying patients and their families. Studies could be done looking at classroom or clinical rotations that focus on education and patient hands on activities that incorporate communication skills with educational modules and

experiences. The studies could compare students' thoughts and feelings of working with dying patients and their families before and after such experiences or the study could be done using comparison groups.

This study was limited to basic level undergraduate students. It would be equally important to study senior level students to see if there are different issues that arise or if they have the same concerns and issues as the sophomore/junior level students. Also, the senior students have a critical care rotation where they may have more opportunity to work with dying patients and their families.

Many schools now have accelerated programs with students who have at least a baccalaureate degree in a different field and come in and complete the nursing program. These students may have no experience with death and dying patients where some of the basic students have been working in the medical field and have some exposure to nursing. A study of this group would be beneficial in helping to identify learning needs of these students. A comparison study looking at the accelerated students compared to the basic students would be beneficial. It is important for educators to see what needs there are of students at different levels and in different programs to better plan educational material to meet the students needs. A comparison study could help to do this.

The student's age can have an impact on the data collected. Life experiences can affect data collected. It may be beneficial to conduct a study looking at life experiences and age in relation to the topic of death and dying and the student's thoughts and feelings. This could be done in the basic or accelerated program or it could be a mixed study using age as a criterion for what study group a participant may be placed.

Another part of the study could be adding journaling to the data collection. Students could record their thoughts and feelings about their experiences in the clinical area. This would provide additional data to a qualitative study and may clarify or provide more in depth information and data. In the current study, participants were talking about experiences over two clinical rotations. Some of the intensity of their thoughts and feelings may have been lost over time. Journaling would help keep the intensity of the emotions more intact.

The literature shows that there are concerns with nurses working in the nursing field who may work with dying patients on a regular basis. There seems to be a lack of education about death and dying (Robinson, 2004; Sullivan, Lakoma, & Block, 2002; Coolican, Stark, Doka, & Corr, 1994), communication skills (De Araujo and de Silva, 2003, 2004; Degner, Gow & Thompson, 1991) and lack of diversity training (Srivastava, 2007; Boyer, 2006; Collins, 2006; Campinha-Bacote, 2003). A longitudinal study need to be conducted to examine the long term implications of students and their change over time, if any, in relation to death and dying issues. The study could look to see if their thoughts and feelings about working with dying patients and their families change over time and with their experiences in class and in the clinical area. The study could follow the student from sophomore through graduation. This type of study would also address the issue of Benner's theory of novice to expert in seeing over time if the students have changes in their thoughts, feelings, communication skills, and multicultural diversity issues. Some of the outcomes would be affected by educational opportunities that students had in the clinical area and with on the job training.

A study using quantitative collection methods would be helpful. Using an already established instrument or developing one about thoughts and feelings about death and dying could provide helpful information that could be used to develop instructional material. There are several instruments available that have been used in other studies that were identified in the literature (Dunn, Otten & Stephens, 2005; Cramer, McCorkle, Cherlin, Johnson-Hurzeler & Bradley, 2003).

IMPLICATIONS FOR STUDENT NURSING PRACTICE

The implications for practice are also evident through the findings of this study. The data from this study suggest that there are many thoughts and feelings that students have when working with dying patients and their families. Participants identified communication and working with other cultures as being difficult. Although death is not new, the concept of care, end of life needs and communication with dying patients and their families have become important areas that need to be addressed not only with nurses but especially with students.

Many students have not had a lot of experience with death and dying. The topic of death is not one that is in most people's everyday conversation, yet the chances of a student having to care for someone who is dying, or who has passed on increases when they start nursing school. Being able to feel comfortable and confident when working with this population is important. It is so important that an End of Life Consortium has been formed to help train healthcare professionals on important issues at end of life, and how to communicate with dying patients and their families.

The data from this research demonstrates that there are a lot of emotions and thoughts that students have. The data does confirm a need for students to be able to talk

about their experiences in the clinical setting when working with dying patients and their families. Post conferences seem to be an opportune time for students to do this. Clinical instructors need to use time in post conferences to allow students to discuss their thoughts and feelings about the patients they cared for. It is not only a time for students to vent, but a time for the instructor to help guide students (Norton & Thacker, 2004) in how to work with the patients and their families. This may be one of the areas that need to be addressed by faculty. Not all clinical instructors are comfortable themselves with working with dying patients and their families. It would be important to help staff work through their own emotions and take continuing education classes in order to be better prepared to help the students get the most out of their clinical experience. Research demonstrates that the clinical experience can be an important part of a death education program (Johansson & Lally, 1991).

Providing more learning opportunities for students in the classroom is an important way to help students feel more prepared. This can be done through incorporating more discussions on death and dying into the curriculum or by developing a class specifically on the topic of death and dying that will allow students the opportunity to explore the topic in depth and explore their own thoughts and feelings about death and dying.

IMPLICATIONS FOR NURSING TRAINING

This study also suggests a need for more education in general about death and dying issues and more specifically, communication skills and preparing for morgue care. There are now competencies that are included on the NCLEX-RN licensing examination about care, communication and cultural awareness when working with dying patients

(Wendt, 2001). Participants stated that they felt that there was very little time spent in the classroom on the topic of death and dying. They also felt that the education should be spread out over more courses. The first semester seemed to be where students got one or two days of discussion on the topic of death and dying. There was also no discussion about morgue care and what was involved. Many of the participants had never really seen a dead body before and very few had actually touched a dead body. Having to provide morgue care was identified as frightening and scary by the participants. Faculty members need to look at the curriculum and plan either a class by itself on death and dying, or include many more discussions throughout the course on death and dying (Coolican, Stark, Doka & Corr, 1994; Ferrell, Virani & Grant, 1999; Robinson, 2004). Although students are taught therapeutic communication skills in the classroom, their education does not focus on death and dying conversations and how to talk to a patient about their diagnosis. This may be something that should be addressed when students learn therapeutic communication techniques.

The other area that was brought out in the data from this study was that of multicultural issues. Although students did not have a lot of contact with different cultures in this study, it was identified by participants as another area where more time needs to be spent discussing it in the classroom. Participants did not feel like they were prepared to work with other cultures especially those who were dying. They again stated that very little time was spent in the classroom on multiculturalism and that it was a topic that needs to be discussed throughout the nursing program.

The main themes from this research indicate a need for students to be and feel more prepared to be in the clinical area especially when working with dying patients and

their families. In addition, multicultural issues were another area that participants felt unprepared. Making sure that instructors can help facilitate that learning by being an example for students to follow, and making sure that instructors are comfortable themselves with working with dying patients and their families and with other cultures is something that is very important in the nursing program. Providing training for faculty or taking advantage of the many conferences available in the area of death and dying and multiculturalism is one way to do improve faculty knowledge and understanding.

LIMITATIONS

A limitation of this study is that it was only with one cohort of students in the basic nursing track at one university. It would be very important to look at other cohorts not only at one school, but in other nursing schools in the area. Being able to compare the findings with other groups may provide different data that would help develop long term learning goals for other programs as well.

This study did not take into account the participants age or life experiences that may have an effect on the data collected. This may be something that needs to be considered in a future study. Because many students are going back to school for a second career, the age of the students can be 40 to 50 years old. Life experiences and past careers may have an impact on the data.

A third limitation of this study is with the interviewer and the relationship with the students. Even though the interviewer did not have any of these students in a clinical rotation, they were all students that were familiar to the researcher. This may have hindered the students from fully expressing their thoughts and ideas in the interview process.

CONCLUSIONS

As an educator who has worked in the nursing program for over 10 years, I see that there has been a change in the focus of working with dying patients and their families. It has become an important topic in many nursing conferences and there are a number of training programs available to the medical community in this area. I see that it is also something that students have a lot of emotions and concerns about. Part of being a nursing instructor is being able to lead and guide students to be prepared to be caring, knowledgeable nurses in the nursing field. Part of this knowledge comes with hands on experience in the clinical setting. The classroom and clinical areas are important in the training and preparation of new nurses. This study demonstrates the need to provide further education and knowledge in the area of death and dying, communication and multicultural diversity in the nursing curriculum. This study also shows the need to have knowledgeable faculty who are able to provide an example to students and to be able to provide emotional support to them when they are in situations that may make them uncomfortable and emotional. How our nursing programs choose to incorporate the needed education into the nursing programs is of great importance to nursing students and their learning. It is something that nursing programs should evaluate and then make any necessary changes to help students be more prepared to enter the nursing field.

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APPENDIX

APPENDIX A

Demographic Questionnaire

Age_____

Gender_____

Please check the appropriate box or write in the appropriate answer for the following sections:

Ethnic background:

European American	_____
Native American	_____
Hispanic	_____
African American	_____
Asian/Pacific Islander	_____
Other	_____

Highest level of education completed:

Content area of degree

Associates degree	_____	_____
Baccalaureate degree	_____	_____
Master's degree	_____	_____
Other	_____	_____

Have you ever worked or volunteered in a medical setting?

Yes	_____
No	_____

If yes, length of experience: _____ years _____ months

If yes, describe your experience:

APPENDIX B

Interview Questionnaire

1. Describe your experiences working with dying patients and their families during your clinical experience.
 - Was there one patient or several
 - What happened
 - How much involvement did you have with the patient
 - How much involvement did you have with the family
 - What other experiences working with dying patients and their families did you have

2. When you have worked with dying patients and families, what thoughts and feelings did you have?
 - Were the thoughts and feelings positive/negative/neutral
 - How intense were the thoughts and feelings
 - Did you experience these feelings physiologically?
 - i. Examples- muscle tension, nausea, butterflies, headache, stress
 - How did you deal with the feelings you experience?
 - i. Ask about each feeling stated
 - How do you think you will deal with those feelings if they come up again?
 - Do you think your experience will be different in the future?
 - i. If yes, how
 - People have varying worldviews (i.e., how you view the world, life, death, your beliefs, values, etc) which include ideas about death and dying. Have your experiences with dying patients and families been consistent and/or inconsistent with your own worldview?
 - Do you think your own thoughts and feelings about death and dying influence your work with patients and their families?
 - How have your thoughts and feelings changed, if at all, since working with death and dying patients and their families?
 - i. Particularly to patients and their families with cultural worldviews that are similar and different than your own
 - How has your coursework influenced your thoughts about death and dying, if at all?

3. When you worked with dying patient, what was the *experience* of talking to them like for you?
 - Did these experiences vary if the patient had a different cultural background from your? If yes, can you give an example?
 - What challenges did you face in communicating with patients?
 - Their families?

- Did you have any worries or concerns about communicating with patients and their families?
- Did you have any experiences with therapeutic communication. If yes, can you tell me about that.
- Positive/negative/neutral experiences
- Has your experience been different communicating with patients and families who's cultural and worldview are different from your own?

APPENDIX C

Informed Consent

My name is Joan Niederriter and I am doing research on the perceptions of death and dying of nursing students. Through this research, I hope to gain a better understanding of how students view death and dying and how this impacts their nursing practice. I will be doing one interview asking questions related to the topic of death and dying. The interviews will be anonymous to all but me. There will also be a short individual follow-up meeting reviewing my findings and confirming the data with each participant.

The interview will be about 60 minutes long and consists of questions related to your experiences in the clinical setting. Each interview will be taped in order to get the full conversation.

Your participation in this research is completely voluntary. If, at any time, you wish to withdraw from the research, you are free to do so. Due to the nature of the topic and the possibility of emotional stress, if you feel the need for counseling, you can contact the CSU counseling center at 687-2277.

My supervisor for this project is Dr. Schultheiss from the college of education.

Please read and sign below the following paragraph:

I have read and understand the information that has been provided regarding the procedure, my tasks, and the risks that may be involved in this research project. I understand that my participation is voluntary and that I may withdraw at any time. I understand that if I have questions about my rights as a research subject, I may contact the Cleveland State University Institutional Review Board at (216) 687-3630 or I may contact Joan Niederriter at (216) 875-9874 or Dr. Schultheiss at 687-5063..

Signature

Date