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# The Effects of a Community-Based Hospice Experience on Attitudes and Self Perceived Competencies of Senior Nursing Students

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# THE EFFECTS OF A COMMUNITY-BASED HOSPICE EXPERIENCE ON ATTITUDES AND SELF PERCEIVED COMPETENCIES OF SENIOR NURSING STUDENTS

by

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Abstract

THE EFFECTS OF A COMMUNITY-BASED HOSPICE EXPERIENCE ON ATTITUDES AND SELF PERCEIVED COMPETENCIES OF SENIOR NURSING STUDENTS

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Death is a universal phenomenon. Of all health professionals, the nurse is the most likely one to be present at the time of death. Although nursing curricula provide mandatory clinical experiences in labor and delivery, pediatrics, psychiatry and adult medical surgical areas, there is no mandatory requirement for a clinical experience with death. In fact, before 1999, there was not even a requirement to teach about death and dying in undergraduate nursing curricula. As a result, students (who later become nurses), feel unprepared to take care of dying patients.

Because death has meanings beyond just the cessation of vital signs, students develop attitudes about death that come from their culture, religion or previous experience. Discomfort with end-of-life (EOL) comes from these attitudes as well as feeling unprepared to care for the dying patient. In order to provide competent EOL care, students need factual knowledge but they also need the opportunity to explore and evaluate attitudes that may help or hinder their nursing practice

Transformational Learning Theory (TLT) provides a framework for teaching EOL care. TLT is an adult learning theory that focuses on attitudes as an important part of the learning process. By participating in learning environments that challenge attitudes as well as teach skills, students have the opportunity to identify, reflect on and discuss their attitude with others and hear others' perspectives. This process may change their attitude and ultimately modify their behavior the next time they encounter a similar situation. In order to provide competent EOL care, students need opportunities to explore their attitudes about death and dying.

## Table of Contents

## Overview of Study

### Purpose

Death is an inevitable consequence of life and yet few nursing education programs include clinical experiences with dying patients. As early as the 1990's, nursing authors have been aware of the lack of end of life (EOL) education in nursing curricula (Beck, 1997; Frommelt, 1991; Kaye, Gracely, & Loscalzo, 1994). Ferrell (1999) highlighted the problem when she reviewed 50 nursing textbooks for end of life content and found very little information on EOL care. In fact, some books addressed the care of the body after death but made no mention of symptom management of the dying patient or bereavement needs of the grieving family. A follow up examination of 14 critical care textbooks by Kirchoff, Beckstand, and Anumandla, (2003) showed that no textbook addressed all of the essential EOL content and three of the textbooks did not address any needs of the dying patient. A survey by Ferrell (2000) of 725 Deans and faculties of nursing schools and representatives of state boards of nursing also identified gaps in EOL education in nursing curricula.

This glaring omission of EOL content led to two major developments in the past ten years that have had an impact on nursing curricula. The first was the development of EOL competencies by American Association of Colleges of Nursing (AACN). AACN, along with experts in EOL practice, identified 14 competencies that nurses graduating from all basic nursing programs needed to demonstrate (AACN, 1998). The second major development was the launching of the End of Life Nursing Education Consortium

(ELNEC) in 2000. ELNEC was a project between AACN and the City of Hope Cancer Center and was funded by Robert Wood Johnson Foundation (RWJF) for the purpose of providing training on EOL care to nurses. Key content was divided into nine modules (nursing care at the end of life, pain management, symptom management, ethical/legal issues, cultural considerations, communication, grief and bereavement, quality EOL care, and preparation for the time of death). The content was offered in select cities free of charge with the first one starting in January, 2001. To date, these courses have trained 900 nursing faculty and 802 staff development educators and continuing education providers (AACN, 2010). In addition to the core courses, subsequent funding led to the development of specialty ELNEC courses in Pediatrics, Critical Care, and Geriatrics. A total of 2790 nurses attended these specialty sessions (AACN, 2010).

In spite of these educational initiatives, recent studies of nursing students show that they still experience anxiety and do not feel adequately prepared to take care of dying patients and their families (Allchin, 2006; Chen, Ben, Fortson, & Lewis., 2006; Shlairet, 2009; Wallace et al., 2009). Death anxiety is a common experience for nursing students. Students enter nursing school with little or no experience of death and have already developed their own attitudes about death (Allchin, 2006; Kurz & Hayes, 2006; Kwekkeboom, Vahl, & Eland, 2005; Mallory, 2003). A review of the literature since 1999 found a scarcity of articles addressing implementation of educational strategies in EOL care. Most studies reported on effects of classroom knowledge. Only two studies described outcomes resulting from clinical experiences with dying patients (Allchin, 2006; Kwekkeboom et al., 2005) but these had inconsistent clinical experiences, a self-selected small sample, and researchers who were course faculty. The purpose of this

study was to examine the effect of a planned clinical experience with dying patients on student attitudes and competencies in end-of-life care.

**Introduction to Articles Appended**

Two articles are appended to this document. The first, Transformational Learning Theory: A Useful Paradigm for Nursing Education, (see Appendix A) presents the theoretical framework that guided the research study and its application to nursing education. What sets TLT apart from other adult learning theories is its focus on attitudes as an important component of learning. According to the theory, attitudes affect actions. It is important for nursing students to be aware of attitudes they have developed over time, reflect on those attitudes, learn new perspectives through discourse with others, and re-evaluate the usefulness of the attitude in their nursing practice. This process may lead to changed action the next time a similar situation presents itself. The emphasis on evidence based practice mandates that nurses question habitual ways of doing things and challenges them to evaluate their actions. The second manuscript, The Effects of a Community-based Hospice Experience on Attitudes and Self Perceived Competencies of Senior Nursing Students (see Appendix B), describes the original research studying the effects of a hospice experience on senior nursing students' attitudes towards death and their self-reported competencies.

**Evaluation of the Findings**

This experimental study examined the differences in students' attitudes and competencies between control group and intervention group following a clinical experience in a hospice setting. No studies were located that examined the effects of a planned clinical experience on students' attitudes and competence in EOL care. The

literature review yielded few studies that described the effects of experiential learning (visits to a morgue, role play, poetry) on student outcomes. All student participants received the same sensitization to EOL issues and interacted with persons who were dying. This experience changed how the students viewed death and dying. Additionally, this study looked at attitudes towards death of a multi-ethnic group where comparisons of attitudes about an event (death) that has strong cultural overtones can be useful to the nursing community

In the U.S., the issue of limited health resources has and will continue to focus on when and how to deal with end of life, the most expensive time period in a person's disease trajectory. This study opens a pathway for the study of EOL, fosters a dialogue about how and when to prepare nurses to provide optimal EOL care, and offers recommendations regarding how students and educational systems should be involved in teaching EOL care.

**Recommendations Based on Findings**

In spite of developments over the past decade in EOL education, clinical experiences with dying patients are not mandatory for graduation from nursing school. This study has demonstrated the positive impact a hospice clinical experience had on students' attitudes about death. Detailed orientation and daily debriefings in clinical conference help students deal with their own attitudes regarding death and dying, and provide a forum to learn about other perspectives about death. Extended exposure to the care of persons that are dying may increase their knowledge base and improve the attitudes of graduating student nurses. Changed attitudes lead to changed actions and improved EOL care for dying patients in all practice settings.

## Results of Original Research

### Quantitative Findings

At baseline, there were no statistically significant differences between the two groups in demographics or on mean scores for attitudes and competencies. In addition, there was no statistically significant relationship between age, ethnicity, religion and previous experience with death and attitudes or competencies for all students.

To test the first hypothesis, senior nursing students who have had a hospice experience will have better attitudes towards death than students who have not had a hospice experience, a multiple regression model was developed with Mid-Attitudes (attitudes after intervention in experimental group only) as the outcome variable. The primary independent variable was group (intervention vs. control) and control variables included baseline attitudes score, age, ethnicity, religion and previous experience. Ethnicity, religion and previous experience were coded as dichotomous, dummy variables. Age, ethnicity, religion and previous experience were not statistically significant; in the interest of parsimony, these variables were removed from the model. After removing these covariates, the final model was statistically significant ($p<.001$), explaining 39% of the variance in Mid-Attitudes ($R^2 = .396$). Of the two independent variables in the final model, baseline attitude scores made the larger contribution (beta = .584), with the intervention effect (beta = -.221) explaining 7.5% of the variance which was statistically significant ($p = .035$). Adjusted mean attitude scores for Group A were 1.59 points lower than scores for group B yielding a medium effect (Cohen's $d = .48$). These results indicate that the group receiving the intervention had a better attitude towards death than the group who had not yet received the intervention.

To test the second hypothesis, senior nursing students who have had a hospice experience will report greater competence in care of dying patients than their counterparts who have not had the experience, a second multiple regression model was developed with Mid-Competencies (self-reported competencies) as the outcome variable. Independent variables were group, baseline competency scores, age, ethnicity, religion and previous experience. With this model, the group variable was not a significant predictor; Mid-Competencies did not differ significantly between the intervention and control groups after controlling for covariates.

**Qualitative Findings**

To supplement the quantitative findings, student and preceptor report forms documented new knowledge acquisition that occurred during the day spent with the preceptor. One hundred and twenty two daily report forms and 61 reflections were collected from the students. Sixty preceptors completed the preceptor report forms. These forms supported the attitudes quantitative findings but differed from the competencies. The students felt they were more competent in the qualitative data even though competence did not change according to quantitative findings. Data from these forms provided evidence for the effect of the hospice rotation on student attitudes and competencies related to care of dying patients.

The action variable was assessed by student comments in the student report forms and student reflections. Comments like "I will use the new skills and communication I learned in my future career as a nurse" and that the experience will "definitely help me in the future when providing care to a dying patient" indicated the potential for future changed action as the result of the experience. Some students indicated an interest in

working in hospice which they never considered before the experience. Many student reflections indicated more comfort about caring for the dying patient, less need to avoid the rooms where patients are dying, and empowered to actively engage in care of the dying patient. One student summarized by saying. One student summarized by saying

> I believe that I will now be more comfortable addressing death. It does not seem as much of a taboo to me as it did before. I believe that I am more comfortable with talking about death, informing patients and families that death may be the end result of a condition, and I now better understand how to talk to families about death. I have been in death situations before when I avoided the patients family (in clinical), however, I now know how to speak with the family, and provide comfort and coping techniques

All students reported learning new skills during the clinical experience in the hospice setting. Report forms demonstrated frequent discourse between the preceptor and student about pain and symptom management, communication with the patient and family, direct care of a homebound patient, assessment of signs and symptoms of death, time management and cultural and spiritual issues at the end of life. Experiencing a death event and discussing legal and regulatory issues happened less frequently. Some students also mentioned they learned about the roles of the social worker and chaplain; and the importance of including the family in the care plan. Repeatedly, students commented on the bedside manner of the preceptors they observed. One student summed it up by saying

> I witnessed an amazing level of compassionate bedside manner along with appropriate use of therapeutic touch. I think these are priceless qualities that each and every nurse must have no matter what area of the nursing profession they are working in.

Another student commented that she "learned that being honest and open is of utmost importance when communicating with the patient and their families" and "teaching and promoting family involvement is very crucial".

After the first day many students reported that the experience was nothing like they were expecting. They envisioned "that most of these patients would be on their death bed, unconscious, but that was not the case". Students commented that it "was rewarding to see how the patients had such a positive outlook on life and did not let the doctor put an expiration date on them".

The reflections and student report forms were saturated with comments about changed attitudes about death. One student said:

> The experience I had today in hospice really opened my eyes to the reality of the end stage of life. The day led me to look deeper into my beliefs and spirituality and I felt that it not only strengthened my faith but gave me a fresh outlook on the palliative aspect and the need for comfort for a dying patient.

Another student reflected:

> I believe that a hospice rotation is the only reason why I have any beliefs about caring for dying patients. Before the beliefs were all speculation and not based on any real world experience I have had. After hospice I can say that there is no way to cure every patient. For most nurses and healthcare professionals it is sometimes hard to cope with the fact that medicine can only do so much, death is inevitable for us all. Now I know that death is not always sad, for some families death is a way to end the suffering their loved ones are going through, and for some it is still hard to let go. Even though we cannot cure some dying patients, we can still keep them from pain and suffering. This has definitely helped me to see death in a different way.

A third student commented:

> Today I learned that in the beginning I had a bias look at hospice care. I didn't fully understand what it brings to patients nor did I take the time to research and find out. Through this experience I learned that I am very intrigued by how a nurse can care for a patient in all different aspects and being a hospice nurse brings out everything you were taught in nursing school and told a nurse could be. You are able provide all types of care from basic skills, to medication administration and emotional support for the patient and their family and caregivers. I learned that seeing this type of nursing really brought out the passion that I have for nursing and helped me to remember why I wanted to be a nurse and what impact they make.

Quantitative and qualitative data both supported changed attitudes about death. Although the qualitative data also supported improved comfort levels suggesting new skills learned, this was not statistically significant in the quantitative data as measured by the end-of-life competencies. Interestingly, the skills the students reported learning in their reflections (compassion, caring) were not skills measured in the survey.

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Manuscript 1

# Transformational learning theory: A useful paradigm for nursing education

## Abstract

Transformational Learning Theory (TLT) has been identified as a useful theory for adult education since 1978. Over the past three decades, educators have found many uses for this theory not only in higher education but also in workplace settings and in community programs that foster social change. What sets TLT apart from other adult learning theories is its focus on attitudes as an important component of learning. In nursing, students come with their own sets of assumptions (attitudes) about the world in general and about life events in particular through their prior experiences. Throughout nursing school, students are exposed to a multitude of life events (sickness, birth, death) about which they have pre-conceived assumptions. Based on the literature reviewed, few attempts have been made to question or challenge students' assumptions in a formal way during their nursing education programs. Assumptions affect actions and TLT may offer a framework on which faculty can help students raise awareness, analyze and transform attitudes towards better educational outcomes. The purpose of this paper is to describe the phases and core concepts of TLT and discuss the value of applying this theory to nursing education.

## Transformational Learning Theory: A Useful Paradigm for Nursing Education

Nursing education involves more than just the acquisition of knowledge and skills necessary to fulfill the professional role. Nurses deal with many persons in their most vulnerable moments throughout the lifespan. These moments represent life events such as sickness, birth, death and a multitude of others in between. The persons involved in these important occasions (nurses, patients, families) represent a variety of cultures, age groups, religions, economic levels, etc. All persons enter into these lived experiences with their own attitudes and meanings about these events. It is important for nursing students to be aware of their pre-conceived attitudes, examine these attitudes, and determine if and how these attitudes serve as the basis of action as the students care for patients. Transformational Learning Theory (TLT) can provide some direction in identifying and analyzing these attitudes that may ultimately lead to graduates being better equipped to think and act autonomously and be freed from the influence of attitudes and habitual actions.

TLT was first identified by Mezirow in 1978 after interviewing women who had gone back to college after a long hiatus from school (Mezirow, 1981). This study, using a grounded theory methodology, included women of all ages enrolled in twelve diverse community college programs (Mezirow, 2009). Most of these women had undergone a significant life event, usually a loss of spouse through divorce or death, which prompted them to go back to school (Mezirow, 1981). What became apparent in these interviews is that the women needed to undergo a process of "perspective transformation" in order to be successful not only in school but also in their new workforce roles (Mezirow, 1981). This process involved reflecting on their stereotypical assumptions associated with

acknowledging traditional womens' roles, assimilating what they were learning, and changing their own perspectives about the role of women in society. The learning came from the classroom, other students, faculty, as well as the workplace. Additionally, the women experienced similar perspective transformation patterns which prompted Mezirow to identify 10 separate phases in the process of transformational learning. Mezirow recognized core concepts of an adult learning theory he initially called a "perspective transformation theory" and in 1991 renamed the theory Transformational Learning Theory. Discussion of these phases, the core concepts of the theory, and the value of applying this theory to nursing education is the purpose of this paper.

## Transformational Learning Theory

Mezirow postulates that humans need to understand and assign meanings to their experiences. If, as children, meanings cannot be made of experiences, those meanings come from explanations provided by culture, religion, and authority figures in a child's life (Mezirow, 2000). These meanings serve as the basis of the attitudes formed about the experience. These attitudes (also called pre-suppositions by Mezirow) are acquired passively throughout life, and many times adults may not be completely aware of their own attitudes, beliefs and values as these are so covertly acquired over time. These attitudes serve as a filter when looking at the world. They structure the meanings assigned to experiences, and therefore they create "habits of expectation" (Mezirow, 1990, p 4) that dictate how one should feel or act in a situation.

Mezirow agrees with Habermas's two domains of learning: instrumental and communicative (as cited on p.8 in Mezirow, 2000). Instrumental learning is a task oriented process that leads to improved knowledge or competence in an area (Mezirow,

2000). It is a learning of facts as in learning didactic content. Mezirow refers to instrumental learning as informational learning in a later chapter of the same book as he differentiates between this type of learning and transformational learning. Mezirow believes that most adult education is informational and generally includes anticipated learning outcomes, behavioral objectives, and knowledge testing through a written examination or demonstration of skills (Mezirow, 1994). In nursing, the ultimate test of instrumental knowledge learned during school is the state board exam that determines if a student can practice as a registered nurse in the state. Communicative learning on the other hand, involves understanding what others mean when they communicate and involves feelings, intentions, and values that lead to development of attitudes or pre-suppositions (Mezirow, 2000). Communicative learning occurs through lived experience, self reflection and discourse with others. Communicative learning is the foundation for transformational learning which uses attitudes and change of attitudes as the core activity in the teaching/learning interchange. By carefully planning an experience in a classroom, faculty can teach skills and facts and also challenge student attitudes.

**Core Concepts**

There are four main components of Transformational Learning Theory: *experience, critical reflection, critical discourse,* and *action* (Mezirow, 2000). The process begins with an *experience* in which the learner's assumptions of the experience are challenged. Mezirow calls this a disorienting dilemma and the first phase of the process of transformational learning (Mezirow, 1990). The learner engages in *reflection* to examine assumptions that have been developed over time (how and why they developed) and begins questioning the validity of those assumptions. Through *critical*

*discourse* with others the learner begins to gain knowledge of others' perspectives and meanings of the experience that leads to the development of a transformed perspective about the experience. A change in perspective may result in a change in behavior when a similar experience is encountered in the future. *Action* is the final component of the theory. It could be an immediate action, a delayed action, or just a decision about something that would indicate a future change in behavior (Mezirow, 1990). Although action is an important part of the theory in Mezirow's earlier works, his later versions of the theory identify only the lived experience, critical reflection and reflective discourse as core concepts of the theory (Mezirow, 2009). In spite of Mezirow's evolved theoretical dismissal of the action as a core component of TLT, a changed action is important in nursing and will be included in this discussion. The interdependent relationship between the experience (simulated or actual), critical reflection and discourse has the potential to lead to a changed perspective or action, or transformation.

**Lived Experience**

Experience in TLT refers to two separate but related meanings. One meaning refers to all of the prior life experience that a student brings to the learning situation which includes the influence of family, religion, and culture. The second meaning refers to the simulated experience that an educator can create through classroom and/or clinical experiences that might expose the student to other points of view and challenge previously held assumptions (Mezirow, 2009). These educator developed activities can serve as triggers (disorienting dilemmas according to Mezirow) for critical reflection and can serve as a basis for discourse about attitudes and beliefs that were generated during the experience (Mezirow, 2009). The more life experience the student brings to the

learning activity, the "deeper the well to draw from" in critical reflection and discourse (Mezirow, 2009, p 6).

**Critical Reflection**

Critical reflection involves questioning the validity of assumptions based on prior experience to determine if these assumptions hold true in the present circumstance. Developing an awareness of feelings and emotions is critical to the reflective process (Mezirow, 2009). This is a process that leads the student to self critique prior knowledge and attitudes about the phenomenon. Critical refection focuses on the content of the assumptions that have developed over time and also on the process of how these assumptions developed. Critical reflection can be triggered by an actual or simulated experience in which the students' assumptions are challenged and they try to gain a new understanding of a phenomenon (Mezirow, 2009). According to Mezirow (1990), critical refection is the most important step in the process of transformation.

**Critical Discourse/Dialogue**

Critical discourse is a special use of dialogue "devoted to searching for a common understanding and assessment of the justification of an interpretation or belief" (Mezirow, 2000, p.10). Part of this discourse is assessing assumptions (attitudes) with others. According to the theory, discourse with others helps the learner see other perspectives and ways of thinking and doing. Mezirow does not feel that this dialogue necessarily needs to be analytical but it must occur in an atmosphere of trust where students are comfortable sharing their beliefs and assumptions in a group setting (Mezirow, 2009).

## Action

In his early writings about TLT, Mezirow identified action or potential for a changed action as a core concept of TLT. However, this component was minimized in his most recent book in 2009 and the importance of critical reflection of assumptions was emphasized (Mezirow, 2009). According to the older version of the theory, a change in attitude can lead to a change in action the next time the learner is in a similar situation. In his 1990 book, Mezirow differentiates between reflective action and non-reflective action. Reflective action occurs as a result of critical reflection of presuppositions which leads to a changed action as opposed to a non-reflective action which comes as a result of habit without reflection (see Figure 1). In nursing, it is reflective action that includes elements of critical thinking and has the potential to improve nursing care.

## Phases of Perspective Transformation

TLT has ten phases. The process begins with an experience that includes a disorienting dilemma. This is an event or series of events that forces the learner to question assumptions. This is followed by: self-examination and feelings of guilt; a critical assessment of assumptions; recognition that one's discontent is shared and that others have negotiated a similar change; exploration of options for new roles, relationships, and actions; planning a new course of action; acquisition of knowledge and skills for implementing this new course; trying these new roles; building confidence and competence in new roles; and a reintegration into one's life as dictated by one's new perspective (Mezirow, 1991).

## Application to Nursing Education

A literature search of the use of TLT yielded six articles in nursing education and one in medical education. Macleod and Egan (in Mezirow, 2009) used TLT as the foundation for a palliative care course developed for medical students in New Zealand. The authors first describe the assumptions held by medical students. These assumptions were formed by the students' personal life experiences and the medical school culture. According to the authors, the latter suppresses "empathy and the humane aspects of caring" (p.112) by focusing on the physical disease symptoms rather than the patients' lived experience. The School of Medicine, in conjunction with a local hospice, developed a module in palliative care that required students to make multiple visits to families where someone was dying. The students were asked to keep a portfolio of patient/family stories, observations of the type of care the patient received, and reflections of their own feelings about the experience. At the end of the module, the students participated in oral presentations of their portfolios to their faculty and classmates. This was followed by a discussion which addressed the effects of the experience on them as individuals and as professionals. The themes identified were: the experience was very different from what they were expecting; identification of emotions experienced during and after the visit; identification of spiritual and religious elements; and identification of ways that their future caring practices would be affected by the experience. The visits served as the experience that triggered a disorienting dilemma that made students question their assumptions. Their critical reflections helped them critique the value of these assumptions. Through discourse with patients/families, classmates and

faculty, they learned about other perspectives and the medical students reported that they would care for patients differently in the future.

Cragg and Andrusyszyn (2005) reported on a qualitative study using semi-structured interviews to determine if 22 masters' nursing students experienced the phases of Mezirow's TLT as they progressed through their graduate programs. Faulk, Parker, and Morris (2010) repeated Cragg and Andrusyszyn's study and found similar results with their 22 participants. Both groups reported increased knowledge, a broadening of perspectives and changes in practice and attitudes as a result of their graduate school education. Some participants in both groups did not feel shame or guilt and they felt the steps of the process were not linear as described by Mezirow. Additionally, two participants in the Faulk et al. study denied that they experienced a disorienting dilemma.

Lynam (2009) described pedagogies used in nursing education. She suggested the use of Mezirow's theory in nursing education as a means of effecting social changes to remedy health care disparities by creating activities that challenge assumptions of nursing students.

In their qualitative descriptive study that included 10 participants, Morris and Faulk (2007) identified 13 learning activities that created a conflict of values (disorienting dilemmas) that ultimately resulted in a change of professional behavior in a group of RN to BSN students. For example, the learning activity, a family assessment, helped transform the students' perspective on the value of including the family in developing individual care plans. Likewise, a community assessment learning activity helped students see the role of the community in the health of the individual.

McAllister and McKinnon (2009) provided a literature review of resilience and suggest that resilience needs to be learned during nursing school to better prepare nurses for the workplace. Because TLT requires critically examining assumptions and the use of critical and constructive thinking, they suggested TLT as an educational framework for teaching resilience although this is minimally explored in their article.

Parker and Myrick (2010) explored the use of TLT as an appropriate model for planning high fidelity simulation scenarios in nursing education. The authors clearly identify the core concepts of TLT and how each of these concepts is applied to the planning and implementing of the high fidelity simulation experience. They offer an extensive review of the simulation literature to support the use of the model. They relate the phases of the typical simulation scenario to the core concepts of TLT. The careful planning of the simulation experience (which allows for the creation of a disorienting dilemma by including moral and ethical issues), is the first step. Another phase of the simulation scenario which supports TLT includes focus on the importance of debriefing very soon after the experience which consists of both critical reflection and discourse about the skills learned and emotions felt. The authors suggest that simulation experiences could be used as an opportunity for perspective transformation in addition to learning clinical skills and adding to informational knowledge.

## Discussion

Nursing education requires clinical hours in specialty areas. Care plans and concept maps, although helpful in determining if the student has acquired the knowledge necessary for safe practice, do not address students' attitudes and beliefs. According to TLT, it is through affecting attitudes and beliefs that one can achieve a change in

behavior. For example, if a student has the attitude that nothing can be done to make the dying patient better, the student may avoid rooms of patients who are dying and instead focus on patients for whom curative measures are effective. If however, the student's attitude about death can be transformed to one in which comfort measures are as important as curative measures, then the student's behavior towards dying patients may change. The key components in this transformation are the awareness of this attitude, a critical reflection on this attitude and a discussion about this attitude with others. This process may result in a plan for behavior change that will better serve the needs of the dying patient.

Strategies for transformational learning might include having students write a critical reflection about the clinical day and reflect on an event or series of events that were particularly difficult. This activity could be followed by critical discourse during clinical conference and include how the student felt about the challenges or rewards experienced that day. As Parker and Myrick (2010) indicated, there are numerous opportunities for using strategies to foster transformational learning in the popular use of nursing simulation labs. Although not based on TLT, Smith-Stoner (2009) used high fidelity simulation to educate students about end-of –life care. The scenarios simulate the 30 minutes before death and 30 minutes after death and include moral, cultural, and ethical dilemmas. Debriefing immediately after the simulation is an integral component of the process and is the "most important pedagogical aspect of the simulation experience" (Parker & Myrick, p. 330).

## Conclusion

The goal of nursing education is to prepare students with the knowledge and skills necessary to function in an increasingly complex health care environment. Much of this preparation is providing informational knowledge. However, programs would be remiss if they did not also teach students to critically reflect on assumptions, to question habitual ways of doing through discourse with others, and to investigate new ways of doing/feeling/acting in particular situations. Unlike children who uncritically assimilate explanations from authority figures in their life, professional nurses are expected to question assumptions, be responsible for their own actions, and be capable of thinking critically instead of simply mimicking behavior and actions of others. The emphasis on evidence- based practice mandates that nurses question habitual ways of doing things and challenges them to evaluate their actions and underlying attitudes hidden in those actions. Faculty need to adapt strategies that encourage students to examine attitudes, to question what they do and why they do it, and to engage in actions that come from careful reflection. TLT provides a model for nursing education that offers a chance to actualize the concept of critical thinking which is essential for nurses today.

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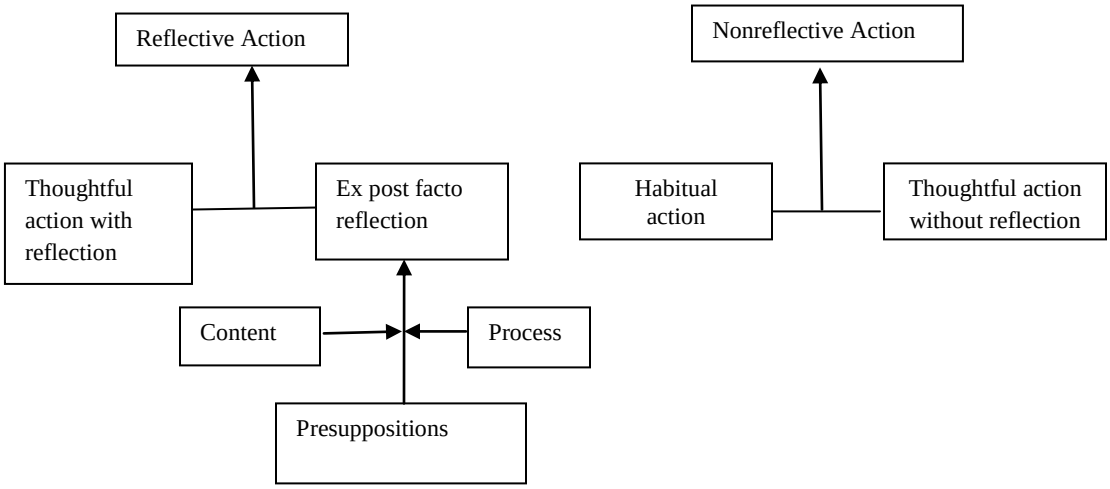


*Figure 1*. Mezirow's Critical Reflection Reproduced from Mezirow (1990) p.7.

Manuscript 2

# The Effects of a Community-based Hospice Experience on Attitudes and Self Perceived Competencies of Senior Nursing Students

Abstract

Educational programs preparing nurses have devoted little time in curricula to care of the dying patient and the grieving family. The few programs that have reported an experiential component in end- of- life care have included visits to cadaver labs and funeral homes or role play exercises but have not included actual care of dying patients. An experimental design was used to determine the effect of a 2 day hospice experience on attitudes and competencies of 61 students enrolled in their last semester of nursing school in a baccalaureate program. Measures included an end of life attitudes survey and an end of life competency survey before and after the intervention and student comments on assignments post experience. There was a significant change ($p$ = .035) in attitudes between the 2 groups indicating a better attitude as a result of the intervention. Although there were changes in mean scores in competency, between group differences in mean change in competency scores did not differ significantly. Student journals were also used to assess for changes and these supported attitude changes about end-of-life care and improved competencies. Larger samples and longer exposure to care of the dying are needed to more accurately assess the impact of a hospice experience on student attitudes and competencies related to end-of-life care.

## The Effects of a Community-based Hospice Experience on Attitudes and Self Perceived Competencies of Senior Nursing Students

Death is an inevitable consequence of life and can occur at any phase of the life span and in any setting. Of all health care professionals, it is the nurse who is most likely to be present at the time leading up to the death, during the dying, and immediately after the death. Nursing programs are focused on pathophysiology, assessments and treatments/cures. Lesser emphasis is placed on caring for persons for whom there is no cure. Science in the past century has made possible longer life spans, cures for infections, and remissions for many chronic diseases all of which have led to the development of an attitude towards death as a 'failure' of the health care system rather than a natural and unavoidable part of life. With an aging population and shortage of health care resources, new nurses need to be comfortable dealing with issues of death and dying in all practice settings and yet many nurses feel ill-prepared for taking care of dying patients (Allchin, 2006; Chen, Ben, Fortson, & Lewis, 2006; Shlairet, 2009; Wallace, Grossman, Campbell, Robert, Lange, & Shea, 2009).

### Background

Deficiencies in end-of- life (EOL) content in undergraduate nursing curricula were identified about 20 years ago (Beck, 1997; Frommelt, 1991; Kaye, 1994). Ferrell (1999) highlighted the problem when she reviewed 50 nursing textbooks for end- of- life content and found very little content on EOL with some books addressing the care of the body after death, but making no mention of symptom management of the dying patient or bereavement needs of the grieving family. A follow up examination of 14 critical care textbooks by Kirchoff et al. (2003), showed that no textbook addressed all of the essential EOL content and three of the textbooks did not address any needs of the dying patient.

In the past ten 10 years two major developments have occurred to address deficiencies in nursing education related to EOL care. First, in 1999, the American Association of Colleges of Nursing (AACN) identified 14 End-of-Life (EOL) competencies that students are expected to possess upon graduation from their basic nursing programs. Second, the End of Life Nursing Education Consortium (ELNEC) was developed and implemented in 1999 to teach nursing faculty about EOL care. To date, these courses have trained 900 nursing faculty and 802 staff development educators and continuing education providers (AACN, 2010). In addition to the core courses, subsequent funding led to the development of specialty ELNEC courses in Pediatrics, Critical Care, and Geriatrics. Almost 3000 nurses have attended these specialty sessions (AACN, 2010).

An eleven year review of the literature from 1999 to 2010 revealed limited study related to implementation of educational strategies for EOL care into nursing curricula; most studies relied on descriptive designs and used samples of less than 100 participants. Narrative descriptions of undergraduate curricula suggest a reliance on didactic content with limited to no experience with dying patients and their families. Only two studies described outcomes resulting from clinical experiences with dying patients (Allchin, 2006; Kwekkeboom, 2005) but these had inconsistent clinical experiences, a self-selected small sample, and researchers who were course faculty. Five studies reported on effects of didactic content only (Barrere, 2008; Ferrell, 2005; Robinson, 2004; Wallace et al., 2009; Walsh & Hogan, 2003). Some studies included an experiential component of writing poetry (Dakin, 2003), seeing cadavers (Birholz, 2004; Mallory, 2003), visiting funeral homes (Birkholz, 2004; Thompson, 2005) and role play (Frommelt, 2003).

Inclusion of EOL content into existing curricula improved comfort levels (Allchin, 2006; Kwekkeboom, 2005; Thompson, 2005), knowledge (Birkholtz, 2004; Kwekkeboom, 2005; Wallace et al., 2009), and attitudes (Barrere, 2008; Frommelt, 2003; Kwekkeboom, 2005; Mallory, 2003) of nursing students towards death and dying. These studies represented small samples, weak designs, minimal or no experience in patient and family care settings and tested only for knowledge of didactic content.

Often, students enter nursing school with little or no experience of death and have already developed their own attitudes about death. Chen, Delben, Fortson, and Lewis (2006) found, in assessing death anxiety among student nurses versus non nursing students, nursing students had greater anxiety about 'Fear of the Unknown' in relation to death than non nursing students. One possible explanation of the students' feelings of inadequacy and anxiety about death is most teaching strategies have focused on didactic or informational knowledge without addressing the students' attitudes towards death and dying patients. These attitudes impact the way a student acts in the presence of a dying patient and grieving family.

## Theoretical Framework

The framework that guided this study was Transformational Learning Theory (TLT) as first identified by Mezirow in 1978 (see Figure 1). Mezirow postulates that humans need to understand and assign meanings to their experiences. If, as children, meanings cannot be made of experiences, those meanings come from explanations provided by authority figures or role models (parents, teachers, and others) that represent the culture and/or religion in a child's life (Mezirow, 2000). These meanings serve as the basis for attitudes formed about the experience. These attitudes (also called pre-

assumptions by Mezirow) are acquired passively throughout life and many times adults may not be completely aware of their own assumptions, beliefs and values as these are so covertly acquired over time. When a person is placed in an experiential situation that challenges these attitudes, critical discourse and thoughtful reflection help the person identify and re-evaluate these attitudes. As a result, the individual may change the attitude and the consequent action the next time the situation presents itself (Mezirow, 1990).

Mezirow agrees with Habermas's two domains of learning: instrumental and communicative (as cited on p.8 in Mezirow, 2000). Instrumental learning is a task oriented process that leads to improved knowledge or competence in an area (Mezirow, 2000). Communicative learning on the other hand, involves understanding what others mean when they communicate and involves feelings, intentions, and values that lead to development of attitudes or pre-suppositions (Mezirow, 2000). Communicative learning occurs through lived experience, self reflection and discourse with others.

There are four main concepts of TLT: experience, critical reflection, critical discourse, and action (Mezirow, 2000). The process begins with an experience in which the learner's assumptions of the experience are challenged. Mezirow calls this a disorienting dilemma and the first phase of the process of transformational learning (Mezirow, 1990). The learner engages in critical reflection to examine assumptions that have been developed over time (how and why they developed) and begins questioning the validity those assumptions. Through discourse with others the learner begins to gain knowledge of others' perspectives and meanings of the experience that leads to the development of a transformed perspective about the experience. A change in perspective

may result in a change in behavior or action when a similar experience is encountered in the future. Action is the final component of the theory. It could be an immediate action, a delayed action, or just a decision about something that would indicate a future change in behavior (Mezirow, 1990).

In this study, the planned clinical experience, critical discourse, student reflection and action are linked to TLT. The planned experience consisted of two 8 hour clinical days the student spent with a preceptor in a hospice setting. Critical discourse was the content discussed between the student and the preceptor and documented on the Student and Preceptor Report Forms. Critical discourse is the basis for both communicative learning (meaning of previous experiences with death), and, instrumental learning (factual knowledge about EOL care). Student reflections were assessed using the Student Report Form and student reflection assignment which provided information about changed attitudes, changed levels of competencies, and a potential for a changed action the next time they care for a dying patient.

This study measured attitudes and perceived competence before and after an educational intervention which included an experience with dying patients, critical discourse, a reflection about the experience and a stated intent to act differently the next time the situation presents itself.

**Hypotheses**

The purpose of this study was to examine the effects of a clinical hospice experience with dying patients, including critical discourse, a reflection about the experience, on senior nursing students' attitudes towards death and perceived competency in providing EOL care. The hypotheses were: (1) Senior nursing students

who have had a hospice experience will have better attitudes towards death than students who have not had a hospice experience; (2) Senior nursing students who have had a hospice experience will report greater competence in care of dying patients than their counterparts who have not had the experience. Confounding variables for this study include age, ethnicity, religion, and prior experience with death which influence attitudes according to the model. Although age is not a part of Mezirow's Theory, it was included because other studies have noted significant correlations between age and attitudes towards death (Chen, Del Ben, Fortson, & Lewis, 2006; Lange, Thom, & Kline, 2008).

## Methods

This study utilized an experimental pretest/posttest design to evaluate the effect of the hospice experience within and between groups. Demographic characteristics and pre-test scores for the intervention and control groups were analyzed for the impact of potentially confounding variables such as age, religion, ethnicity, and previous experience with death. These findings provided the basis for additional analyses to control for differences between groups.

### Setting

The setting for the study was a Leadership/Management required course in a faith-based university in the southwestern United States. The course is offered in the final semester of the baccalaureate nursing program. The university is a federally designated Hispanic serving institution with 57% of the undergraduate student body being Hispanic, 24% Caucasian and the remainder listed as Asian, Black, American Indian, or unknown. The demographics of the student body at this school reflect the demographics of the city in which it is located.

**Sample**

A convenience sample of 61 students was recruited over two consecutive semesters. A G-power analysis with a .80 power level, $p<.05$, and a medium effect size indicated a sample of at least 82 students was needed, however, only 61 student were enrolled in the two semesters of the study. A medium effect size is supported by Wong and Wong (2008) who reported standardized effect sizes for attitudes (.48) and knowledge (.70) as the result of an educational intervention.

Twenty-four students volunteered in Fall, 2010, and 37 in Spring, 2011. Students were randomly assigned to groups. Both groups participated in the hospice experience with Group A participating in the first 2 weeks of the semester and Group B participating in the second two weeks. All students enrolled in the Leadership/Management required course were eligible to participate and there was 100% participation. Over half of students were Hispanic (*n*=36; 59%), the majority were female (*n*=56; 92%), Catholic (*n*=36; 59%), and 25 years old or less (*n*=42; 69%) (see Table 1).

**Instruments**

Two self administered instruments were used for data collection, which occurred in a controlled environment and were administered by the researcher who was not connected with the course. The Attitudes Towards Death Survey (Strumpf, 1999) is a 28 item Likert scale with five choices for each item ranging from Strongly Agree (1) to Strongly Disagree (5). The instrument is divided into three subscales. The first subscale consists of 10 questions which describe attitudes about death. The second 11- item subscale identifies important problems in caring for the dying. The third subscale consists of 7 items which ask students about improving EOL education in their school.

The tool is scored so that the lower the number in the attitude subscale the better the attitude. The tool has been used in previous research (Stillman, Strumpf, Capezuti, Tuch, 2005). This tool has also been used by this researcher in an unpublished study and the Cronbach's alpha reliability coefficient was .717 in that sample of 27 senior nursing students . A panel of eight doctorally prepared nurses reviewed the tool and agreed on its' face validity. The Cronbach's alpha for this study was .696 when assessed at baseline and .741 when analyzed at the second data collection point.

The End- of- Life Competencies Survey was developed by the City of Hope as part of the ELNEC project. The tool consists of 5 demographic items (age, gender, religion, ethnicity, prior death experience) and 14 Likert type questions with a choice of 5 responses for each item ranging from Not at all Effective (1) to Very effective (5). The Likert type questions are divided into 2 subscales. The first subscale consists of 7 items which refer to competencies. The second subscale also has 7 items and asks the students to rate the effectiveness of their education in each of the competencies. The tool is scored so that the higher number reflects more competence. Internal consistency reliability analysis for this study revealed a Cronbach's alpha of .906 at baseline and .878 at the midpoint collection.

In addition to the two quantitative instruments, data were collected from student and preceptor report forms and student reflection assignments. The preceptor forms asked preceptors to document daily which topic areas (pain management, communication, etc) were discussed with students that day. The student report forms asked students to document daily discussion of the same topics as were noted on the preceptor forms with additional questions addressing their anxiety. These were submitted

electronically to the course web site. Student reflections, which were completed at the end of the 2-day experience, addressed attitudes, skills, anxiety about the experience, and a discussion of how the experience may change future action. These qualitative data were analyzed to supplement quantitative findings.

**Procedure**

Following approval from the university Institutional Review Board for Protection of Human Subjects, the purpose of the study was described to potential student participants orally and in writing by the researcher, on the day of their clinical orientation in each of 2 semesters. Students who volunteered to participate signed a consent form and completed the baseline surveys. Students in each class were randomly assigned using a SPSS feature to either Group A or Group B. In a variation of a crossover design, all students received the intervention. Following baseline data collection, one half of the group (Group A) started the 2 day hospice experience (one 8-hour day each week for two weeks) while the Group B continued with scheduled clinical experiences. At the end of 2 weeks, the tools were re-administered to both groups during a scheduled class time. Group B then participated in the 2 day hospice intervention. The instruments were administered a third time to all the study participants after Group B had completed the hospice experience and two weeks after Group A had completed their hospice rotation.

Preceptors were recruited at an all-staff meeting at the agency before the students began their clinical experience in the Fall and Spring semesters. Preceptor report forms were explained and orange copies of the forms were left with the educator at the agency. Preceptors who chose to participate were asked to complete an orange form which would make them eligible to receive a gift certificate to a restaurant located near the agency.

Completed preceptor report forms were collected at the agency and picked up weekly by the researcher

### Statistical Analysis

Data were analyzed using SPSS 17.0. Demographic data between the control and experimental group were compared using an independent samples *t*-test or Chi-square. The relationship between age and attitudes and competencies was investigated using Pearson product-moment correlation coefficient. The mean score differences between groups on attitudes towards death and competencies were analyzed at baseline, after one group received the intervention and the other had not, and after both groups received the intervention using an independent samples *t* test. Mean score differences within groups were analyzed using a paired *t* test. Multiple regression analyses were used to control for confounding variables and determine the effect of the intervention on attitudes and competencies. For the multiple regression models, variance inflation factors were reviewed to assure that multicollinearity was not a problem, and residuals were reviewed to assess goodness of fit. For all analyses, *the a priori* level of significance was .05.

Qualitative data were organized per responses to each question on the student report form, preceptor report form and student reflections. Codes were generated done via line by line coding and grouped into categories.

## Results of Original Research

### Quantitative Findings

There were no statistically significant differences between the two groups at baseline in demographics or on mean scores for attitudes and competencies. There was

no statistically significant relationship between age, ethnicity, religion and previous experience with death and attitudes or competencies at baseline for all students.

To test the first hypothesis, senior nursing students who have had a hospice experience will have better attitudes towards death than students who have not had a hospice experience, a multiple regression model was developed with Mid-Attitudes (attitudes after intervention in experimental group only) as the outcome variable. The primary independent variable was group (intervention vs control) and control variables included baseline attitudes score, age, ethnicity, religion and previous experience. Ethnicity, religion and previous experience were coded as dichotomous, dummy variables. Age, ethnicity, religion and previous experience were not statistically significant; in the interest of parsimony, these variables were removed from the model. After removing these covariates, the final model was statistically significant ($p<.001$), explaining 39% of the variance in Mid-Attitudes ($R^2 = .396$). Of the two independent variables in the final model, baseline attitude scores made the larger contribution (beta = .584), with the intervention effect (beta = -.221) explaining 7.5% of the variance which was statistically significant ($p = .035$). Adjusted mean attitude scores for Group A were 1.59 points lower than scores for group B yielding a medium effect (Cohen's $d = .48$). These results indicate that the group receiving the intervention had a better attitude towards death than the group who had not yet received the intervention.

To test the second hypothesis, senior nursing students who have had a hospice experience will report greater competence in care of dying patients than their counterparts who have not had the experience, a second multiple regression model was developed with Mid-Competencies (self-reported perceived competencies) as the outcome variable.

Independent variables were group, baseline competency scores, age, ethnicity, religion and previous experience. With this model, the group variable was not a significant predictor; Mid-Competencies did not differ significantly between the intervention and control groups after controlling for covariates.

**Qualitative Findings**

To supplement the quantitative findings, student and preceptor report forms documented new knowledge acquisition that occurred during the day spent with the preceptor. One hundred and twenty two daily report forms and 61 reflections were collected from the students. Sixty preceptors completed the preceptor report forms. These forms supported quantitative findings and provided evidence or explanation for the effect of the hospice rotation on student attitudes and perceived competencies related to care of dying patients.

The action variable was assessed by student comments in the student report forms and student reflections. Comments like "I will use the new skills and communication I learned in my future career as a nurse" and that the experience will "definitely help me in the future when providing care to a dying patient" indicated the potential for future changed action as the result of the experience. Some students indicated an interest in working in hospice which they never considered before the experience. Many student reflections indicated more comfort about caring for the dying patient, less need to avoid the rooms where patients are dying, and empowered to actively engage in care of the dying patient. One student summarized by saying

> I believe that I will now be more comfortable addressing death. It does not seem as much of a taboo to me as it did before. I believe that I am more comfortable with talking about death, informing patients and families that death may be the end result of a condition, and I now better understand how to talk to families

> about death. I have been in death situations before when I avoided the patients family (in clinical), however, I now know how to speak with the family, and provide comfort and coping techniques.

All students reported learning new skills during the clinical experience in the hospice setting. Report forms demonstrated frequent discourse between the preceptor and student about pain and symptom management, communication with the patient and family, direct care of a homebound patient, assessment of signs and symptoms of death, time management and cultural and spiritual issues at the end of life. Experiencing a death event and discussing legal and regulatory issues happened less frequently. Some students also mentioned they learned about the roles of the social worker and chaplain; and the importance of including the family in the care plan. Repeatedly, students commented on the bedside manner of the preceptors they observed. One student summed it up by saying

> I witnessed an amazing level of compassionate bedside manner along with appropriate use of therapeutic touch. I think these are priceless qualities that each and every nurse must have no matter what area of the nursing profession they are working in.

Another student commented that she "learned that being honest and open is of utmost importance when communicating with the patient and their families" and "teaching and promoting family involvement is very crucial".

After the first day many students reported that the experience was nothing like they were expecting. They envisioned "that most of these patients would be on their death bed, unconscious, but that was not the case". Students commented that it "was rewarding to see how the patients had such a positive outlook on life and did not let the doctor put an expiration date on them".

The reflections and student report forms were saturated with comments about changed attitudes about death. One student said:

> The experience I had today in hospice really opened my eyes to the reality of the end stage of life. The day led me to look deeper into my beliefs and spirituality and I felt that it not only strengthened my faith but gave me a fresh outlook on the palliative aspect and the need for comfort for a dying patient.

Another student reflected:

> I believe that a hospice rotation is the only reason why I have any beliefs about caring for dying patients. Before the beliefs were all speculation and not based on any real world experience I have had. After hospice I can say that there is no way to cure every patient. For most nurses and healthcare professionals it is sometimes hard to cope with the fact that medicine can only do so much, death is inevitable for us all. Now I know that death is not always sad, for some families death is a way to end the suffering their loved ones are going through, and for some it is still hard to let go. Even though we cannot cure some dying patients, we can still keep them from pain and suffering. This has definitely helped me to see death in a different way.

A third student commented:

> Today I learned that in the beginning I had a bias look at hospice care. I didn't fully understand what it brings to patients nor did I take the time to research and find out. Through this experience I learned that I am very intrigued by how a nurse can care for a patient in all different aspects and being a hospice nurse brings out everything you were taught in nursing school and told a nurse could be. You are able provide all types of care from basic skills, to medication administration and emotional support for the patient and their family and caregivers. I learned that seeing this type of nursing really brought out the passion that I have for nursing and helped me to remember why I wanted to be a nurse and what impact they make.

Quantitative and qualitative data both supported changed attitudes about death. Although the qualitative data also supported improved comfort levels suggesting new skills learned, this was not statistically significant in the quantitative data. Interesting to note that the skills the students reported learning in their reflections (compassion, caring) were not skills measured in the survey.

## Discussion

This study found that a 2 day planned experience with dying patients in a hospice setting led to no statistically significant changes between groups in self-reported

competencies but had a significant effect on attitudes towards death. Figure 2 presents the mean scores of the competency scale for both groups over the three data collection periods; a higher score reflects greater competency. The competencies (as measured by the End- of- Life Competencies Survey) although not statistically significant, showed evidence of improvement after the intervention. An objective test of knowledge before and after the intervention may be a more accurate way to assess competencies than self-report. A larger sample or a longer intervention may have a greater effect on competence. Of particular interest is that the competencies of the first intervention group (Group A) continued to improve after the intervention when they were no longer in the hospice setting. Longitudinal studies may be needed to further explore this phenomenon.

Figure 3 compares mean attitude scores of both groups over the three data collection periods; the lower score indicates a better attitude. Both groups had a significant improvement in attitude after the intervention. Although the sample was small, the intervention had a statistically significant effect on students' attitudes towards death ($p = .035$). There was slight improvement in Group B's attitude before the intervention that could be explained by individuals in different groups talking to each other, a threat to internal validity. An interesting finding is that attitudes of the first experimental group (Group A) began to trend back to baseline attitudes two weeks after the intervention was completed and they were in their regular clinical setting suggesting the need for longer immersion experiences or repeated doses of information to maintain behavior. Longitudinal studies and larger samples are needed to investigate this trend.

The analysis of student comments for a changed attitude towards death overwhelmingly supported the quantitative findings. All students reported anxiety on the

first day of their clinical experience because they did not know "what to expect" which is consistent with other research findings (Chen, Delben, Fortson, Lewis , 2006). The new skills learned that were most frequently mentioned in student reflections related to compassion, caring and family involvement which were not competencies measured on the quantitative tool.

TLT proved to be a helpful model for this study. The hospice experience provided the disorienting dilemma that Mezirow (1990) indicates is the first step in the transformative process and did create some anxiety for the students. In two days they provided care for dying patients, discussed their attitudes about death with their preceptors and learned new perspectives about death, reflected on old attitudes and new perspectives and had a better attitude towards death as a result of the experience which was supported by quantitative and qualitative findings. Although religion, ethnicity and previous experience did not have a relationship to attitudes as suggested by the theory, this could be due to the homogeneity of the sample. The sample was primarily Hispanic and Catholic (or other Christian religion category). The quantitative findings did not support an increase in perceived competencies, but the qualitative data showed that students reported more comfort with care of dying patients, and a determination to provide better EOL care to dying patients in their future practice settings which are outcomes consistent with the early model.

## Implications

There is a scarcity of research on outcomes of educational strategies in end-of-life care. Since nurses are the most likely health professional to be present during the dying process and death, more research is needed on how nursing education can best prepare

students to function in this situation. This study suggests that attitudes towards death can change after a two day experience with dying patients in a hospice setting. TLT suggests that changed attitudes will change future actions. It is important for students to have an experience with dying patients built in to the curriculum. It is possible that a longer immersion in the hospice experience may have an even better outcome. More studies and larger samples are needed to test the relationship of length of time of immersion in the experience and attitudes. Additionally, longitudinal studies are needed to determine if the change in attitude is sustained over time.

Although attitudes were not influenced by ethnicity, religion and previous experience in this study as suggested in the model, larger, more heterogeneous samples are needed to better test the theory. Competencies did not change significantly as a result of the experience according to the quantitative findings, however the use of a knowledge test instead of reported competencies may more accurately reflect new skills learned.

## Conclusion

In order to provide better EOL care, students need to have the experience of taking care of a dying patient and the family as well as the didactic content that is offered in a classroom. Quantitative findings in this study suggest improved attitudes and these findings are supported by the qualitative data. Competencies did not improve according to the quantitative findings, but the qualitative data did support new skills learned and more comfort with EOL care. Visits to cadaver labs and funeral homes as mentioned in previous studies, while valuable in providing students exposure to bodies after death, do not provide the kind of experience necessary to take care of a dying patient and a grieving family. In addition, students need to reflect on their own attitudes about death. These

experiences need to be offered to all nursing students as part of the basic curriculum not just a selected few students and the effects of these experiences must be investigated.

In summary, this study assessed the impact of an educational intervention that included strategies that challenged students' attitudes towards death in addition to providing knowledge about EOL competencies. Through exposure to the care of persons who are dying, students may increase their knowledge base. In addition, critical reflection and discourse offer the opportunity for students to re-evaluate their attitudes towards death. Increased knowledge and newly transformed attitudes have the potential for improving EOL care for dying patients in all practice settings.

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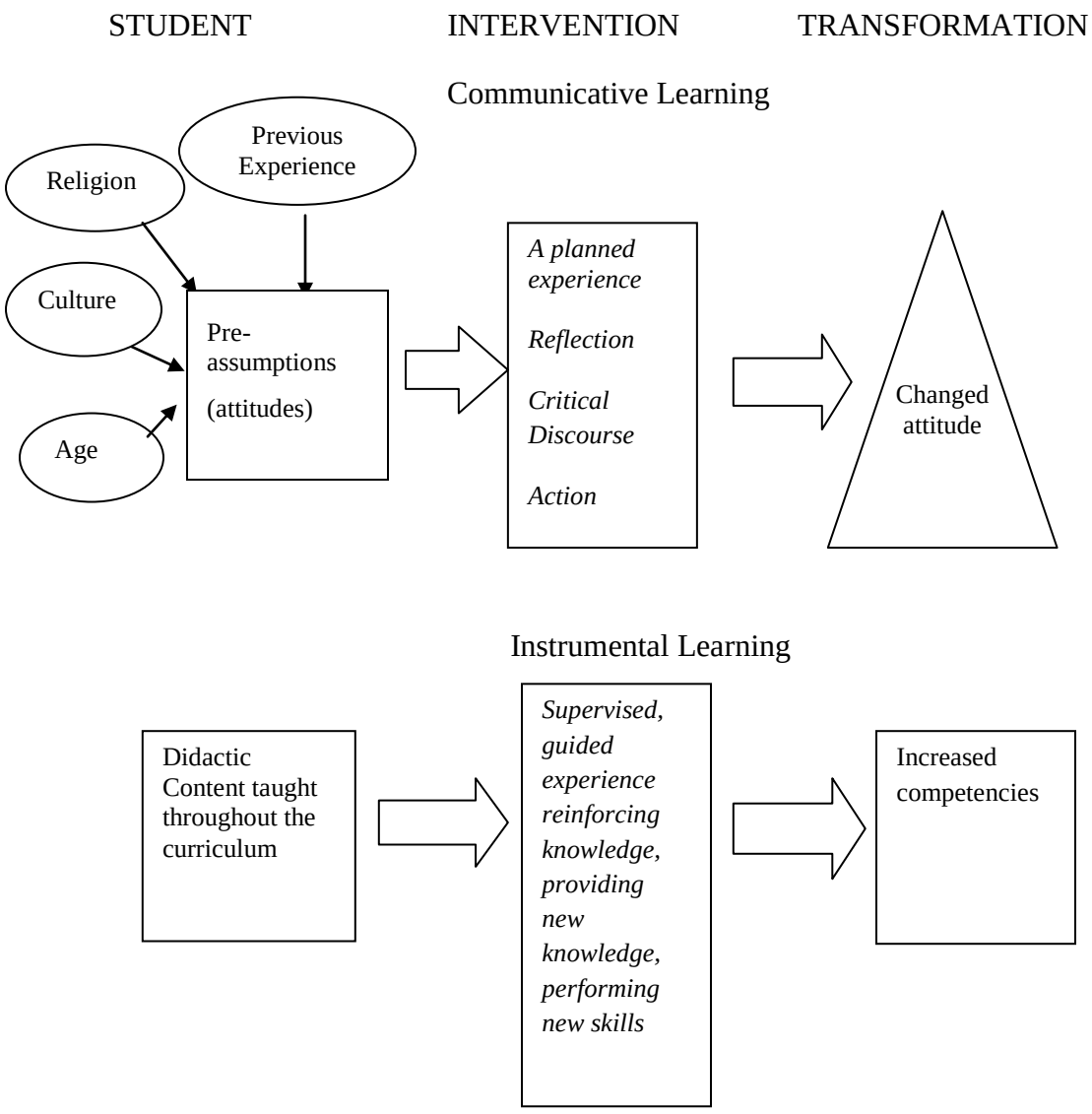


*Figure 1*. Model of core concepts adapted from Mezirow's Transformational Learning Theory as used in this study.

Figure 2. Mean Competencies over Time

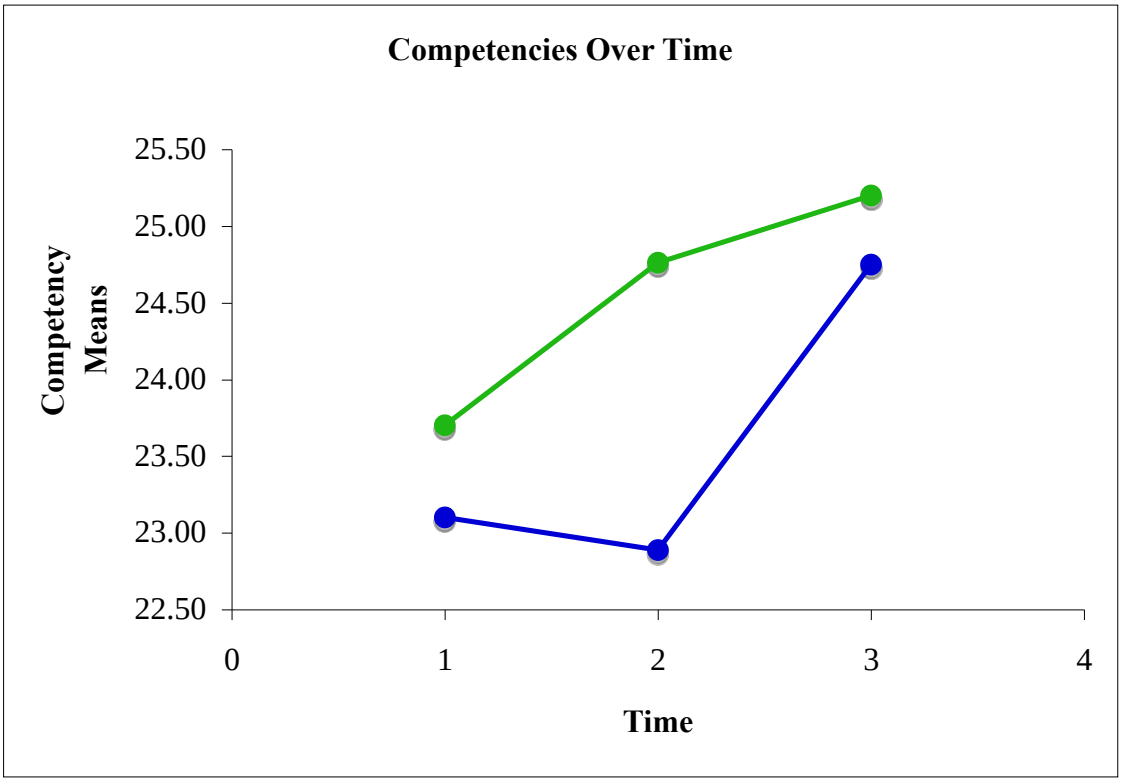


*Figure 2.* Mean Competencies Over Time. The green line represents the mean scores of the first intervention group over three data collection periods; the blue line represents mean scores of the second intervention group over the three data collection periods. The tool is scored so that the higher number reflects more competency.

Figure 3. Attitudes over Time

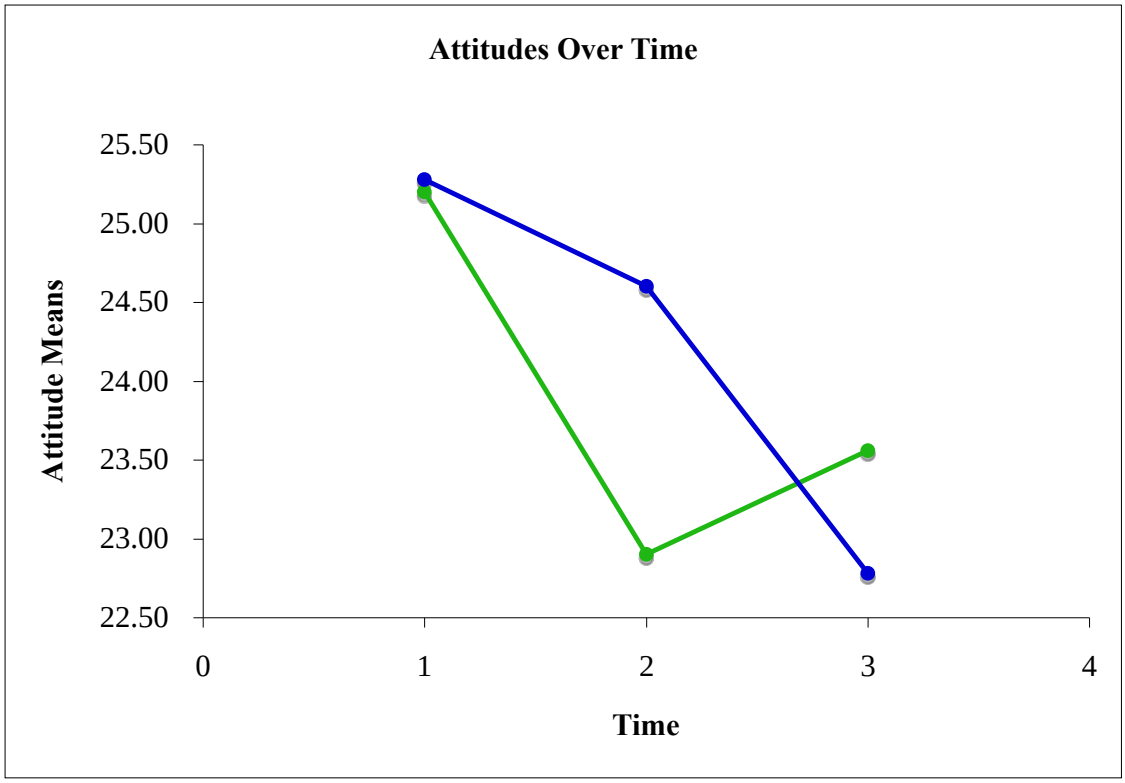


*Figure 3*. Mean Attitudes Over time. The green line represents the mean attitude scores of the first intervention group over three data collection point. The blue line represents the mean attitude scores of the second treatment group. This tool is scored so that the lower score reflects better attitudes.

Table 1. Characteristics of Groups

*Description of Treatment and Control Groups. N (%) or Mean±SD*

| Characteristic | Group A | Group B | *p*-value[a] |
|---|---|---|---|
| Sex | | | .371 |
| Male | 4 (12.9) | 1 (3.3) | |
| Female | 27 (87.1) | 29 (96.7) | |
| Age (years) | 27.4±8.6 | 25.1±5.1 | .206 |
| Race/Ethnicity | | | .350 |
| Hispanic | 16 (52) | 20 (67) | |
| Other | 15 (48) | 10 (33) | |
| Religion | | | 1.0 |
| Catholic | 18 (58) | 18 (60) | |
| Non-Catholic | 13 (42) | 12 (40) | |
| Experience with Death | | | 1.0 |
| Yes | 17 (54.8) | 17 (56.6) | |
| No | 14 (45.2) | 13 (43.3) | |

[a] Chi square or independent samples *t* test

Appendix A

## Intervention Protocol Forms

**Project Title**: **The Effects of a Community-based Hospice experience on attitudes and competencies of senior nursing students**

**Question to be answered**:

Will nursing students have an improved attitude towards death after a clinical experience in Hospice?

Will nursing students report a higher competency in taking care of dying patients after a clinical experience in Hospice?

**Purpose:** The purpose of this study is to determine if an actual experience in a hospice setting with dying patients and their families can change student nurses' attitudes about death and if they feel more competent in taking care of dying patients.

**Recruitment and training of preceptors:** Preceptors will be recruited from licensed staff (registered nurse, social worker, chaplain) at the same hospice agency. At least one week prior to the start of the student clinical, the researcher will meet with the interested group of preceptors after a Monday morning 'Stand-up' meeting when all staff is present to review the goals of the project, the preceptor forms, and paper management process. All preceptors who agree to participate will receive a gift certificate to a local restaurant. This incentive will be offered only after all paperwork is submitted.

**Recruitment of students**: Students will be recruited from a leadership/management class in the last semester of nursing school in a baccalaureate program. All students enrolled in the class will be eligible to participate. The researcher will meet with the students on the first day of clinical orientation to describe the goals of the project, sign consents, review student forms, and administer the first round of surveys.

**Intervention:**

1. Each student will be assigned to a hospice clinical rotation for 2 eight hour days ( one day a week on 2 consecutive weeks) at the same agency during the Leadership/Management course in their final semester of nursing school. The group will be divided in half, with Group A beginning their hospice rotation in the first 2 weeks of the semester while Group B goes to the hospital for their leadership/management experience. After 2 weeks, the groups will switch. The faculty teaching the course will assign students to groups.
2. On the day of their clinical orientation, the researcher will meet with the students in Groups A and B, describe the project and recruit volunteers to participate.

Once consents are signed, the two surveys (Attitudes Towards Death Survey (Strumpf, 1999) and End of Life Competencies Survey) will be administered to all the students who volunteered for the study.

3. Once the surveys are completed, both groups will get a 2 hour orientation from the educator at the hospice agency which covers topics like: what is hospice; organizational structure of the agency; some facts about death in America; Hospice philosophy; communication with the dying patient and family; the role of the nurse on the Hospice team; and general student info (HIPPA reminders, dress code, etc.)
4. Each student will be assigned a licensed preceptor (Chaplain, Social Worker, Registered Nurse) for each of the 2 days while in the hospice clinical. One of these days must be with a registered nurse.
5. Each student will participate in the care of dying patients and their families alongside the assigned preceptor for the 2 days of clinical.
6. Each student will fill out the student report form outlining the activities of each clinical day. The student will share this form with their preceptor on day 2 of clinical to make sure that topics not covered on day one will be discussed. The students will return this form to their clinical faculty at the end of the second day. These forms are intended to be used to guide the experience and to provide some consistency in the experience.
7. The surveys (Attitudes Towards Death Survey (Strumpf, 1999) and End of Life Competencies Survey) will be re-administered by the researcher to both groups during scheduled class time at the end of 2 weeks when group A has completed the Hospice clinical and Group B has not begun.
8. The surveys will be administered a third time by the researcher two weeks later when all students have completed their hospice experience.
9. Each preceptor will fill out a Preceptor Report Form outlining the activities (including discussions) that have occurred with each student on each clinical day and submit to the education coordinator at the agency. If this is the second day of the student's clinical experience, the preceptor will ask to see the Student Report form from Day one so that topics can be addressed that were not previously addressed.

**The Effects of a Community-based Hospice experience on attitudes and competencies of senior nursing students**

**Student Report Form: Day 1**

Name: _____ Date:_____

Name and Specialty of Preceptor:_____

*Instructions to students*: Please complete this form for each day that you are in clinical. If you lose the forms that were provided during orientation, copies of the forms will be available on the Blackboard site for your class and in the office of David Johns at Odyssey. On day 2 of your experience, review your day one activities with your preceptor to guide your preceptor in deciding the experiences that still need to be provided. After the second clinical day, return the completed forms to your clinical instructor.

1. I felt uncomfortable when I learned I was coming to Hospice. Why/Why not?

2. Did anything happen today to ease my anxiety?

3. Today I learned about (check all that apply)

   Direct care of the patient

   Instruction on pain management

   Instruction on other symptom management

   Communication with patient &/or caregivers

   A death event

   Cultural/spiritual issues at the end of life

   Legal/regulatory issues

   Other: Explain

Appendix A (Continued)

**Student Report Form: Day 2**

Name: _____ Date:_____

Name and Specialty of Preceptor:_____

*Instructions to students*: Please complete this form for each day that you are in clinical. If you lose the forms that were provided during orientation, copies of the forms will be available on the Blackboard site for your class and in the office of David Johns at Odyssey. On day 2 of your experience, review your day one activities with your preceptor to guide your preceptor in deciding the experiences that still need to be provided. After the second clinical day, return the completed forms and your reflections to your clinical instructor.

1. I felt uncomfortable when I learned I was coming to Hospice.

2. Did anything happen today to ease my anxiety? Did this come from the patient? Family? Preceptor?

3. Today I learned about (check all that apply)

   Direct care of the patient

   Instruction on pain management

   Instruction on other symptom management

   Communication with patient &/or caregivers

   A death event

   Cultural/spiritual issues at the end of life

   Legal/regulatory issues

   Other: Explain

**Reflections**

*Please respond to the following statements as honestly and completely as you can. There are no right or wrong responses. You may use additional pages if there is not enough space provided.*

1. This experience has caused me to examine my beliefs about caring for dying patients. Comments:

2. What I learned today equipped me with new skills that I can use the next time I take care of someone who is dying.

3. What did I learn about taking care of dying patients today? How was this different from what I expected?

4. I will feel more comfortable taking care of dying patients I am assigned to in the future as a result of the experience in hospice. Comments

5. What did I learn about myself today? Comments:

**Preceptor Report Form: Instructions**

Thank you in advance for participating in this study. The following Preceptor Report Form is a list activities in which the students should participate as part of the study procedures. This theory based study looks to provide students with lived experiences related to care of the dying person. Work varies from day to day and opportunities might present themselves for which you are able to provide in depth education on one subject. However, please try to provide educational opportunities for as many of the following topics as possible while with your student. This will help ensure that the experience is as consistent as possible from one student to the next, an important facet of the research process.

One of the critical concepts of the theory proposes that discussion of attitudes and experiences will impact formulation of interpretations and beliefs about a topic. These interpretations and beliefs in turn affect one's attitudes and competencies. For this reason, you are asked to have specific conversations with the students about:

1. The student's past experiences with death. (You might ask if the student has experienced a death in the family? Ever worked with dying patients? Known someone who has died.)

2. The student's attitudes about death. ( How did the student feel when the family member died? How does the student feel about taking care of someone who is dying? What are the student's beliefs about death?)

If you agree to participate, you will be assigned to a student by the education department of at least one week in advance of the student experience. You will only have one student per assigned day. The Preceptor Report form needs to be submitted for each student on each clinical day. These forms will be available in the Odyssey education department. At the end of the clinical day, please place the completed forms in the education office. At the end of September when the students are finished with their hospice clinical, all preceptors who have completed the paperwork for all assigned students will receive a gift certificate for a dinner at a local restaurant.

Appendix A (Continued)

**Preceptor Report Form**

Name of preceptor:_____ Date of experience:_____

Number of hours spent with the student: _____

Name of student:_____

**Activities:**

1. How many patients were seen today? _____
2. Which of the following activities occurred on this day? (Check all that apply)

   Direct care of the patient

   Instruction on pain management

   Instruction on other symptom management

   Communication with patient &/or caregivers

   A death event

   Cultural/spiritual issues at the end of life

   Legal/regulatory issues

**Discussions:**

Did you discuss the student's past experience with death? Yes_____ No_____

Did you discuss the student's attitude about death? Yes_____ No_____

**Did you get the sense that the student's attitude about death was changing as a result of today's** experience? Why or why not?

**Please place completed forms in the education office**. Thank you

# Appendix B

## Instruments

UIW IR Form 0120 - 026

I am being asked to complete this voluntary, anonymous, and completely confidential survey to aid researchers to develop palliative care programming at the University of the Incarnate Word. This information will be used as aggregated data only. By completing and returning the form to Ms. Irene Gilliland, I am giving consent to participate. If I desire more information, I can call Ms. Gilliland at 829-3970 or pager 715-1810.

### Attitudes Toward Death Survey

The last four digits of my SSN:__ __ __ __ [Validation purposes only]

Please indicate how much you agree or disagree with each of the following statements by filling in the response that best describes your feelings: Strongly Agree, Agree, Nor Sure or Mixed Feelings, Disagree, or Strongly Disagree. There are no right or wrong answers; just fill in the response that describes *your* feelings.

| | Strongly Agree | Agree | Not Sure/ Mixed | Disagree | Strongly Disagree |
|---|---|---|---|---|---|
| 1. The end of life is a time of great suffering | 5 | 4 | 3 | 2 | 1 |
| 2. Little can be done to help someone achieve a sense of peace at the end of life | 5 | 4 | 3 | 2 | 1 |
| 3. The use of strong pain medication can cause the patient to stop breathing | 5 | 4 | 3 | 2 | 1 |
| 4. I am not comfortable caring for the dying patient | 5 | 4 | 3 | 2 | 1 |
| 5. I am not comfortable talking to families about death | 5 | 4 | 3 | 2 | 1 |
| 6. When a patient dies, I feel that something went wrong | 5 | 4 | 3 | 2 | 1 |
| 7. Feeding tubes should be used to prevent starvation at the end of life | 5 | 4 | 3 | 2 | 1 |
| 8. The nursing home is not a good place to die | 5 | 4 | 3 | 2 | 1 |
| 9. Patients have the right to refuse a medical treatment, even if that treatment prolongs life | 5 | 4 | 3 | 2 | 1 |
| 10. Dying residents should be referred to Hospice | 5 | 4 | 3 | 2 | 1 |

| 11. What do you think are the most important problems in caring for the dying resident? | Very Important | Important | Don't Know | Unimportant | Very Unimportant |
|---|---|---|---|---|---|
| a. Control of pain | 5 | 4 | 3 | 2 | 1 |
| b. Depression | 5 | 4 | 3 | 2 | 1 |
| c. Loneliness | 5 | 4 | 3 | 2 | 1 |
| d. Legal concerns | 5 | 4 | 3 | 2 | 1 |
| e. Regulatory concerns | 5 | 4 | 3 | 2 | 1 |
| f. Communications with doctor | 5 | 4 | 3 | 2 | 1 |
| g. Communications with other caregivers | 5 | 4 | 3 | 2 | 1 |
| h. Communications with family | 5 | 4 | 3 | 2 | 1 |
| i. Concern for other residents | 5 | 4 | 3 | 2 | 1 |
| j. Inability to meet spiritual needs | 5 | 4 | 3 | 2 | 1 |
| k. Uncertainty about what is best care | 5 | 4 | 3 | 2 | 1 |

| 12. What do you think would help improve end of life education in your school? | Definitely Needs Improvement | Could Be Better | Neutral | Fairly Good | No Improvement Necessary |
|---|---|---|---|---|---|
| a. Education and training in pain control | 1 | 2 | 3 | 4 | 5 |
| b. Education and training in management of other symptoms | 1 | 2 | 3 | 4 | 5 |
| c. Greater access to Hospice experiences | 1 | 2 | 3 | 4 | 5 |
| d. Education in legal and regulatory concerns | 1 | 2 | 3 | 4 | 5 |
| e. Education in ethical issues | 1 | 2 | 3 | 4 | 5 |
| f. Greater emphasis on spiritual care | 1 | 2 | 3 | 4 | 5 |
| g. Elective on palliative care | 1 | 2 | 3 | 4 | 5 |

Comments: _____

# End of Life Competencies Survey

**Date:** _____ **Circle one:** Pre/Post

**1. Are you a(n):** (1) Nursing Student (2) Pharmacy Student (3) Other: _____

**2. Do you have any experience with taking care of dying patients?** (1) Yes (2) No

If yes, what kind? _____

**3. What is your age?** _____

**4. What is your race?**

(1) American Indian (3) African American/Black (5) Asian/Pacific Islander

(2) Caucasian (4) Hispanic (6) Other_____

**5. What is your religion?**

(1) Baptist (3) Catholic (5) Methodist

(2) No Preference (4) Non-Christian (6) Non-Denomination

**6. What is your gender?** (1) Female (2) Male

**7. Overall, how effective do you believe you are in the following areas?**

| | Not at all effective | Somewhat effective | Neutral | Fairly effective | Very effective |
|---|---|---|---|---|---|
| a. Pain management | (1) | (2) | (3) | (4) | (5) |
| b. Other symptom management | (1) | (2) | (3) | (4) | (5) |
| c. Communication with terminally ill patients | (1) | (2) | (3) | (4) | (5) |
| d. Communication with family caregivers | (1) | (2) | (3) | (4) | (5) |
| e. Managing the death event at home | (1) | (2) | (3) | (4) | (5) |
| f. Cultural issues in end-of-life care | (1) | (2) | (3) | (4) | (5) |
| g. Overall end-of-life care for the terminally ill | (1) | (2) | (3) | (4) | (5) |

**8. Overall, how effective do you think your education has been in these areas?**

| | Not at all effective | Somewhat effective | Neutral | Fairly effective | Very effective |
|---|---|---|---|---|---|
| h. Pain management | (1) | (2) | (3) | (4) | (5) |
| i. Other symptom management | (1) | (2) | (3) | (4) | (5) |
| j. Communication with terminally ill patients | (1) | (2) | (3) | (4) | (5) |
| k. Communication with family caregivers | (1) | (2) | (3) | (4) | (5) |
| l. Managing the death event at home | (1) | (2) | (3) | (4) | (5) |
| m. Cultural issues in end-of-life care | (1) | (2) | (3) | (4) | (5) |
| n. Overall end-of-life care for the terminally ill | (1) | (2) | (3) | (4) | (5) |

**Comments:** _____

_____

_____

Appendix C

IRB/Institutional approvals

The University of Texas at Tyler
Institutional Review Board
August 20, 2010

Dear Ms. Gilliland:

Your request to conduct the study entitled: *The Effects of a Community-based Hospice Experience on Attitudes and Perceived Competencies of Senior Nursing Students*, IRB #SUM2010-54, has been approved by The University of Texas at Tyler Institutional Review Board with use of written informed consent. **Please review the UT Tyler IRB Principal Investigator Responsibilities, and acknowledge your understanding of these responsibilities and the following through return of this email to the IRB Chair within one week after receipt of this approval letter**:

- This approval is for one year, as of the date of the approval letter
- Request for Continuing Review must be completed for projects extending past one year
- Prompt reporting to the UT Tyler IRB of any proposed changes to this research activity
- Prompt reporting to the UT Tyler IRB and academic department administration will be done of any unanticipated problems involving risks to subjects or others
- Suspension or termination of approval may be done if there is evidence of any serious or continuing noncompliance with Federal Regulations or any aberrations in original proposal.
- Any change in proposal procedures must be promptly reported to the IRB prior to implementing any changes except when necessary to eliminate apparent immediate hazards to the subject.

Best of luck in your research, and do not hesitate to contact me if you need any further assistance.

Sincerely,

Gloria Duke, PhD, RN,

Chair, UT Tyler IRB

APPLICATION FOR INSTITUTIONAL REVIEW BOARD APPROVAL FORM
University of the Incarnate Word ,

***Attitudes and Competencies of Senior Nursing Students in End of Life Care***

1. **Principal Investigator**: Irene Gilliland, RN, CNS, ACHPN
2. **Co-Investigator**: Jennifer Cook, PhD, MBA, RN, CNS
3. **Division/Discipline**: Nursing
4. **Research Category**: a. _x_ Exempt b.___Expedited Review c.___Full Board Review
5. **Purpose of Study**: To assess students' attitudes about death; to assess student competencies related to care of dying patients; to evaluate the effect of a hospice experience on attitudes and competencies.
6. **Number of Subjects**:_50___ Controls:__n/a___
7. Does this research involve any of the following:

| | YES | NO | | YES | NO |
|---|---|---|---|---|---|
| Inmates of penal institutions | | x | Fetus in utero | | x |
| Institutionalized mentally retarded | | x | Viable Fetus | | x |
| Institutionalized mentally disabled | | x | Nonviable Fetus | | x |
| Committed patients | | x | Dead Fetus | | x |
| Mentally retarded outpatient | | x | In vitro fertilization | | x |
| Pregnant women | | x | Minors (under 18) | | x |

For each "Yes", state what precautions you will use to obtain informed consent.

8. **Duration of study**: January 1, 2010 to May, 2011
9. **How is information obtained**? The project involves collection and analysis of data from 2 surveys administered to volunteer senior nursing students before and after their Hospice leadership/management clinical. Tool reliability will also be established with test-retest with 6-8 nursing faculty.
10. **Confidentiality** – (Are identifiers used for subjects?: _____Yes ___x_ _No). All data gathered from participants will be used as group data. No names identifying the subjects will be used. The surveys will be identified by the last 4 digits of the participants Social Security number. Only the Principal Investigator will have access to the information identifying the participants. Once data are scanned, data will be converted to an Excel spreadsheet by the UIW Office of Information and each subject will be assigned a project identification number. Completed surveys and consent forms will be kept in a locked file cabinet in the PI's UIW office.
11. **Benefit of research**: The benefit to the Nursing program is moderate in that the surveys may indicate the need for adding additional content on End of Life Care; it is a way of measuring end of life competencies which is one of the required competencies for graduates of nursing programs; it will demonstrate program evaluation to the accrediting

body that will be reviewing our program next year. The major benefit to the student volunteers is to allow them to experience the research process.

12. **Possible risk to subjects**: The risks to volunteer participants are low. The data will be used for program evaluation and will not affect their grade. Confidentiality of all participants will be maintained.

***IF CHANGE IN RESEARCH OCCURS THE BOARD MUST BE NOTIFIED BEFORE RESEARCH IS CONTINUED.***

Principal Investigator signature [signature] Date: 10 December 2009

IRB Approval signature [signature] Date 10 Dec 2009 1/14/2010

Application # 10-01-001

Appendix D

**THE UNIVERSITY OF TEXAS AT TYLER**

**Informed Consent to Participate in Research**

**1**. **Project Title:** The Effects of a Community-based Hospice experience on attitudes and perceived competencies of senior nursing students

**2**. **Principal Investigator's Name**: Irene Gilliland

**3**. **Participant's Name**: _____

*To the Participant*:
You are being asked to take part in this study at The University of Texas at Tyler (UT Tyler). This consent form explains why this research study is being performed and what your role will be if you choose to participate. This form also describes the possible risks connected with being in this study. After reviewing this information with the person responsible for your enrollment, you should be able to understand and make an informed decision on whether you want to take part in this study.

***DESCRIPTION OF PROJECT:*** *This project will examine the effects of an experience in hospice on student attitudes about death and their self reported competencies about taking care of dying patients.*

**4**. **Purpose of the Study** . The purpose of this study is to examine the effects of an experience in hospice which includes a clinical experience with dying patients, critical discourse and a reflection about the experience, on senior nursing students' attitudes towards death and perceived competency in providing EOL care.

**5**. **Research Procedures**: You will be asked to complete 2 surveys three times this semester. The first time will be on the day of your clinical orientation, the second in class 2 weeks later, then a final time 4 weeks after the initial surveys were completed. You will also be asked to keep track of your activities while with your preceptor in the hospice setting, and to write down your reflections of the experience at the end of your hospice rotation.

**6. Risks.** There is always the risk of emotional distress when working with a patient who is dying. The student counseling center on campus will be available in the event that a referral is necessary. Please keep in mind that unpredicted risks may exist**.**
If you have concerns after completing the questionnaires, please call Irene Gilliland (210 452-8371).

**7.Potential Benefits**. Your participation in this study may help researchers discover information that can help other people. There are no direct benefits to you by participating in this study.

**Understanding of Participants**

**8.** I have been given an opportunity to ask any questions concerning the procedures involved in this study and the investigator has been willing to answer my questions. This survey will be conducted at the University of the Incarnate Word but approved by The University of Texas at Tyler as part of the project titled, numbered, and described above. I hereby authorize _Irene Gilliland_, the principal investigator, **to** *administer* the survey.

**9.** I have been told and I understand that my participation in this study is strictly voluntary and that I may refuse to participate without penalty or loss of benefit to which I am otherwise entitled.

**10.** I have been told and I understand that I may withdraw my consent and stop my participation in this study at any time, and that such withdrawal of consent or discontinuation will involve no penalty or loss of benefits to which I am otherwise entitled.

**11**. I have been assured that confidentiality will be preserved and that my name will not be revealed in any reports or publications resulting from this study without my expressed written consent, except that qualified investigators from the Department of Health and Human Services may review my records where appropriate and necessary.

I also understand that any personal health information or other information collected during this study may be shared with the following as long as no identifying information as to my name, address or other contact information is provided):

• Organization contributing money to be able to conduct this study
• Other researchers interested in combining your information with information from other studies
• Information shared through presentations or publications

I understand The UT Tyler Institutional Review Board (the group that ensures that research is done correctly and that measures are in place to protect the safety of research participants) may review documents that have my identifying information on them as part of their compliance and monitoring process. I also understand that any personal information revealed during this process will be kept strictly confidential.
I also understand that any information regarding safety of drugs must be shared, but in regards to any other information, I may cancel my permission at any time to share information collected from me by contacting the researcher named in this consent at the following address:

Irene Gilliland
The University of Texas at Tyler
Institutional Review Board
c/o Office of Sponsored Research
3900 University Blvd
Tyler, TX 75799

**12**. I have been informed of the reasonably foreseeable risks associated with participation in this research project. I have been informed that should I suffer any injury as a result of participation in this project, Student Health Center is available. I understand, however, that in the absence of negligence on the part of The University of Texas at Tyler personnel, I cannot expect to receive any payment for medical expenses or any financial compensation for such injury.

**13**. I understand that I will not be charged for any costs involved in this project.
My insurer and/or I will be responsible for the cost of any supportive or treatment of any research-related complications or injuries**.**
I also understand that I will not be compensated for any patents or discoveries that may result from my participation in this research.

**14**. If I have any questions concerning my participation in this project, I shall contact Irene Gilliland (210 452 8371) If I have any questions concerning my rights as a research subject, I shall contact Dr. Gloria Duke, Chair of the IRB, at (903) 566-7023. I understand that I may contact Dr. Duke with questions about research-related injuries.

**15. CONSENT/PERMISSION FOR PARTICIPATION IN THIS RESEARCH STUDY**
Based upon the above, I consent to participate in the research. I give the principal investigator or study researcher permission to enroll me in this study. I have received a signed copy of this consent form.

_____ _____ ___
Signature of Participant Date

_____ _____ _____ _____
Signature of Person Responsible Relationship to Participant

_____ _____ _____ _____ _____
Signature of Child (ages 13-17 years)

_____ _____
Witness

16. I have discussed this project with the participant using language that is understandable and appropriate. I believe that I have fully informed this participant of the nature of this study and its possible benefits and risks, and I believe the participant understood this explanation

_____ Investigator

_____Date

## Appendix E

## Biographical Sketch

Name: Gilliland, Irene

Position Title: Instructor, University of the Incarnate Word

Clinical Nurse Specialist, Odyssey Health Care

### Education/Training

| | | | |
|---|---|---|---|
| Villanova University, Villanova, PA | BSN | 1972 | Nursing |
| University of Virginia, Charlottesville, VA | MSN | 1986 | Nursing |
| University of Texas at Tyler, Tyler, TX | | | |

### Employment

| | |
|---|---|
| 2008-Present | University of the Incarnate Word, Graduate CNS Program Lead Faculty |
| 2006-2008 | University of the Incarnate Word, Recruitment Specialist for graduate nursing program |
| 1991-2006 | University of the Incarnate Word, Nursing Instructor |
| 1994-Present | Hospice Case Manager and CNS |
| 1988-Present | Cost Containment Specialist- Auditing hospital bills on behalf of insurance carriers |
| 1984-1991 | Virginia Western Community College, Nursing Instructor |
| 1980-1986 | Charles Gilliland M.D. P.C., Office Manager |
| 1972-1975 | John F. Kennedy Memorial Hospital, Philadelphia, PA. Critical Care Nurse, Staff Educator, and Supervisor |

## Honors

| | |
|---|---|
| 2004 | Fulbright Scholarship for travel to China |
| 2001 | Sigma Theta Tau Image Maker Award for excellence in practice |
| 1999 | Helen Fuld Fellowship in Nursing Education |

## Peer Reviewed Articles

Gilliland, I. (2011). Clinical Nurse Specialist in education: Preparing practice portfolios. Clinical Nurse Specialist: *The Journal for Advanced Nursing Practice, 25* (2), 81.

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Etnyre, A., Rauschhuber, M., Gilliland, I., Cook, J., Mahon, M., Allwein, D., Sethness, R., Lowry, J., Jones, M.E. (2006) Cardiovascular risk among older Hispanic women. *AAOHN Journal, 54* (3), 120-8.

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Kolb, S., Deliganis, J., Gilliland, I. (2003). Ministerio de Salud: Development of a mission driven partnership for addressing health care disparities in a Hispanic community. *Journal of Multicultural Nursing and Health, 9* (3), 6-12.

Gilliland, I. (2003). Life and Death in Tribal Africa. *Nursing Forum, 38* (2), 29-31.

Gilliland, I. (2001). Final Thoughts. *Journal of Hospice and Palliative Nursing, 3* (2), 71.

Gilliland, I. (2000). Hospice in Russia. *Journal of Hospice and Palliative Nursing, 2* (2), 73-75.

Gilliland, I. (1999). She was her daughter and I was only her Nurse. *Journal of Hospice and Palliative Nursing, 2* (1), 6, 30.

Gilliland, I. (1999). Using Aromatherapy as a Therapeutic Nursing Intervention. *Journal of Hospice and Palliative Nursing, 1*(4), 157-8.

Gilliland, I. (1996). Cost Containment at the Bedside. *American Journal of Nursing Science, 1* (5/6), 208-9.