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Palliative Care and Hospice Community Education

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Palliative Care and Hospice Community Education

Mary Castang

Submitted as partial fulfillment for the Doctor of Nursing Practice Degree

Regis University

August 4, 2014

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Executive Summary

Palliative Care and Hospice Community Education

Problem

In the researcher's home hospice practice, a need for community education regarding Palliative Care and Hospice is recognized. Patients and family members need information about End of Life (EOL) care options prior to the urgency of a crisis. According to Szirony, Oopko, Masiulaniec and Binder (2011) many patients and family members learn of hospice and palliative care services only after admission into a program. The decision to sign in to a program reflects their perception of there being no other choice rather than understanding the options and benefits (Szirony, et al, 2011). The Capstone practice question is as follows: In patients and families dealing with life limiting illness, how does provision of an educational discussion to demystify Palliative Care and Hospice options and benefits, compared to no community education, influence their report of increased understanding of Palliative Care and Hospice options and benefits?

Purpose

The project was implemented for the purpose of providing accurate and consistent education for the community about the Palliative Care and Hospice options for EOL care. Many eligible patients who could benefit from hospice care are not receiving it until the last couple weeks or days of life, or often not at all. Rickerson, Harrold, Kapo, Carroll and Casarett (2005) quote three weeks stay in hospice for the median length of stay, with 10% of patients signing in to hospice on the last day of life.

Goal

The goal this project intends to accomplish is to establish trust and promote a comfortable situation for EOL care dialogue, resulting in participants understanding the process and the benefits of accepting Palliative Care and Hospice, and a venue to ask questions about the options. The hope is for understanding of and enrollment in Palliative Care and Hospice sooner rather than later, resulting in patient outcome of easier and comfortable transitions in life limiting illnesses and end of life.

Objective

The objective, the benefit and the ultimate outcome are for the participants to have an increased understanding of EOL care options and benefits, specifically palliative care and hospice. To this end, dissemination of accurate and current information regarding palliative care and hospice and engagement of participants in dialogue during the intervention is the key objective.

Plan

The plan to provide education to demystify palliative care and hospice and to clarify options and benefits available for managing care during the End of Life process began with identification of the need. The ensuing steps were to plan the intervention content, advertise the offering and engage the participants.

Outcomes and Results

Forty one total participants completed both the pre- and post-intervention measurement surveys. A statistically significant improvement in mean knowledge scores was noted on the post-interventions surveys, suggesting that the intervention was successful in providing increased understanding of palliative care and hospice to the participants.

Acknowledgements

With a humble and grateful heart I acknowledge my Heavenly Father for His blessings and for providing me the opportunity to continue my education in His service. I want to acknowledge all the patients I have had the honor to care for over the years, and the community members who participated in this capstone project.

I appreciate my capstone chair, Dr. Alma Jackson, clinical mentor, Karen White, and each Regis course faculty for their support and encouragement during this program. Thank you to my colleagues and classmates for continual inspiration and collaboration. Without you all, this program and project would have been infinitely more challenging.

I dedicate this project to my mother, Malwee Dearest, my husband, Dean Barr, and my brother, Donald Castang, all three of whom provided ongoing inspiration through the program.

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Palliative Care and Hospice Community Education

This report of a Doctor of Nursing Practice (DNP) project describes a palliative care and hospice educational intervention for participants in community settings. Included in the report is the practice problem recognition and definition, review of the evidence, and the project plan and evaluation. In addition, the project findings and results are presented, with limitations, recommendations and implications for change. This capstone project is a quantitative analysis of seven pre and post survey questions from 41 participants who attended an educational intervention regarding palliative care and hospice.

Problem Recognition and Definition

Statement of Purpose

The focus of the DNP Capstone project is lack of consistent and accurate information surrounding end of life (EOL) care options, specifically Palliative Care and Hospice. The purpose of the project is to provide accurate and consistent education for the community about the Palliative Care and Hospice options for EOL care. EOL care is defined by Alsop (2010) as assistance for patients and families who are impacted by an incurable disease in the late stages to continue to live as comfortable as possible until death by controlling physical and psychological symptoms and providing social and spiritual support.

In the current practice of Home Hospice nursing, the DNP student recognizes a knowledge gap regarding Palliative Care and Hospice benefits, philosophies and eligibility criteria for persons facing EOL transitions. Often patients, families and health care workers either are unfamiliar with or have misinterpreted knowledge about choices for EOL care and support, thus benefits of Palliative Care or Hospice are avoided or declined. Providing education

regarding EOL options for members of the community could be beneficial for those persons faced with decisions regarding the care for themselves or their loved ones.

Problem Statement

The project problem statement is that eligible patients who could benefit from palliative care and hospice are either not receiving these services and benefits at all or not receiving them until the last days of life. According to Szirony, Oopko, Masiulaniec and Binder (2011) many patients and family members learn of hospice and palliative care services only after admission into a program. The decision to sign in to a program is because of their perception of there being no other choice rather than understanding the options and benefits (Szirony, et al, 2011).

PICO Statement and Practice Question

The DNP Capstone practice question is as follows: In patients and families dealing with life limiting illness, how does provision of an educational discussion to demystify Palliative Care and Hospice options and benefits, compared to no community education, influence their report of increased understanding of Palliative Care and Hospice options and benefits? The inset below illustrates the Population Intervention Comparison Outcome (PICO) format which led to development of the practice question.

Population: Patients and families in the community dealing with life-limiting illnesses

Intervention: Education to Intervention to demystify Palliative Care and Hospice and clarify options and benefits available for managing care during the EOL process.

Comparison: No current formal community education process for the specific population.

Outcome: Participants report increase in understanding and awareness of the options and benefits of Palliative Care and Hospice measured by a pre and post survey.

Project Significance, Scope and Rationale

The following discussion reveals the significance, scope and rationale for the project from the DNP student's examination of studies related to education surrounding palliative care and hospice. Included in the discussion are specific elements related to the proposed study and clarification for the target population and a review of the literature providing the rationale. Two quantitative studies in the literature search shed light on perceptions of older people on issues surrounding dying and search for answers to why patients do not enroll in hospice.

Significance for clinical practice is for patients and families to enroll in Palliative Care and Hospice sooner rather than later in the course of a life limiting illness or the dying process thus receiving comfort care earlier in their illness and dying process and experience easier transitions after enrollment with Palliative Care or Hospice. After review of the project variables and PICO, and reflection on the goal of the project, the DNP student also recognized part of the significance to clinical practice in addition to the intervention and the outcome, is to make the most of the interactions with the participants. Each contact is a unique opportunity for reciprocal growth and gaining knowledge.

Project scope and Background Information

The scope of the project is a pilot study with a small, purposive convenience sample of local communities, recruited from community organizations where a venue is free to participants, such as churches, libraries, community centers and fire stations. Interested patients and family members will self-enroll or attend and voluntarily participate. Many eligible patients who could benefit from hospice care are not receiving it until the last couple weeks or days of life, or often not at all. Rickerson, Harrold, Kapo, Carroll & Casarett (2005) quote three weeks stay in hospice

for the median length of stay, with 10% of patients signing in to hospice on the last day of life. There are patients who could have had a better quality of life in their last six months by management of symptoms, social work interventions and general ease of their situation by getting involved in palliative care and hospice earlier in their EOL journey.

The goal for this project is to establish trust and promote a comfortable situation for EOL care dialogue resulting in participants understanding the process and the benefits of accepting Palliative Care and Hospice, and a venue to ask questions about the options. Patient education is integrated into the standards of practice for the nursing profession. Sanford's (2000) nursing perspective on patient education states a central focus of nursing is education of patients and families, with an anticipated consequence of a knowledgeable population. The benefit and the ultimate outcome are for the participants to have an increased understanding of EOL care options and benefits, specifically Palliative Care and Hospice.

DNP role in relation to PICO, Outcomes and Rationale

This problem and the proposed patient-sensitive outcomes relate to the emerging role of the DNP in several areas. According to the American Association of Colleges of Nursing (AACN) (2006) essential two, a DNP practice includes a focus on the needs of a particular population to eliminate health disparities and to improve patient and healthcare outcomes. AACN also promotes 'generation of evidence through practice to guide improvements in practice and outcomes' (p.12). The project plan includes gathering of data prior to and after giving educational offerings which will direct the focus of the intervention for participants. Essential four (AACN, 2006) expects the DNP to 'evaluate consumer health information sources for accuracy, timeliness, and appropriateness' (p.13).

The Agency for Healthcare Research and Quality (AHRQ, 2000) includes mortality as an end result experienced by people, and as such is included in outcomes research. A patient-sensitive outcomes area where the DNP prepared Registered Nurse (RN) can make a difference is education in the community regarding benefits and options surrounding EOL care specifically palliative care and hospice. A DNP role in community hospice nursing includes solicitation of feedback from patients and families regarding their health understanding with each home visit or phone call. This ongoing dialogue is a venue for the evaluation of accuracy and suitability set forth by the AACN. This project is a continuation of that assessment, with intervention and evaluations ongoing throughout the educational process.

Essential seven (AACN, 2006) endorses the DNP role as addressing gaps in care and improving access patterns for individuals and populations which specifically aligns with the focus of this DNP project. Tymkow (2011) believes nurse leaders prepared with a DNP are obliged to apply their education and experience to develop and advance both practice and outcomes. In the practice area of Home Hospice, the DNP student is involved in both the initial consultation and the subsequent care of patients and families for whom palliative care or hospice care has been recommended. Throughout the admission process and ensuing care there are evident gaps in knowledge and perceptible misconceptions surrounding palliative care and hospice both in the health caregiver communities and the populations they serve.

The Essentials of Doctoral Education for Advanced Practice Nursing (AACN, 2006) endorses quality improvement initiatives by a DNP nurse leader to ‘promote safe, timely, effective, efficient, equitable, and patient-centered care’ (Tymkow, 2011, p. 67). Equitable is the element in this statement that stands out for the specific context for this investigator’s DNP project. In order for patients and their families to make informed decisions about their EOL care,

they need to be knowledgeable about the availability and the options for care. A DNP prepared nurse is current on the evidence provided by outcomes research in order to underscore educational offerings to colleagues, patients in the community and to their families.

Theoretical Foundations

The theoretical underpinning for the DNP project is Story Theory, proposed by Smith and Liehr (2010), who state that when nurses discuss what matters to the patient regarding a particular need, Story Theory can be used to initiate and continue dialogue. For example, a patient or family member faced with EOL decisions may begin a relationship talking about something seemingly unrelated. However, by listening in a way that assures the person there is all the time that is needed to have a discussion, the nurse finds out what worry is prevalent for the person in the moment. Story Theory concepts include purposeful dialogue to ascertain past experiences and creating ease (Smith & Liehr, 2010), without assumptions about what matters most to the patient.

Smith and Liehr's (2010) Story Theory describes information gathering and analysis as storytelling which is a 'core dimension of nursing practice evidence and contributes to substantive nursing knowledge' (p. 440). 'Each time a nurse engages a patient about what matters most regarding a health challenge, Story Theory is applicable' (Smith & Liehr, 2010, p. 441). Story Theory is based on the assumptions that people change across many flowing dimensions, yet live in the present moment where both past and future experience influence the 'creative unfolding' of their awareness (Smith & Liehr, 2010). According to Smith & Liehr (2010), the three concepts of the theory are intentional dialogue, connecting with self-in-relation, and creating ease (p. 441). This theory underpins the nurse educator process for approaching EOL care discussions with persons by beginning with relationship and ending with comfort or

ease. In the process, dialogue and connecting are the important components that contribute to gathering nursing knowledge.

A second and significant theoretical foundation for the project is the adult learning theory of andragogy described and promoted by Malcolm Knowles, where adult learners are self-directed learners, and as such, require distinctive and dynamic methods of instruction (McGrath, 2009). According to McGrath (2009), adult learners differ from traditional students in several ways and their instructor to be a facilitator for learning rather than a teacher. “Adults tend to take responsibility for their own learning and they do not want to be directed by the lecturer during class” (McGrath, 2009, p. 100). This concept calls for the instructor to recognize, assess and respond to the needs of the adult learner in an ongoing interchange during the education process.

Knowles defines an informal type of adult learning in a group or forum setting (McGrath, 2009) and five key concepts of andragogy; inform students of the benefits of learning the material and provide learning objectives, promote self-confidence by encouraging learners to discuss and present personal views during class, assume the life experience the adult learner brings to the classroom, and recognize that a sense of belonging motivates adult learners to engage in discussion. Finally, Knowles points out that for andragogy to be successful, the facilitator must support a safe environment for participation in the adult learning experience (McGrath, 2009).

Community participants interested in learning about Palliative Care and Hospice represent diverse life experience along with different backgrounds and levels of learning. The common ground is that they are adult learners and have come to the educational offering with a desire to participate and learn about the content. Chan (2010) points out six assumptions of andragogy; “self-directedness, need to know, use of experience in learning, readiness to learn,

orientation to learning and internal motivation” (p. 25), and explains the principles promote trust between participant and facilitator and develop self-awareness and empowerment in participants. Taylor and Kroth (2009) describe these six assumptions of Knowles as the foundation for adult learning and are essentially a “personal interactive agreement” (p. 46) between a participant and presenter, where the learning process is centered on application of knowledge to a life problem or task. The DNP student facilitator has a responsibility to cultivate and encourage the self-directed adult learner by engaging them in meaningful dialogue during the educational presentation and develop an individualized learning experience for each participant. Both of these theoretical foundations provide the teaching methodology for this DNP Capstone Project.

Review of Evidence

A systematic review of literature was conducted (see Appendix C), using well-known search engines that include Cumulative Index to Nursing and Allied Health Literature (CINAHL), MEDLINE, Medscape, and Psych INFO as the main sources. Parameters and search words included full text articles, English language, and articles published from, 2004 to 2012: the main key words used independently and collectively were Nurse Manger, Nurse Leader, Burnout, Stress, Emotional Intelligence, Transformational Leader, Disengagement, change, and Support. The systematic assessment of each article included identification of the following elements: purpose, hypothesis/research questions, theoretical framework, setting, sample, methods/design, conclusion, nursing implication, and findings. The initial findings, using the identified key words individually and collectively revealed 73 articles. The final analysis revealed 31 articles which consisted of 12 qualitative articles, five quantitative articles, eight integrative literature reviews, and six informational articles from content experts that served as key resources for validating information related to this capstone project.

Literature Review and Scope of Evidence

The first study by Lloyd-Williams, Kennedy, Sixsmith and Sixsmith (2007), found that although concerns relating to EOL care are a chief source of apprehension for older people, these issues are rarely talked about by the persons, their families or the professional persons involved in their care. Six areas were addressed with the participants, relating to EOL: ‘fears related to EOL, the inevitability of death, thoughts and wishes related to EOL, preparations for EOL, euthanasia or assisted dying, and thoughts regarding an afterlife’ (p.62). Interviews by Lloyd-Williams, et al (2007) found many of the fears expressed relate to the quality of life near the EOL, fear of being a burden to family, not being able to stay at their own home and suffering or undignified death. This study is applicable to the DNP project proposal by validating observations for the need for EOL care education for the community members who are patients and families dealing with life-limiting illnesses.

The second study identified reasons why eligible patients do not choose the hospice benefit, and points out some strategies for dialogue regarding hospice education. This study confirms observations in practice and gives authenticity to the goal of developing an educational offering for the community. Vig, Starks, Taylor, Hopley and Fryer-Edwards (2010) interviewed patients and/or family members as well as hospice staff in their study to understand cause and consequence during the admittance discussions for hospice care. According to Vig, et al (2010) found that the initial presentation of hospice could impact whether patients enrolled, and that those presentations by hospice staff during the information visits and the admission visits were varied and confusing for the patients and families.

This finding confirms personal practice observations regarding need for clarification and education for the community regarding palliative care and hospice benefits, philosophies and

admission criteria in different organizations. In the DNP student investigator's experience, patients and families hear and retain only a small amount of the information offered by admission nurses because they are in crisis and unable to process the overwhelming amount of unfamiliar information. For this reason, hospice staff routinely review conversations and answer questions throughout the hospice stay. If some of this dialogue could occur prior to the crisis, perhaps in an environment in the home or community patient choices for EOL care may be easier and more dignified.

According to research by Jackson et al. (2012), listening firsthand to experiences of patients and family surrounding EOL care is important long before the decisions need to be made, as it provides insight regarding their perceptions and gives them opportunity to reflect on the dying process. Jackson, et al, (2012) also found families and patients reported that having conversations with EOL health care teams helped them to anticipate potential situations as they prepare for the dying process, and that knowledge was helpful in dealing with the associated emotional changes. Families and patients also conveyed that physical comfort during end of life "affected what they perceived as the quality of death" (Jackson, et al, 2012, p. 307), reporting feelings of ease when they knew their loved ones were also calm, content and comfortable.

Norlander and McSteen (2000) posit that hospice nurses are exceptionally situated to assist in EOL care discussions with patients and families, and can facilitate dialogue to instruct the patient and family about benefits, options and choices to be made before a family member becomes too debilitated to participate and prior to crisis situations. Although these are some of the more challenging conversations, "patients and families prefer that these discussions take place outside of an acute care setting before a crisis occurs" (Norlander and McSteen, 2000, p. 534). The authors also found during their interviews that patients acknowledged existing

misconceptions and unfounded fears regarding EOL care options and care planning, which are easily allayed by providing current information for an informed decision. Miles, Koepp & Weber (as cited in Norlander & McSteen, 2000) state “the actual process of discussing EOL issues stimulates therapeutic conversations between patients and healthcare professionals and leaves patients and families with an increased sense of feeling cared for and understood”(p. 538).

A study by Rickerson, Harrold, Kapo, Carroll and Casarett (2005) found that families and patients who sign into hospice with a short stay prior to EOL do not receive as much benefit as those with longer lengths of stay. Dussen, Culler and Cagle (2011) find that even with many hospice programs available, persons who qualify often do not take advantage of the benefits for many reasons. Some of these reasons include lack of knowledge about hospice or choosing to pursue treatments in the face of life-threatening illness, instead of giving up hope for finding a cure or prolonging life as long as possible. Dussen, et al, (2011) believe their study indicates a need to inform the public regarding hospice. The complete Systematic Review of the Literature (SROL) tables are included in the appendices.

Project Plan and Evaluation

The project plan and evaluation covers the market and risk analyses which are the strengths, weaknesses, opportunities and threats (SWOT), as well as the driving and restraining forces. Also included are the needs assessment, resources and sustainability, feasibility, risks and unintended consequences for the project. The stakeholders and project team are introduced, and the mission vision and goals are stated with the process and outcomes objectives and logic model. In addition, the population and sampling parameters, setting and Evidence Based Practice (EBP) design and methodology and measurement are provided. The protection of human rights

component was completed and included in the appendices. Finally, the instrumentation, intended statistics and data collection procedure are discussed.

Market/Risk Analyses

SWOT Analysis Table

<p>Strengths (internal)</p> <p>Small circle to promote trust</p> <p>Undivided attention</p> <p>DNP student is content expert</p>	<p>Weaknesses (internal)</p> <p>Fear of acknowledgement</p> <p>Preconceived ideas</p> <p>Participant reluctance to engage</p>
<p>Opportunities (external)</p> <p>Interprofessional Collaboration</p> <p>Community Partnerships</p> <p>Collective knowledge</p>	<p>Threats (external)</p> <p>Societal Norms</p> <p>Social Taboos</p> <p>Hospice Marketing strategies</p>

Strengths of the project and planned intervention include the use of a small group for discussion in a round table or chairs style, informal and simple, to promote trust and undivided attention for the questions and concerns of the participants. The DNP student facilitating the educational intervention spent the last 30 years in practice in the nursing profession attending patients and families through the dying process in the Emergency Department, Critical Care and Home Hospice. This provides the background in experience and knowledge required for successfully conveying knowledge to the community.

One of the weaknesses of the project and the planned intervention is the fear of the participants to acknowledge the inevitability of dying. Often persons have preconceived ideas about End of Life care which mean ‘giving up’ or ‘assisted death’. Another weakness is the

participant reluctance to engage in conversations about their mortality or their loved one's mortality prior to, or even during a crisis situation. It is possible that some participants will need more time to get comfortable and engage in the discussion and the facilitator will take this into consideration with an ongoing needs assessment during the educational intervention.

An opportunity exists for the DNP student to enter into interprofessional collaborative relationships and community partnerships to draw on the collective knowledge and experience of a support team. Development of a collaborative team is paramount to the success of the project. Another opportunity is for development of the project into a second educational offering such as advanced care planning for patients and families. Potential threats to the success of the educational intervention are societal norms and social taboos. For example, the mention of physician reimbursement for advanced care planning discussions in the Affordable Care Act was publicized as something that would result in 'death panels' and ration health care in the United States (Giovanni, 2012). Other Hospice marketing strategies, such as promising to provide care that cannot be delivered under the hospice/palliative care Medicare benefit, are potential external threats to the project intervention.

Driving and Restraining Forces

Driving and Restraining Forces for the project are modeled after Lewin's Theory of Planned Change (Shirey, 2013) where a Force Field Analysis specifies movement toward a goal. Lewin suggested that behavior is a function of a group environment and the forces driving that behavior, relating to the elements of unfreezing, transitioning, and refreezing (Shirey, 2013). In relation to this project those elements are engaging, teaching and sustaining. Success of the project depends on reinforcing the driving forces and weakening the restraining forces.

A driving force for the educational intervention can be expressed by Sanford's theory of Caring through relation and dialogue: a nursing perspective on patient education, relates to the PICO statement by giving articulation and authority to education of patients and families as a central focus for nursing, with an expected outcome for a well-informed population. Sanford (2000) believes since patient education is incorporated into professional standards for practice, nursing must articulate philosophic and theoretical perspective for this critical aspect of nursing care' (p.2). Sanford (2000) uses parts of Henderson's philosophy of nursing in discussing a philosophy of patient education; 'knowledge is a factor that empowers all parties to engage as equals in discussions and decisions about health and health care choices' (p. 4). Sanford (2000), points out that teachers (nurses) are not the only one who teaches, but also are taught when in dialogue with students (patients/families), who in turn while being taught also teach (p.6). This philosophy of tolerance, acceptance and humility provides a solid setting in order for each participant in the dialogue to consider what and how to teach and learn and is congruent with other theories in consideration as foundations for the DNP project.

A restraining force for the educational intervention is the reluctance for change or transition. Nurses tend to be the caregivers of persons undergoing transition, prepare persons for impending transitions, and facilitate the learning processes related to the transitions according to Meleis, Sawyer, Im, Messias, & Schumacher (2000), in their Experiencing Transitions theory. In order to pass on the knowledge surrounding transitions, the nurse educator must keep in mind each path of transition and the processes involved varies depending on diverse conditions and levels of personal understanding and acceptance.

According to Meleis et al. (2000), the need to feel and stay connected, specifically to health care professionals who can answer questions, facilitates a comfortable transition (p.24).

Much of the care, comfort and education work of nurses revolves around transitioning persons whose lives are disrupted leaving them vulnerable to suffering and teaching others who are involved in the transitions. Specifically, Hospice nurses enter relationships with persons in the midst of multiple transition crises who are in varying stages of perceptions and emotions, and tentative levels of understanding and comfort. Meleis et al. (2000) describe a critical point or event associated with most transitions, and during a period of uncertainty, a number of critical points depending on the nature of the transition (p. 21). Each person enters and experiences both the transition and critical events differently, with particular vulnerabilities and evolving complexities of care and comfort. The DNP student facilitator comes into and cultivates the connection of continuously knowing both persons in transition and persons learning about transitions, with a full awareness of the vulnerability surrounding the persons in those moments of interaction.

Needs, Resources and Sustainability

The assessment framework/model chosen for this project is from the University of Kansas Community Toolbox (KUCT) for Assessing Community needs and resources (2010). This model was chosen as it closely follows and resembles the nursing process for patient assessment. The model begins with a needs assessment for the population in order to understand and successfully distinguish the requirements and to aptly and effectively intervene. During the initial assessment stage, the KUCT model recommends preparing a community profile from interviews and meeting sessions to find out what the population considers most important for their needs, and what the existing resources are to effect the desired change.

After the profile, an outline is prepared with five specific descriptions of the population, including context and history, issues that matter most, key stakeholders, priorities, and barriers

and resources to provide guidance for this project. The KUCT model provides a framework for evaluation of the chosen population through the lens of epidemiology and it is the hope of the consultant that this excursion into epidemiology will open understanding for how educational intervention can decrease health disparities among the population community of Palliative Care and Hospice patients.

The DNP student facilitator planned for approximately 50 participants, allowing for a potential for twice that many, not knowing how many persons in the community would actually come for the interventions. The hope is for sustainability and requests to return to the venue for future educational discussions which will attract and retain community participants. The potential growth for the intervention unlimited, since all persons will eventually age and enter a dying process, sometimes sooner due to terminal illnesses. The DNP student anticipates that interest in the intervention may follow cyclical or seasonal trends, since persons with chronic illnesses sometimes tend to exacerbate during holidays or days of remembrance which result in additional stress. Some patients with chronic illness cycle into the hospital every few months for a ‘tune-up’ if they have mixed up or neglected their medication regimens. The goal of education regarding Palliative Care and Hospice is to recommend support for these persons so the cycles become less frequent and the persons can live out their lives in relative comfort.

Stakeholders and Project Team

The key players and stakeholders for the educational intervention are the patients, their families and care providers. These persons make up the social structures and major factors in our society that impact the Palliative Care and Hospice population since they are most closely connected in the end of life processes. Community Forums such as faith community meetings or adult community services are ways to involve caregivers and loved ones, and often the patients

themselves. In this way, members of the community can share opinions regarding needs, access to services, questions and general interaction regarding Palliative Care and Hospice concerns. A specific focused Hospice discussion can yield data to support community needs, understanding and perspective.

In order to be successful, the members of the community that the consultant views as excellent resources and sources for collaboration and community partnerships are the patients and family members who will be attending the educational discussions. The participants play a collaborative role in the relationships which will unfold during the educational discussions. The consultant will be attentive to the needs expressed by the patients and family members and be receptive to the gifts of knowledge and life experience each person brings to the discussion.

The project team includes a group of clinical content experts to provide validity and authority for the proposed intervention as well as the evaluation process. These persons include a clinical mentor who is a RN Palliative Care and Hospice Nurse Liaison, two Nurse Practitioners (NPs) for Hospice Inpatient Unit and Palliative Care at Home, three Hospice RN colleagues with a combined experience of 45 years in Hospice Case Management, a social worker, bereavement coordinator and chaplain. The Clinical Mentor is an expert in Palliative Care and Hospice, with a Master's Degree in Divinity to provide direction for the needs assessment and intervention as well as evaluation questions.

The two NPs are care provider experts for Hospice and Palliative Care both inpatient and Home programs and are expert symptom management providers. Three Hospice RN Colleagues are chosen as they are case management experts and symptom management experts and will provide feedback on validity of intervention content and evaluation process. A Palliative Care and Hospice social worker will provide insight on target population and needs assessment and

the Hospice Bereavement coordinator will provide insight on content of intervention and needs assessment. The Chaplain provides insight on spiritual aspects of intervention content and target population needs assessment.

Cost-Benefit Analysis

The cost benefit analysis shows why this project is sustainable to organizations and agencies that provide Palliative Care and Hospice. The cost for sustainability is minimal, since the organizations and agencies already employ experienced hospice RNs that can provide community education regarding Palliative Care and Hospice. Benefits to a Hospice organization is increased enrollment in Palliative Care and Hospice Programs, which means increased revenue.

If this study were to be reproduced, in terms of cost for the researcher, his/her time would likely be not paid, more of an In-kind donation, unless the project was completed as a work related study. About three hours of preparation and presentation time would be required, and with an estimate of \$50 per hour comes to a total of \$150. Printing surveys and the participant information sheets and purchasing pencils for the participants cost \$20, and fuel was a consideration since the travel distance between venues was substantial, resulting in a total of \$100 fuel expenditure for initial and subsequent meetings. For replication of this study, the cost of hiring a statistician for the statistical analysis is included in the budget at an estimated cost of \$200. The total cost would be approximately \$470 for reproduction of a similar study.

The expected benefits for the participants are increased scope of knowledge surrounding end of life care options, including program philosophies and services, team members and patient role, payment sources and benefits, eligibility and referral processes. The overall benefit is for

participants to gain confidence to make an informed decision regarding Palliative Care or Hospice for themselves or for a family member.

Mission and Vision

The vision for the project is to provide education and support to community populations interested in learning about end of life options, by listening, discussing, and understanding individual and group needs. The mission of the DNP project is to serve communities by providing education to patients and families for the end of life journey, through participant centered group education and discussion, focused on expanding knowledge and understanding of options and benefits for end of life care. The DNP student facilitator will endeavor to communicate the vision and mission to colleagues and customers by exemplifying effective listening and consideration for the uniqueness of each situation and each relationship in the project activities, and verbally and visually communicate the vision and mission for the participants at the beginning of the educational discussions.

Ethical values of the DNP student that drive the vision are compassion, reverence, accountability and an obligation to improve health care for the population. In their code of ethics, the American Nurses Association (ANA) (2001) sets forth a framework of nine ethical standards, including respect for the inherent dignity of individuals, duty to foster and preserve individuals' self-worth and responsibility to advocate for patients. The ethical values that inform the project vision and mission align with this code of ethics and express the expectation for the intervention provided by the DNP student.

Glasper (2012) refers to nursing as a 'coveted' image, where persons have physical, emotional and spiritual safety when cared for by a nurse. Bularzik, Tullai-Mcguinness, & Sieloff, (2013) believe that nurses must practice in an atmosphere of autonomy where they can realize

their goals, maintain their ethical values, and exercise professional judgment when caring for their patients, and links these actions directly to improvement in patient outcomes.

Davidson and Williams (2009) describe compassion as fundamental to nursing, and a most precious asset and strength for the profession. These ethical values embrace the personal and professional obligation to improve health care to persons for which the DNP is in service.

Goals

As stated in the background information under the Problem Statement, the goal for this project is to establish trust and promote a comfortable situation for EOL care dialogue resulting in participants understanding the process and the benefits of accepting Palliative Care and Hospice, and a venue to ask questions about the options. The DNP student facilitator will do this by developing an educational offering for the community and locating an acceptable location to hold the discussions.

Short term goals are participants report increased understanding and awareness of the options and benefits of Palliative Care and Hospice and participants express increased ability to make fully informed decisions regarding EOL care. Another short term goal is for participants to recognize the as a resource for End of Life care discussions. A long term goal is for patients and families to enroll in Palliative Care and Hospice sooner rather than later in the course of a life limiting illness or the dying process. Another long term goal is for patients to receive comfort care earlier in their illness and dying process and thus experience easier transitions after enrollment with Palliative Care or Hospice.

Project Process Objectives

1. Design a one hour educational intervention for offering to patient and families experiencing End of Life transitions.

2. Disseminate accurate and current information regarding options and benefits of Palliative Care and Hospice.
3. Assume a leader, educator and facilitator role for the intervention to enable meaningful dialogue between participants.
4. Integrate an ongoing needs assessment during the intervention, with a question and answer session incorporated into the educational offering.
5. Determine whether an educational intervention has significant effect on participants at the end of the discussion.

Outcomes Objectives

1. Participants report increased understanding of End of Life care benefits related to Palliative Care and Hospice options for care
2. Participants express increased ability to make fully informed decisions regarding EOL care.
3. Participants distinguish the difference between Palliative Care and Hospice
4. Participants recognize eligibility and payment options for Palliative Care and Hospice

Logic Model

The conceptual model for this study design is a logic model explained by the narrative description below and illustrated in the appendices. The Logic Model Program Plan and Implementation charts are derived from Kellogg (2001) and depict the planning and implementation of a program to educate community participants regarding Palliative Care and Hospice options and benefits for EOL care. Included in the narrative description are details of the advanced practice nursing outcome measures addressed in the project.

Earp and Ennett (1991) characterize a concept as empirically observed or measured, and a conceptual model as a diagram of the anticipated associations among a collection of related concepts thought to be connected to a specific public health related concern. According to Earp and Ennett (1991) the importance of a conceptual model partly lies in its allowance for “inclusion of processes or characteristics not grounded in formal theory, but that represent empirical findings or the experience of practicing professionals” (p. 164). This logic model addresses a gap in community knowledge regarding Palliative Care and Hospice EOL care options and benefits recognized in practice of home hospice nursing.

The sections of the model are Resources, Activities, Potential Outputs, Anticipated short and long term Outcomes and Ultimate Impact (Zaccagnini & White, 2011). Donatti, Wild & Hareendran (2007) recommend interviews with participants to gather material to identify relationships between variables and to do so early in a project to “facilitate development of measurement strategies” (p.3) for outcomes evaluations. Relevant inputs in the resource section, lists a needs assessment and surveys of the participants in order to document a beginning point of reference to compare to the endpoint evaluations. Zaccagnini & White (2011) associate resources with the relevant inputs, so included in this section are handouts, pencils, facility scheduling and preparation of the presentation. Goals for this section include an investigation of the audience requirement for education and to recognize the portions of the presentation that need to be addressed for this particular audience.

Planned activities during the intervention include story gathering from the participants, presentation of the educational offering and a question and answer session following the presentation to facilitate trust and engagement in the activity. The planned activities of the development model and the influential factors and potential constraints of the program planning

model coincide since the activities are directly impacted by the influential factors listed in box number four of the program plan. According to Donatti, et al (2007), “seeking input from patients and clinicians helps to ensure the content validity” (p.7) of a conceptual model. Story gathering is an activity that allows the participants to engage in the educational offering and to learn by sharing their experiences.

The potential benefits and the advanced practice nursing outcomes to be measured by the project are a widened knowledge base and increased understanding of persons in the community regarding Hospice and Palliative Care options and benefits through dissemination of current and accurate information. This outcome will be measured by a survey of the community participants prior to and after the educational presentation, and address questions regarding presumptions, prior experience or knowledge of hospice and palliative care benefits and options. Three other expected outcomes beyond the scope of outcomes evaluations for this project, but are included in the Logic model in Anticipated Long term Outcomes and Impact for the community. They are patient and family experience easier transitions after enrollment with Palliative Care and Hospice, enrollment in Hospice or Palliative care sooner rather than later in the course of a life limiting illness or crisis and finally, patient and families experience easier transitions after enrollment with Hospice or Palliative Care.

Clarke (2011) believes “healthcare utilization is a nurse-sensitive outcome”(p.477), and as such recommends “nurses and nursing to offer partial answers to dilemmas of optimizing access and quality while containing costs in health systems”. To this end, this DNP project offers a community education opportunity, reaching out specifically to local community members and venues, in an effort to optimize access and decrease costs during EOL journeys for patients and their families.

Population and Sampling Parameters

Calculation of sample size and recruitment of participants

The target population for the educational intervention is patients and family members dealing with life-limiting illnesses. A representative sample of the community population will be obtained by purposive sampling, a type of non-random sampling (Terry, 2012) where the characteristics of the population of interest are identified, specifically those individuals interested in learning about Palliative Care and Hospice. This was accomplished by scheduling an educational offering regarding Palliative Care and Hospice in a venue of community churches, libraries, community centers and fire stations. A DNP project may be carried out in partnership with a community organization or church (Zaccagnini and White, 2011). This intervention will explain the options Palliative Care and Hospice, describe the benefits for each and provide guidance for EOL care for community members interested in learning more about Palliative Care and Hospice options. In addition the education can be replicated for other venues as set forth by Zaccagnini and White (2011).

Rationale for this sampling strategy and the chosen venue follows Terry's (2011) recommendation to recruit participants for sample from organizations or groups of persons who may be anticipative of the content. Interested individuals who choose to attend provide homogeneity of the sample populations through voluntary participation. Terry (2011) defines the homogeneity aspect of a sample as the degree in which the participants in a study resemble each other related to the features being observed or studied.

Participants will take part in an educational discussion surrounding end of life care options, specifically Palliative Care and Hospice benefits. According to Terry (2011), conducting a pre/post assessment of each subject in a group during a single encounter will achieve 'power'

equivalent to multiple assessments over time, but more subjects are needed thus a sample size of approximately 50 persons is chosen, with a goal of ten persons for each discussion group.

Another reason for single assessment of the population of interest is follow up is lost once the session is over. According to the Central Limit Theorem (Cullen, 2012) the bigger the sample, the less the standard error expected, thus a projected sample size of 50 persons may yield more interested persons than a smaller sample. The participants will serve as their own control by using a pre and post evaluation method.

Setting

The settings of the educational interventions were at a community library, fire station and church venues where a physical place to meet was available and free for the community. The opportunity was open to any participants interested in learning more about the EOL journey, specifically the population who is experiencing transitions to EOL situations, either themselves or their family or friends. The educational discussion was about one hour in length with time set aside for stories and questions to facilitate openness and trust among the participants and DNP student facilitator. The intention of the intervention is to provide education regarding Palliative Care and Hospice benefits and options and widen the scope of knowledge for those persons facing EOL decisions.

Methodology and Measurement

The methodology discussion for this DNP project includes an explanation of how the practice concern translates into the identified primary outcome measures as well as classification and description of the independent, dependent and extraneous variables. In addition, a chosen study design is articulated with associated reliability and validity, and rationale for determining sample population and size is presented. Finally, rationale is provided justifying determination of

population sample and sample size, recruitment of participants and responsibilities related to human subjects protections.

Primary outcomes for palliative care and hospice education in the community

The practice concern under consideration is lack of knowledge and understanding in the community regarding EOL care benefits, specifically Palliative Care and Hospice options. The primary identified outcome for the proposed project is for participants to have increased awareness and a broader knowledge base regarding Palliative Care and Hospice benefits in order to make fully informed decisions regarding EOL care. This outcome will be measured by pre and post surveys completed by the participants and an open inquiry and answer discussion following the educational offering.

According to Donatti, Wild & Hareendran (2007), content validity is confirmed by pursuing involvement from participants when developing a measurement strategy. By drawing on existing understanding and information learned in the course of the educational intervention, the facilitator and the participants connect in conversations toward the expected outcome. Keeping in mind that in order to be evaluated, outcomes must be specific and measurable; offering question and answer sessions during the educational sessions has value in terms of stories and anecdotal examples shared by the participants. In this way, the facilitator will recognize whether needs have been met as the participants acquire knowledge regarding diverse methodologies to EOL care discussions with their families who are facing the end of life journey.

Identification and explanation of variables

Independent, dependent and extraneous variables all influence each other to affect the proposed outcome of an intervention (Christenbery, 2011). The independent variable for this proposed project is the educational intervention for the community and the dependent variable is

the expected outcome. According to Christenbery (2011), extraneous variables interfere with the relationship between the independent variable and the dependent variable, or the associated outcomes. Extraneous variables which may influence both the independent and dependent variable for this project are preconceptions or expectations regarding Palliative Care and Hospice which influence the attitudes and comfort levels of persons when discussing EOL care. Participants may be hesitant to talk about death and dying. According to Gardner (2012) persons in our society avoid conversations about death and dying and states even though these conversations are complex, they are critical and must be timely to make certain care for chronically ill and dying patients is offered.

Study design

The study design for this DNP project is a quasi-experimental quantitative study with an educational intervention with pre and post-test assessment questions for the participants. Polit (2009) describes quantitative data as containing numerical information which, when ‘organized, synthesized, and interpreted’ (p.3) through data analysis, may answer a research question. This study is a quantitative study, in the quasi-experimental category, with a pre-test-post-test design. Although the pre-test-post-test design has inherent weakness due to lack of randomization and control group (Terry, 2011), this design can be used by the DNP researchers to evaluate the impact of an intervention, as it provides a practical method of assessment.

The focus of the project was implementation of an educational process and how the participants interpret the experience and the DNP student was the primary instrument for data collection and analysis. Burns and Grove (2009) describe one type of quasi-experimental research, which serves the purpose of testing the effectiveness of nursing interventions by a combination of identifying and examining the significance of causal relationships and clarifying

why certain events happened. Quasi-experimental design was chosen for this project since the variables for the intervention are beyond manipulation and the participants are a convenience sample.

During development of the connection and relationships between the facilitator and the participants, the DNP student facilitating the discussion gives diligence to observing and listening to both verbal and non-verbal responses from the participants in order to guide the discussion toward expected outcomes. The study measure was categorized as condition-specific, in the sense that the goal is to consider each participant's requisite needs and expectations for the educational sessions and to measure that need prior to and after the intervention.

Instrumentation Reliability and Validity and Intended Statistics

This was a quasi-experimental design and used an existing measurement tool to quantify responses. A tool representative of the data gathering was the common Likert scale measurement tool which measured participants' responses to seven survey questions, on a one to five scale and is included in the appendices of this proposal. The response options are not at all, somewhat, enough, good and great, with five representing good and one being not at all, to survey questions regarding knowledge about understanding Palliative Care and Hospice options, benefits and enrollment. This Likert scale was chosen to assist in a quantitative measurement of measuring the amount of the participants' perception of knowledge gained from the intervention. The intervention content and the survey questions were posed to a group of nine Hospice or Palliative Care nurses who are experts in their field in order to establish content validity.

Potential threats to validity and reliability for the project include missing data, sampling error, and measurement error (Lange and Jacox, 1993). Missing data was one question on the pre intervention survey that was not answered. Sampling errors for this project could be that the

sample selection may not be considered random since the intervention content attracted a sample population with potential bias regarding the intervention. Each person will bring with them preconceptions regarding Palliative Care and Hospice, perhaps increasing the potential for imbalanced dissemination of extraneous variables. This is addressed by combining the intervention groups and the comparison groups as one group, with a pre and post intervention measurement of response.

Measurement errors can be minimized by assuring that the indicators for measurement fit the study design (Lange and Jacox, 1993). For example, the independent variable may change slightly depending on an ongoing needs assessment by the investigator, during the intervention. Thus the content of the intervention may change depending on the audience, but not significantly. This change is minimized by presenting and adhering to the objectives for the session, with a summarized review after the question and answer session. Polit (2010) refers to reliability of a measurement being dependent partially on how the person completing the scale ‘misinterprets the questions’ or ‘misrepresents their opinions’ (p. 354), and believes a measurement scale with more items is representative of the concepts being measured. This intervention and measurement uses both a smaller scale and a smaller sample, yet creates an opportunity for future studies, of similar sample populations.

A potential threat to external validity, or generalization of findings to a larger population (Cullen, 2012) for this study, may be selection effect. It could be argued for example, that the reason for success is the study subjects enrolled with the goal of learning about Palliative Care and Hospice, therefore the findings cannot be inferred to the general population. The investigator will address this potential threat by keeping the content of the intervention straightforward and

clear, with the objectives presented and the discussion level conducted with transferability and replicability in mind.

Data Collection and Treatment procedure/protocol

The educational intervention and ensuing discussion with the pre and post evaluation was about 1 hour long. On arrival each participant received a packet with the participant information sheet and the survey tool. The intervention began with introductions in which participants were invited to share prior experience with hospice and Palliative Care and what brings them to the educational offering. Participants were invited to review the participant information sheet and the DNP student facilitator read it out loud and explained each section.

Next a thorough explanation of the survey tool was provided. Each participant had two identical surveys in their packet which were stapled together. One was labeled before and one labeled after. Prior to the actual educational intervention, participants were given time to fill out the survey labeled before and instructed to keep the surveys stapled together, not to put their names or any identifying information on the survey, and reminded that participation is completely voluntary. After the one hour educational intervention and ensuing discussion and question answering session, participants were given time to fill out the after survey, and reminded again that filling out the survey is completely voluntary.

Protection of Human Subjects

DNP student responsibilities related to human subjects' protections for this project include awareness of ethical principles and established federal guidelines associated with human rights. Although the sampling process employed for the study was purposeful with a specific population sample in mind, participation in the education intervention was voluntary, addressing the ethical principle of autonomy. Terry (2011) defines autonomy as 'the right to make an

informed decision about whether to participate in a research study' (p.52). Prior to the educational intervention participants were informed of minimal to no risk related to the content of the discussion or answering the pre and post assessments related to end of life care knowledge. Benefits of the discussion were also presented as well as stressing that each individual has the freedom to choose whether the educational sessions are of interest and whether they will participate in the discussion and the survey.

This leads to the next ethical principle of beneficence, or protection from harm. During the educational intervention, the DNP student guided the discussions with attentiveness to participant reactions, promoting expressive responses and respect for the individuality of persons in the group. Cullen (2012) describes the ethical principle of respect for persons as the interrelatedness, interconnectedness, equality and uniqueness of all people. Although this study is considered very minimally invasive, the obligation remains to avoid unintentional harm as set forth in the principle of non-maleficence (Cullen, 2012). Keeping in mind the duties of veracity and fidelity, the facilitator will be honest, trustworthy and straightforward in communication. Justice, according to Terry (2011) and Cullen (2012) directs the behavior of the DNP student facilitator to ensure participants are recruited and treated fairly in education or resource allocation with disregard to socioeconomic status, gender, ethnicity or religious faith. The venues and educational intervention to provide guidance and clarity for end of life care are open to any and all interested persons.

Federal guidelines impacting the study include informed consent, self-determination, human rights and vulnerable populations (Cullen, 2012). Written consent is not necessary for the pre and post assessment survey during the study according to Terry (2011), who states the 'Code of Federal Regulations does not require written consent for surveys unless the information that is

collected is recorded in a manner that allows participants to be identified' (p.54). Data collected in the pre and post assessments was anonymous with no associated identification for persons and will be used merely for needs assessment and outcomes measurements of individuals in the group. The worldwide agreement set forth in the Nuremberg Code (Cullen, 2012) mandates the DNP student facilitator will advise the participants that participation is optional, right to self-determination, and that any time during the discussion, their right to leave is preserved without prejudice or judgment. In addition, the participants will be reminded of their right to privacy, anonymity and confidentiality. The study is not directed to vulnerable populations as defined by Cullen (2012) to include very old, disabled or institutionalized persons or pregnant women. The volunteer participants in the study population did not comprise any minor children or institutionalized persons.

This study achieved exempt from review status from the Regis University Institutional Review Board (IRB). Since the study and project was an educational intervention it is considered to be a program initiative, the risks are less than minimal and survey data is de-identified and anonymous. In summary, the DNP student facilitating the educational intervention will strictly adhere to the nursing discipline code of ethics and ethical principles as well as established federal guidelines surrounding participant involvement in the study.

Project Findings and Results

The project findings and results are presented as they relate to the project process objectives and outcomes objectives which are included again below for reference. The objectives were not linked to benchmarks for a similar intervention since no benchmarks were located in the literature.

Project Process Objectives

1. Design a one hour educational intervention for offering to patient and families experiencing End of Life transitions.
2. Disseminate accurate and current information regarding options and benefits of Palliative Care and Hospice.
3. Assume a leader, educator and facilitator role for the intervention to enable meaningful dialogue between participants.
4. Integrate an ongoing needs assessment during the intervention, with a question and answer session incorporated into the educational offering.
5. Determine whether an educational intervention has significant effect on participants at the end of the discussion.

Outcomes Objectives

1. Participants report increased understanding of End of Life care benefits related to Palliative Care and Hospice options for care
2. Participants express increased ability to make fully informed decisions regarding EOL care.
3. Participants distinguish the difference between Palliative Care and Hospice
4. Participants recognize eligibility and payment options for Palliative Care and Hospice
5. Participants had enthusiastic response and engagement in discussion. (addition to original objectives)

After completion of the intervention and running the statistics, a fifth outcomes objective was added, which is not captured or conveyed in the data, nevertheless definitely worth mentioning, in order to convey the essence of the atmosphere of interventions, and share the actual experience with the community participants. There was an overwhelming sense of interest and

eagerness from the community participants. A couple of the sessions went past an hour and several persons stayed over to talk about personal experiences and ask specific questions. One elderly gentleman even returned for a second session that was scheduled in the same community, at a different location. The participants expressed willingness to discuss the content and relate individual stories, showing their comfort level and understanding of a Palliative Care and Hospice discussion. The participants expressed gratitude for *free* education, they said, and also expressed interest in more offerings of the same nature, for example planning ahead of time for end of life care decisions. This study is meaningful in that the DNP student felt it would likely make a difference, but did not realize how much of a difference until performing the actual intervention and the ensuing data analysis. The table on the following page is a sample part of the intervention as it relates to the objectives. This was a handout and was also drawn on a white board during the intervention. The objectives relate to the questions in the left column.

	Palliative Care	Hospice
Who is eligible for care?	Anyone with a serious, life-limiting illness, who needs symptom management	Hospice diagnosis, with six months or less best guess, two physicians conferring
Who pays for care?	Medicare or private insurance depending on benefits and treatment plan	Medicare or private insurance depending on benefits and treatment plan
Care Team	Physician, Nurse Practitioner, Social Worker	Physician, Registered Nurse, Social Worker, Certified Nurse Aid, Chaplain, Volunteer, Pharmacist, Bereavement
Resources and Benefits	Education, Social worker assistance, medication management	Education, Social worker assistance, medication management, medical equipment and supplies, medication related to diagnosis, Spiritual/emotional care. Bereavement support for one year

Where is care provided?	Wherever the patient calls home. In the hospital.	Wherever the patient calls home.
How to get enrolled? Who can ask for a referral?	Ask your physician for a referral. Anyone can ask.	Ask your physician for a referral. Anyone can ask.
Availability of care	Limited visits from Nurse Practitioner and Social worker, typically 1-2 times per month	Unlimited visits from care team. Five days of respite care every 60 days. Continuous crisis care.
Options for Care	May continue with curative treatment. Focus on symptom management, comfort, quality of life.	No longer seeking curative care. Focus on symptom management, comfort, quality of life.
Restrictions		Must meet eligibility criteria and have a measureable decline related to diagnosis. Reevaluated every 60 days.

Key elements and instrumentation of findings

The study is a quantitative analysis of seven pre and post survey questions from 41 participants who attended an educational intervention regarding palliative care and hospice. There is a pre education survey and a post education survey, each with the same seven questions, resulting in a total of 14 variables. The statistical tests used to analyze the data are the paired samples T-test and descriptive statistics frequency tables. These tests were chosen in order to generate the means for each variable, the correlation between pairs, the standard deviation and the p value for significance. According to Polit (2009) when the same subject or same group is tested at two points in time, “for example, before and after an intervention” (p. 121), and the selection of the second group of variables is constrained by the first group of variables, this situation is best suited for a paired samples T-test.

By doing the paired samples T-test, a comparison can be visualized between the means for each pre and post question and the correlations and significances can be assessed. The second test is a descriptive statistics test for frequencies, which shows each of the 14 variables individually in a frequency table and shows mean, standard deviation and variance for each in a statistics table. Approval for these two tests was obtained by course faculty and several other tests were run which did not produce any other significant results. Therefore, the paired samples T-test is the appropriate test for the data.

Statistical Package for the Social Sciences (SPSS), version 22 is the software package used for the data analysis. SPSS is the chosen software due to the ease of importing data, and the efficiency of running several statistical tests to see which yields the results that are to be reviewed. In addition, the SPSS software does not require the user to input formulas and provides a separate window for results from the tests, so the original data stays intact. There is a low risk for error, several different tests can be compared, and if an attempt is made to run something that will not work, it will not run and there will be no useful output.

The collected data is comprised of 41 documents, one document from each participant. Each document has two pages, a pre education survey, and a post education survey, which remained stapled together during the collection process, assuring the pre and post pair stayed together and intact. The following narrative describes the coding process. The documents were numbered 1-41. In a new SPSS data file, each document was given a participant number (1-41) which was entered in the first column of the Data View tab of the file. Under the Variable View tab, each of the seven pre education questions and each of the seven post education questions were listed under Name in the first column, using Pre 1.1 through Pre 1.7 and Post 1.1 through Post 1.7. The Type column for all variables is numeric, and ordinal is chosen for each variable

for the Measure column. Next, under the Data View tab the response (one through five) for each question was recorded under the participant number. The data entry is now complete and ready for analysis. Excel was not utilized for the data set up since SPSS provides a similar spreadsheet and after the data was coded, entry directly into the SPSS worksheet was more efficient.

Statistical Data and Reliability of Findings

The plan to bring meaning to the data included in this study began with consideration for statistical power, or the probability that the study will produce a statistically significant result. Polit (2010) defines power as the likelihood of ‘correctly rejecting the null hypothesis’ in a study (p.98), and a power analysis as the methods used to calculate sample size required to ‘minimize risk of a Type II error’. In this study, Type II error would be revelation from the data that there was no difference in understanding of the participants after the interventional discussion, or according to Cohen (1992) receiving a false null hypothesis.

Initial preparation for analyzing the outcomes data starts with consideration of the four components involved in power analysis. Polit (2010) recognizes significance criterion, or the alpha, desired power, population effect size and sample size as the variables in a power analysis, and states if three of the components are known or estimated, the fourth can be calculated. The DNP student reflected on the following questions; How sure do I want to be that the intervention will have the desired effect (acceptable power), what is the estimated percent of missing or incomplete data and assumptions regarding participant responses (effect size) in order to calculate desired sample size.

Cohen (1992) discusses the interrelationship between these variables, pointing out that each is a function of the other three. Therefore, when considering the parameters, the investigator weighs the chance of Type I versus Type II errors in order to project effect size and sample size.

When the relationship between the intervention and the outcome is strong, a smaller sample size is acceptable in order to produce a statistically significant effect (Cullen, 2012). In this study design, interval data provide strength for belief in the results. Since the smaller the sample size, the more actual improvement must be seen in order to call it effective at the same probability level a 95% acceptable power was chosen.

Test Results and Effect size

The first test results were obtained from SPSS by running an analysis to compare means in a paired samples T-test. The output yielded the three boxes shown in the following page, a chart of **Paired Samples Statistics** (first box), **Paired Samples Correlations** (second box), and **Paired Samples Test** (third box). In the paired samples statistics chart, the results specify the mean and standard deviation in the pre and post survey of each pair.

		Mean	N	Std. Deviation	Std. Error Mean
Pair 1	Pre1.1	2.2195	41	1.08426	.16933
	Post1.1	3.9756	41	.82121	.12825
Pair 2	Pre1.2	1.8049	41	1.00547	.15703
	Post1.2	3.8537	41	.79250	.12377
Pair 3	Pre1.3	2.1707	41	1.22275	.19096
	Post1.3	4.4390	41	.67264	.10505
Pair 4	Pre1.4	1.8537	41	1.08538	.16951
	Post1.4	4.0244	41	.93509	.14604
Pair 5	Pre1.5	2.1463	41	1.17390	.18333
	Post1.5	4.1951	41	.98029	.15310
Pair 6	Pre1.6	2.1463	41	1.27595	.19927
	Post1.6	4.1463	41	1.03829	.16215
Pair 7	Pre1.7	2.5250	40	1.13199	.17898
	Post1.7	4.1500	40	1.00128	.15832

The paired samples correlations chart below shows the significance and the correlation between the pre and post values of each pair.

Paired Samples Correlations

		N	Correlation	Sig.
Pair 1	Pre1.1 & Post1.1	41	.399	.010
Pair 2	Pre1.2 & Post1.2	41	.246	.122
Pair 3	Pre1.3 & Post1.3	41	.180	.260
Pair 4	Pre1.4 & Post1.4	41	.398	.010
Pair 5	Pre1.5 & Post1.5	41	.431	.005
Pair 6	Pre1.6 & Post1.6	41	.436	.004
Pair 7	Pre1.7 & Post1.7	40	.336	.034

The paired samples test chart below shows the difference in the means of the paired answers to each question, the standard deviation, the confidence interval, and the 2-tailed significance.

Paired Samples Test

		Paired Differences					t	df	Sig. (2-tailed)
		Mean	Std. Deviation	Std. Error Mean	95% Confidence Interval of the Difference				
					Lower	Upper			
Pair 1	Pre1.1 - Post1.1	-1.75610	1.06725	.16668	-2.09296	-1.41923	-10.536	40	.000
Pair 2	Pre1.2 - Post1.2	-2.04878	1.11694	.17444	-2.40133	-1.69623	-11.745	40	.000
Pair 3	Pre1.3 - Post1.3	-2.26829	1.28500	.20068	-2.67389	-1.86270	-11.303	40	.000
Pair 4	Pre1.4 - Post1.4	-2.17073	1.11585	.17427	-2.52294	-1.81853	-12.456	40	.000
Pair 5	Pre1.5 - Post1.5	-2.04878	1.16084	.18129	-2.41519	-1.68237	-11.301	40	.000
Pair 6	Pre1.6 - Post1.6	-2.00000	1.24499	.19443	-2.39297	-1.60703	-10.286	40	.000
Pair 7	Pre1.7 - Post1.7	-1.62500	1.23387	.19509	-2.01961	-1.23039	-8.329	39	.000

Finally, the Frequencies Statistics table (below) shows the mean for each of the pre and post survey questions, the standard deviation and the variance. The frequencies were run through the descriptive statistics option in SPSS and the output yields two headings, Frequencies and the Frequency tables. The first box is under the Frequencies heading and is labeled Statistics. The rest of the boxes (14 total) are under the Frequency tables heading and labeled Pre 1.1, and Post 1.1.... each of the questions are separated. This gives us each question individually so it is another way we can get information and analyze what is going on with that particular question. The Frequency tables for each question are included in the appendix. In the Statistics box, we can look at the mean for each question, Std. error of mean, Std. Deviation, Variance.

Frequencies

		Statistics													
		Pre1.1	Pre1.2	Pre1.3	Pre1.4	Pre1.5	Pre1.6	Pre1.7	Post1.1	Post1.2	Post1.3	Post1.4	Post1.5	Post1.6	Post1.7
N	Valid	41	41	41	41	41	41	40	41	41	41	41	41	41	41
	Missing	0	0	0	0	0	0	1	0	0	0	0	0	0	0
	Mean	2.2195	1.8049	2.1707	1.8537	2.1463	2.1463	2.5250	3.9756	3.8537	4.4390	4.0244	4.1951	4.1463	4.1707
	Std. Error of Mean	.16933	.15703	.19096	.16951	.18333	.19927	.17898	.12825	.12377	.10505	.14604	.15310	.16215	.15579
	Std. Deviation	1.08426	1.00547	1.22275	1.08538	1.17390	1.27595	1.13199	.82121	.79250	.67264	.93509	.98029	1.03829	.99756
	Variance	1.176	1.011	1.495	1.178	1.378	1.628	1.281	.674	.628	.452	.874	.961	1.078	.995
	Range	4.00	4.00	4.00	4.00	4.00	4.00	4.00	3.00	3.00	3.00	3.00	3.00	3.00	3.00
	Minimum	1.00	1.00	1.00	1.00	1.00	1.00	1.00	2.00	2.00	2.00	2.00	2.00	2.00	2.00
	Maximum	5.00	5.00	5.00	5.00	5.00	5.00	5.00	5.00	5.00	5.00	5.00	5.00	5.00	5.00

Effect size is described by Polit (2009) as a calculation of the magnitude of the strength of a relationship between variables and “can be viewed as an index of how wrong the null hypothesis is” (p. 126). The Paired Samples Correlations table above shows the significance values (p-value) and the correlation. The p-value significance level is preset at $<.05$ to show statistical significance in a relationship and the correlation coefficient ranges from -1 to +1, and the closer it is to zero, the weaker the relationship. To evaluate the effect size for each of the paired questions, first consider the significance, then the correlation. For Pair one, the significance is $p=.010$, which shows the relationship is statistically significant and did not happen by chance and the correlation is $.399$ which shows a strong relationship and the effect size is large enough to be meaningful.

Another way to show effect size is with Cohen’s d which is a popular standard where effect sizes of $.20$ are small, $.50$ are medium, and $.80$ are large (Thalheimer and Cook, 2002). For example, in question number one, the pair of pre and post answers show a mean difference of -1.756 . A calculated Spooled (Standard deviation pooled) is $.950$ so the Cohen’s $d = 1.848$, which is greater than $.80$ indicating a strong effect size.

SPSS provides a variety of different ways to analyze the same information, however, after looking at the data in several other ways, no further significant SPSS output was noted for this data. For this data, the paired samples t-test is the best choice to find out the answer to the

capstone question of whether provision of an educational discussion to demystify Palliative Care and Hospice options and benefits, compared to no community education, influence the participant report of increased understanding of Palliative Care and Hospice options and benefits.

Analysis of Test Results

In the second box, Paired Samples Correlations, the significance is the p value in the last column. The third box, Paired Samples Test, the 2-tailed significance in the last column are all .000, so next look at the correlation in the middle column in the second box, Paired Samples Correlations to compare the correlation and the significance. The closer to .000 in the p value, the higher is the correlation.

The question that is most closely correlated is question six with a p value of .004. This tells us that the education impacted question six the most. The next question impacted would be question five, with a p value of .005. Question five and question six are the most significant. Questions four and question one both have a p value of .010, which is also low but shows significance. Question seven is also low at .034. Questions two and three show a p value of .122 and .260 respectively which are higher than the standard value of .05.

Standard deviation and mean are the next items to assess in the comparison of means of paired samples T-tests. The Paired Sample Statistics chart indicates the mean of each pair. A close look at the means for the pre and the post in each pair shows the mean has changed, it has increased in value. The significance is also fairly low for all of the pairs except for pair three which is twice as high as pair two and considerably higher than the rest of the pairs. Consideration and comparison of each mean shows a significant increase in the mean. This increase indicates that the educational intervention has helped. Each pair shows that the intervention helped for that particular question. Some of the means have doubled, or even more.

Pair four, for example, the mean has gone from 1.8537 to 4.0244. This is a vast jump in the mean and where significance is noted. By doing this particular test, the Paired Samples T test, the means for each question can be compared.

Interpretation and Application of Test Results

The answer to the evidence-based practice question, ‘Is there any benefit to the intervention?’ is indisputably yes. The Paired Samples T-test provides the information needed about the data to determine if there was an effect. A comparison of the means for each pair (each question) shows that each question has been impacted by the education. The seven questions are listed in the appendix. As shown in the Paired Samples Statistics table, the mean for each question shows an increase in the post mean, after the education was given.

In the Paired Samples Test table the first column shows the difference in the pre and post means for each question. Question seven, for example, had a mean difference of -1.62500. This question asked the participant to consider whether they might ask for palliative care or hospice earlier rather than later. Since the goal of the education was to equip the participant with knowledge to make an educated choice regarding palliative care and hospice, the lower mean could be interpreted that although many of the participants thought perhaps they would seek palliative care and hospice earlier, several were still hesitant. Nonetheless, overall this question showed significant effect.

Another question with a lower mean difference than the other questions was question one, with a mean value of -1.75610. This question asked whether the participant was familiar with the palliative care and hospice options for patient care. The interpretation of this result could mean that even after the one hour educational intervention and discussion about palliative care and hospice, some questions remain among participants about these options for patient care.

Limitations, Recommendations, Implications for Change

Limitations

Limitations of this study are the sample size, selection effect, and restriction to boundaries of a geographic area within a 50 mile radius of a major urban area. The relatively small sample size of N=41 somewhat limits power and generalizability of the study. According to Polit (2010) risk of possibility for Type I errors (false positives) and Type II errors (false negatives) is increased when sample size is a smaller representative of a population. A second limitation to generalization of this study to a larger population is selection effect (Polit, 2010), where preexisting similarities/differences threaten validity between group comparisons. Since the participants chose to attend the educational intervention/discussion with specific learning objectives related palliative care and hospice, it could be contended that the findings are not transferable to the general population. Finally, the study was conducted in a relatively small geographical area, compared to the total population in the United States who may be or have family members or friends facing EOL transitions.

Recommendations

The findings of this study warrant further exploration into the needs in our communities for education and discussion about palliative care and hospice. In addition, the findings suggest a need to promote social awareness of the significant obstacles faced by families and patients when faced with a crisis situation, and how these obstacles can be addressed prior to the crisis by education and discussion about palliative care and hospice.

Another recommendation is for a study replication to include a qualitative response from participants, in which the participants' questions about palliative care and hospice are logged and analyzed for inclusion in a follow up educational intervention. An alternative strategy which may

be advantageous is to ask participants at the beginning of the educational intervention to write down questions they have, collect the questions and address each one during the course of the educational intervention. Finally, a question can be added to the survey asking whether the participant would attend more community educational offerings if they were available. This would provide data regarding sustainability for follow-up discussions and future educational offerings.

Implications for Change

Implications for practice change are grouped into-categories of contribution to nursing practice, including theory, research, advanced leadership education and health care policy. From a theoretical perspective and a research perspective, implications for practice change involve communication and follow through. According to Long (2011), ‘effective communication is essential for individuals to make informed decisions about their healthcare and life planning, and these skills are vitally important in palliative and end-of-life care practice’ (p. S136).

Communication between care providers and the patients and families they serve is often multidimensional and involves a process of listening and interpretation of verbal and nonverbal components of the exchange. Communication of education specifically requires skill on the part of the educator to recognize the learning level and participation readiness of the audience, particularly an audience who has self-enrolled in an educational discussion. Following the educational intervention with recurring offerings of similar content to reinforce the education and offer a chance for participants to return with more or different questions, may lead to a clearer understanding of palliative care and hospice options for patient care.

It is evident from the data that the educational intervention did improve the overall understanding about palliative care and hospice among the participants. This study shows a

considerable difference between pre and post educational intervention survey questions, and a lack of knowledge of knowledge of palliative care and hospice in the pre intervention survey. Since links to benchmarks for similar interventions could be found in current literature, this study can provide a foundational benchmark for a similar study. This study is a contribution to the nursing profession and advanced leadership education by showing that community education provided by a nurse leader significantly improved participant understanding of the intervention content.

In order for this type of education to be continued for the community and developed into a sustainable program of recurring educational offerings, health care policies on many levels, from department policies in smaller organizations to state and federal agencies, must be transformed to address the growing need for community awareness. Funding is needed for nurse leaders to set up community educational sessions and to provide venues and time for patients and family members to get current and accurate information and to ask questions regarding their particular individual circumstances regarding EOL care planning.

Summary

This project presents reasoning, background, influences and theoretical support for community education regarding the EOL options of palliative care and hospice. This project engaged community members in dialogue and established trust and comfort for open exchange, resulting in an outcome of deeper understanding for the EOL care needs experienced by patients and families and the options to address those needs. The DNP student used a strategic plan that articulated the processes and resources to manage and develop opportunities for education, according to the needs of the intended recipients and affect change toward decreasing health inequities in relation to palliative care and hospice.

Consistent and accurate information for populations as they navigate health systems, specifically EOL support and services, addresses disparities among community members with life-limiting illnesses who are facing EOL transitions. The project addressed the recognized need for community education surrounding the dying process and EOL care in our society. In order to make well informed decisions community members rely on current, accurate information regarding delivery and management of care. This project incorporated the vision, mission and values into the overall plan and objectives, to include the population of interested persons in local communities and provide information on living comfortably during EOL transitions with the benefits of palliative care and hospice.

With an awareness of and understanding for the intricacies of health services for the terminally ill and dying in the community, nurse leaders guide terminally ill patients and their families to recognize the benefits of palliative care and hospice and consider those options for EOL care sooner rather than later in the course of an illness. Evaluation of the current health care market, risk analysis, feasibility, stakeholders and unintended consequences provided background information for the process and the initial practice concern. Effective communication and collaborative relationships with community agencies and colleagues promoted the delivery of the educational intervention for the participants.

Data were analyzed from 41 participants' pre and post surveys, using the paired samples T-test and descriptive statistics frequencies tables and show a statistically significant increase in the pre and post survey question means of all seven questions in the survey. A look at the p values and the correlations showed a strong relationship and the effect size was large enough to be meaningful. Analysis of each question shows areas for improvement in the educational intervention as it relates to participant understanding and need for review of the educational

content. These findings provide insight regarding the need for community education and that community education has positive outcomes.

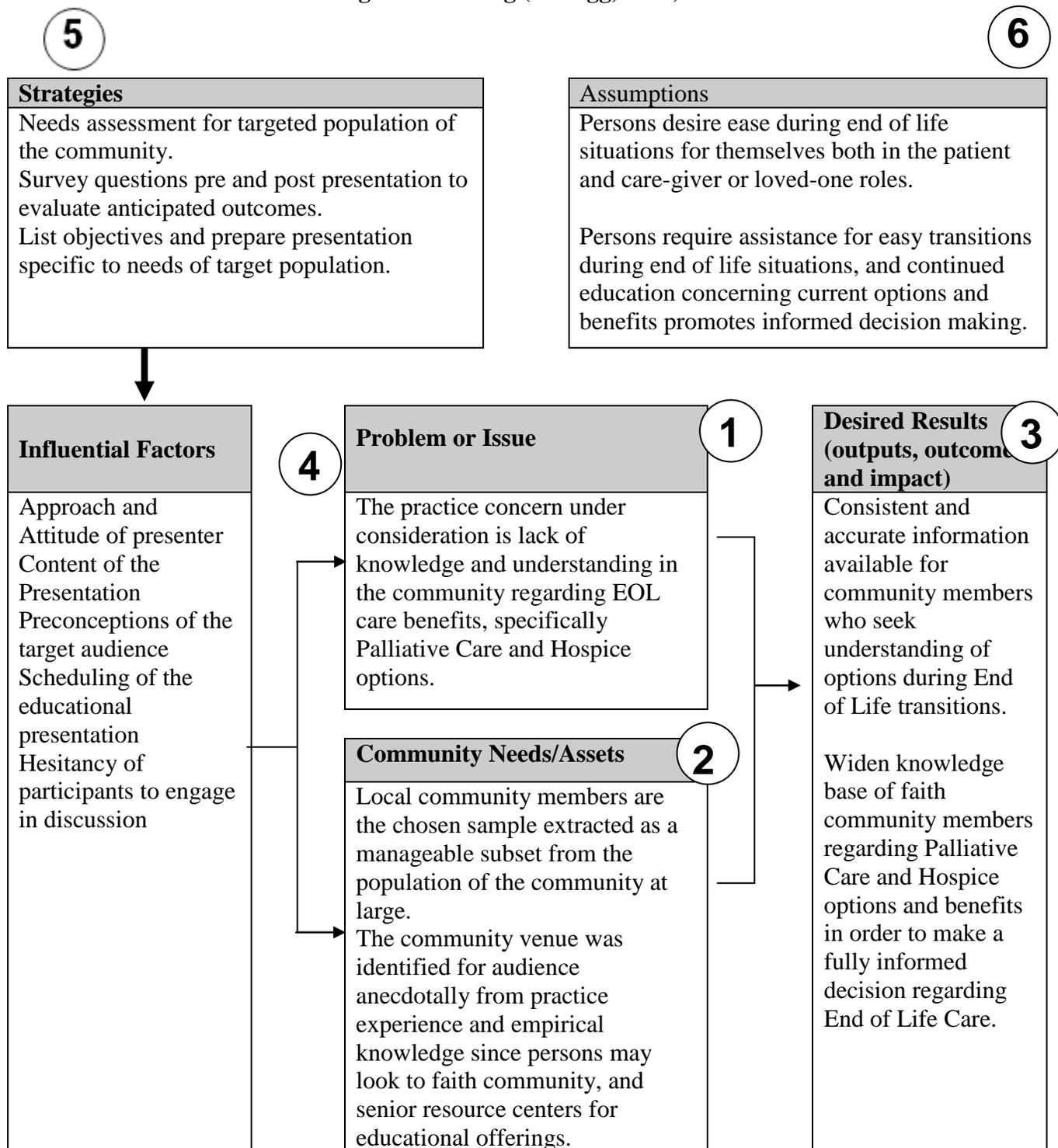
Recommendations and Implications for practice include development of a sustainable program for recurring community education, effective communication, spending time listening to what participants and patients need, and providing time and opportunity for participants to think of questions regarding their individual situations. The educational intervention for palliative care and hospice improved the perceived knowledge of this subject for the participants, adding to the body of knowledge in the nursing profession. This study validates that community education can be considered a priority for nursing practice, research and policy. Follow up studies and continued educational offerings are needed to increase knowledge for nursing and knowledge for our communities regarding palliative care and hospice.

Appendices

SWOT Analysis

<p>Strengths</p> <p>Small circle to promote trust</p> <p>Undivided attention</p> <p>DNP student is content expert</p>	<p>Weaknesses</p> <p>Fear of acknowledging dying</p> <p>Preconceived ideas about EOL care</p> <p>Participant reluctance to engage</p>
<p>Opportunities</p> <p>Interprofessional Collaboration</p> <p>Community Partnerships</p> <p>Collective knowledge</p>	<p>Threats</p> <p>Societal Norms</p> <p>Social Taboos</p> <p>Other Hospice Marketing strategies</p>

**Logic Model Development
Program Planning (Kellogg, 2001)**



Logic Model Development (Kellogg, 2001)

RESOURCES	ACTIVITIES	OUTPUTS	SHORT & LONG-TERM OUTCOMES	IMPACT
<i>In order to accomplish our set of activities we will need the following:</i>	<i>To provide the intervention the following activities will be accomplished:</i>	<i>We expect that once accomplished these activities will produce the following evidence of service delivery:</i>	<i>We expect that if accomplished these activities will lead to the following changes in 1-3 then 4-6 years:</i>	<i>We expect that if accomplished these activities will lead to the following changes in 7-10 years:</i>
Time for preparation of educational intervention and needs assessment	Educational Presentation on Palliative Care and Hospice options and benefits with associated objectives	Dissemination of current and accurate information regarding options and benefits of Palliative Care and Hospice.	Patients and families receive care earlier in the dying process and experience easier transitions after enrollment with Palliative Care or Hospice.	Enrollment in Palliative care and Hospice sooner rather than later in the course of a life limiting illness or crisis.
Schedule time with faith community venues Provide handouts and pencils for participants	Story gathering from participants to establish trust Question and answer session following presentation	Participants report increased understanding and awareness of the options and benefits of Palliative Care and Hospice.	Persons recognize faith communities, senior resource centers and recreation centers as resources for EOL care discussions.	Patients and families experience easier transitions after enrollment with Palliative Care or Hospice
Schedule time for data analysis Budget for paper and ink and access to a printer	Prepare survey measurement tool Needs assessment for participants	Participants express increased understanding in ability to make fully informed decisions regarding EOL care.	Enrollment in Palliative care and Hospice sooner rather than later in the course of a life limiting illness or crisis.	



Academic Grants

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IRB – REGIS UNIVERSITY

March 25, 2014

Mary Castang
PO Box 186
Buffalo Creek, CO 80425**RE: IRB #: 14-141**

Dear Ms. Castang:

Your application to the Regis IRB for your project, “Hospice and Palliative Care Educational Intervention,” was approved as an exempt study on March 25, 2014. This study was approved per exempt study category of research 45CFR46.101.b(#1).

The designation of “exempt” means no further IRB review of this project, as it is currently designed, is needed.

If changes are made in the research plan that significantly alter the involvement of human subjects from that which was approved in the named application, the new research plan must be resubmitted to the Regis IRB for approval.

Sincerely,

Patsy McGuire Cullen, PhD, PNP-BC
Chair, Institutional Review Board
Professor & Director
Doctor of Nursing Practice & Nurse Practitioner Programs
Loretto Heights School of Nursing
Regis University

cc: Dr. Alma Jackson



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Community Partner Letter of Support

To Mary Castang DNP student,

I understand that you request to provide an educational intervention for local the community regarding palliative care and hospice options for End of Life care at this community facility. I recognize the following information which is provided for review.

Researcher: Mary Castang, DNP student, casta321@regis.edu

A. Jackson, PhD, Capstone Chair

P. Cullen, PhD IRB Chair, irb@regis.edu

Regis University

Rueckert-Hartman College for Health Professionals

Loretto Heights School of Nursing

3333 Regis Boulevard

Denver, CO 80221-1099

303-458-4338

Description: The researcher will provide an educational intervention regarding palliative care and hospice options for End of Life care. Included in the education are program similarities and differences, eligibility criteria and payment sources and benefits, with a question and answer session for participant sharing. The purpose of this study is to find out whether community education about life limiting illness and end of life care, specifically palliative care and hospice helps increase understanding of participants for these care options. Participants will be asked to fill out a questionnaire before the class, and again after the class about their knowledge of palliative care and hospice.

Risks and Benefits: The expected benefits of attending are increased knowledge about end of life care options, specifically palliative care and hospice. No associated risks are identified.

Voluntary Participation and Right to Withdraw: Participation is voluntary, and participants may cease participation at any time during the discussion the right to leave is preserved without prejudice or judgment.

Confidentiality: Participants have the right to privacy, anonymity and confidentiality. Responses and any information shared within the group or with the nurse educator will remain confidential. There are no personal identifiers attached to the measurement survey or tool that can link you to your individual responses. All data will be stored in a secured and locked file cabinet for three (3) years and will then be destroyed.

I respond on behalf of Pine Library with support for this community effort. DNP student Mary Castang may use this facility for the community group education regarding palliative care and hospice and post a flyer on our information bulletin area to announce the education dates and times.

Signature Tom Benton Date 2-12-14



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I respond on behalf of Berkeley Community Church with support for this community effort. DNP student Mary Castang may use this facility for the community group education regarding palliative care and hospice and post a flyer on our information bulletin area to announce the education dates and times.

Signature *Paul Claypool* Date 2-12-2014



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I respond on behalf of Augustana Lutheran Church with support for this community effort. DNP student Mary Castang may use this facility for the community group education regarding palliative care and hospice and post a flyer on our information bulletin area to announce the education dates and times.

Signature Sheryl Steiner, Parish Nurse Date 2/26/2014



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I respond on behalf of Metro-Denver Prosh Nurse Association with support for this community effort. DNP student Mary Castang may use this facility for the community group education regarding palliative care and hospice and post a flyer on our information bulletin area to announce the education dates and times.

Signature *Shirley Stenmark, RN, MSN, FNPC* Date 2/26/2014



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I respond on behalf of North York Fire Protection District with support for this community effort. DNP student Mary Castang may use this facility for the community group education regarding palliative care and hospice and post a flyer on our information bulletin area to announce the education dates and times.

Signature Jon Slaughter Pequin Date 2/20/2014



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Risks and Benefits: The expected benefits of attending are increased knowledge about end of life care options, specifically palliative care and hospice. No associated risks are identified.

Voluntary Participation and Right to Withdraw: Participation is voluntary, and participants may cease participation at any time during the discussion the right to leave is preserved without prejudice or judgment.

Confidentiality: Participants have the right to privacy, anonymity and confidentiality. Responses and any information shared within the group or with the nurse educator will remain confidential. There are no personal identifiers attached to the measurement survey or tool that can link you to your individual responses. All data will be stored in a secured and locked file cabinet for three (3) years and will then be destroyed.

I respond on behalf of Wheatridge United Methodist Church with support for this community effort. DNP student Mary Castang may use this facility for the community group education regarding palliative care and hospice and post a flyer on our information bulletin area to announce the education dates and times.

Signature Carol M. Gray Date Feb. 12, 2014

Budget and Resources

In order to replicate this particular study, the following budget and resource needs can be anticipated.

Time:

In-kind Donation 3 Hours @ \$50/hour	\$150.00
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Purchases:

Printing and Pencils	\$ 20.00
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Fuel	\$100.00
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(Statistician)	<u>\$200.00</u>
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	\$470.00
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The study had no funding sources. If this study were to be reproduced, in terms of cost for the researcher, his/her time would likely be not paid, more of an In-kind donation, unless the project was completed as a work related study. About three hours of preparation and presentation time would be required, and with an estimate of \$50 per hour comes to a total of \$150. Printing surveys and the participant information sheets and purchasing pencils for the participants cost \$20, and fuel was a consideration since the travel distance between venues was substantial, resulting in a total of \$100 fuel expenditure for initial and subsequent meetings. For replication of this study, the cost of hiring a statistician for the statistical analysis is included in the budget at an estimated cost of \$200. The total cost would be approximately \$470 for reproduction of a similar study.

Time Frame

This timeline for two years, beginning with fall 2012 with the project creation, through summer 2014 with the project defense and graduation.

August 2012	Project Creation
September 2013	Project Compilation
October 2013	Project written and oral proposal
December 2013	IRB Submission
March 2014	IRB Approval, Intervention Begins
May 2014	Intervention Complete
June 2014	Statistical Analysis
July 2014	Final Compilation of Project
August 2014	Project Defense and Graduation

Measurement Survey and Measurement Tool

Flesch-Kincaid Grade Level 7.5

By filling out this form you consent to participate in the survey and in this evidence based research project. Your participation is voluntary and you may cease participation at any time without loss of any benefit to which you are entitled. Not all questions have to be answered. You can choose not to answer any questions, or not to participate, and you can leave the discussion or quit the survey at any time.

In the space next to the sentence circle a number from 1 to 5 depending on what you know about palliative care and hospice.

1. I am familiar with the palliative care and hospice options for patient care.

1 = Not at all 2= Somewhat 3=Enough 4=Good 5=Great

2. I know who is eligible for and who pays for palliative care and hospice.

1 = Not at all 2= Somewhat 3=Enough 4=Good 5=Great

3. I know the difference between palliative care and hospice.

1 = Not at all 2= Somewhat 3=Enough 4=Good 5=Great

4. I know who makes up a palliative care and hospice team.

1 = Not at all 2= Somewhat 3=Enough 4=Good 5=Great

5. I know who to ask if I want palliative care or hospice.

1 = Not at all 2= Somewhat 3=Enough 4=Good 5=Great

6. I know enough about palliative care and hospice to decide if I want it.

1 = Not at all 2= Somewhat 3=Enough 4=Good 5=Great

7. I might ask for palliative care or hospice earlier rather than later.

1 = Not at all 2= Somewhat 3=Enough 4=Good 5=Great

Participant Information Sheet

Flesch-Kincaid Grade Level 7.5

Title: Palliative care and hospice education for the Community

Researcher: Mary Castang, DNP student, casta321@regis.edu

A. Jackson, PhD, Capstone Chair

P. Cullen, PhD IRB Chair, irb@regis.edu

Regis University

Rueckert-Hartman College for Health Professionals

3333 Regis Boulevard

Denver, CO 80221-1099

303-458-4338

A Regis University Doctor of Nursing Practice student will provide a one hour education meeting about palliative care and hospice. You will learn the difference between these two programs, the benefits, who can enroll, how to enroll, what the services are and who pays for the services. During the meeting you can ask questions and feel free to talk about any concerns.

The reason for the education is to find out if it helps our community members to better understand the palliative care and hospice options for care.

You will have the option of filling out a short survey before the meeting and then again afterward, to see if the education and discussion helped you understand palliative care and hospice.

Risks and Benefits: The risks are less than minimal and the benefit is learning about palliative care and hospice.

Privacy: The survey and the discussion are unidentified and all information shared during the session will remain confidential. You may choose to not complete any question on the survey. Your responses will remain confidential and will not identify you personally in any way. All the surveys completed during this project will be stored in a locked and secure file for three years and will then be destroyed.

CITI Collaborative Institutional Training Initiative

Human Research Curriculum Completion Report Printed on 10/30/2012

Learner: Mary Castang (username: mcastang)

Institution: Regis University

Contact Department: LHSON

Information Email: casta321@regis.edu

Social Behavioral Research Investigators and Key Personnel:

Stage 1. Basic Course Passed on 10/30/12 (Ref # 9022290)

Required Modules	Date Completed	
Introduction	10/21/12	no quiz
History and Ethical Principles - SBR	10/21/12	4/5 (80%)
The Regulations and The Social and Behavioral Sciences - SBR	10/21/12	5/5 (100%)
Assessing Risk in Social and Behavioral Sciences - SBR	10/21/12	5/5 (100%)
Informed Consent - SBR	10/30/12	5/5 (100%)
Privacy and Confidentiality - SBR	10/30/12	5/5 (100%)
Regis University	10/30/12	no quiz

For this Completion Report to be valid, the learner listed above must be affiliated with a CITI participating institution. Falsified information and unauthorized use of the CITI course site is unethical, and may be considered scientific misconduct by your institution.

Paul Braunschweiger Ph.D.
Professor, University of Miami
Director Office of Research Education
CITI Course Coordinator

Frequency Table

Pre1.1

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 1.00	10	24.4	24.4	24.4
2.00	21	51.2	51.2	75.6
3.00	2	4.9	4.9	80.5
4.00	7	17.1	17.1	97.6
5.00	1	2.4	2.4	100.0
Total	41	100.0	100.0	

Pre1.2

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 1.00	19	46.3	46.3	46.3
2.00	16	39.0	39.0	85.4
3.00	2	4.9	4.9	90.2
4.00	3	7.3	7.3	97.6
5.00	1	2.4	2.4	100.0
Total	41	100.0	100.0	

Post1.6

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 2.00	5	12.2	12.2	12.2
3.00	4	9.8	9.8	22.0
4.00	12	29.3	29.3	51.2
5.00	20	48.8	48.8	100.0
Total	41	100.0	100.0	

Pre1.3

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 1.00	16	39.0	39.0	39.0
2.00	11	26.8	26.8	65.9
3.00	7	17.1	17.1	82.9
4.00	5	12.2	12.2	95.1
5.00	2	4.9	4.9	100.0
Total	41	100.0	100.0	

Post1.7

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 2.00	4	9.8	9.8	9.8
3.00	5	12.2	12.2	22.0
4.00	12	29.3	29.3	51.2
5.00	20	48.8	48.8	100.0
Total	41	100.0	100.0	

Pre1.4

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 1.00	20	48.8	48.8	48.8
2.00	13	31.7	31.7	80.5
3.00	3	7.3	7.3	87.8
4.00	4	9.8	9.8	97.6
5.00	1	2.4	2.4	100.0
Total	41	100.0	100.0	

Post1.1

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 2.00	2	4.9	4.9	4.9
3.00	8	19.5	19.5	24.4
4.00	20	48.8	48.8	73.2
5.00	11	26.8	26.8	100.0
Total	41	100.0	100.0	

Pre1.5

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 1.00	15	36.6	36.6	36.6
2.00	14	34.1	34.1	70.7
3.00	4	9.8	9.8	80.5
4.00	7	17.1	17.1	97.6
5.00	1	2.4	2.4	100.0
Total	41	100.0	100.0	

Post1.2

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 2.00	3	7.3	7.3	7.3
3.00	7	17.1	17.1	24.4
4.00	24	58.5	58.5	82.9
5.00	7	17.1	17.1	100.0
Total	41	100.0	100.0	

Pre1.6

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 1.00	17	41.5	41.5	41.5
2.00	12	29.3	29.3	70.7
3.00	3	7.3	7.3	78.0
4.00	7	17.1	17.1	95.1
5.00	2	4.9	4.9	100.0
Total	41	100.0	100.0	

Post1.3

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 2.00	1	2.4	2.4	2.4
3.00	1	2.4	2.4	4.9
4.00	18	43.9	43.9	48.8
5.00	21	51.2	51.2	100.0
Total	41	100.0	100.0	

Pre1.7

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 1.00	8	19.5	20.0	20.0
2.00	14	34.1	35.0	55.0
3.00	8	19.5	20.0	75.0
4.00	9	22.0	22.5	97.5
5.00	1	2.4	2.5	100.0
Total	40	97.6	100.0	
Missing System	1	2.4		
Total	41	100.0		

Post1.4

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 2.00	3	7.3	7.3	7.3
3.00	8	19.5	19.5	26.8
4.00	15	36.6	36.6	63.4
5.00	15	36.6	36.6	100.0
Total	41	100.0	100.0	

Post1.5

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid 2.00	3	7.3	7.3	7.3
3.00	7	17.1	17.1	24.4
4.00	10	24.4	24.4	48.8
5.00	21	51.2	51.2	100.0
Total	41	100.0	100.0	

Systematic Review of Literature

Article/Journal	Attentively Embracing Story: A Middle-Range Theory with Practice and Research Implications/Scholarly Inquiry for Nursing Practice: An International Journal
Author/Year	Smith, M and Liehr, P.(1999)
Database/Keywords	EBSCO/Middle-Range Theory, Story, Nursing Practice
Research Design	Non-experimental descriptive studies
Level of Evidence	
Study Aim/Purpose	To describe the middle-range theory of embracing story and propose that the theory describes a process of dialogue that fosters human development.
Population/ Sample size Criteria/Power	Comparative studies/Case studies/ 2 particular studies were related in the article
Methods/Study Appraisal Synthesis Methods	Traditional review of literature
Primary Outcome Measures/Results	Walking with persons through their stories in a research situation contributed to naming the story concept theory
Conclusions/Implications	Author proposes that participating in intentional dialogue to promote ease will add to nursing knowledge and strengthen practice-research unity.
Strengths/Limitations	Middle range theory strengthens the gap between research and practice.
Funding Source	None noted
Comments	Capstone Theoretical Underpinning

Article/Journal	Ambivalence at the end of life: How to understand patients' wishes ethically/Nursing Ethics
Author/Year	Ohnsorge, K., Keller, H., Widdershoven, G., & Rehmann-Sutter, C. (2012)
Database/Keywords	EBSCO/End of Life, Patients' experience, wish to die, ambivalence, identity
Research Design	empirical case studies
Level of Evidence	Level VI
Study Aim/Purpose	To contribute a more careful and reflective practice of understanding patients' experiences and meaning making at the end of life, and nurse's role in this practice.
Population/ Sample size Criteria/Power	Patients with incurable disease, already informed about their disease. N=116, all from one hospice and one hospital palliative care ward, 2008-2011.
Methods/Study Appraisal Synthesis Methods	A combination of Grounded Theory and Interpretive Phenomenological Analysis, continuous analysis during interview period
Primary Outcome Measures/Results	Clustering of case studies, emerging themes regarding ambivalent patient responses.
Conclusions/Implications	Perceptions of ambivalence may result in misunderstandings in communication or lack of knowledge. Take care not to pathologize contradictory patient behavior
Strengths/Limitations	Illustrates the strength of phenomenon of ambivalence of a patient can be meaningfully understood.
Funding Source	Oncosuisse/Foundation Cancer Research, Gottfried und Julia Bangerter-Rhyner-Stiftung, Foundation of the Hospice Arlesheim.
Comments	Relates to Capstone study regarding patient/family education regarding end of life care.

Article/Journal	Evidence Based Practice Self-efficacy Scale/ Clinical Nurse Specialist
Author/Year	Tucker, S., Olson, M., Frusti, D. (2009)
Database/Keywords	Referred from a colleague/ evidence based nursing practice, self-efficacy, validity and reliability
Research Design	Quasi-experimental pretest/posttest design
Level of Evidence	Level VI
Study Aim/Purpose	To examine preliminary evidence of the reliability and validity of the EBPSE scale
Population/ Sample size Criteria/Power	2 cohorts of nurses, 93 total from hospital, ambulatory, long-term care, and hospice settings.
Methods/Study Appraisal Synthesis Methods	participants completed assessment measures at baseline, after first half and after second half of the program. Data analysis consisted of descriptive and inferential statistics.
Primary Outcome Measures/Results	The findings suggest promise for the EBPSE scale as a measure of EBPSE.
Conclusions/Implications	Any of the 17 items could be targets for additional education and assistance in daily patient care practices. Study provides preliminary encouraging evidence and key areas for future investigation.
Strengths/Limitations	Validity provided by a panel of nurse leaders writing and rewriting the items. Coefficients for the scale measured exceeded the standard for a newly developed instrument. Limitations: small sample size and missing data, lack of a control group
Funding Source	Internal innovation funding program at Mayo Clinic
Comments	Review of pre/posttest stems for use as Capstone measurement tool

Article/Journal	The Decision to Accept Hospice Services/Journal of Hospice and Palliative Nursing
Author/Year	Szirony, T., Sopko, P. Masiulaniec, B., Binder, M. (2011)
Database/Keywords	EBSCO/decision making, end-of-life care, hospice
Research Design	Qualitative method of phenomenology
Level of Evidence	Level VI
Study Aim/Purpose	To identify themes that influence an individual's decision to accept hospice services
Population/ Sample size Criteria/Power	19 Adult patients who had enrolled in hospice in the last 90 days
Methods/Study Appraisal Synthesis Methods	Open ended and semi-structured interview questions/ one hour interview taped then transcribed to identify themes and variables.
Primary Outcome Measures/Results	participants agreed overwhelmingly that honest and direct communication contributed to accepting hospice services
Conclusions/Implications	Four specific influences identified in the decision to accept hospice care which can be utilized by nurses to support patients and families and develop evidence based interventions for initial visits.
Strengths/Limitations	Limitation - small sample size. Further research is needed to develop innovative interventions to assist in the decision-making process for hospice
Funding Source	None noted
Comments	Relates to Capstone with implications for community education

Article/Journal	Hospice Admission and Eligibility/Journal of Hospice and Palliative Nursing
Author/Year	Jones, M., Harrington, T., Mueller, G. (2013)
Database/Keywords	EBSCO/eligibility criteria, hospice admission, staff education
Research Design	Analysis and overview of teaching and learning strategies
Level of Evidence	Level VI
Study Aim/Purpose	To describe an approach to staff education designed to prepare staff to admit patients to hospice programs.
Population/ Sample size Criteria/Power	RNs, social workers and chaplains involved in the admission process for Hospice
Methods/Study Appraisal Synthesis Methods	Four hour session utilizing real patient scenarios and examples from practice to assist clinicians to develop their skills in teaching the patient and family about hospice services, benefits, levels and philosophy of hospice care.
Primary Outcome Measures/Results	Demonstrates that an educational program designed specifically for teaching eligibility criteria, understanding benefits and communication for end-of-life discussions builds on knowledge and skills of hospice clinicians.
Conclusions/Implications	Hospice Clinicians may find strategies useful for application to their practice settings and educational support to meet regulatory requirements
Strengths/Limitations	Strength: Small groups discussions that facilitates interactive learning
Funding Source	None noted
Comments	Educational insight for Capstone intervention

Article/Journal	The End of Life: A Qualitative Study of the Perceptions of People over the age of 80 on issues surrounding death and dying/Journal of Pain and Symptom Management
Author/Year	Lloyd-Williams, M., Kennedy, V., Sixsmith, A., Sixsmith, J. (2006)
Database/Keywords	EBSCO/elderly, older people, end-of-life care, palliative care, assisted dying
Research Design	Qualitative study
Level of Evidence	Level VI
Study Aim/Purpose	To describe some of the views and experiences regarding end of life, as described by a group of older people in the 80s.
Population/ Sample size Criteria/Power	40 participants, living independently, both randomly and purposively selected to reflect and include diversity in demographics and socioeconomics.
Methods/Study Appraisal Synthesis Methods	In-depth, semi-structured interviews facilitating purposive discussion between researcher and participant, in their own homes, lasting approximately one hour or more. Interviews were recorded and transcribed, key themes identified, thematic analysis done.
Primary Outcome Measures/Results	Six key themes identified, highlighting the need for elderly persons to discuss issues surrounding end-of-life care.
Conclusions/Implications	Little is known about the experiences of older people living and dying in the community. Learning about such experiences is important in planning care for this population.
Strengths/Limitations	Limitation: Most of the sample were of low dependency, lived in ordinary housing, and were all in reasonable health. Strength: Intimate knowledge of elderly experience surrounding end-of-life topics.
Funding Source	European Union grant
Comments	Supports Capstone population assessment process

Article/Journal	It is 'Too Late' or is it? Bereaved Family Member Perceptions of Hospice Referral when their family member was on Hospice for Seven Days or Less/ Journal of Pain and Symptom Management
Author/Year	Teno, J., Casarett, D., Spence, C., Connor, S. (2012)
Database/Keywords	EBSCO/Hospice, length of stay, access, quality of care
Research Design	Analysis and overview of data based studies
Level of Evidence	Level IV
Study Aim/Purpose	To examine bereaved family members' perceptions of the timing of hospice referral to identify aspects of the referral process that can be improved.
Population/ Sample size Criteria/Power	100 narrative interviews of family members of hospice patients who died within the first week of enrollment
Methods/Study Appraisal Synthesis Methods	Open-ended interviews of bereaved family members of patients conducted in seven hospice programs.
Primary Outcome Measures/Results	More than one in three family members stated an earlier hospice referral was not possible. Results yielded expected findings of concerns with physician communication and prognostication.
Conclusions/Implications	Need for systems for delivery of high quality of care for persons who will receive hospice services for only a short period of time.
Strengths/Limitations	Limitations: Retrospective nature of interviews support using caution in interpreting findings.
Funding Source	American Cancer Society Grant
Comments	Capstone support for needs assessment of population

Article/Journal	Using Evidence-Based Instruments to Document Eligibility and Improve Quality of Life in Hospice Patients./Home Health Care Management & Practice
Author/Year	Lang, S., Cabin, W., Cotton, C., Domizio, L. (2010)
Database/Keywords	EBSCO/Medicare, hospice, documentation, evidence-based practice, functional performance assessments
Research Design	Descriptive study, analysis and overview
Level of Evidence	Level VI
Study Aim/Purpose	Examination of how a hospice program designed multifaceted program to simultaneously improve regulatory compliance and improve quality of life.
Population/ Sample size Criteria/Power	Presentation of the development and implementation of six patient assessment scales, targeting four symptoms
Methods/Study Appraisal Synthesis Methods	Select evidence based instruments for baseline and ongoing measurement of patient status.
Primary Outcome Measures/Results	Hospice agency can simultaneously comply with regulatory requirements, reduce claim denial vulnerability and improve patient quality of life
Conclusions/Implications	Hospice agencies will benefit from a systematic team-based approach to identify the most valid and practical instruments to facilitate problem solving
Strengths/Limitations	Limitations: Used one hospice agency. Strength: Used existing tools for validity
Funding Source	None stated
Comments	Support and Assessment of Capstone Intervention

Article/Journal	Family caregiver views on patient-centered care at the end of life/Scandinavian Journal of Caring Sciences
Author/Year	Brazil, K., Bainbridge, D., Ploeg, J., Krueger, P., Taniguchi, A., Marshall, D. (2012)
Database/Keywords	EBSCO/patient-centered care, palliative care, community, access to care, caregivers
Research Design	Qualitative method to obtain and analyze data from questionnaires
Level of Evidence	Level VI
Study Aim/Purpose	To evaluate the patient-centeredness of community palliative care from the perspective of family members who were responsible for the care of a terminally ill family member.
Population/ Sample size Criteria/Power	111 family caregivers of a deceased family member who had been designated as palliative and had received formal home care services in the central west region of Ontario, Canada.
Methods/Study Appraisal Synthesis Methods	Survey questionnaire mailed to family member. Bivariate analysis using standard deviations and frequencies, descriptive analysis
Primary Outcome Measures/Results	Demonstrates how to evaluate patient-centered care in the provision of care.
Conclusions/Implications	Patient-centered care should be recognized as an important outcome to assess the quality of service delivery. A requirement of patient-centered care is to redesign service systems to focus on the patient.
Strengths/Limitations	Limitation: Participation rate (111/243..46%) raises question regarding generalizability of findings.
Funding Source	We Care Foundation
Comments	Capstone needs assessment for families and patients of Palliative Care

Article/Journal	Challenges Facing Families at the End of Life in Three settings/Journal of Social Work in End-of-Life and Palliative Care
Author/Year	Kehl, K., Kirchhoff, K., Kramer, B., Hovland-Scafe C. (2009)
Database/Keywords	EBSCO/family caregiver, settings, terminal care
Research Design	Exploratory, retrospective and descriptive study
Level of Evidence	Level VI
Study Aim/Purpose	Examination and comparison of the challenges faced by family members at the end of life in different care settings, with a primary goal to promote independence and quality of life.
Population/ Sample size Criteria/Power	30 family members of individuals who died at home, assisted or skilled care or a hospital in a Midwestern city, in the previous 6-12 months.
Methods/Study Appraisal Synthesis Methods	45-90 minute telephone or in-person interviews , audio-recordings of 16 open-ended questions regarding the experience of the last week of life for their family member.
Primary Outcome Measures/Results	12 primary challenges identified relating to the responses to universal human experience of death and dying.
Conclusions/Implications	Lack of knowledge about family perceptions of care for a dying person hinders efforts to educate caregivers and impairs the ability to optimize care. Common concerns across care settings.
Strengths/Limitations	Limitations: small sample size and not representative of the racial and ethnic mix in the community. Member checking was not feasible and was not used.
Funding Source	Charlotte Jane and Ralph A. Rodefer Chair at the University of Wisconsin - Madison, School of Nursing, Grant from the Clinical and Translational Science Award program of the National Center for Research Resources and National Institutes of Health
Comments	Good resource for identifying needs and challenges for families facing end-of-life situation

Article/Journal	University-Community Partnerships and Community-Based Participatory Research: One Community's Approach to Enhance Capacity in End-of-Life and Bereavement Practice, Research, and Education/Journal of Social Work in End-of-Life & Palliative Care
Author/Year	Jones, B., Pomeroy, E., Sampson, M. (2009)
Database/Keywords	EBSCO/Bereavement, community-based participatory research, end-of-life, grief, qualitative
Research Design	Qualitative study
Level of Evidence	VI
Study Aim/Purpose	Present one community's effort to conduct community-based participatory research in order to increase awareness and understanding of grief and loss and to develop evidence-based practice in this field.
Population/ Sample size Criteria/Power	44 clinicians, researchers, educators and community members, convince sampled to participate in four randomly-assigned focus groups, with specific questions.
Methods/Study Appraisal Synthesis Methods	Multi-phase needs assessment, Focus groups
Primary Outcome Measures/Results	Important step in understanding the needs of persons experiencing grief and loss
Conclusions/Implications	Increased awareness, education, research and community collaboration in advancing the field of grief, bereavement, and end-of-life care.
Strengths/Limitations	Limitation: did not differentiate between the voice of the family member and the providers. Strength: Vehicle to provide a needs assessment for grief and loss.
Funding Source	None stated
Comments	Capstone support for community education

Article/Journal	Preferences for end of life: views of hospice patients, family carers, and community nurse specialists/International Journal of Palliative Nursing
Author/Year	Holdsworth, L., King, A. (2011)
Database/Keywords	EBSCO/Hospice, Preferences, Place of death, End of Life, Palliative care, Communication
Research Design	Exploratory qualitative study
Level of Evidence	VI
Study Aim/Purpose	To identify issues around discussing and recording preferences on place of death from the perspective of hospice patients, carers, and hospice community nurses.
Population/ Sample size Criteria/Power	Purposive sample from three hospices in the south east of England of six community nurse specialists, five patients, five carers, and five bereaved carers. Patients were recruited if they had a life-limiting illness.
Methods/Study Appraisal Synthesis Methods	Focus groups and semi-structured one to one interviews transcribed and emerging themes coded and compared
Primary Outcome Measures/Results	Most patients chose the inpatient hospice as their chosen place of death. A common complaint was lack of information regarding what to expect of the dying experience.
Conclusions/Implications	Being explicit about the choices that must be made at the end of life can help patients and carers feel more in control of their situations which may in turn improve bereavement outcomes.
Strengths/Limitations	Limitation: small scale study, specific group may not be generalizable to the whole hospice population.
Funding Source	None stated
Comments	Capstone support for patient and caregiver needs assessment.

Article/Journal	Late referral to Hospice and Bereaved Family Member Perception of Quality of End-of-life Care/Journal of Pain and Symptom Management
Author/Year	Schockett, E., Teno, J., Miller, S., Stuart, B. (2005)
Database/Keywords	EBSCO/Hospice access, quality of end-of-life care
Research Design	qualitative and descriptive study
Level of Evidence	Level IV
Study Aim/Purpose	Examine associations of bereaved family members report of whether or not hospice referral was made too late, satisfaction with hospice care and reasons for 'late referral'.
Population/ Sample size Criteria/Power	Random sample of deaths in the prior 3-6 months for home hospice teams in two programs, Rhode Island and California. 237 surveys via telephone or mail
Methods/Study Appraisal Synthesis Methods	Open-ended questions using the Family Evaluation of Hospice Care tool
Primary Outcome Measures/Results	The most commonly reported family-related reason for later referral was lack of awareness of hospice or its eligibility requirements.
Conclusions/Implications	There is opportunity to improve as one in seven persons report referral was too late and higher rate of concerns, unmet needs and dissatisfaction with the quality of end-of-life care.
Strengths/Limitations	Small sample size.
Funding Source	Robert Wood Johnson Foundation
Comments	Informs and Supports Capstone family/patient needs assessment

Article/Journal	Effect of a population-based education educational intervention focusing on end-of-life home care, life-prolonging treatment and knowledge about palliative care/Palliative Medicine
Author/Year	Miyashita, M., Sato, K., Morita, T., Suzuki, M. (2008)
Database/Keywords	EBSCO/barriers, education, home death, intervention studies, palliative care
Research Design	Educational intervention study
Level of Evidence	Level VI
Study Aim/Purpose	To provide clarity on the effectiveness of an educational intervention for the general public focusing on end-of-life care, life prolonging treatment and knowledge about palliative care.
Population/ Sample size Criteria/Power	595 participants from the general public recruited from the 11 districts of Fukushima City, Japan
Methods/Study Appraisal Synthesis Methods	Pre and post intervention questionnaire filled in by participants at the one hour educational lecture
Primary Outcome Measures/Results	The feasibility of a home death increased from 9% to 34% after the intervention, as well as attitudes toward end-of-life care.
Conclusions/Implications	The population-based educational intervention was effective in changing beliefs regarding the feasibility of home care, preference for life-prolonging treatment and attitudes toward the end of life care.
Strengths/Limitations	Limitation: study conducted in a rural area of Japan, may be difficult to extrapolate to urban areas in Japan. Intervention was shown to have only a short term effect, therefore sustainability is unknown.
Funding Source	Grant-in-aid from Fukushima Prefecture Palliative Care Support Network
Comments	Capstone support for community education

Article/Journal	The Kitchen Table Discussion: A creative way to discuss end-of-life Issues/ Home Healthcare Nurse
Author/Year	Norlander, L., McSteen, K. (2000)
Database/Keywords	EBSCO/End of life discussion
Research Design	Analysis and Overview of data based studies
Level of Evidence	Level VI
Study Aim/Purpose	Presentation of a tool and a strategy to encourage discussions between patients, their families, and their healthcare providers about goals and wishes for care at the end of life.
Population/ Sample size Criteria/Power	One case study was given as an example for helpful and supportive phrasing to initiate conversations
Methods/Study Appraisal Synthesis Methods	Educational suggestion and offering of a tool for Hospice nurses that suggests clinical indicators to initiate kitchen table discussions
Primary Outcome Measures/Results	Many suggestions for incorporating end of life discussions into clinical practice, including role playing and walking through the process using the tool
Conclusions/Implications	Comprehensive discussion regarding end of life options are a vital component of holistic nursing practice for any patient with a life-limiting illness. Home care and Hospice nurses can use their unique positions to facilitate these conversations.
Strengths/Limitations	None noted
Funding Source	Allina Foundation
Comments	Capstone support for intervention discussions

Article/Journal	Why don't patients enroll in hospice? Can we do anything about it?/ Journal of General Internal Medicine
Author/Year	Vig, E., Starks, HI, Taylor, J., Hopley, E., Fryer-Edwards, K. (2010)
Database/Keywords	EBSCO/hospice, decision making, terminally ill, terminal care
Research Design	Semi-structured interviews analyzed using content analysis
Level of Evidence	Level V
Study Aim/Purpose	To identify reasons that eligible patients do not enroll in hospice and to identify strategies used by hospice providers to address these reasons.
Population/ Sample size Criteria/Power	30 patients and/or family members who had a hospice admission visit, but did not enroll, 19 hospice staff and national experts.
Methods/Study Appraisal Synthesis Methods	Participants were asked to describe the patient's illness, the hospice referral and why they had not enrolled, then a content analysis was performed. Hospice admissions staff and experts described their response to each reason, from which key phrases were identified
Primary Outcome Measures/Results	Reasons that patients did not enroll were 3 main categories, from which a summary of recommendations was prepared.
Conclusions/Implications	Clinicians may want to adopt some of the strategies used by hospice staff/experts for discussing hospice with patients/families and may want to become familiar with hospice organizations in their area. Hospices may want to reconsider their admission procedures in light of patients'/families' perspectives and concerns.
Strengths/Limitations	Limitations: in order to protect confidentiality, participants had to call if they wanted to enroll, therefore most participants were knowledgeable and in favor of hospice. Proportion of eligible patients is not known.
Funding Source	Grant from the National Institute on Aging
Comments	Capstone project support for needs assessment

Article/Journal	Family Perspectives on End-of-Life Care/Journal of Hospice and Palliative Nursing
Author/Year	Jackson, J., Derderian, L., White, P., Ayotte, J., Fiorini, J., Ohall, R., Shay, J./2012
Database/Keywords	EBSCO/ decision making, end-of-life, family perspectives, long term settings
Research Design	Semi-structured interviews analyzed using content analysis
Level of Evidence	Level V
Study Aim/Purpose	To explore family perspectives of end-of-life care in long-term-care settings from interviews of family members who have had a loved one die in a long-term-care facility
Population/ Sample size Criteria/Power	Family members who had lost a loved one in a long-term-care facility during the prior 3-18 months
Methods/Study Appraisal Synthesis Methods	19 face to face interviews, qualitative content analysis to examine interview data, identifying categories and factors in end-of-life experiences
Primary Outcome Measures/Results	Open and frequent communication is essential to satisfaction of all participants at the end of life
Conclusions/Implications	Quality end-of-life experience is characterized by open communication, continuity of providers, preparation for impending death, and detailed advance directives in place
Strengths/Limitations	Limitation: small sample size.
Funding Source	None noted
Comments	Informs and supports capstone project needs assessment

Article/Journal	Timing of Hospice Referral and Families Perceptions of Services: Are Earlier Hospice Referrals Better?/Journal of the American Geriatrics Society
Author/Year	Rickerson, E., Harrold, J., Kapo, J., Carroll, J., Casarett, D./2005
Database/Keywords	EBSCO/hospice, home care, caregiver burden
Research Design	Semi structured interviews at the time of hospice enrollment and 1 month after the patient's death, supplemented by medical record review
Level of Evidence	Level V
Study Aim/Purpose	To determine whether families of patients who enroll in hospice near the end of life believe that they receive less benefit from hospice services than families of patients who enroll earlier.
Population/ Sample size Criteria/Power	281 initial and 250 follow up interviews of families of patients enrolled in hospice for the first time and one month after death. Power:>0.08
Methods/Study Appraisal Synthesis Methods	Descriptive statistics to summarize responses to questions. Agreement evaluated using the quadratic ally weighted kappa statistic
Primary Outcome Measures/Results	Longer lengths of stay reported receiving more helpful services. Short lengths of stay met the needs. Results from this study may help to identify an optimal length of stay from families and patients perspectives
Conclusions/Implications	Even with a short length of stay, hospice can deliver needed and valued services, but families perceived significantly more benefits with longer lengths of stay.
Strengths/Limitations	Limitation: single hospice in a single geographic region and selective enrollment
Funding Source	None noted
Comments	Provides insight to Capstone, specifically questions asked in interviews, patients and families perspectives

Article/Journal	Perceptions about Hospice from a community-Based Pilot Study: Lessons and Findings/ American Journal of Hospice and Palliative Medicine
Author/Year	Dussen, D., Culler, K., Cagle, J./2011
Database/Keywords	EBSCO/hospice, palliative care, information, education, attitudes, baby-boomers, racial/ethnic disparities
Research Design	cross sectional correlation , secondary analysis
Level of Evidence	Level VI
Study Aim/Purpose	Exploration of an urban area's perceptions and awareness of hospice through local churches
Population/ Sample size Criteria/Power	Diverse sample of older adults in eastern Ohio. 168 participants from randomly chosen faith communities. Alpha level 0.05.
Methods/Study Appraisal Synthesis Methods	referral based sampling strategy to conduct a community based pilot study about the attitudes, perceptions, and knowledge about hospice. Descriptive statistics and bivariate analyses were used to describe the sample.
Primary Outcome Measures/Results	Attitudes toward Hospice generally favorable, majority did not know or understand the financial aspects.
Conclusions/Implications	The churches that provided reasons for participation refusal were from populations the study intended to investigate. For future studies, rapport building for the clergy is essential.
Strengths/Limitations	relatively small sample size, limited to 3 counties in eastern Ohio. Possible selection bias based on refusal rates, possible misinterpretation of questions by respondents.
Funding Source	Hospice of the Valley, Raymond John Wean foundation, National Institute on Aging
Comments	Insight into public awareness of Hospice to inform Capstone project

Article/Journal	The Colorado Patient-Centered Interprofessional Evidence-Based Practice Model: A Framework for Transformation/Sigma theta Tau International
Author/Year	Goode, C., Fink, R., Krugman, M., Oman, K., Traditi, L./2010
Database/Keywords	EBSCO/evidence-based practice models, interprofessional practice, patient and family centered care, evidence based practice
Research Design	Overview of an Evidence Based Practice Model
Level of Evidence	Level VII
Study Aim/Purpose	To present a framework that can be used to transform an organization and foster the use of evidence by interdisciplinary team members.
Population/ Sample size Criteria/Power	Organizations and clinicians who implement evidence based policies, protocols and guidelines
Methods/Study Appraisal Synthesis Methods	Presentation of an evidence based intervention to demonstrate how the model is operationalized. Five steps that clinicians should use as they identify a clinical problem, gather the evidence, and move the evidence into practice.
Primary Outcome Measures/Results	Eight Non-research evidence sources described and examples provided to exhibit moving evidence into practice from a clinician's perspective
Conclusions/Implications	Need to obtain non-research forms of evidence when current valid research does not exist or does not fully answer the clinical question. The eight non-research evidence sources provide the best available evidence to integrate into the decision-making process
Strengths/Limitations	Strength: strategy to prepare for model dissemination proved to be the actual revision process.
Funding Source	None noted
Comments	Informs and supports Capstone through relating evidence to practice

Article/Journal	Ambivalence at the end of life: How to understand patients' wishes ethically/ Nursing Ethics
Author/Year	Ohnsorge, K., Gudat Keller, H., Widdershoben, G., Rehmann-Sutter, C./ 2012
Database/Keywords	EBSCO/ambivalence, end of life, identity, narratives, patients' experience, wish to die
Research Design	Analysis of case stories based on narrative interviews
Level of Evidence	Level V
Study Aim/Purpose	Investigates the seemingly contradictory normative statements by patients in communication with others, from a hermeneutical-ethical perspective
Population/ Sample size Criteria/Power	2 patients and their caregivers, samples from a series of empirical case studies, both have terminal cancer and are aware of their imminent death, inpatients of a hospice.
Methods/Study Appraisal Synthesis Methods	Semi-structured interviews of 1 hour with patients and families, 20 minutes with caregivers. Continuous analysis during interview period. Cases were selected because the members of the health care team described the patient as ambivalent
Primary Outcome Measures/Results	Respectful approach to patients requires acknowledging that coexistence of opposing wishes can be part of authentic, multi-layered experiences and moral understandings at the end of life.
Conclusions/Implications	Caregivers need to understand when contradictory statements point to tensions in a patient's moral experience that require support and be careful not to negatively label or even pathologize seemingly contradictory patient statements
Strengths/Limitations	Limitation: small sample size
Funding Source	Oncousuisse/Foundation Cancer Research, Gottfried und Julia Bangerter-Rhyner-Stiftung, Foundation of the Hospice Arlesheim.
Comments	Provides insight to patients fluctuating behavior and comments during the end of life process

Article/Journal	Hospice Providers' Key Approaches to Support Informal Caregivers in Managing Medication for Patients in Private Residences/ Journal of Pain and Symptom Management
Author/Year	Lau, D., Joyce, B., Clayjman, M., Dy, S., Ehrlich-Jones, L., Emanuel, L., Hauser, J., Paice, J., Shega, J./ 2012
Database/Keywords	EBSCO/ Hospice home services, family caregivers, pain management
Research Design	Qualitative study
Level of Evidence	Level V
Study Aim/Purpose	Explores the key approaches that hospice providers use to facilitate medication management for caregivers
Population/ Sample size Criteria/Power	22 providers - 14 nurses, four physicians, four social workers from four hospice organizations around an urban setting in the Midwestern U. S.
Methods/Study Appraisal Synthesis Methods	Semi-structured, open-ended interviews to gain insight about how hospice providers prepare and support caregivers with medication-related tasks.
Primary Outcome Measures/Results	Five key approaches emerged based on the interviews, each hospice discipline used multiple approaches.
Conclusions/Implications	More efforts are needed to ensure that caregivers' barriers to medication management are adequately addressed during interdisciplinary team meetings and the role of social workers in facilitating medication management is valued by other hospice providers and caregivers.
Strengths/Limitations	The study uses qualitative data from a non-probabilistic sample, limiting the generalizability of the findings, also did not include the perspective of the caregivers; therefore providers' reported clinical approaches could not be validated.
Funding Source	National Institute on Aging
Comments	provides insight for Capstone intervention regarding needs of patients and families

Article/Journal	Living with advanced chronic obstructive pulmonary disease: patients' concerns regarding death and dying/ Palliative Medicine
Author/Year	Gardiner, C., Gott, M., Small, N., Payne, S., Seamark, D., Barnes, S., Halpin, D., Ruse, C./2009
Database/Keywords	EBSCO/palliative care, chronic obstructive pulmonary disease, communication, death and dying
Research Design	Qualitative methodology
Level of Evidence	Level V
Study Aim/Purpose	Exploration of the experiences of patients with COPD, particularly fears surrounding death and dying.
Population/ Sample size Criteria/Power	21 patients with moderate to severe COPD recruited from a sample of 64 patients who were participating in a pilot study to explore palliative care needs in COPD.
Methods/Study Appraisal Synthesis Methods	Semi-structured interviews
Primary Outcome Measures/Results	Patients reported fears and concerns and desires surrounding the dying experience yet none of the patients had discussed what dying may be like with a health care professional.
Conclusions/Implications	Results highlight a need for a palliative care approach which may enable patients to be better educated about their condition, and take an active role in the management of their condition towards the end of life and to make informed choices about the care they choose to receive.
Strengths/Limitations	Small sample size from 3 GP practices, may not be representative of entire UK population.
Funding Source	Dunhill Medical Trust
Comments	Informs Capstone project by providing insight to patient and family needs and concerns regarding death and dying.

Article/Journal	Understanding Enrollment Conversations: The role of the Hospice Admissions Representative/American Journal of Hospice & Palliative Care
Author/Year	Wittenberg-Lyles, E., Thompson, S./2006
Database/Keywords	EBSCO/hospice, decision making
Research Design	Qualitative method to obtain and analyze data from observations.
Level of Evidence	Level VII
Study Aim/Purpose	To explore patients' perceptions of hospice care in order to understand how hospice patients construct meanings of holistic care.
Population/ Sample size Criteria/Power	10 patients from a non-profit hospice in the southwestern U.S., in a home care setting, 60-90 years of age. Had been in the program between 1-14 months. The study was guided generally by social constructionism which offers the framework to study how people create meaning for themselves and others.
Methods/Study Appraisal Synthesis Methods	Nonparticipant observation of initial meetings between hospice admission representatives and patients and families. Each conversation was broken down and coded to establish a pattern through relating the codes.
Primary Outcome Measures/Results	Findings indicate that patients and a primary family member take on particular roles during these initial conversation and hospice admissions representatives engage in 1 to 3 types of talk when engaging in enrollment conversations.
Conclusions/Implications	When engaging in enrollment conversations with families, hospice admission representatives direct their comforting statements toward reappraising uncertainty about hospice and uncertainty about death and dying.
Strengths/Limitations	small sample size, may not be representative of suburban or rural hospices
Funding Source	None noted
Comments	Provides insight for family and patient education regarding Hospice benefits and options to inform Capstone project.

Article/Journal	Advance Care Planning and Hospice Enrollment: Who Really makes the decision to enroll?/Journal of Palliative Medicine
Author/Year	Hirschman, K., Corcoran, A., Straton, J., Kapo, J./ 2010
Database/Keywords	EBSCO/hospice enrollment
Research Design	Anonymous survey study design used to collect data from the family caregiver of a patient who died while enrolled in hospice.
Level of Evidence	Level VII
Study Aim/Purpose	To assess patient participation in advance care planning and the decision to enroll in hospice.
Population/ Sample size Criteria/Power	165 family members of patients who died in hospice over a 9 month period from a hospice operated by a large, university-affiliated health system.
Methods/Study Appraisal Synthesis Methods	anonymous survey asking about family caregiver/patient demographics and characteristics, decision making to enroll in hospice and advance care planning.
Primary Outcome Measures/Results	Highlights that patients are involved in the decision to enroll in hospice, have advance care planning discussions and complete written advance directives.
Conclusions/Implications	Although the majority of patients are involved in the decision to enroll in hospice, 49.1% allow family and physicians to guide their decisions. White Americans are more likely to have advance planning discussions. Many family caregivers find themselves without the knowledge, judgment or courage to perform their responsibility as a proxy decision maker.
Strengths/Limitations	Limitations: It is possible that the families recollections were different from what the patients' perspectives on advance care planning and the decision to enroll in hospice might have been. 70% of the sample distribution was cancer patients. It may have been useful to ask questions about spirituality but was not done due to respondent burden.
Funding Source	None noted
Comments	Supports Capstone intervention regarding needs of patients and families for end of life education.

Article/Journal	Hospice patients' construction of Hospice's Holistic Care Approach in a Biomedical Culture/Death Studies - Routledge Taylor and Francis Group
Author/Year	Pederson, S., Emmers-Sommer, T./2012
Database/Keywords	EBSCO/hospice care, patient view
Research Design	Qualitative semi-structured Interviews, themes and clusters of meanings identified
Level of Evidence	Level VII
Study Aim/Purpose	To explore patients' perceptions of hospice care in order to understand how hospice patients construct meanings of holistic care.
Population/ Sample size Criteria/Power	10 patients from a non-profit hospice in the southwestern U.S., in a home care setting, 60-90 years of age. Had been in the program between 1-14 months. The study was guided generally by social constructionism which offers the framework to study how people create meaning for themselves and others.
Methods/Study Appraisal Synthesis Methods	Six themes emerged that encompassed patients' understanding of hospice care, which was often unrelated to any holistic elements. Patients regard psychological, emotional and spiritual needs as not a part of their health care treatment, instead the emphasis is on the disease and body as ailing parts.
Primary Outcome Measures/Results	Responses revealed that patients do not experience this comprehensive holistic service that is the design of hospice, perhaps because the hospice mission is co-constructed with the biomedical model of medicine in mind so the holistic services may be lost in translation.
Conclusions/Implications	Findings offer significant insight into the communication of hospice care. The variety of services hospice facilities offer is problematic. Hospice interdisciplinary teams must increase their efforts to communicate the hospice mission to patients.
Strengths/Limitations	Limitations: small sample size, patients were all from the same hospice program, could be considered outliers in that the average length of time with hospice exceeded the 6-month eligibility requirement.
Funding Source	None Noted
Comments	Informs Capstone by providing background for population understanding of hospice and insight into the communication of hospice care.

Article/Journal	Advance Care Planning and Hospice Enrollment: Who Really makes the decision to enroll?/Journal of Palliative Medicine
Author/Year	Hirschman, K., Corcoran, A., Straton, J., Kapo, J./ 2010
Database/Keywords	EBSCO/hospice enrollment
Research Design	Anonymous survey study design used to collect data from the family caregiver of a patient who died while enrolled in hospice.
Level of Evidence	Level VII
Study Aim/Purpose	To assess patient participation in advance care planning and the decision to enroll in hospice.
Population/ Sample size Criteria/Power	165 family members of patients who died in hospice over a 9 month period from a hospice operated by a large, university-affiliated health system.
Methods/Study Appraisal Synthesis Methods	anonymous survey asking about family caregiver/patient demographics and characteristics, decision making to enroll in hospice and advance care planning.
Primary Outcome Measures/Results	Highlights that patients are involved in the decision to enroll in hospice, have advance care planning discussions and complete written advance directives.
Conclusions/Implications	Although the majority of patients are involved in the decision to enroll in hospice, 49.1% allow family and physicians to guide their decisions. White Americans are more likely to have advance planning discussions. Many family caregivers find themselves without the knowledge, judgment or courage to perform their responsibility as a proxy decision maker.
Strengths/Limitations	Limitations: It is possible that the families recollections were different from what the patients' perspectives on advance care planning and the decision to enroll in hospice might have been. 70% of the sample distribution was cancer patients. It may have been useful to ask questions about spirituality but was not done due to respondent burden.
Funding Source	None noted
Comments	Supports Capstone intervention regarding needs of patients and families for end of life education.

Article/Journal	Hospice patients' construction of Hospice's Holistic Care Approach in a Biomedical Culture/Death Studies - Routledge Taylor and Francis Group
Author/Year	Pederson, S., Emmers-Sommer, T./2012
Database/Keywords	EBSCO/hospice care, patient view
Research Design	Qualitative semi-structured Interviews, themes and clusters of meanings identified
Level of Evidence	Level VII
Study Aim/Purpose	To explore patients' perceptions of hospice care in order to understand how hospice patients construct meanings of holistic care.
Population/ Sample size Criteria/Power	10 patients from a non-profit hospice in the southwestern U.S., in a home care setting, 60-90 years of age. Had been in the program between 1-14 months. The study was guided generally by social constructionism which offers the framework to study how people create meaning for themselves and others.
Methods/Study Appraisal Synthesis Methods	Six themes emerged that encompassed patients' understanding of hospice care, which was often unrelated to any holistic elements. Patients regard psychological, emotional and spiritual needs as not a part of their health care treatment, instead the emphasis is on the disease and body as ailing parts.
Primary Outcome Measures/Results	Responses revealed that patients do not experience this comprehensive holistic service that is the design of hospice, perhaps because the hospice mission is co-constructed with the biomedical model of medicine in mind so the holistic services may be lost in translation.
Conclusions/Implications	Findings offer significant insight into the communication of hospice care. The variety of services hospice facilities offer is problematic. Hospice interdisciplinary teams must increase their efforts to communicate the hospice mission to patients.
Strengths/Limitations	Limitations: small sample size, patients were all from the same hospice program, could be considered outliers in that the average length of time with hospice exceeded the 6-month eligibility requirement.
Funding Source	None Noted
Comments	Informs Capstone by providing background for population understanding of hospice and insight into the communication of hospice care.

Article/Journal	Ethics Seminar: The Hospice patient in the ED: An Ethical approach to Understanding Barriers and Improving Care/Academic Emergency Medicine
Author/Year	Zieske, M., Abbott, J. / 2011
Database/Keywords	EBSCO/
Research Design	Integrated review of
Level of Evidence	Level VI
Study Aim/Purpose	Describes the case of a hospice patient who presented with sepsis and end-stage cancer to the ED.
Population/ Sample size Criteria/Power	One case study of a hospice patient who is treated in the ED, admitted to ICU, later to have treatment withdrawn.
Methods/Study Appraisal Synthesis Methods	Presentation of a case of a hospice patient who arrived extremis to the ED and review of the ethical principles surrounding hospice care, highlight the barriers of ED hospice situations and recommendations toward achieving best care for hospice patients in the ED.
Primary Outcome Measures/Results	Hospice patients pose unique ethical challenges when they present to the ED for various but important reasons. ED care providers need to recognize that there are barriers and complexities to the best management of hospice patients and commit to strategies that optimize their care.
Conclusions/Implications	The goal in the ED should be to determine the best way to address terminally ill patient needs while respecting wishes to limit interventions that will only increase suffering near the end of life.
Strengths/Limitations	Limitation: one case study
Funding Source	None noted
Comments	Relates to capstone regarding education of patients and families

Article/Journal	Humanistic Nursing Theory: application to hospice and palliative care/Journal of Advanced Nursing
Author/Year	We, H., Volker, D./ 2011
Database/Keywords	EBSCO/hospice palliative care, Humanistic Nursing Theory, nurses, phenomenology
Research Design	Discussion Paper
Level of Evidence	Level VII
Study Aim/Purpose	To explore patients' perceptions of hospice care in order to understand how hospice patients construct meanings of holistic care.
Population/ Sample size Criteria/Power	10 patients from a non-profit hospice in the southwestern U.S., in a home care setting, 60-90 years of age. Had been in the program between 1-14 months. The study was guided generally by social constructionism which offers the framework to study how people create meaning for themselves and others.
Methods/Study Appraisal Synthesis Methods	Data source presentation of theoretical and research articles and books focused on Humanistic Nursing Theory, which states an understanding of hospice nurses' experiences can be investigated by application of relevant constructs in the theory.
Primary Outcome Measures/Results	The philosophical perspective of Humanistic Nursing Theory are relevant to the practice of Hospice and Palliative care Nursing. By 'being with and doing with', hospice and palliative nurses can work with patients to achieve their final goals in the last phase of life.
Conclusions/Implications	Use of core concepts from Humanistic Nursing Theory can provide a unifying language for planning care and describing interventions. Future research efforts in hospice and palliative nursing should define and evaluate these concepts for efficacy in practice settings.
Strengths/Limitations	Not applicable to the theory discussion
Funding Source	None noted
Comments	Informs Capstone by offering a mid range nursing theory

Article/Journal	Oncology Nurses' Personal Understandings about Palliative Care/Oncology Nursing Forum
Author/Year	Mahon, M., McAuley, W./2010
Database/Keywords	EBSCO/palliative care, hospice, nursing, knowledge
Research Design	Qualitative interviews and analysis
Level of Evidence	Level V
Study Aim/Purpose	To explore the personal understandings that oncology nurses hold about palliative care in general, including its dimensions of symptom management, decision making, and end-of-life care, and their beliefs about when, how and for whom palliative care should be provided.
Population/ Sample size Criteria/Power	12 nurses representing different aspects of oncology nursing
Methods/Study Appraisal Synthesis Methods	An interview guide was employed to ensure that specific topics were covered, and interviews were transcribed verbatim. Qualitative analysis consisted of independent multiple reviews of the transcripts to share initial findings and identify, refine, and reach consensus on major themes and subthemes.
Primary Outcome Measures/Results	Nurses perceptions of palliative care focused on symptom management. Most did not distinguish between palliative care and hospice, and believed that only patients who were near the end of life should receive palliative care, and viewed their role in decisions regarding palliative care to be limited and indirect.
Conclusions/Implications	Although oncology nurses should be at the cutting edge with regard to palliative care, these nurses' personal understandings could serve to limit care for many patients with cancer who could benefit from it.
Strengths/Limitations	study limited to a specific nursing specialty
Funding Source	Sigma Theta Tau
Comments	Informs Capstone intervention with regard to needs assessment

Article/Journal	Preferences for end of life: views of hospice patients, family carers, and community nurse specialists/International Journal of Palliative Nursing
Author/Year	Holdsworth, L., King, A./2011
Database/Keywords	EBSCO/ hospice, preferences, place of death, end of life, palliative care, communication
Research Design	exploratory qualitative study
Level of Evidence	Level VII
Study Aim/Purpose	To explore patients' perceptions of hospice care in order to understand how hospice patients construct meanings of holistic care.
Population/ Sample size Criteria/Power	10 patients from a non-profit hospice in the southwestern U.S., in a home care setting, 60-90 years of age. Had been in the program between 1-14 months. The study was guided generally by social constructionism which offers the framework to study how people create meaning for themselves and others.
Methods/Study Appraisal Synthesis Methods	Semi-structured focus groups facilitated by two researchers with 4 specific topics included. Data analysis from transcription and themes manually coded and compared across the four groups.
Primary Outcome Measures/Results	The patients and carers said it was important to them to discuss their preferences but that discussing dying was difficult. The CNSs stated that there are barriers that inhibit end of life discussions and that these discussions are not a primary goal of care planning. The carers responses showed having more knowledge about what to expect, knowing the wishes of the dying and understanding the role of hospice and palliative care could improve the experience.
Conclusions/Implications	Recording patient preferences is important to ensure patient focused care is delivered, for planning services and for outcome measurement for end of life research.
Strengths/Limitations	small scale study representing a specific group of hospice service users
Funding Source	None noted
Comments	Insight for Capstone regarding patient and family understanding and needs surrounding end of life services.

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