

PALLIATIVE CARE: VIEWPOINTS FROM NURSES

by

Nancy Buttry

B.S.N., California State University, 1979

M.S.N., University of Evansville, 1983

A Dissertation

Submitted in Partial Fulfillment of the Requirements for the  
Doctor of Philosophy Degree in Education  
In the field of Health Education.

Department of Health Education and Recreation  
in the Graduate School  
Southern Illinois University Carbondale  
December 2015

Running head: PALLIATIVE CARE

DISSERTATION APPROVAL  
PALLIATIVE CARE: VIEWPOINTS FROM NURSES

By  
Nancy K. Buttry

A Dissertation Submitted in Partial  
Fulfillment of the Requirements  
for the Degree of  
Doctor of Philosophy in Education  
in the field of Health Education

Approved by:

Kathleen Welshimer, PhD., Chair

Roberta Ogletree, H.S.D.

Kim Miller, PhD.

Dona Reese, PhD.

Richelle Rennagarbe, PhD.

Graduate School  
Southern Illinois University Carbondale

TABLE OF CONTENTS

| <u>CHAPTER</u>                       | <u>PAGE</u> |
|--------------------------------------|-------------|
| CHAPTER 1 – Introduction.....        | 1           |
| Background.....                      | 3           |
| Problem Statement.....               | 7           |
| Purpose of the Study.....            | 8           |
| Need for the Study.....              | 9           |
| Significance.....                    | 10          |
| Research Questions.....              | 11          |
| Research Design.....                 | 12          |
| Sample.....                          | 12          |
| Data Collection Procedures.....      | 13          |
| Data Analysis.....                   | 14          |
| Limitations.....                     | 14          |
| Delimitations.....                   | 15          |
| Assumptions.....                     | 16          |
| Definition of Terms.....             | 16          |
| Summary.....                         | 19          |
| CHAPTER 2 – Literature Review.....   | 20          |
| Purpose.....                         | 20          |
| Quality of Life.....                 | 20          |
| Palliative Care.....                 | 22          |
| Basic (Primary) Palliative Care..... | 22          |

|  |    |
|--|----|
| Specialty Palliative Care .....  | 23 |
| Hospice .....  | 24 |
| History of Palliative Care and Hospice .....                                   | 25 |
| Access to Palliative Care .....  | 28 |
| Barriers to Palliative Care.....   | 29 |
| Theoretical Framework.....   | 32 |
| Nursing.....   | 34 |
| Nursing Education and Palliative Care.....                                     | 35 |
| Basic Nursing Preparation .....  | 35 |
| Nurses’ Knowledge and Palliative Care .....                                    | 36 |
| Research Related to Palliative Care and Nursing .....                          | 37 |
| National Institute of Nursing Research.....                                    | 37 |
| Older Adults and Long Term Care Palliative Care Issues.....                    | 38 |
| Oncology Nursing and Palliative Care .....                                     | 40 |
| Palliative Care in Critical Care Nursing .....                                 | 41 |
| Nursing Attitudes and Palliative Care.....                                     | 42 |
| Nursing Issues, Concerns, and Needs Related to Providing Palliative Care ..... | 43 |
| Palliative Care Team.....  | 45 |
| Public Health, Palliative Care, and Health Education .....                     | 46 |
| Summary .....  | 49 |
| CHAPTER 3– Method.....   | 51 |
| Background.....  | 51 |
| Purpose of the Study .....   | 51 |

|  |    |
|--|----|
| Research Questions.....                                    | 51 |
| Research Design.....                                       | 52 |
| Research Method .....                                      | 52 |
| Sample.....  | 53 |
| Data Collection .....                                      | 55 |
| Research Instruments .....                                 | 57 |
| Interview Guide .....                                      | 57 |
| Demographic Information.....                               | 58 |
| Data Analysis .....  | 58 |
| Validity and Reliability.....                              | 60 |
| Summary .....  | 62 |
| REFERENCES .....   | 63 |
| APPENDICES   |    |
| Appendix A – Correspondence.....                           | 77 |
| Appendix B – Demographic form .....                        | 84 |
| Appendix C – Recruitment Flyer.....                        | 85 |
| Appendix D – Description of study .....                    | 86 |
| Appendix E – Permission letter .....                       | 87 |
| Appendix F – Informed Consent Form.....                    | 88 |
| Appendix G – Informed Consent to Audio-tape interview..... | 89 |
| Appendix H – Script for Focus Group/Interview .....        | 90 |
| Appendix I – Interview Guide .....                         | 91 |

## CHAPTER 1

*You matter because you are you.  
You matter to the last moment of your life.  
We will do all we can to help you, not only die peacefully  
but to live until you die*

Dame Cicely Saunders (1918-2005)  
(Ferrell & Coyle, 2010, p. vi)

Personal experiences with friends and family who did not have a good quality of life before they died has caused me to wonder why more information on palliative care was not provided when it was needed. As a nurse, it was frustrating to deal with unrealistic family members' beliefs that the patient who had a massive stroke was going to walk and talk again after years of being disabled. It was also difficult to deal with the situation of the loved one with liver cancer, in constant pain. Should she be resuscitated in case a cure for cancer was discovered even though she could not breathe without the assistance of the ventilator due to pulmonary hypertension and chronic obstructive pulmonary disease?

These loved ones were not experiencing the quality of life that they would have desired, but due to their medical conditions the family members were controlling the decision-making. I found the lack of understanding on the part of some family members about the patients' true condition frustrating. The question arose that if I found it frustrating I wondered what the doctors and nurses caring for my mother and mother-in-law thought. I observed as the doctors and nurses tried to deal with the dying patients and stressful family dynamics and wondered how it made them feel. I wondered why there had not been more discussion about the importance of comfort measures when there was little to no chance of recovery and if those discussions would have made a difference.

Hospice care was recommended for my mother-in-law on more than one occasion, during the last year of her life, but the family could not agree so no hospice consult was initiated until the day before her death. Hospice for my mother was not mentioned until the day prior to her death even though she had numerous life-threatening health conditions and could no longer care for herself at home for months before her death. My mother had an advance directive but it was not honored due to the fact that she aspirated while being fed by my sister. Mom experienced a respiratory arrest and my sister, not the nursing staff, initiated cardiopulmonary resuscitation which resulted in the intubation and admission to the intensive care unit on a ventilator. Palliative care was not initiated until the very end of both my mother's and my mother-in-law's lives, much later than it should have been and too late to make a difference in the quality of their life.

Hospice was not involved until the last 24 hours of my mother-in-law's life because a family member believed the myth that hospice "just provides morphine (pain medicine) until the patient dies." I wondered what the nurses thought about the family's reluctance to call in hospice when it was so apparent that it was needed. I also wondered how they felt about some family members' insistence for costly, invasive procedures, and hospitalizations that could not change the outcome while other family members were saying "let's keep Mom comfortable."

There were numerous times that I observed as family members insisted on seeking curative measures and high-tech procedures when the prognosis was poor. There were numerous experiences of participating in resuscitation on the dying person while they were surrounded by hospital staff and equipment and no loved ones. I developed the philosophy that I would rather have my loved ones present, holding my hand, instead of someone doing compressions on my chest and putting a tube down my throat to breathe for me artificially. While teaching nursing I

often asked the students to think about what they would want for themselves and their loved ones and to question what their patient would want. Would the patient prefer palliative care?

In order to know if the patient and family would prefer palliative care it is necessary that they know what it is. Definitions of palliative care vary depending on who you ask. Nurses providing care should have a clear understanding of what it means and be able to explain it to the patient and family. It is important to know how the nurse feels about providing and sharing palliative care information with people who have serious or life threatening conditions.

What are nurses' experiences related to palliative care? Do nurses who work in various roles have a clear understanding of palliative care? What are the nurses feelings about the patients' choice to seek or decline palliative care? What do nurses believe about when palliative care should be initiated? Are nurses comfortable discussing palliative care with the patient and medical staff? Do the nurses feel prepared to provide palliative care in their role as a staff nurse, with or without, the existence of a specialist palliative care team? How do nurses feel about providing spiritual support during palliative care? These questions about nurses and palliative care have provided the interest for this study

### **Background**

Nurses are in a unique situation to incorporate and develop the principles and practice of the palliative approach into their daily work (Becker, 2009, para 4). "Hospice and palliative nursing practice is the provision of nursing care for the patient and family, with emphasis on their physical, psychological, emotional and spiritual needs when experiencing a life-limiting illness and through bereavement" (National Board for Certification of Hospice and Palliative Nurses, 2014). According to Becker (2009, para. 4) "the values and beliefs that underpin high-quality

palliative care are integral to good nursing”. Coyle (2010, p. 5) indicates that palliative care is a therapeutic approach that is appropriate for all nurses to practice.

Coyle (2010) describes palliative care nursing as follows:

Palliative care nursing reflects a ‘whole person’ philosophy of care implemented across the lifespan and across diverse health care settings. The patient and family are the unit of care. The goal of palliative nursing is to promote quality of life along the illness trajectory through the relief of suffering, and this includes care of the dying and bereavement follow-up for the family and significant others in the patient’s life (p. 5).

This description of palliative care summarizes some of the important points that relate to nursing. Other terms that appear in the literature that confuse the meaning of palliative care are hospice care, supportive care, terminal care, and end-of-life care. Palliative care for the purpose of this study will include the care provided from the time of diagnosis of a serious or life-threatening illness to bereavement, which will include hospice and end-of-life care.

According to Miller and Ryndes (2005, p. 46), it is essential for growth of palliative care to occur to adequately address the needs of the Baby Boom population. Palliative care should be promoted by healthcare providers, public health professionals, and government entities (Miller & Ryndes, 2005; Giovanni, 2012; White, McClelland, VanderWielen, & Coyne, 2013). Meier (2010) indicated that improving access to palliative care within the current payment system would require:

- A public knowledgeable about what palliative care is and when they should demand it
- Health care professionals with the knowledge, skill, and attitudes necessary to provide palliative care

- Hospitals, nursing homes, office practices, home care agencies, and others equipped with the resources necessary to deliver palliative care services (p. 60).

Nurses are healthcare professionals who are in a position to improve access to palliative care and impact on the policy changes needed. Oftentimes, basic palliative care is provided by healthcare professionals who have not been certified or who are not specialists in palliative care and who may not be invested in pursuing changes.

Palliative care is integral to all healthcare delivery settings (Malloy, Virani, Kelly, Jacobs, & Ferrell, 2008 & End-of-Life Nursing Education Consortium, 2012). According to the *Scope and Standards of Practice Palliative Nursing*

Palliative nursing is provided in the following locations, including inpatient, home, or residential hospice; acute care hospitals or palliative care units; long-term care facilities; rehabilitation facilities; home; ambulatory or outpatient palliative care primary care or specialty clinics; veterans' facilities; correctional facilities; homeless shelters; and mental health settings (American Nurses Association & Hospice and Palliative Nurses Association, 2014, p. 5).

According to the End-of-Life Nursing Education Consortium (ELNEC) nurses must be trained across all health care settings so that as the patient is transferred to different settings the nurses understand and can deliver seamless palliative care (End-of-Life Nursing Education Consortium, 2012, p. 23).

Palliative care is a nursing as well as a public health education issue since patients, their loved ones, and communities need to be aware of what to expect. The American Public Health Association (APHA) action steps include “promotion of the use of hospice and palliative care through education about their availability and benefits among health care providers, public health

professionals, and government entities” (American Public Health Association, 2013). The APHA also urges the federal and state governments to make funding available to “support education and training to develop public health, gerontological, and generalist-level palliative care workforce (including physicians, nurses, social workers, and other health professionals and direct care workers)...” in order to improve population and gerontological health and well being (APHA, 2013). The APHA policy statement includes that the “promotion of the quality of life of seriously ill and dying individuals and their family members, caregivers, and survivors is integral to achievement of the Healthy People 2020 goals” (APHA, 2013, para 7).

The World Health Organization (WHO) definition of palliative care indicates that it relieves suffering and improves quality of life for both patients and families throughout the illness and not just at the end of life (World Health Organization, 2014). According to Stjernsward, Foley, and Ferris, 2007, p. 486) palliative care is only reaching a fraction of the people who need it. Even though providers are referring more patients to hospice care, palliative care and end-of-life programs are still underused. Studies indicate that more than one million patients who could have benefited from hospice care died each year without receiving it (National Quality Forum, 2014). Another concern, according to Meier, (2010, p. 57) is that palliative care does not appear to be timely. The issue of late referral is identified. There is a need for palliative care aimed at symptom management and quality of life to begin at diagnosis (Hermann & Looney, 2011; End of Life Nursing Education Consortium, 2012; & Meier & Brawley, 2011).

Every patient with a life-limiting illness should receive a palliative care consult at the time of diagnosis, according to the End-of-Life Nursing Education Consortium (ELNEC) (2012, p.1). Palliative care has been shown to provide for improved symptom distress and a better quality of life for patients (Meier & Brawley, 2011). Meier & Brawley (2011), refer to the harmful effects

of pain and symptom distress and the benefits of palliative care in addressing them as arguments for earlier and greater involvement of palliative care (p. 2751). Elderly persons who are living with one or more chronic illnesses may benefit from palliative care long before they reach the end of life or need hospice care (National Institutes of Health Senior Health, 2014). According to the NIH Fact Sheet on End-of-Life (2010) approximately 25% of deaths occur in long-term care settings and this figure is expected to increase to 40% by the year 2040. This increase indicates a need for long-term care nurses to be competent in providing palliative care.

According to the *Scope of Palliative Nursing Practice* (American Nurses Association & Hospice and Palliative Nurses Association, 2014), “The nature of palliative care involves inherent stress and emotional demands.” “From the outset, palliative nursing involves providing care that other healthcare providers are uncomfortable or unfamiliar with...” (p. 16). The *Scope of Palliative Nursing Practice* also indicates that caring for patients with serious or life-threatening illness results in constant exposure to crisis, loss, dying, and death (2014, p. 16).

### **Problem Statement**

Nurses interact with people who are affected by serious or life-threatening illnesses in their role as caregivers on a regular basis in numerous settings and in a variety of roles. Appropriate nursing actions can ensure that patients and their loved ones experience quality palliative care from the time of diagnosis through death and bereavement.

The issue of “moral distress” has been discussed as a result of providing end of life care and the controversies that arise during that care. The exposure to a high level of moral distress for the nurses may result in frustration, stress, burnout, feeling worn down, compassion fatigue, and attrition (Kirkey, 2014). Harris (2013) indicated that recruitment and retention of hospice nurses has been a challenge due in part to workplace stress and that the very nature and

emotional demands of the nursing profession make nurses susceptible to workplace stress (p. 446). These conditions can have an impact on the care provided and affect the nurses who provide palliative care.

Nurses employed in small and/or critical access hospitals (hospitals with 25 beds or less), long term care, and community health organizations may not have access to palliative care professionals and will be responsible for providing basic palliative care for their patients. It is not known if these nurses have had basic education, continuing education, or orientation on the topic of palliative care or if there are procedures for access to specialized palliative care for their patients. It is also not known how long term care nurses and community health nurses perceive palliative care, or if any of the nurses have become certified or belong to the professional organizations for hospice and palliative care.

The Institute of Medicine report (2014, p. 2) indicated that “one of the greatest remaining challenges is the need for better understanding of the role of palliative care among both the public and professionals across the continuum...”. Currently there is not a clear understanding of what registered nurses in this mostly rural area know and believe about palliative care or if they perceive that providing palliative care has an impact on them professionally or personally. Viewpoints from nurses who provide care in various healthcare settings in Southern Illinois and Southwestern Indiana will provide a description of palliative care as it exists in this geographic region and may highlight areas of importance related to the provision of palliative care.

### **Purpose of the Study**

The purpose of this study is to describe the perceptions, impact, and meaning of palliative care from the viewpoint of nurses who provide care to patients and their families.

### **Need for the Study**

According to Weissman & Meier (2011) “The need to improve care for patients with serious, complex, and potentially life-threatening or life limiting medical conditions is unquestioned” (p.1). One of the recommendations from the Institute of Medicine (IOM) (2015) was that “all clinicians across disciplines and specialties who care for people with advanced serious illness should be competent in basic palliative care, including communication skills, interprofessional collaboration, and symptom management...” (p.10). The report from the IOM (2014) also indicated that “one of the greatest remaining challenges is the need for a better understanding of the role of palliative care among both the public and professionals across the continuum of care so that hospice and palliative care can achieve their full potential for patients of all ages with serious advanced illness” (p. S-8).

This study will provide information related to a better understanding of the role of palliative care from the viewpoint of the nurse professional. Nurses care for patients with serious advanced illness in the small hospitals, long term care, and community organizations and should be competent in basic palliative care. The question arises as to whether they feel they have been adequately prepared for this role and do they have adequate support or resources for providing quality palliative care in the small hospitals and organizations that exist in this region.

The issue and delivery of competent palliative care involves all nurses and makes it important to know what nurses believe about this issue and how it affects them. Learning what nurses believe about their palliative care experiences will provide information that can be used by nurses in planning palliative care for patients and their families. The information can also be used by nurses, nurse educators, and health education specialists in developing palliative care education for healthcare professionals, patients and families, and for the community.

### **Significance/Importance**

Nurses are at the forefront of providing care to people with serious life-limiting diseases and conditions (American Nurses Association, 2014; White et al., 2013). Nurses' experiences and needs are important factors in ensuring quality care. It is important to examine their beliefs, experiences, perceptions, and issues because they care for patients who are seriously ill and facing death (White et al., 2013, p. 360).

Nurses spend more time than any other healthcare professional at the bedside, in the community, and in clinics caring for people who face end-of-life issues and assist patients in navigating the healthcare system according to ELNEC (2012). Palliative care expands the traditional disease-model medical treatments and embraces quality of life for patients and family members (End-of-Life Nursing Education Consortium, 2012, p. 1).

The nurse's role in the transition to palliative care is to provide care, educate and advocate for patients, and encourage reflection on the implications of end of life (Lewis, 2013, p. 22). Inadequacies in professionals' educational preparation related to end of life conversations and the quality of end of life care have been identified (Giovanni, 2012, p.127) and would affect the patient and their family as well as the nurse.

Numerous studies related to the topic of palliative care focus on knowledge of palliative care principles and professional caregivers' responses to surveys on palliative care skills (Dunn, Otten, & Stephens, 2005; White & Coyne, 2011; White, Coyne, & White, 2012; &White et al., 2013). Principles and skills are important aspects of care but how the nurses feel about their care is also important.

This study will focus on the beliefs, understanding, and feelings of nurses related to palliative care in their role as a caregiver. The recent Institute of Medicine consensus report,

*Dying in America: Improving Quality and Honoring Individual Preferences near End of Life*, (2014) indicated that:

Although palliative care is well established in most large hospitals and professional education programs, the committee identifies the need for greater understanding of the role of palliative care—by both the public and care professionals—as one of the greatest remaining challenges to the delivery of high quality end-of-life care. (Institute of Medicine, 2014, p. 2)

A goal of this study is to learn more about what area nurses understand about palliative care in the settings in which they care for patients. Nurses experience first-hand the palliative care situation and can inform others of their perceptions,

### **Research Questions**

The following research questions were developed:

1. What does palliative care mean to you?
2. What are your experiences related to palliative care?
3. What are your feelings about providing palliative care for your patients?

It is expected that the responses to these questions will provide information about the types of patients cared for, the nurses' ability and comfort level in providing palliative care, any barriers and/or rewards of providing palliative care in their setting, and any other concerns that arise related to palliative care. I will be listening for information related to communication with the patient, family members, and other healthcare professionals and any issues related to providing spiritual care. I will also be listening for information related to educational preparation for providing palliative nursing care that may arise during the discussions with the nurses.

## **Research Design**

The design planned for this study is qualitative research. This phenomenological approach is proposed to gain an understanding and description of nurses' perceptions of their palliative care experiences in this rural geographic area. According to Merriam (2009) "the phenomenological approach is well suited to studying affective, emotional, and often intense human experiences" (p. 26). Palliative care can be an emotional and intense human experience for the patient and their loved ones, as well as for the nurses who provide care for the patients, therefore it is appropriate for this study. Cresswell (2013) defines a phenomenological study as one that "describes the common meaning for several individuals of their lived experiences of a phenomenon" (p. 76). It is my hope that the words of the various nurses about palliative care will describe the phenomenon as they experience it and the meaning it holds for them.

## **Sample**

Purposive sampling, which allows the researcher to select respondents who best meet the purposes of the study (Neutens & Rubinson, 2010, p. 140) will be used in order to reach nurses who can inform on the topic of palliative care. I will contact nurse colleagues, palliative care team nurses, nurse educators, and agency/hospital nurse administrators in Southern Illinois and Southwestern Indiana and ask them to serve as key informants to assist in the recruitment of registered nurses to interview. The nurse administrators will be asked for permission to recruit nurses from their organizations. If needed, a snowball sample will be used, in which those nurses who agree to participate are asked to suggest other nurses. Snowball sampling utilizes well informed people to identify others who have a great deal of information about a phenomenon (Cohen & Crabtree, 2006, & Merriam, 2009).

### **Data Collection Procedures**

Approval will be sought from the Human Subjects Committee, Southern Illinois University prior to the start of the study. Consent forms and procedures for maintaining confidentiality will be reviewed by the committee. Pseudonyms will be used in the written transcripts and data reporting to ensure privacy to the individual.

Once approval is received, key informants, such as the nursing or agency administrator, will be contacted to request suggestions for potential nurses to invite to participate in the focus groups and individual interviews. The researcher will contact the nurses recommended and arrange focus groups and interviews at the time and place agreed upon with the nurses who participate in the study.

Questions from participants will be answered and consent forms completed prior to the start of the focus group or interview. Participants will be made aware that they may decline to answer questions and may withdraw at any time. Focus groups and interviews will be audio-taped once permission is granted. Tapes and transcripts of the focus groups and interviews will be kept secure at the home of the investigator.

Initially, 2-3 focus groups will be conducted, with 6-10 participants each so that, group interaction on the topic of palliative care can be observed. These focus groups are planned so that common themes can be identified from the discussions of the participants. It is estimated that the focus groups will last from 60-90 minutes each. An interview guide will be used for the focus groups and will be revised prior to the interviews based upon the themes that arise during the focus groups.

Following the focus groups individual interviews will be conducted using the revised interview guide to expand on the themes that were identified during the focus group discussions.

The interviews will also last from 60-90 minutes each and will be arranged at a time and place agreed upon with the participant. A total of 10-12 interviews are planned but may be adjusted based on reaching saturation. According to Merriam (2009) the number of participants must be adequate to answer the study question (p. 80). Saturation has been defined as the point where no new additional themes arise during data collection.

### **Data Analysis**

Immediately following each focus group or interview the observational notes will be reviewed for completeness. A transcription service will be used to transcribe the recordings verbatim for analysis. Once the transcription has been received it will be reviewed for accuracy by listening to the recording and comparing it to the transcription. The observational notes will then be added to the transcription for review.

A research journal will be used to keep track of the research process from the beginning through the completion of the study. According to Merriam (2009) the journal should include reflections, questions, and decisions made with regard to problems, issues, or ideas encountered in data collection and throughout the analysis and interpretation (p. 223).

NVivo 10 for Windows (QSR International, 2014) is a computer software program that will be used to organize and file the information from the verbatim transcripts of the interviews, the observation notes, and the research journal. The software will allow the researcher to identify, code, and organize the themes identified in the data. Transcripts will be reviewed by two other nurses and the themes identified by each will be compared with those identified by the researcher as a peer review process.

### **Limitations**

The limitations of the study include the following:

1. The use of focus groups for identification of themes may not result in all themes related to palliative care being identified.
2. There is a possibility that nurses may have difficulty identifying or remembering specific patient situations that involve the issue of palliative care and may not be able to recall or be willing to share their feelings.
3. Results will not be generalizable to all nurses in this or other geographic regions.
4. Snowball sampling may result in the participants having similar backgrounds and may decrease the opportunity for varied responses.
5. Nurses may not be willing to participate in a focus group or interview that lasts from 60-90 minutes.
6. The small number of nurses involved in the focus groups and interviews may not reflect all of the pertinent issues that might arise with additional participants.
7. My personal beliefs and experiences related to palliative care, as well as my nursing experience, may have an influence on the data collection, analysis, and conclusions.
8. Key informants will be used to identify participants and may not reflect as broad of a sampling of nurses as desired.

### **Delimitations**

The delimitations that should be considered include:

1. Nurses will be registered nurses, who are not certified in hospice and palliative care.
2. Nurses will not be a member of a palliative care team or currently employed in hospice nursing.

3. The sampling of nurses will be limited to Southern Illinois and Southwestern Indiana.
4. The data collection will occur over a 3-4 month period in 2015.
5. The participant will be involved in a single focus group or interview which may not allow for in-depth exploration and reporting of their feelings.

### **Assumptions**

The study was based on the following assumptions:

1. Nurses will be honest and frank during the focus group and interview.
  2. The nurses can recall and are willing to share their experiences about patients and palliative care.
  3. It is expected that most of the nurses' experiences will relate to care of adult patients.
  4. Nurses will be able to recall what they have been taught about palliative care.
  5. The phenomenon of palliative care is, initially, assumed to be the same for registered nurses who provide care across the continuum of healthcare settings.
- This assumption will be tested during the study.

### **Definition of Terms**

*Basic palliative care*-Palliative care that is delivered by health care professionals who are *not* palliative care specialists, such as primary care physicians who are disease-oriented specialists (such as oncologists and cardiologists); and nurses, social workers, pharmacists, chaplains, and others who care for this population but are not certified in palliative care (Institute of Medicine, 2014, p.1-6).

*Bereavement*- “the state of having experienced the death of a significant other” (Ferrell & Coyle, 2010, p. 598)

*Critical access hospitals (CAH)* - a hospital certified under a set of Medicare conditions of participation which include having no more than 25 inpatient beds, maintaining an annual average length of stay no more than 96 hours for acute inpatient care, offering 24-hour, 7-day-a week emergency care and being located in a rural area at least 35 miles drive away from any other hospital or CAH (fewer in some instances) (U. S. Department of Health and Human Services, n.d.).

*End-of-life care*- “Refers generally to the processes of addressing the medical, social, emotional, and spiritual needs of people who are nearing the end of life. It may include a range of medical and social services, including disease specific interventions as well as palliative and hospice care for those with advanced serious conditions who are near the end of life” (Institute Of Medicine, 2014, p. 1-6).

*Hospice*- “Is a service delivery system that provides palliative care for patients who have a limited life expectancy and require comprehensive biomedical, psychosocial, and spiritual support as they enter the terminal stage of an illness or condition” (National Quality Forum, 2006, p. 3). It also supports family members coping with the complex consequences of illness, disability, and aging as death nears and during bereavement.

*Moral distress*- “the emotional condition in which a clinician is unable to act upon the ethically appropriate course of care due to external or internal constraints” (Weissman, 2009, p. 865).

*Palliative care*- “Care that provides relief from pain and other symptoms, supports quality of life, and is focused on patients with serious advanced illness and their families.

Palliative care may begin early in the course of treatment for a serious illness and may be delivered in a number of ways across the continuum of health care settings, including in the home, nursing homes, long-term acute care facilities, acute care hospitals, and outpatient clinics. Palliative care encompasses hospice and specialty palliative care, as well as basic palliative care” (Institute Of Medicine, 2014, p. 1-6) “Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information and choice” (National Consensus Project for Quality Palliative Care, 2013, p. 3).

*Palliative care team-* partnership of patient, medical specialists, and family. Usually a team of experts, including palliative care doctors, nurses and social workers, who provide care and work with the patient’s doctor (Center to Advance Palliative Care, 2014). An area of special expertise within medicine, nursing, social work, pharmacy, chaplaincy, and other disciplines according to the Task Force on Palliative Care (1997, para. 3).

*Serious or life-threatening illnesses-* Includes populations of patients at all ages within the broad range of diagnostic categories where they are living with a persistent or recurring medical condition. These conditions adversely affect the person’s daily functioning or will predictably reduce their life expectancy, or result in poor quality of life. It includes people who are unlikely to recover or stabilize (National Consensus Project, 2013, p. 8-9).

*Specialty palliative care-* “Palliative care that is delivered by health care professionals who *are* palliative care specialists, such as physicians who are board certified in this specialty; palliative-certified nurses; and palliative care-certified social workers, pharmacists and chaplains” (Institute Of Medicine, 2014, p. 1-6).

*Quality of life*- “a broad ranging concept that is affected in a complex way by the person’s health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment” (World Health Organization, 1997).

### **Summary**

Listening to the voices of nurses discuss palliative care can provide information about what palliative care means to nurses. The results of the study can be used by nurses, public health professionals, and health education specialists in program and educational planning. I found no studies that focused on nurses’ perceptions of basic palliative care for this region or that sought perceptions from registered nurses who work in small and critical access hospitals, long-term care, and community health settings.

This chapter includes the introduction, background, problem statement, purpose of the study, and need for the study, significance, research questions, research design, sample, data collection procedures, and data analysis. The limitations, delimitations, assumptions, and definition of terms for this study are also included in this chapter.

## **CHAPTER 2**

### **LITERATURE REVIEW**

This chapter presents a review of the literature related to palliative care and nursing. It will include information on quality of life, palliative care, hospice, the history of palliative care, access to palliative care in the United States, and a theoretical framework related to palliative care delivery. This chapter will also include information on nursing and palliative care research, palliative care teams, and public health and palliative care.

#### **Purpose**

The purpose of this study is to describe the perceptions, impact, and meaning of palliative care from the viewpoint of nurses who provide care to patients and their families. Information gained from the interactions with nurses will provide insight into what the nurses understand about palliative care in the settings in which they care for patients.

#### **Quality of Life**

Quality of Life has been defined by the World Health Organization (WHO). It can be used to describe quality of life for all patients and their families and is written as follows:

WHO defines Quality of Life as individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment. (World Health Organization, 1997, p. 1)

Quality of life is what palliative care is all about according to Cramer (2010, p. 54).

Palliative care includes providing good symptom management, being able to have difficult

conversations, being “present”, and championing quality of life. Meier and Brawley indicate that “the need for palliative care is no longer linked to prognosis” and that it should be provided to all patients with serious and advanced illness (p. 2750). O'Shea (2014) indicated that nurses can potentially improve the quality of life for hospitalized older adults by acting as informed advocates and promoting palliative care services earlier in the course of the illness trajectory (p. 33).

Palliative care describes care of patients living with a potentially life-limiting illness that focuses on maximizing quality of life and is not limited by prognosis or setting of care (Lynch, Dahlin, Huffman, & Coakley (2011, p 106). According to the Institute of Medicine , “A palliative approach can offer patients near the end of life and their families the best chance of maintaining the highest possible quality of life for the longest possible time” (IOM, 2014, p. S-5). The IOM (2015) indicated that palliative care has been associated with a higher quality of life (p. 101).

Hermann and Looney (2011) indicate that understanding the symptom experience, particularly symptom distress, is crucial to improving care for individuals near the end of life. Their research supported the concept that patients experiencing the most symptom frequency, severity, and distress, including depression, reported the lowest quality of life (p. 29). However, Meier and Brawley (2011) explain that earlier palliative care may address the harmful effects of pain and symptom distress which would lead to improved outcomes related to quality of life (p. 2751). Nurses have responsibility for providing pain and symptom management.

The American Nurses Association (ANA) has adopted a position statement on nursing roles and responsibilities in providing expert care and counseling at the end of life. Providing “the highest quality of remaining life and support at the end of life for both patients and their

loved ones” is considered part of the role of the nurse (Nursing World, 2010). This nursing role is considered traditional, accepted, and expected, according to Nursing World (2010) and includes the relief of suffering, whether physical, emotional, or spiritual.

### **Palliative Care**

“Palliative nursing embraces and reflects a holistic philosophy of care provided to patients with serious or life-threatening illness in diverse health settings, across the lifespan.” (American Nurses Association & Hospice and Palliative Nurses Association, 2014, p. 4). According to the *Scope of Palliative Nursing Practice* (p. 2) palliative care is patient and family centered care across the spectrum of illness; begins with supportive care at the time of diagnosis of a serious or life-threatening illness and ends with bereavement care; and relieves physical, psychological, emotional and spiritual suffering of those with a serious or life-threatening illness. In addition it is comprehensive and reaches across health settings and is interdisciplinary and collaborative. Palliative care research has demonstrated that palliative care decreases hospitalizations and promotes better care (ANA and HPNA. 2014, p. 16).

### **Basic (primary) Palliative Care**

Palliative care has been described as being embedded in nursing practice which means that all nurses practice primary palliative care (ANA and HPNA, 2014, p. 19). Areas considered essential for palliative nursing include: “self-awareness and compassion; sensitivity to death and dying; strong communication skills with patients, families, and interdisciplinary colleagues; keen assessment skills; and the ability to devise and implement evidence-based plans” (p. 19). According to the *Scope of Palliative Nursing Practice the National Council Licensure Examination for Registered Nurses* (NCLEX-RN) includes palliative care content for licensure.

The definition for basic palliative care according to the IOM (2014, p. 27) states:

basic (or, as it is sometimes called in the literature, “primary”) palliative care, delivered by health care professionals who are *not* palliative care specialists, such as primary care clinicians, physicians who are disease-oriented specialists (such as oncologists and cardiologists), and others (such as nurses, social workers, pharmacists, and chaplains) who care for this population but are not certified in palliative care.

There is a desire for more generalist hospice and palliative nurses to become certified as Hospice and Palliative Nurses.

### **Specialty Palliative Care**

Currently specialty palliative care is hospital based and offered as a consultative service but recently there has been growth in services in outpatient settings, at home, in nursing homes, and long-term acute care facilities (IOM, 2015). The definition for specialty palliative care according to the IOM (2015, p. 27) is as follows:

Palliative care that is delivered by health care professionals who *are* palliative care specialists, such as physicians who are board certified in this specialty; palliative-certified nurses; and palliative care-certified social workers, pharmacists, and chaplains.

Hospice and palliative nurses care for patients who have difficult pain and symptom issues. The nurses high-dose opioids; medications normally reserved for intensive care units within general care units; withdrawal of technology such as ventilators, noninvasive oxygen, pressors, antibiotics, dialysis, artificial nutrition and hydration; and palliative sedation (ANA and HPNA, 2014, p. 14).

The Standards of Practice for Palliative Nursing include competencies for hospice and palliative registered nurses and in addition have indicated additional competencies for the hospice and palliative graduate-level prepared specialty nurse or the advanced practice registered nurse. Specialty nurses will not be included for the purposes of this study.

### **Hospice**

Hospice is a program of care for people who are terminally ill and have been determined by their physician and the hospice medical director to be terminally ill and have six months or less to live (Centers for Medicare & Medicaid Services 2013). The focus of hospice is on comfort and not on curative measures. “Hospice is an important approach to addressing the palliative care needs of patients with limited life expectancy and their families” (Institute of Medicine, 2014, p. S-5). The IOM report (2014) includes that “for people with a terminal illness or at high risk of dying in the near future, hospice is a comprehensive, socially supportive, pain-reducing, and comforting alternative to technologically elaborate, medically centered interventions” and that it has many features in common with palliative care (p. S-5). Some of the services provided are physical care, counseling, drugs, equipment, and supplies for the terminal illness and related conditions and the care is generally provided in the home (Centers for Medicare & Medicaid Services, 2013).

Meier and Brawley (2011, p. 2750) indicate that “hospice professionals focus on caring for patients who have a clearly defined life expectancy and who have made an informed decision to discontinue curative care”. Hospice has been viewed as a subset of palliative care that is especially targeted to the needs of those near death according to Jennings, Ryndes, D'Onofrio, and Baily (2003, p. 57). Harris (2013) indicates that nursing has and continues to be a prominent

force in the hospice movement and that in addition to pain control and symptom management the nurse must also provide psychological and spiritual support (p. 446).

Most of the patients receiving hospice care receive that care in the place that the patient calls “home” which might include a private residence, nursing home, or residential facility (National Hospice and Palliative Care Organization, [NHPCO], 2014). Others may be in a hospice inpatient facility, acute long-term care facility, or acute care hospital. Nurses interact with hospice patients in all of these places.

The primary diagnosis for patients admitted to hospice was cancer at 36.5% in 2013 (NHPCO, 2014, p. 7). The top four non-cancer diagnosis included dementia (15.2%), heart disease (13.4%), lung disease (9.9%), and debility unspecified (5.4%) (NHPCO, 2014, p. 7). It is interesting to note that 48.8% of patients admitted to hospice died or were discharged within 14 days of admission and the median length of service was 18.5 days in 2013 (NHPCO, 2014). The percentage of hospice patients by race reported in 2013 was White/Caucasian at 80.9% with Black/African American next at 8.4%. (p. 7). It is important to remember that palliative care may be provided as part of hospice care for those patients who have been diagnosed with a life expectancy of six months or less.

### **History of Palliative Care & Hospice**

The term “hospice” can be traced back to medieval times when it referred to a place of shelter or a place to rest for weary or ill travelers on a long journey (National Hospice and Palliative Care Organization, [NHPCO], 2014). Dame Cicely Saunders created the first modern hospice, St. Christopher’s Hospice, in a residential suburb of London. Saunders introduced the idea of specialized care for the dying to the United States in 1963 during a visit to Yale University. In 1968 Florence Wald went to St. Christopher’s Hospice to learn about hospice and

in 1974 she founded Connecticut Hospice in Branford, Connecticut with two pediatricians and a chaplain. Dr. Elizabeth Kubler-Ross was a pioneer in research on death and dying and wrote *On Death and Dying* which was based upon more than 500 interviews with dying patients in 1969. Her writings are credited with popularizing the approach and concept of hospice in the United States (IOM, 2015, p. 60).

The term “palliative care” was coined by Dr. Balfour Mount, a surgical oncologist, from Montreal, Canada in 1974 in order to avoid the negative connotations of the word hospice in French culture (Loscalzo, 2008, p. 465). The United States Department of Health, Education, and Welfare task force report in 1978 reports that “the hospice movement as a concept for the care of the terminally ill and their families is a viable concept and one which holds out a means of providing more humane care for Americans dying of terminal illness while possibly reducing costs” and “is the proper subject of federal support” (NHPCO, 2014). In 1979 the Health Care Financing Administration (HCFA) initiated demonstration programs at 26 hospices across the country to assess the cost effectiveness of hospice care and to help determine what a hospice is and what it should provide (NHPCO, 2014). A Medicare hospice benefit was enacted in 1982 with a sunset provision in 1986. In 1986 the Medicare Hospice Benefit was made permanent. States were given the option of including hospice in their Medicaid programs, and hospice care became available to terminally ill residents in nursing homes. In 1991 hospice care was recommended to be included in the veteran’s benefit package.

By 1997 the growing end-of-life movement focused national attention on quality of life at the end-of-life as well as the need for increased public awareness and physician education. The hospice philosophy and concept of care were considered central to models for palliative and end-of-life care (NHPCO, 2014).

Hospice and palliative medicine was recognized as a medical specialty in 2006 by the American Board of Medical Specialties (NHPCO, 2014). In 2007 research published in the *Journal of Pain and Symptom Management* reported that hospice patients live an average 29 days longer than similar patients without hospice care (NHPCO, 2014). The NHPCO called for increased access to palliative care in critical care settings in 2008 (2014). In 2009 *Quality Guidelines for Hospice and End-of-Life Care in Correctional Settings* was published and a campaign to help improve the hospice and palliative care provided to Veterans was launched by NHPCO in collaboration with the Department of Veterans Affairs in 2010.

A program for certification of the specialty practice of hospice and palliative care nursing was developed and the first certification exam for hospice nursing was given in 1994 (National Board for Certification of Hospice and Palliative Nurses, 2014). Doctors and nurses can now provide specialty palliative care if they have been certified. In 1999 the certification for registered nurses was expanded to include palliative care and successful nurses were credentialed as Certified Hospice and Palliative Nurses.

Current observations related to palliative care are that there is an increasing number of elderly Americans who have frailty, physical and cognitive disabilities, multiple chronic illnesses, and functional limitations; and that palliative care services are not keeping pace with the growing demands (Institute of Medicine, 2014, p. 1-4). Another current issue related to palliative care concerns the availability to vulnerable populations. McHugh, Arnold, & Buschman (2012, p. 141) write that it is important to reach out to those who are vulnerable, marginalized, and alienated from health care and who are experiencing chronic and terminal illnesses. Vulnerability factors include poverty, lower educational achievement and health literacy, ethnic minorities, undocumented immigrants, mental illness, incarceration, and

homelessness. Nurses may come in contact with these vulnerable populations who need palliative care in shelters, prisons, hospitals, nursing homes, and other settings in which nurses are employed (McHugh, et al., p. 142).

### **Access to Palliative Care**

Even though it is important for palliative care to begin at the time of diagnosis there is evidence that it may not be a reality for all people. Even though research shows that palliative care programs are increasing in the United States there is disparity in access and quality geographically (Giovanni, 2012 & Meier, 2010). “The prevalence of palliative care in U.S. hospitals with 50 beds or more has increased 157.1% over the past 11 years” (Center to Advance Palliative Care, [CAPC], 2013). Palliative care programs in the Midwest totaled 53% regardless of hospital size compared to 74% of hospitals in the more densely populated Northeast (CAPC, 2013). According to the Center to Advance Palliative Care (2012) palliative care has been one of the fastest growing trends in health care over the last ten years.

Chances of having access to palliative care are extremely limited if you live in a region where there are only small hospitals, less than 50 beds (CAPC, 2011). Palliative care in the small, rural agencies that do not have access to palliative care teams may be different than that provided in larger urban agencies. Hospitals with fewer than 50 beds in Illinois and the Midwest region that had palliative care teams were both 13% compared to the National rate of 22% (CAPC, 2011). This area needs more palliative care programs to keep pace with the national rate to ensure that palliative care is available when needed. This supports the need for all nurses to be familiar with palliative care.

Nurses who are employed in the numerous critical access hospitals (CAH) and small hospitals in rural areas need to be able to provide basic palliative care because the smaller

agencies are less likely to have established palliative care programs and teams so the nurses in these agencies must be knowledgeable and comfortable with providing palliative care.

The IOM (2015) indicated that “the number of hospice and palliative care specialists is small, which means that the need for palliative care must be met through primary care...”. Also, even though the education of health professionals who provide end-of-life care has improved substantially in the past two decades the knowledge gains have not necessarily been transferred to clinicians caring for people who are nearing the end of life (IOM, 2015, p. 2). Another challenge identified is the failure of the availability of palliative care services to keep pace with the growing demand and that palliative care is still currently unavailable in many geographic areas and in many settings where people with advanced serious illness receive care (IOM, 2015, p. 102).

Palliative care should encompass access to an interdisciplinary palliative care team, including board certified hospice and palliative medicine physicians, nurses, social workers, and chaplains and access may be on site, via virtual consultation, or by transfer to a setting with these resources and this expertise (IOM, 2015, p. 103). In addition it is recommended that all people with advanced serious illness have access to skilled palliative or hospice (if appropriate) care in all settings where they receive care. Nurses should be able to share information on the status of palliative care in this rural region.

### **Barriers to Palliative Care**

Primary barriers to palliative care and hospice are the variability in access by geographic and other characteristics, an inadequate workforce and workforce pipeline to meet the needs of patients and their families, and the need for an adequate research evidence base to guide and measure quality of care (Meier, 2011, p. 354). Meier also identified the lack of public

knowledge of, and demand for, the benefits of palliative care and hospice as barriers (2011). An inadequate medical and nursing workforce with expertise in palliative care was one of the greatest barriers to access according to Meier (2011, p. 356).

The fact that nurses play a key role in the coordination and delivery of palliative care in rural settings prompted a study to identify barriers and enablers to providing palliative care in rural Canadian communities from a nursing perspective (Kaasalainen et al., 2012). This study was a qualitative descriptive study that found that community-dwelling clients who are dying need nurses who are equipped with the knowledge, tools, and skill sets to provide optimal palliative care. Telephone interviews were conducted to gain information on the barriers and enablers that nurses experienced while trying to provide palliative care to clients who lived in a rural community. Working with families, conflict among the health care team, and unpredictable trajectories of illness in care management were considered barriers to palliative care. In addition, long distances involved and time required for visiting in the homes were also indicated as barriers by the nurses. The study concluded that “further work is needed to build stronger supportive networks between rural clinicians and specialized care clinicians, both among rural and urban communities” (Kaasalainen et al., 2012, p. 97).

The 2012-2015 Research Agenda published by HPNA (2011) indicated concern that there is sparse empirical evidence to support the integration of palliative care concepts into standard care, especially in rural, resource poor communities. The absence of discussions from formal and informal caregivers and those living with complex illness was also noted in the report. “Additional research about the barriers to providing palliative care to those with complex chronic illness can better inform healthcare policy” according to the research agenda published by the Hospice and Palliative Nurses Association (2011, p. 6).

O'Shea (2014) referred to the “lack of clarity” about what is meant by the term palliative care as a barrier to its use. In her research on staff nurses’ perception regarding palliative care she found that participants in the study commonly equated palliative care with hospice care and that nurses used the terms interchangeably (O'Shea, 2014, p, 32). Recommendations from her study included providing education and promoting use of best-practice guidelines to integrate palliative care content with core competencies for all health care providers and to further research into the perceptions and experiences of staff nurses who care for hospitalized older adults (pp.33-34).

Palliative nursing competencies identified in the *Scope of Palliative Nursing Practice* include clinical judgment, advocacy and ethics, professionalism, collaboration, systems thinking, cultural competence, facilitation of learning, and communication (ANA and HPNA, 2014, pp 22-24). The core competencies, identified by the European Association for Palliative Care (EAPC), indicate that these are globally relevant to all who practice palliative care at the general level and include the following:

1. Apply the core constituents of palliative care in the setting where patients and families are based
2. Enhance physical comfort throughout the patients’ disease trajectories
3. Meet patients’ psychological needs
4. Meet patients’ social needs
5. Meet patients’ spiritual needs
6. Respond to the needs of family carers in relation to short-, medium- and long-term patient care goals

7. Respond to the challenges of clinical and ethical decision-making in palliative care
8. Practice comprehensive care co-ordination and interdisciplinary teamwork across all settings where palliative care is offered
9. Develop interpersonal and communication skills appropriate to palliative care
10. Practice self-awareness and undergo continuing professional development

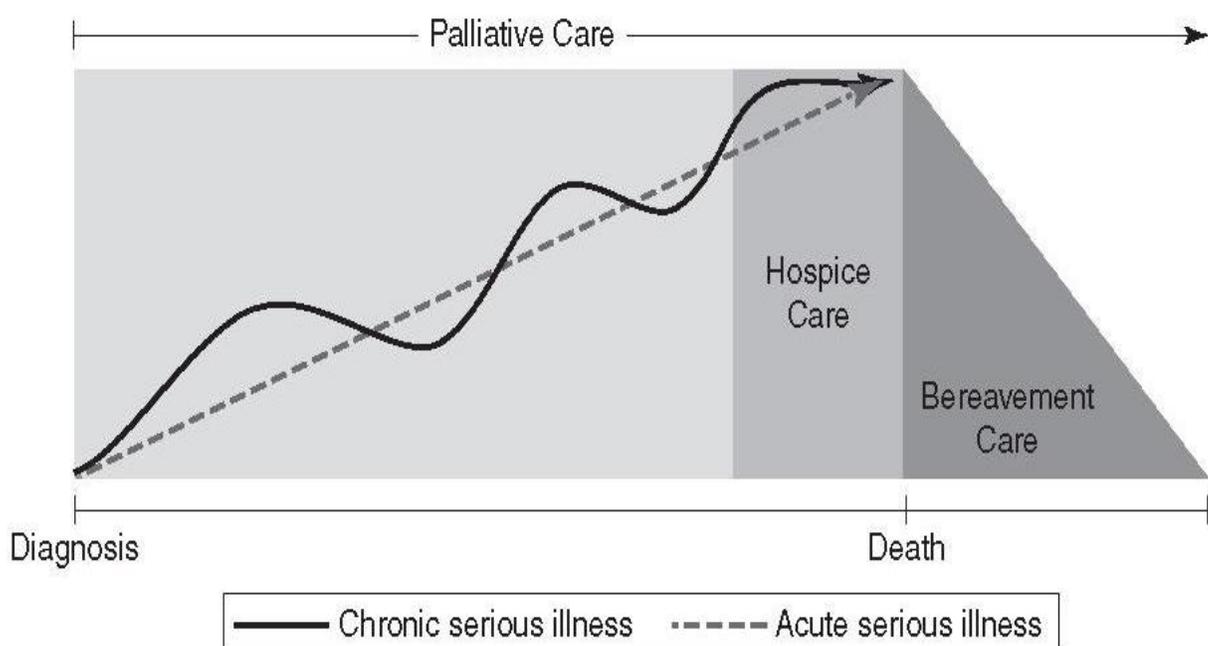
(Gamondi, Larkin, and Payne, 2013, p. 90).

### Theoretical Framework

The *Palliative Care's Place in the Course of Illness* model provides a picture view of the components of palliative care, curative or disease modifying care and discharge. Note that the model depicts the diagnosis as the beginning of both curative therapy and palliative care measures, with more focus on curative in the early phase of the condition (National Consensus Project, 2009). Ferrell (2004) indicated that palliative care needs to be initiated earlier, at the time of diagnosis, and not just in the weeks or months preceding death and this model demonstrates that concept. The literature supports the need for palliative care to be initiated early in the course of the diagnosis and throughout (Meier & Brawley, 2011; Hermann & Looney, 2011; & Institute of Medicine, 2014). (Permission granted to use model CAPC)



A newer model of palliative care indicates that the course of illness may at times be more focused on disease-modifying or palliative symptom management depending on the course of the illness. It signifies that the course of the care might be less linear and more of a continuum of ups and downs. This means that the caregiver will be required to be flexible depending on the wishes of the patient and family. It is also possible that not all of the patients will choose to engage in hospice care prior to their death.



©HOSPICE AND PALLIATIVE NURSES ASSOCIATION, 2013

(Figure used with permission from Hospice and Palliative Nurses Association)

The *Trajectories of Palliative Care* model shows the trajectories of chronic serious illness and acute serious illness from the time of diagnosis to death (American Nurses Association & Hospice and Palliative Nurses Association, 2014, p. 2). The wave-like progression of the chronic condition depicts the periods of stabilization and exacerbation which results in more variable palliative care needs as the condition progresses and time passes. Curative and palliative care begins at diagnosis. Palliative care continues through hospice care, which may or may not be

initiated during the last six months of life, and includes a period of bereavement. Knowledge of the palliative care trajectories provides focus for the delivery of care. It can provide nurses with a clear understanding that care for the patient can occur all along the continuum in numerous settings.

Nurses care for patients in hospitals, long term care facilities, living in communities (home-visiting and public health) and who are healthy and independent as well as those who are sick and dependent (Izumi, Nagae, Sakurai, & Imamura, 2012, p. 616). Nurses are involved in providing relief of pain and other symptoms while the determination is made between comfort care and disease-oriented care (Mazanec et al., 2009). Nurses are a part of the care when people may be suffering from a chronic and/or serious illness and interact with patients and their families all along the continuum from diagnosis to death and can relate to this model.

### **Nursing**

The Hospice and Palliative Nurses Association has published position statements that guide the nursing care of patients. The statements include that; “competent professional nursing care is critical to achieving health care goals of patients, families, communities and populations through the end of life” and “palliative nursing can serve as a model for addressing the needs of the chronically ill” (HPNA, 2011, p. 2).

Another statement from HPNA (2013): *Assuring High Quality in Palliative Nursing*, includes that “all patients with serious or life-threatening illness should have access to high-quality palliative care” and “as individuals and as members of the interdisciplinary team, nurses are accountable for the quality of palliative care provided to patients and their families” (p. 3). Nurses in all specialties are at the forefront of providing care to persons with a serious life-limiting diagnosis according to White, McClelland, VanderWielen, & Coyne (2013). “Nursing,

like palliative care, focuses on pain and symptom management, patient advocacy and education of the patient and family” (Robert Wood Johnson Foundation, 2012). Nurses care for patients with or without a palliative care team so they need the basic competencies of palliative care and will be providing care along the continuum whether the care is curative or palliative.

Essential concepts for palliative nursing are self-awareness and compassion; sensitivity to death and dying; strong communication skills with patients, families, and interdisciplinary colleagues; keen assessment skills; and the ability to devise and implement evidence-based plans (American Nurses Association & Hospice and Palliative Nurses Association, 2014. p. 19).

“Because palliative care is embedded in nursing practice, all nurses practice primary palliative care” according to the Scope and Standards of Practice for Palliative Nursing (American Nurses Association & Hospice and Palliative Nurses Association, 2014, p. 19). White et al., (2013, p. 365) state that “Nurses in all specialties need competencies in care for persons with serious life-limiting illnesses and an understanding of the benefits of palliative care options”.

## **Nursing Education and Palliative Care**

### **Basic Nursing Preparation**

Nurses spend more time with patients and families facing the end of life than any other health professional according to the ELNEC: End-of-Life Nursing Education Consortium (City of Hope & American Association of Colleges of Nursing, 2014). In addition ELNEC believes that nurses are intimately involved in all aspects of end-of-life/palliative care. The document *“Peaceful Death: Recommended Competencies and Curricular Guidelines for End-of-Life Nursing Care”* resulted from a roundtable project hosted by the American Association of Colleges of Nursing (AACN) and described the knowledge and skills needed by nurses to

provide quality care. The document also encouraged that the content be integrated into nursing curriculum.

AACN and the City of Hope developed the End-of-Life Nursing Education Consortium curriculum. The core curriculum contains eight modules that address critical aspects of end-of-life care. The modules include 1) Palliative Nursing Care; 2) Pain Management; 3) Symptom Management; 4) Ethical Issues in Palliative Care Nursing; 5) Cultural Considerations in Palliative Care; 6) Communication; 7) Loss, Grief & Bereavement; and 8) Final Hours.

### **Nurses' Knowledge and Palliative Care**

Research to measure nurses' knowledge of palliative care and to identify educational needs has been conducted (Ross, McDonald, & McGuinness, 1996 & Chiplaskey, 2008). A tool called the *Palliative Care Quiz for Nursing* (PCQN) was developed to assess knowledge, stimulate discussion about provision of palliative care, and identify misconceptions about palliative care practice (Ross, McDonald, & McGuinness, 1996). This research allowed the participant to respond to questions about palliative care but did not allow for the verbal sharing of personal experiences or concerns that might be gained from a qualitative study.

Communication issues with patients and their family members were identified as concerns for nurses providing care for dying patients by Peterson et al., (2010, p. 185). The results of their research resulted in the conclusion that communication training programs are needed to benefit the nurses and to provide the best care for their patients (Peterson et al., 2010, p. 186). How to talk to patients and their families about death and dying ranked in the top three of the core competencies in research done by White and Coyne (2011). Symptom management and basic palliative care knowledge were the other care competencies, in the top three, identified by the nurses studied (p. 716). The implications from the White and Coyne (2011) study

included that there is a need for quality palliative care education and that palliative care continuing education should be viewed as a basis for continued competency in evidence-based nursing practice (p 717).

Another study involved development of a web-based survey to investigate educational needs of professionals providing end of life and palliative care (Lazenby, Ercolano, Schulman-Green, & McCorkle, 2012). The study included nurses, physicians, and social workers in one state and focused only on the professional educational needs. The research was done to validate an instrument that focused on the eight domains of palliative care which include structure and processes of care; physical aspects of care; psychological and psychiatric aspects of care; social aspects of care; spiritual, religious, and existential aspects of care; cultural aspects of care; care of the patient at the end of life; and ethical and legal aspects of care.

### **Research Related to Palliative Care and Nursing**

#### **National Institute of Nursing Research**

The Director of the National Institutes of Health (NIH) in 1997 designated the National Institute of Nursing Research (NINR) as the lead institute for end of life care research because of nursing science's emphasis on the understanding and enhancing the care of persons with serious and advanced illnesses across the lifespan (National Institute of Nursing Research, [NINR], 2013). The NINR reviewed the published EOL and palliative care research literature over the period of time from 1997 to 2010 in order to determine the trends, nature and extent of end of life palliative care research (NINR, 2013, p.iv).

The topics and the funding for the NINR project research publications were reviewed for the purpose of addressing existing gaps and priorities for future EOL and palliative care research. It was interesting to note that the number of publications in EOL and palliative care science had

tripled. A total of 3,155 research publications with EOL and palliative care themes were identified and coded (NINR, 2013, p. v). More than two-thirds of the publications reviewed focused on cancer as the primary health condition. The majority of the published research on EOL and palliative care science focused on advance care planning (12.5%), care settings and types of care (12%), and pain and other symptom management (11%). Only 5.2% of all publications focused on education and training and less than 5% of all the research publications focused on areas such as caregiving, standards of care, models of care, and others (NINR, 2013, p. x).

One of the trends identified, related to end of life palliative care research, was the changing demographics. Demographics such as age, sex, and race impact the rank order of the leading causes of death in the United States. The majority of Americans now die from chronic, progressive illnesses or degenerative diseases that are often accompanied by prolonged periods of physical dependency and increased frailty (NINR, 2013, p. 4). These trends guide research needs. According to the NINR report (2013) “Identifying research priorities to guide evidence-based palliative and end-of-life care becomes increasingly important as our population ages”.

### **Older Adults and Long Term Care Palliative Care Issues**

The National Center for Chronic Disease Prevention and Health Promotion states that the current growth in the number and proportion of older adults in the United States is unprecedented in our nation’s history (Centers for Disease and Prevention, 2013, p. 1). It is projected that by 2030 the over 65 population will nearly triple as a result of the Baby Boomers and that more than six of ten will be managing more than one chronic condition (American Hospital Association and First Consulting Group, 2007 p. 2). According to the report *When I’m 64: How Boomers will Change Health Care* (American Hospital Association and First

Consulting Group) boomers will require palliative care to manage pain, control symptoms, and improve quality of life for as long as life remains (p.8).

Ersek, Kraybill, and Hansen (2006) indicate that by the middle of this century more than 40% of American deaths are expected to occur in nursing homes and that this indicates a need for long term care staff to be prepared for this trend. Ersek et al. also write that studies suggest that staff working in this setting lack sufficient knowledge about hospice and palliative care. Kelly, Ersek, Virani, Malloy, and Ferrell (2008) recognize that educating geriatric nurses to provide end-of-life and palliative care is an important health care priority and that the End-of-Life Nursing Education Consortium (ELNEC) Geriatric Training Program is an initiative to improve care provided by nurses in long-term care facilities and nursing homes.

Long term care may be provided in the home, the community, or in a nursing home. Wilson (2010) writes that palliative care concepts should be an integral part of nursing home care . “The older people are, the more likely they are to die in a nursing home” and “Elderly residents in long-term care settings often have multiple chronic illnesses and are among the most frail Americans” are key points made by Wilson (2010, p. 879). A study conducted by Hanson, Henderson, and Menon (2002, p. 122) focused on terminal care in nursing homes. The study found that nurse participants desired training in palliative care and communication skills, increased time to spend with dying patients, and increasing the involvement of hospice services, volunteers, and family.

According to Meier, Lim, and Carlson (2010) delivery of simultaneous hospice and palliative care is impeded by inadequate training and numbers of nursing home staff and that there needs to be a change in the Medicare benefit that would allow for simultaneous access to palliative care and restorative care (p. 137). Barriers to formal palliative care identified in the

nursing home include regulatory payment and staffing patterns. “All nursing home staff should be required to demonstrate discipline-specific competencies in geriatric palliative care” according to Meier et al. (2010, p. 139). In addition Meier et al. indicate that policy change and investment are needed to make appropriate access to high-quality palliative care a reality in the nursing home for those with dementia as well as those with other progressive conditions (p. 140). A recent study found that the more nursing directors know about palliative care the lower the likelihood that their (nursing home) patients would experience futile, aggressive end-of-life care. The study found that one in five surveyed directors had little or no basic palliative care knowledge (Brown University, 2015).

### **Oncology Nursing and Palliative Care**

Palliative care should be part of the usual care available to all patients with cancer according to Mahon & McAuley because patients who have cancer often have to live with significant symptom burdens and are confronted with complex decisions that they do not feel prepared to make (2010, p. 142). A study was conducted with oncology nurses to comprehend the nurses’ personal understanding about palliative care. The results indicated that most nurses equated palliative care with hospice care and so provision of education about palliative care was recommended.

A study by Pavlish and Ceronsky (2009) exploring oncology nurses’ life experiences with palliative care found that most all participants described palliative care nursing as a process of working with patients and their families to alleviate suffering, to achieve holistic comfort and well-being, and attain the patients’ quality-of-life goals and preferences (p. 405). Pavlish & Ceronsky also found that most of the participants believed that palliative care is restricted to patients toward or at the end of life instead of across the continuum of oncology care. This

indicates that more education is required to recognize that palliative care is needed more than at the end of life (p. 409).

The National Institute of Nursing Research Report (2013) identified that cancer was the most frequent focus of all health care conditions that was researched. It was studied in more than two-thirds of the end of life and palliative care disease condition publications reviewed (p. ix). Cancer in the 1970's made up the largest percentage of hospice admissions compared to today where cancer admissions account for less than half (36.5%) of all hospice admissions (National Hospice and Palliative Care Organization, 2014, p. 7).

### **Palliative Care in Critical Care Nursing**

Research has been conducted with critical care nurses to determine their perceptions of end of life care by Hansen, Goodell, Dehaven, & Smith (2009). The background of their study indicated that nurses working in intensive care units may lack knowledge and skills in end of life care, find caring for dying patients and their families stressful and that they lack support (Hansen, et al., 2009, p. 263). The study was conducted in four adult intensive care units at a medical center and focused on the responses of registered nurses on an investigator-designed tool. The results indicated a desire for better communication among nurses, physicians, and patients' families and a request for more frequent palliative care rounds and family conferences. The second most frequent request was for education related to the dying process.

Beckstrand, Callister, & Kirchhoff (2006) collected suggestions from critical care nurses for improving end of life care in intensive care units. Some of the nurses' suggestions included "making environmental changes to promote dying with dignity, being present, managing pain and discomfort, knowing and following patient's wishes for end of life care, promoting earlier cessation of treatment or not initiating aggressive treatment at all, and communicating effectively

as a healthcare team” (Beckstrand et al., 2006, p. 41). It was concluded that implementation of specific suggestions might increase the quality of end of life care and facilitate a good death for intensive care patients. Additional suggestions included more involvement from pastoral staff, palliative care specialists, and ethics committee members.

### **Nursing Attitudes and Palliative Care**

A study conducted in the Midwest used the *Professional End-of-Life Care Attitude Scale* to investigate hospital nurses’ attitudes in caring for the dying patient (Weigel, Parker, Fanning, Reyna, & Gasbarra, 2007). Surveys were used to collect data from nurses across units and the results showed that the nurses were apprehensive in providing care for the patient at the end of life. The results were based on the use of a self-report survey and did not allow for verbalization of perceptions or to assess non-verbal cues and only focused on palliative care at the end of life. The findings of the study suggested that more professional exposure and training regarding interacting with dying patients and their families were needed (Weigel et al., 2007, p. 90).

Wessel and Rutledge (2005) conducted a study to determine the relationships among home health and hospice nurses’ attitudes toward death and caring for dying patients and the impact of palliative education. The study indicated that educational efforts need to include an assessment of participants’ attitudes toward death and caring for the dying. The use of *Frommelt’s Attitudes toward Care of the Dying* (FATCOD) provided information on nurses’ attitudes toward caring for dying patients and their family members. Use of the *Death Attitude Profile* measured nurses’ attitudes toward death (Wessel & Rutledge, 2005). Findings indicated that end of life education can reduce nurses’ negative attitudes of death that could positively impact the care of dying patients.

Dunn, Otten, and Stephens (2005) also used the *Frommelt Attitudes toward Care of the Dying* (FATCOD) Scale in their research of nurses. In addition to the FATCOD they used a *Death Attitude Profile Scale* and used a demographic survey to examine the relationship among demographic variables and nurses' attitudes toward death and caring for dying patients. It was interesting to note that 69% of the sample felt that their nursing education did not adequately prepare them to deal with death and dying (Dunn et al., 2005, p. 100). In the conclusion they indicate that as the older population increases nurses will be in contact with more dying patients and need to develop expertise in caring for the dying.

### **Nursing Issues, Concerns, and Needs Related to Providing Palliative Care**

White, McClelland, VanderWielen, and Coyne (2013) conducted a qualitative study of members of the Hospice and Palliative Nurses Association (HPNA) to gain understanding of palliative nursing practice and competencies to learn more about the particular issues, concerns, and needs of nurses. The participants were asked open-ended survey questions and to rank order a list of EOL core competencies. In the discussion, White et al., indicated a need for future research to examine the views, experiences, and issues of nurses in all specialties to gain insight into general nursing perceptions of the benefits and appropriate timing of palliative care (White et al., 2013, p. 365).

A study to examine the nurses' beliefs, experiences, and perceptions of caring for patients who are dying was conducted for the purpose of determining what HPNA members believe about the type, quality, and amount of continuing education they receive on the topic of palliative care (White, Coyne, & White, 2012). This study used a survey that requested information about palliative care core competencies, questions about employer-sponsored continuing education, and the organization of palliative care practice. The findings of this study

indicated that the nurses desired continuing education in management of symptoms, pain management, and communication. It should be noted that most of the respondents were mostly certified and practicing hospice and palliative care nurses in specialized settings.

The nature and emotional demands of the nursing profession make nurses susceptible to increased stress (Harris, 2013, p. 446). Numerous studies have been conducted on the issue of end of life care and the stress and anxiety of providing care for these patients (Melvin, 2012; Peters et al., 2012; White, Wilkes, Cooper, & Barbato, 2004). Nurses reported feelings of helplessness, distress, vulnerability, frustration, and a sense of failure and that physical symptoms of stress and crying might result (White et al., 2004). Melvin (2012, p. 606) identified the terms professional compassion fatigue, burnout, and accumulated loss phenomenon to refer to the cumulative physical and emotional effects of providing care over extended periods of time. According to Melvin (2012) there are clear physical and emotional health consequences for nurses who provide hospice and palliative care over extended periods of time and therefore we need to develop strategies to protect the nurses.

Unrelieved patient suffering described by the nurses included unrelieved physical symptoms such as pain and vomiting; fear; loss of self; loss of body image; facing mortality; unresolved family dynamics; lack of meaning at the end of life; discontent with their situation; a general feeling of loss; and hopes and aspirations not being fulfilled (White et al., 2011, p. 438). Peters et al. indicated that palliative nurses frequently experience stressful situations related to death and dying (p. 561) and concluded that organizational, workplace, patient and patient-family factors were stressors that were implicated in the stress experienced by palliative nurses (p. 567).

Weigel et al. (2007) state that care of a dying human being is emotionally taxing for the family but also for the nurse caring for the person (p. 86). Nurses described reactions to the stress of dying patients as causing feelings of dissatisfaction, frustration, and grief (Wallerstedt & Andershed, 2007, p. 38)

Qualitative research conducted by Harris (2013) with hospice nurses sought understanding of how hospice nurses coped with the stresses related to caring for terminally ill patients and the family and/or caregivers. Focus groups were used to collect hospice nurses' perceptions of coping and workplace stress. Three major themes emerged related to the primary ways of coping among the group interviewed. The themes included social support, humor, and prayer/meditation (Harris, 2013, p. 449).

Caring for terminally ill patients was identified as an area that general nurses in the acute care setting found particularly difficult (McCourt, Power, & Glackin, 2013, p. 515). Nurses shared that dealing with the emotional responses of terminally ill patients and families and their own emotions were stressful, frustrating, and upsetting. The nurses also indicated that time constraints, lack of experience and education, and poor symptom management were factors that made care difficult (McCourt, Power, & Glackin, 2013, p. 515).

### **The Palliative Care Team**

The National Palliative Care Research Center on the web page "*About Palliative Care, What is Palliative Care?*" describes palliative care as being provided by a team (National Palliative Care Research Center, 2013). It states that:

Comprehensive palliative care services integrate the expertise of a team of providers from different disciplines in order to adequately assess and address the complex needs of seriously ill patients and their families. Members of a palliative

care team typically include professionals from medicine, nursing, and social work, with additional support from chaplaincy, nutrition, rehabilitation, pharmacy, and other professional disciplines as needed.

Palliative care teams by definition must include a physician, a nurse and a social worker, and may include spiritual leaders and professionals from other fields (Robert Wood Johnson Foundation, 2012). The Institute of Medicine (2014) describes an interdisciplinary palliative care team as including board-certified hospice and palliative medicine physicians, nurses, social workers, and chaplains. The team may also include other health professionals including geriatricians.

### **Public Health, Palliative Care, and Health Education**

Nurses are involved in the care of the community as home health, hospice, and public health nurses. They have a need to be informed about issues of public health. Cohen and Deliens (2012) indicate that palliative care or care with an end of life focus will need to become public health priorities in order to guarantee a good quality of end of life (p. 10). This means that nurses will be involved in end of life care in practice areas other than just acute and long term care settings.

Public health challenges for palliative care in primary care are the high number of patients not dying in the place they wish, experiencing inappropriate hospital admissions at the very end of life, and an increasing number of people with chronic and serious illnesses who need to be taken care of in the community setting. The lack of sufficient experience and equipment of general practitioners to provide specialist palliative care, and the need for specialist palliative care teams to back-up the primary caregivers are also public health challenges (Cohen &

Deliens, 2012, p.120). Nurses may be familiar with these challenges or may identify additional challenges that they experience in providing palliative care in the community.

A study aimed at exploring public perceptions towards palliative care in a region in the United Kingdom was conducted to identify the public's understanding and perceptions of palliative care, explore factors that contribute to the public's knowledge and expectations of palliative services and identify actions and strategies the public consider might enhance awareness and understanding of palliative care (McIlfatrick et al., 2014). The goal of the study was to obtain detailed and comprehensive knowledge of public members' views towards palliative care in order to target education and policy campaigns, to manage future needs, expectations and resourcing of end of life care (McIlfatrick et al., 2014, p. 274).

Strategies identified to promote public awareness of palliative care included enhancing public awareness and public education (McIlfatrick et al., 2014, p. 277). A recommendation from the study was that palliative care and public health services should work together to develop health promotion that would benefit palliative care and change public knowledge, attitudes, and behavior (McIlfatrick et al., 2014, p. 279). Knowledge of the public's expectations and recommendations about palliative care can provide nurses and health education specialists with information to plan appropriate care and education.

A similar study conducted in the United States was commissioned by the Center to Advance Palliative Care entitled the *2011 Public Opinion Research on Palliative Care* (CAPC, 2011). The objectives of this research were to explore key audiences' awareness and understanding of palliative care and test language, terminology, definitions and messaging to be used in discussing palliative care with consumer audiences (p.1). The research confirmed that palliative care was a relative unknown among consumers (70%) and that there was a clear need

to inform consumers about palliative care and provide them with a definition of palliative care (p. 3). A key finding of the study was that once informed about palliative care the consumers wanted to have access to palliative care if they need it and that it was very important for patients with serious illness to have access to palliative care at all hospitals (p. 8). Consumers agreed (95%) that it is important that patients with serious illness and their families be educated about palliative care options available to them together with curative treatment and 94% agreed that palliative care is appropriate at any age and at any stage in a serious illness, and can be provided together with curative treatment (Center to Advance Palliative Care, 2011, p. 10).

According to the American Public Health Association (2013) the public health needs of the chronically and seriously ill population and the needs of their caregivers indicate a heightened emphasis on public health planning. A part of this public health planning includes workforce planning to ensure that an adequate number of primary and generalist-level practitioners are available in palliative care. The APHA policy states that:

With the aging of the population, the severity of the illness burden and the proportion of deaths associated with chronic terminal illnesses will increase, resulting in a growing need for trained public health, generalist level palliative care and gerontological workforce (APHA, 2013).

Increasing and measuring access to safe long-term and palliative care is identified as one of the specific issues that should be monitored over the next decade according to Healthy People 2020 (Healthy People 2020, 2013) in the Access to Health Services Section. According to Healthy People 2020 (2013) access to health care impacts overall physical, social, and mental health status, life expectancy, quality of life, etc. Inclusion in the Healthy People 2020 Topics and Objectives provides further evidence that palliative care is an issue that needs to be

considered for the health of our nation and therefore education on the topic is indicated. Benson & Aldrich (2012) indicate that the public needs better education about palliative care and advance care planning. High-quality palliative care includes advance care planning (IOM, 2014, p. 137).

### **Summary**

Some nurses have had their knowledge related to palliative care at the end of life researched using such tools as the FATCOD and PCQN. Nurses' comfort levels or anxiety related to providing care for the dying has also been studied in some research. Nurses who are members of HPNA have been studied, as well as long-term care, oncology, hospice, community, and critical care nurses. Educational needs related to palliative care and hospice still exist. Research conducted with consumers showed a lack of knowledge of palliative care and a need for public education.

The current access to specialized palliative care programs in smaller hospitals is less than desired. Nurses employed in these agencies will need to be able to provide basic palliative care nursing. The aging population will require an increase in the provision of palliative care in the future. Quality of life is important to everyone and palliative care can help provide a better quality of life from diagnosis through the end-of-life. Palliative care relates to public health, health education, and healthcare providers alike.

This chapter provided information from the literature related to the history of palliative care, hospice, quality of life, models of palliative care, and access to palliative care. Information on palliative care definitions, scope and practice for palliative nursing, palliative care nursing research, and public health palliative care issues has also been included in this chapter. Based upon a review of the current literature, viewpoints related to generalist palliative care

experiences in this region may provide useful information for program planning and education on the topic of palliative care.

## **CHAPTER 3**

### **METHOD**

#### **Background**

According to the literature, quality of life at the end of life is a Healthy People objective that can be impacted by the provision of palliative care. Nurses, who are the primary healthcare provider at the bedside and in the community, can provide information about their experiences with patients and families related to palliative care in the setting in which they practice. The nurses' statements can inform other nurses, nurse educators, public health officials, and health education specialists what their perception of palliative care is and how it affects them. These perceptions may contribute to improvements in the provision of palliative care which in turn can improve the quality of life for those who are living with a life-limiting illness.

This chapter describes the purpose of the study, the research questions, and the research design. It includes the plans for data collection including the selection of participants, the focus group and interview activities, and the interview guide. The planning for analysis and interpretation of the data is also included.

#### **Purpose of the Study**

The purpose of this study is to describe the perceptions, impact, and meaning of palliative care from the viewpoint of nurses who provide care to patients and their families.

#### **Research Questions**

The following research questions were developed for this study:

1. What does palliative care mean to you?
2. What are your experiences related to palliative care?
3. What are your feelings about providing palliative care for your patients?

The responses to these questions may provide information about the types of patients cared for, the nurses' ability and comfort level in providing palliative care, any barriers and/or rewards of providing palliative care in their setting, and any other concerns that arise related to palliative care. I will be listening for information related to communication with the patient, family members, and other healthcare professionals and any issues related to spiritual care. Information regarding the nurses' educational preparation for providing palliative nursing care may also arise during the discussions with the nurses.

### **Research Design**

The design planned for this study is qualitative, phenomenological research. In a phenomenological study the researcher collects data from persons who have experienced the phenomenon and develops a composite description of the essence of the experience for all of the individuals (Creswell, 2013, p. 76) This phenomenological approach is proposed to gain a description of nurses' perceptions of their palliative care experiences and an understanding of its meaning for them. Creswell (2013) defines a phenomenological study as one that "describes the common meaning for several individuals of their lived experiences of a phenomenon" (p. 76). It is my hope that the words of the various nurses about palliative care will describe the phenomenon as they experience it and the meaning it holds for them.

### **Research Method**

The qualitative methods of focus groups and individual interviewing will be used to collect the data for this study. Interviewing is used when the behavior, feelings, or how people interpret the world around them cannot be observed (Merriam, 2009).

Both focus groups and individual interviews will be conducted with nurses from a variety of settings to learn about their experiences related to palliative care. Demographic information

will be sought from all the participants. A form will be used to collect demographic information from each of the participants and is included in Appendix B. Opinion, background, and demographic questions are all identified by Merriam (2009, p. 96) as being types of questions that might be included in an interview.

Semi-structured interviews use a loose structure of open-ended questions which defines the area to be explored and allows the respondent to answer in his or her own words (Meadows, 2003, p. 465). The interview questions will seek information on what the nurses believe palliative care means and what their experiences have been related to providing palliative care. The interviewer will also use probes as appropriate.

Probes or prompts may be used during the interviews if needed to gain additional responses. According to Merriam (2009, p. 100) “probes are also questions or comments that follow up something already asked.” Jacob and Furgerson (2002, p. 4) describe probes or prompts as comments that help keep the interview on track while allowing for unexpected data to emerge. Probes also encourage the interviewee to provide more depth or detail (Meadows, 2003, p. 466).

### **Sample**

Purposive sampling will be used for this study. Purposive sampling is described by Neutens and Rubinson (2010, p. 140) as sampling where the researcher employs his or her own discretion to select the respondents who best meet the purposes of the study. Only registered nurses who are not certified as hospice and palliative care nurses or considered specialist palliative care nurses will be included in the study. At this time I do not plan to include nurses who are currently employed in hospice agencies.

I plan to contact registered nurse colleagues, palliative care team nurses in Southern Illinois and Southwestern Indiana, and nurse educators at universities in Southern Illinois and Southwestern Indiana for suggestions of nurses that I might contact for inclusion in the study. I also plan to contact local hospital nurse executives, long-term-care agency administrators, and community agency administrators for permission to contact nurses at their facilities for inclusion in the study. It is my hope that they will suggest nurses to contact regarding participation in the study.

Once I have a list of nurses to contact I will schedule the focus groups where participants will be asked to share their perceptions about palliative care as they have experienced it and as provided in this geographic region. It is hoped that an adequate number of participants will result from the suggestions made by key informants. If additional names are needed I plan to ask the nurses who participate in the focus groups to suggest other nurses who might be interested in participating. This method is referred to as snowball sampling which involves using a contact to identify other key informants or information-rich cases (Isaac & Michael, 1995, p. 224). A flyer will be available for use in recruiting participants from agencies if needed. The flyers can be found in Appendix C.

Nurses from a variety of settings are sought to increase the breadth and richness of the data. An explanation of the study will be provided to the key informants, agencies, and nurses to use in the recruitment of the participants. A copy of this explanation is included in Appendix D. Permission from the agency may be required and a form for permission to interview employees was developed in case the agency required one. This form can be found in Appendix E.

### **Data Collection**

Approval for the study will be sought from the Human Subjects Committee, Southern Illinois University prior to the start of the study. Consent forms and procedures for maintaining confidentiality will be addressed during this process. A copy of the consent form with contact information will be given to the participant. The consent form for participation is included in Appendix F. Confidentiality will be maintained as much as possible. The nature of focus groups makes it difficult to ensure absolute confidentiality.

Any questions from participants will be answered and consent forms will be completed prior to the start of the focus group or interview. Participants will be made aware that they may decline to answer or withdraw from participation at their discretion. Participants will be informed that no payment will be provided for participation in the interview or focus group. Appreciation will be expressed to those participating and an executive copy of the results will be offered to the participant.

Permission to audio record the focus group or interview will be sought and the consent form for audio-recording will be completed prior to beginning. The consent form for audio-recording can be found in Appendix G. A script for beginning the focus group/interview will be used and is available in Appendix H. The investigator will present the questions in the focus group or interview. The investigator will keep observational notes to add to the transcribed interview so that non-verbal data will be captured during the interview process and can be used when reviewing the transcripts. Note taking during the interview will be kept to a minimum. A research assistant will be used to assist in documenting observations during the focus groups.

Focus groups will be arranged at a time and place agreed upon by the participants and will be audiotaped. Adequate nurses will be invited to participate so that a group of at least 6-10

nurses will participate in each focus group. Merriam (2009) recommended that 6-10 people be included in each focus group (p. 94).

Initially 2-3 focus groups will be conducted using the interview guide to allow for the interaction between multiple nurses. This format may highlight the similarities and differences of the participants and provide rich information about their range of perspectives and experiences (Doody, Slevin, and Taggart, 2013, p. 16). It is understood that there is the possibility that participants may be influenced by other's thoughts and beliefs (O'Shea, 2014, p. 34). It is estimated that the focus groups will last for 60-90 minutes. The time allotment was planned to decrease the risk of fatigue (Meadows, 2003; Jacob & Furgerson, 2012). Common themes identified from the transcripts of the focus groups will be used to modify the interview guide prior to use in the individual interviews.

Following the completion of the focus groups semi-structured individual interviews will be conducted using the modified interview guide as a way to facilitate the collection of data from participants. The researcher will make contact and arrange audiotaped interviews at the time and place agreed upon with the nurse who has agreed to participate in the study. If the participant does not wish to be audio recorded the interview can proceed with the interviewer taking notes during and immediately after the interview to capture as many of the statements as possible. Two audio-recording devices will be used to record the focus groups and interview in order to ensure that at least one good recording is obtained. Participants will be informed that recordings will be kept secure at my home and will be destroyed at the end of the study.

The interview will seek information on the themes identified from the focus groups as well as identification of additional themes that arise from the individual interviews. A total of 10-12 interviews, lasting 60-90 minutes, are planned but may be adjusted based on reaching

saturation. The number of interviews typically conducted for phenomenological studies was 5-25 people according to Polkinghorne (as cited in Cresswell, 2013, p. 149). Interviewing will continue as long as additional information or different perspectives on the subject are forthcoming (Rubin and Rubin, 2012, p. 63). If saturation has not been reached with the projected number of interviews it may be necessary to increase the number to reach the point where no new information is being added. At this time it is not planned that follow-up interview sessions will be used. It is possible that if inadequate information is obtained or clarification is needed a follow-up might be desirable and scheduled.

## **Research Instruments**

### **Interview Guide**

The interview guide will be reviewed by palliative care professionals prior to use in the focus groups. The questions such as “tell me about” were created to allow the interviewee to take the question in different directions and to allow for the emergence of ideas, impressions, and concepts (Jacob & Furgerson, 2012, p. 4).

The questions to be addressed in the focus groups include:

1. Tell me what palliative care means to you.
  - a. How did you learn about palliative care?
  - b. What does palliative care consist of at your agency?
2. Tell me about your experiences with patients who you felt needed palliative care but did not receive it or chose to pursue aggressive curative or intensive care.
  - a. How did you feel about the experiences?
3. Tell me about your experiences with patients who received palliative care.
  - a. How did you feel about the experiences?

4. What do you see as barriers to palliative care in your experiences?
5. What do you see as rewards to providing palliative care?
6. Is there anything else you would like to share about palliative care that we have not discussed?

The interview guide is included in Appendix I. The questions will be modified as needed based upon insights gained from the focus group interviews and/or individual interviews to acquire as much information as possible (Jacob & Furgerson, 2012, p. 5). If any new information arises, from the interviews, it will be incorporated into the interview guide.

### **Demographic Information**

A form for collecting demographic information will be provided to each participant for completion at the beginning of the focus group or interview after the consent forms have been completed. An example of the form can be found in Appendix B. The data to be collected includes the age, race/ethnicity, gender, education, licensure, how many years employed as a nurse, type of agency, and unit or department employed in. Information on basic educational preparation and continuing education focused on palliative care is also requested on the form. I will request that the participants share their email address with me so that I will be able to send them the transcript of the interview for them to review and make comments or corrections.

### **Data Analysis**

Immediately following each focus group and interview the observational field notes will be reviewed and additional comments made as needed. The audio recording will be transcribed verbatim and observational notes taken during the focus group or interview will be linked to the appropriate transcription. According to Rubin & Rubin, (2012, p. 101) transcribing should be done as soon as possible after the interview is finished. A transcription service will be used to

complete the verbatim transcription. This transcription will then be compared to the audio-recording for accuracy. Reviewing the transcribed data will begin with the first focus group and continue with each additional focus group and individual interview. A copy of the transcribed interview will be provided to participants via email to ensure accuracy and clarity (Rubin & Rubin, 2012, p. 64).

Pseudonyms will be attached to participants and locations of employment will not be shared. The type of nursing will be included without identifying any individual person or place. No identifying information will be shared with others. Transcripts will be shared with the peer reviewers as part of the analysis process. After review and analysis transcripts will be kept secure at the home of the investigator as required by the review board for approximately three years after the completion of the study.

Coding of the transcripts so that themes can be identified from the various transcripts will be ongoing beginning with the initial transcript. According to Neutens & Rubinson (2010) coding of the data enables the researcher to organize the data collected (p. 176). Coding involves labeling passages of text according to content (Merriam, 2009, p. 194). Once the data have been coded, they will be sorted so that themes, patterns, categories, and trends can become evident (Neutens & Rubinson, 2010, p. 178).

The qualitative software program, NVivo 10 (QSR International, 2014), will be used to assist in organization and filing of the data. The analysis of the data collected will be ongoing with a mix of manual identification of coding categories and use of the computer software program to organize the information into themes identified. The software will allow the researcher to organize and compare the content found in the transcribed interviews and to build on each transcript as it is available. The software also allows for specific passages from the

transcript to be organized into the appropriate theme(s). Word counts can be completed to identify recurring terms throughout the transcript.

Listening to the audio-recordings, reading the transcripts, and studying field notes will allow the conceptualization of the emergent themes from the data (Meadows, 2003 p. 467). The transcripts will be reviewed by at least two other professionals for identification of themes and will be compared to the themes identified by the researcher. This process is planned to ensure that the coding of themes is consistent.

A reflective journal will be kept for recording perceptions and observations following each focus group and interview and during the analysis and interpretation process. The observational field notes, transcriptions, and reflective journaling will allow for a more comprehensive description of the process and analysis.

### **Validity and Reliability**

Triangulation will be used to attain internal validity. According to Merriam (2009) triangulation means comparing and cross-checking data collected through observations at different times or in different places, or interview data collected from people from different perspectives. Triangulation can also be follow-up interviews with the same people (Merriam, 2009, p. 216). For this study the interviews will be conducted with nurses from various locations throughout the area who work in a variety of facilities and/or types of nursing positions and units. The transcripts will also be reviewed by at least two peer professionals for their analysis of the findings and identification of themes.

Member checks will be used for evaluating and ensuring internal validity and credibility. (Merriam, 2009 p 217). Member checking involves taking preliminary analysis back to some

participants to find out if the interpretation is accurate. It is expected that the participants will respond in an honest manner.

Reflexivity is described by Merriam (2009, p. 229) as “critical self-reflection by the researcher regarding assumptions, worldview, biases, theoretical orientation, and relationship to the study that may affect the investigation”. As a nurse and educator I am acutely aware of the opinions that I have developed in relation to the issue of palliative care. Personal experiences with loved ones, friends, and patients created an interest in why or what we can do better to ensure that everyone has the opportunity to experience palliative care if they choose to do so. I realize that as the investigator I will have to bracket my own personal feelings and remain neutral in the research process. According to Chan, Fung, and Chien (2013, p. 6) the researcher as a human being influences the research process and that bracketing the researcher’s own knowledge and experience will help minimize the researcher’s influence throughout the research process. The goal of the study is to find out what nurses perceive about palliative care and not to bias nurses’ responses.

Peer review/examination is listed as one of the strategies for promoting validity and reliability (Merriam, 2009, p. 229). Peer review will be accomplished by asking another graduate student and a graduate nurse professional to read and comment on the study and the results. My dissertation committee will also be involved in reviewing the study.

The importance of trustworthiness of the research process for this study has been addressed by some of the activities identified. Provisions for addressing the credibility, transferability, dependability and confirmability of the study need to be considered (Shenton, 2004, p. 64). Shenton (2004) includes other provisions that will be included in the processing of

the research such as identifying the shortcomings of the methods (p. 67), and thick description of the phenomenon under study (p. 69).

### **Summary**

This chapter included the purpose of the study, research questions, research design and method, sample selection, and data collection. The research instruments proposed for the study were described in this chapter. The data analysis and interpretation methods were included. The consent form, consent to audiotape, interview guide, demographic information form, and permission forms are included in the Appendices.

## References

- American Hospital Association & First Consulting Group (2007). *When I'm 64 How boomers will change health care*. Retrieved April 15, 2015, from American Hospital Association website: <http://www.aha.org/.../070508-boomerreport.pdf>
- American Nurses Association, & Hospice and Palliative Nurses Association (2014). *Palliative nursing an essential resource for hospice and palliative nurses: Scope and standards of practice*. Silver Spring, MD: American Nurses Association. Retrieved from <http://www.nursesbooks.org>
- American Public Health Association (2013). *Supporting public health's role in addressing unmet needs in serious illness and at the end of life* (APHA policy 2005-9). Washington, DC: U.S. Government Printing Office. Retrieved March 5, 2014, from <http://www.apha.org/advocacy/policy/policysearch/default.htm?id=1450>
- Becker, R. (2009). Palliative care 1: Principles of palliative care nursing and end-of-life [Supplemental material]. *Nursing Times*, 105(13). Retrieved November 27, 2014, from <http://www.nursingtimes.net/nursing-practice/specialisms/end-of-life-and-palliative-care/...>
- Beckstrand, R. L., Callister, L. C., & Kirchhoff, K. T. (2006). Providing a "Good Death": Critical care nurses' suggestions for improving end-of-life care. *American Journal of Critical Care*, 15(1), 38-45.
- Benson, W. F., & Aldrich, N. (2012). *Advance care planning: Ensuring your wishes are known and honored if you are unable to speak for yourself* (Critical Issue Brief). Retrieved

September 11, 2014, from Centers for Disease Control and Prevention website:

<http://www.cdc.gov/aging>

Brown University (2015, March 20). Linked: Knowledge of palliative care and less end-of-life disruption. Retrieved April 12, 2015, from

<http://news.brown.edu/articles/2015/03/palliative>

Centers for Disease Control And Prevention (2013). *The state of aging and health in America 2013*. Retrieved April 15, 2015, from US Department of Health and Human Services

website: <http://www.cdc.gov/aging>

Centers for Medicare & Medicaid Services (2013). *Medicare Hospice Benefits* (CMS Product No. 02154). Baltimore, MD: U.S. Department of Health and Human Services. Retrieved

September 13, 2014, from <http://www.medicare.gov/Pubs/pdf/02154.pdf>

Center to Advance Palliative Care (2014). Defining palliative care. Retrieved March 19, 2014,

from <http://www.capc.org/building-a-hospital-based-palliative-care-program/case/definingpc>

Center to Advance Palliative Care (2011). *2011 Public opinion research on palliative care: A report based on research by Public Opinion Strategies*. Retrieved December 17, 2013,

from American Cancer Society, American Cancer Society Cancer Action Network, and

Centers to Advance Palliative Care website: <http://www.capc.org/tools-for-palliative-care-programs/marketing/public-opinion-research/2011-public-opinion-research-on-palliative-care.pdf>

Center to Advance Palliative Care (2012). What is palliative care? Retrieved March 7, 2014,

from <http://www.getpalliativecare.org/whatis/>

- Center to Advance Palliative Care (2011). *America's Care of Serious Illness: A state-by-state report card on access to palliative care in our nation's hospitals*. Retrieved November 20, 2014, from <http://www.capc.org/reportcard/home/IL/RC/Illinois/713>
- Center to Advance Palliative Care (2013). Growth of Palliative Care in U. S. Hospitals 2013 Snapshot. Retrieved November 20, 2014, from <http://www.capc.org/capc-growth-analysis-snapshot-2013.pdf>
- Chan, Z. C., Fung, Y., & Chien, W. (2013). Bracketing in phenomenology: Only undertaken in the data collection and analysis process? *The Qualitative Report*, 18(59), 1-9. Retrieved from <http://www.nova.edu/ssss/QR/QR18/CHAN.59.pdf>
- Chiplaskey, L. M. (2008). End-of-life care: Are nurses educationally prepared? *RN Journal*, Retrieved March 24, 2014, from <http://rnjournal.com/journal-of-nursing/end-of-life-are-nurses-educationally-prepared>
- City of Hope, & American Association of Colleges of Nursing (2014). ELNEC core Train-the-Trainer Program 2014. Improving palliative care for patients and families.
- Cohen, D., & Crabtree, B. (2006). Qualitative research guidelines project. Retrieved December 21, 2014, from <http://www.qualres.org/HomeSamp-3702.html>
- Cohen, J., & Deliens, L. (2012). *A public health perspective on end of life care* (1st Ed.). New York, NY: Oxford University Press.
- Coyle, N. (2010). Introduction to palliative nursing care. In B. Ferrell & N. Coyne (Eds.), *Oxford textbook of palliative nursing* (3rd ed., pp. 3-11). New York, New York: Oxford University Press.
- Cramer, C. F. (2010). To live until you die: Quality of life at the end of life. *Clinical Journal of Oncology Nursing*, 14(1), 53-56. doi:10.1188/10.CJON.53-56

- Creswell, J. W. (2013). *Qualitative inquiry & research design: Choosing among five approaches* (3rd Ed.). Los Angeles, CA: Sage Publications, Inc.
- Doody, O., Slevin, E., & Taggart, L. (2013). Focus group interviews in nursing research: Part 1. *British Journal of Nursing*, 22(1), 16-19.
- Dunn, K. S., Otten, C., & Stephens, E. (2005). Nursing experience and care of dying patients. *Oncology Nursing Forum*, 32(1), 97-114. doi:10.1188/05.ONF.97-104
- End-of-Life Nursing Education Consortium (2012). *History, statewide effort and recommendations for the future: Advancing palliative nursing care*. Retrieved March 6, 2014, from End-of-Life Nursing Education Consortium website:  
<http://www.aacn.nche.edu/el nec/publications/ELNEC>
- Ersek, M., Kraybill, B., & Hansen, N. R. (2006). Evaluation of a train-the-trainer program to enhance hospice and palliative care in nursing homes [Abstract]. *Journal of Hospice and Palliative Care*, 8(1), 42-49.
- Ferrell, B. R. (2004). Palliative care: An essential aspect of quality cancer care. *Surgical Oncology Clinics of North America*, 13, 401-411. doi:10.1016/j.soc.2004.03.003
- Ferrell, B. R., & Coyle, N. (Eds.). (2010). *Oxford textbook of palliative nursing* (3rd Ed.). New York, NY: Oxford University Press, Inc.
- Gamondi, C., Larkin, P., & Payne, S. (2013). Core competencies in palliative care: An EAPC white paper on palliative care education-Part 1. *European Journal of Palliative Care*, 20(2), 86-91. Retrieved 04/15/1025, from  
<http://www.eapcnet.eu/LinkClick.aspx?fileticket=xc-t/28Ttfk%3D&tabid...>
- Giovanni, L. A. (2012). Managing care at the end of life. *Nursing Management*, 30(3), 127-134.

- Hansen, L., Goodell, T. T., Dehaven, J., & Smith, M. (2009). Nurses' perceptions of end-of-life care after multiple interventions for improvement. *American Journal of Critical Care, 18*(3), 263-271. doi:10.4037/ajcc2009727
- Hanson, L. C., Henderson, M., & Menon, M. (2002). As individual as death itself: A focus group study of terminal care in nursing homes. *Journal of Palliative Medicine, 5*(1), 117-125.
- Harris, L. J. (2013). Caring and coping: Exploring how nurses manage workplace stress. *Journal of Hospice and Palliative Nursing, 15*(8), 446-453. Doi:10.1097/NJH0b013e3182a0de78
- Healthy People 2020 (2013). Access to Health Services. Retrieved from <http://www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=1>
- Hermann, C. P., & Looney, S. W. (2011). Determinants of quality of life in patients near the end of life: A longitudinal perspective. *Oncology Nursing Forum, 38*(1), 23-31. doi:10.1188/11.ONF.23-31
- Hospice and Palliative Nurses Association (2011). *2012-2015 Research Agenda* Retrieved December 23, 2013, from <https://www.hpna.org/Display/Page.aspx?Title=Research>
- Hospice and Palliative Nurses Association (2011). Value of the professional nurse in palliative care. Retrieved January 18, 2014, from <http://www.hpna.org/displaypage.aspx?Title1=Position%20Statements>
- Hospice and Palliative Nurses Association (2013). Assuring high quality in palliative nursing. Retrieved January 18, 2014, from <http://www.hpna.org/DisplayPage.aspx?Title1=Position%20Statements>
- Institute of Medicine (2015). *Dying in America Improving quality and honoring individual preferences near the end of life* (1<sup>st</sup> Ed). Washington, DC: The National Academies Press.

- Institute of Medicine (2014). *Dying in America Improving quality and honoring individual preferences near the end of life* (Prepublication Report). Washington, DC: The National Academies Press. Retrieved September 18, 2014, from <http://www.iom.edu/Reports/2014/Dying-in-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx>
- Isaac, S., & Michael, W. B. (1995). *Handbook in Research and Evaluation* (3rd Ed.). San Diego, CA: Educational and Industrial Testing Services.
- Izumi, S., Nagae, H., Sakurai, C., & Imamura, E. (2012). Defining end-of-life care from perspectives of nursing ethics. *Nursing Ethics, 19*(5), 608-618.  
Doi:10.1177/0969733011436205
- Jacob, S. A., & Furgerson, S. P. (2012). Writing interview protocols and conducting interviews: Tips for students new to the field of qualitative research. *The Qualitative Report, 17*, 1-10. Retrieved from <http://www.nova.edu/ssss/QR/QR17/jacob.pdf>
- Jennings, B., Ryndes, T., D'Onofrio, C., & Baily, M. A. (2003). Access to hospice care: Expanding boundaries, overcoming barriers. *Hastings Center Report Special Supplement, 33*(2), S3-S7.
- Kaasalainen, S., Brazil, K., Williams, D., Willison, K., Marshall, D., & Taniguchi, A. (2012). Barriers and enablers to providing palliative care in rural communities: A nursing perspective [Abstract]. *Journal of Rural and Community Development, 7*(4), 4-19.
- Kelly, K., Ersek, M., Virani, R., Malloy, P., & Ferrell, B. (2008). Geriatric training program: Improving palliative care in community geriatric care settings. *Journal of Gerontological Nursing, 34*(5), 28-35.

- Kirkey, S. (2014, January 15). Doctors and nurses working with critically ill patients suffer moral distress, research finds [Supplemental material]. *Postmedia News*. Retrieved December 21, 2014, from <http://www.ottawacitizen.com/health/Doctors+nurses+working+with+critically+patients/10658168/story.html>
- Lazenby, M., Ercolano, E., Schulman-Green, D., & McCorkle, R. (2012). Validity of the end-of-life professional caregiver survey to assess for multidisciplinary educational needs. *Journal of Palliative Medicine*, 15(4), 427-431. Doi:10.1089/jpm.2011.0246
- Lewis, K. (2013). How nurses can help ease transitions to end of life care [Abstract]. *Nursing Older People*, 25(8), 22-26.
- Loscalzo, M. J. (2008). Palliative care: An historical perspective. *Ash Education Book*, 1, 465. Doi:10.1182. Retrieved December 12, 2014, from <http://asheducationbook.hematologylibrary.org/content/2008/1/465.full.pdf>
- Lynch, M., Dahlin, C., Hultman, T., & Coakley, E. E. (2011). Palliative care nursing: Defining the discipline? *Journal of Hospice and Palliative Nursing*, 13(2), 106-111.
- Mahon, M. M., & McAuley, W. J. (2010). Oncology nurses' personal understandings about palliative care. *Oncology Nursing Forum*, 37(3), E141-E150. doi:10.1188/10.ONF.E141-E150
- Malloy, P., Virani, R. M., Kelly, K., Jacobs, H. H., & Ferrell, B. R. (2008). End-of-life care: Improving communication skills to enhance palliative care [Supplemental material]. *Topics in Advanced Practice Nursing eJournal*, Retrieved April 30, 2014, from [http://www.medscape.org/viewarticle/574420\\_print](http://www.medscape.org/viewarticle/574420_print)

- Mazanec, P., Daly, B. J., Pitorak, E. F., Kane, D., Wile, S., & Wolen, J. (2009). A new model of palliative care for oncology patients with advanced disease. *Journal of Hospice and Palliative Nursing, 11*(6), 324-331.
- McCourt, R., Power, J. J., & Glackin, M. (2013). General nurses' experiences of end-of-life care in the acute hospital setting: A literature review. *International Journal of Palliative Nursing, 19*(10), 510-516.
- McHugh, M. E., Arnold, J., & Buschman, P. R. (2012). Nurses leading the response to the crisis of palliative care for vulnerable populations. *Nursing Economics, 30*(3), 140-147.
- McIlfatrick, S., Noble, H., McCorry, N. K., Roulston, A., Hasson, F., McLaughlin, D.,...Craig, A. (2014). Exploring public awareness and perceptions of palliative care: A qualitative study. *Palliative Medicine, 28*(3), 273-280. Doi:10.1177/0269216313502372
- Meadows, K. A. (2003). So you want to do research? 3. An introduction to qualitative methods. *British Journal of Community Nursing, 8*(10), 464-469.
- Meier, D. E. (2010). The development, status, and future of palliative care. In D. Meier, S. Isaacs & R. Hughes (Eds.), *Palliative Care Transforming the care of serious illness* (1st ed., p. 60). San Francisco, CA: Jossey-Bass.
- Meier, D. E. (2011). Increased access to palliative care and hospice services: Opportunities to improve value in health care. *The Millbank Quarterly, 89*(3), 343-380.
- Meier, D. E., & Brawley, O. W. (2011). Palliative care and the quality of life. *Journal of Clinical Oncology, 29*(20), 2750-2752. doi:10.1200/JCO.2011.35.9729
- Meier, D. E., Lim, B., & Carlson, M. D. (2010). Raising the standard: Palliative care in nursing homes. *Health Affairs, 29*(1), 136-140. doi:10.1377/hlthaff.2009.0912

- Melvin, C. S. (2012). Professional compassion fatigue: What is the true cost of nurses caring for the dying? *International Journal of Palliative Nursing*, 18(12), 606-611.
- Merriam, S. B. (2009). *Qualitative Research A guide to Design and Implementation* (1st Ed.). San Francisco, CA: Jossey-Bass .
- Miller, S. C., & Ryndes, T. (2005). Quality of life at the end of life: the public health experience. *Public Health and Aging, Summer*, 41-47.
- National Board for Certification of Hospice and Palliative Nurses (2014). Certification for hospice and palliative Registered Nurses. Retrieved October 25, 2014, from <http://www.nbchpn.org/DisplayPage.aspx?Title=RN%20Overview>
- National Consensus Project (2009). *Clinical practice guidelines for quality palliative care* (ISBN# 978-1-934654-11-8). Pittsburgh, PA: National Consensus Project for Quality Palliative Care.
- National Consensus Project for Quality Palliative Care (2013). *Clinical Practice Guidelines for Quality Palliative Care*. Retrieved October 25, 2014, from <http://www.nationalconsensusproject.org>
- National Hospice and Palliative Care Organization (2014). History of hospice care. Retrieved October 24, 2014, from <http://www.nhpc.org/history-hospice-care>
- National Hospice and Palliative Care Organization (2014). *NHPCO's facts and figures Hospice care in America*. Retrieved November 26, 2014, from [http://www.nhpc.org/sites/default/files/public/Statistics\\_Research/2012\\_Facts\\_Figures.pdf](http://www.nhpc.org/sites/default/files/public/Statistics_Research/2012_Facts_Figures.pdf)

National Institute of Health Senior Health (2014). Preparing for the end of life. Retrieved September 27, 2014, from

<http://nihseniorhealth.gov/endoflife/preparingfortheendoflife/01.html>

National Institute of Nursing Research (2013). *Building momentum: The science of end-of-life and palliative care. A review of research trends and funding, 1997-2010* (NIH Publication No. 13-7993). Retrieved September 27, 2014, from

<http://www.ninr.nih.gov/sites/www.ninr.gov/files/NINR-Building-Momentum-508.pdf>

National Palliative Care Research Center (2013). About palliative care. Retrieved September 13, 2014, from <http://www.npcrc.org/content/15/About-Palliative-Care.aspx>

National Quality Forum (2006). *A National Framework and Preferred Practices for Palliative and Hospice Care Quality* (ISBN 1-933875-06-2). Retrieved November 27, 2014, from National Quality Forum website: <http://www.qualityforum.org>

National Quality Forum (2014). Palliative care and end-of-life care. Retrieved from

[http://www.qualityforum.org/print\\_content\\_details.aspx?title=Palliative+Care+and+End-of-Life+Care](http://www.qualityforum.org/print_content_details.aspx?title=Palliative+Care+and+End-of-Life+Care)

Neutens, J. J., & Rubinson, L. (2010). *Research techniques for the health sciences* (4th Ed.). San Francisco, CA: Pearson Education, Inc.

Nursing World (2010). Position statement: Registered nurses' roles and responsibilities in providing expert care and counseling at the end-of-life. Retrieved September 24, 2014, from <http://www.nursingworld.org/MainMenuCategories/Policy-Advocacy/Positions-and-Resolutions/ANAPositionStatements/Position-Statements-Alphabetically/etpain14426.pdf>

- O'Shea, M. F. (2014). Staff nurses' perceptions regarding palliative care for hospitalized older adults. *American Journal of Nursing, 114*(11), 26-34. Retrieved November 5, 2014, from <http://ajnonline.com>
- Pavlish, C., & Ceronsky, L. (2009). Oncology nurses' perceptions of nursing roles and professional attributes in palliative care. *Clinical Journal of Oncology Nursing, 13*(4), 404-412. doi:10. 1188/09/CJON.404-412
- Peters, L., Cant, R., Sellick, K., O'Connor, M., Lee, S., & Burney, S. (2012). Is work stress in palliative care nurses a cause for concern? A literature review. *International Journal of Palliative Nursing, 18*(11), 561-567.
- Peterson, J., Johnson, M., Apmann, L., Chang, P. C., Kershek, S., Scherr, C.,...Pincon, D. (2010). What is so stressful about caring for a dying patient? A qualitative study of nurses' experiences. *International Journal of Palliative Nursing, 16*(4), 181-187.
- QSR International (2014). Products. Retrieved September 24, 2014, from <http://www.qrsinternational.com/products.aspx>
- Robert Wood Johnson Foundation (2012, September 27). Advocates call on nurses to take leading role in palliative care [Online forum comment]. Retrieved from <http://www.rwjf.org/en/about-rwjf/newsroom/newsroom-content/2012/09/advocates-call-o...>
- Ross, M. M., McDonald, B., & McGuinness, J. (1996). The palliative care quiz for nursing (PCQN): the development of an instrument to measure nurses' knowledge of palliative care. *Journal of Advanced Nursing, 23*, 126-137.
- Rubin, H. J., & Rubin, I. S. (2012). *Qualitative interviewing: the art of hearing data* (3rd Ed.). Thousand Oaks, CA: Sage Publications, Inc.

- Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information, 22*, 63-75.
- Stjernsward, J., Foley, K. M., & Ferris, F. D. (2007). The public health strategy for palliative care. *Journal of Pain and Symptom Management, 33*(5), 486-493.
- U. S. Department of Health and Human Services (n.d.). *What are critical access hospitals (CAH)?* Retrieved March 19, 2014, from <http://www.hrsa.gov/healthit/toolbox/RuralHealthITtoolbox/Introduction/critical.html>
- Wallerstedt, B., & Andershed, B. (2007). Caring for dying patients outside special palliative care settings: experiences from a nursing perspective. *Scandinavian Journal of Caring Science, 21*, 32-40.
- Weigel, C., Parker, G., Fanning, L., Reyna, K., & Brewer Gasbarra, D. B. (2007). Apprehension among hospital nurses providing end-of-life care. *Journal of Hospice and Palliative Nursing, 9*(2), 86-91.
- Weissman, D. E. (2009 ). Moral distress in palliative care. *Journal of Palliative Medicine, 12*(10), 865-866. doi:10.1089/jpm.2009.9956
- Weissman, D. E., & Meier, D. E. (2011). Identifying patients in need of a palliative care assessment in the hospital setting. *Journal of Palliative Medicine, 14*(1), 1-7. doi:10.1089/jpm.2010.0347
- Wessel, E. M., & Rutledge, D. N. (2005). Home care and hospice nurses' attitudes toward death and caring for the dying: Effects of palliative care education. *Journal of Hospice and Palliative Nursing, 7*(4), 212-218.
- White, K. R., & Coyne, P. J. (2011). Nurses' perceptions of educational gaps in delivering end-of-life care. *Oncology Nursing Forum, 38*(6), 711-717. doi:10.1188/11.ONF.711-717

- White, K. R., Coyne, P. J., & White, S. G. (2012). Are hospice and palliative nurses adequately prepared for end-of-life care? *Journal of Hospice and Palliative Nursing, 14*(2), 133-140.
- White, K. R., McClelland, L. E., VanderWielen, L., & Coyne, P. J. (2013). Voices from the bedside. Palliative nurses' perceptions of current practices and challenges. *Journal of Hospice and Palliative Nursing, 15*(6), 360-365.
- White, K., Wilkes, L., Cooper, K., & Barbato, M. (2004). The impact of unrelieved patient suffering on palliative care nurses. *International Journal of Palliative Nursing, 10*(9), 436-444.
- Wilson, S. A. (2010). Long-Term Care. In B. Ferrell & N. Coyle (Eds.), *Oxford text of Palliative Nursing* (3rd ed., pp. 879-890).
- World Health Organization (2014). WHO Definition of palliative care. Retrieved March 7, 2014, from <http://www.who.int/cancer/palliative/definition/en/>
- World Health Organization (1997). *Measuring quality of life*. Retrieved March 7, 2014, from <http://www.who.int/mental.health/media/68pdf>.

**APPENDICES**

## APPENDIX A

**Correspondence Related to Request for use of Dame Cicely Saunders Quote**

On Thu, Jan 15, 2015 at 4:00 PM, Nancy Buttry <[buttryn@gmail.com](mailto:buttryn@gmail.com)> wrote:

Hello,

I am a doctoral student at Southern Illinois University in Carbondale IL USA and have been working on my dissertation. The topic of my dissertation is palliative care from the viewpoint of rural nurses. I found the quote about "you matter because you are you" and wondered where I might find the primary source for that quote by Dame Saunders. It fits so well with the thoughts that I have for this study and wanted to include it in my paper.

Thank you so very much for any assistance that you can provide.

Nancy Buttry

**Dear Nancy**

**We have sought the source of this quote and found that she said it or something like it at different times. We don't have a specific source but I think "word of mouth" or "reported on many occasions to have said..." would suffice.**

**I hope that helps.**

**All best**

**Brenda Ferns**

## Correspondence for Request to use the Palliative Care Model

Ms. Sieger,

I am a doctoral student at Southern Illinois University, Carbondale, in the process of writing my prospectus for my dissertation on end of life and palliative care from the viewpoint of nurses in the rural Midwest. The model "Palliative Care's Place in the Course of Illness" provides a perfect theoretical basis for my project. I would like very much to gain permission to use the model within the dissertation and wondered if you could help me with obtaining permission. I received your contact info from the Center to Advance Palliative Care representative who returned my call.

Any information or guidance you can provide will be greatly appreciated. Thank you very much.

**Sieger, Carol** <carol.sieger@mssm.edu>

9/21/14

Nancy: Please provide me with the link to what you want to include. Carol

Carol E. Sieger  
Chief Operating Officer  
Center to Advance Palliative Care

**From:** Amy Killmeyer <[amyk@hpnf.org](mailto:amyk@hpnf.org)>  
**Sent:** Monday, October 06, 2014 8:06 AM  
**To:** Nancy Kyle Buttry  
**Subject:** FW: NCP Comment/Question from Website!

Dear Nancy,

Please see approval below and include proper citation.

Thank you.

Amy Killmeyer

Foundation and Coalition Administrative Assistant  
 One Penn Center West  
 Suite 425  
 Pittsburgh, PA 15276  
[412-787-9316](tel:412-787-9316) – Phone  
[412-787-9305](tel:412-787-9305) – Fax  
[amyk@hpnf.org](mailto:amyk@hpnf.org)

*~ Please remember HPNF in your will and estate planning ~*

**From:** Sally Welsh  
**Sent:** Sunday, October 05, 2014 4:32 PM  
**To:** Amy Killmeyer  
**Subject:** Fwd: NCP Comment/Question from Website!

**Approved, send her approval and citation information.  
 Sally**

Sent from my Verizon Wireless 4G LTE smartphone

----- Original message -----

**From:** Connie Dahlin <[connied@hpna.org](mailto:connied@hpna.org)>  
**Date:** 10/05/2014 4:23 PM (GMT-05:00)  
**To:** Sally Welsh <[SallyW@hpna.org](mailto:SallyW@hpna.org)>  
**Subject:** FW: NCP Comment/Question from Website!

**I think this is fine.**

**From:** Nancy Kyle Buttry [<mailto:nbuttry@siu.edu>]  
**Sent:** Saturday, October 04, 2014 12:15 AM  
**To:** Connie Dahlin  
**Subject:** Re: NCP Comment/Question from Website!

Hi Connie,

Thank you so much for responding. The model "Palliative Care's Place in the Course of Illness" diagram that is on page 6 of the Clinical Practice Guidelines for Quality Palliative Care 2nd edition, National Consensus Project. This is what I would like to use in my dissertation. It fits well as a theoretical framework for nursing perception on end of life and palliative care which is the topic of my dissertation. If permission is granted for me to

include the diagram in my paper I would appreciate direction on how you would like for it to be referenced if other than the document where I found the model.

Thank you.

**Nancy Buttry**

**I was asked to follow up on your inquiry. Not sure if you are requesting to use the NCP Domains or the CAPC definition of palliative care. Can you be a bit more specific on what you are using?**

**Connie Dahlin**

**Constance Dahlin, ANP, BC, ACHPN, FPCN, FAAN**

**Director of Professional Practice  
Hospice and Palliative Nurses Association  
One Penn Center West, Suite 425  
Pittsburgh PA 15276-0109  
Phone [412.787.9301](tel:412.787.9301)  
Fax [412.787.9305](tel:412.787.9305)  
[connied@hpna.org](mailto:connied@hpna.org)**

**From: Sally Welsh  
Sent: Monday, September 15, 2014 8:03 PM  
To: Amy Killmeyer; Connie Dahlin  
Subject: RE: NCP Comment/Question from Website!**

**Amy, Connie**

**What is she requestung? Is it in the Guidelines? If so is it ours or CAPC's?  
Sally**

**----- Original message -----**

**From: Amy Killmeyer <[amyk@hpnf.org](mailto:amyk@hpnf.org)>  
Date:09/15/2014 6:31 PM (GMT-05:00)  
To: Sally Welsh <[SallyW@hpna.org](mailto:SallyW@hpna.org)>  
Cc: Amy Melnick <[amym@nationalcoalitionhpc.org](mailto:amym@nationalcoalitionhpc.org)>  
Subject: FW: NCP Comment/Question from Website!**

Hi Sally,

See request below for permission and advise.

Thank you.

Amy

-----Original Message-----

From: [webmaster@nationalconsensusproject.org](mailto:webmaster@nationalconsensusproject.org) [<mailto:webmaster@nationalconsensusproject.org>]

Sent: Monday, September 15, 2014 4:24 PM

To: Amy Killmeyer

Subject: NCP Comment/Question from Website!

Importance: High

NCP COMMENT/QUESTION FROM [NCP.ORG](http://NCP.ORG)!

-----  
CONTACT INFORMATION:

=====  
Nancy K. Buttry MSN RN

[nbuttry@siu.edu](mailto:nbuttry@siu.edu)

111 County Road 300N

Norris City, IL 62869

[618-962-3337](tel:618-962-3337)

COMMENTS:

=====  
I am a doctoral candidate at Southern Illinois University, Carbondale, IL. My dissertation topic is palliative care from the viewpoint of nurses. I would like to use the model of Palliative Care's Place in the Course of Illness as my theoretical framework for the study. Who should I contact for permission to use the illustration that I found under Palliative Care by the Center to Advance Palliative Care? Thank you very much for any assistance that you can provide me.

**Correspondence for Request to use the “Trajectories of Palliative Care” Model**

Feb 21

[Nancy Buttry <buttryn@gmail.com>](mailto:buttryn@gmail.com)

to denajeans

Hello,

My name is Nancy Buttry and I am a Doctoral student at Southern Illinois University in Carbondale, IL. My dissertation is on the topic of Palliative Care and I have an interest in the "Trajectories of Palliative Care" model that I found when reading the Scope and Standards of Practice, Palliative Nursing on page 2. It indicated that it was copyrighted by the Hospice and Palliative Nurses Association.

I would like to include a visual of the model as part of my theoretical framework for my study which is entitled Palliative Care: Viewpoints from Nurses. This is a qualitative study that is seeking information on what nurses perceive about the palliative care in their practice and the model fits with my study.

Your name was given to me when I called the HPNA office. Please advise if you can direct me on how to obtain permission to use the model and if it is possible to get it in .jpeg format for inserting into my dissertation. Thank you so very much for any assistance.

Feb 23

Dena Sutermaster <[denajeans@hpna.org](mailto:denajeans@hpna.org)>

to **Dane**, me

Hi Nancy,

You have permission to use the "Trajectories of Palliative Care" figure for your dissertation titled *Palliative Care: Viewpoints from Nurses* using the statement below. Please send me an electronic copy of your dissertation once completed.

Used with permission from the Hospice and Palliative Nurses Association ([www.AdvancingExpertCare.org](http://www.AdvancingExpertCare.org)). From Dahlin CM, Sutermaster DJ, eds; Hospice and Palliative Nurses Association, American Nurses Association. *Palliative Nursing: Scope and Standards of Practice - An Essential Resource for Palliative and Hospice Nurses*. Silver Spring, MD: [nursesbooks.org](http://nursesbooks.org); 2014:2.

I have cc'd Dane who will send you a JPEG of the figure.

Good luck with your dissertation.

Dena Jean Sutermaster, RN, MSN, CHPN

Education Specialist  
One Penn Center West, Suite 425  
Pittsburgh, PA 15276-0109  
t. [412.282.8203](tel:412.282.8203) f. [412.787.9305](tel:412.787.9305)  
[denajeans@hpna.org](mailto:denajeans@hpna.org)

APPENDIX B  
**Palliative Care: (Demographic Information)**  
**Viewpoints from Nurses**

Age: \_\_\_\_\_ Race/Ethnicity: \_\_\_\_\_

Gender (please circle):    Male    Female

Education (highest grade/degree completed): \_\_\_\_\_

Registered Nurse \_\_\_\_\_      Advanced Practice Nurse \_\_\_\_\_

What year did you receive your license? \_\_\_\_\_

How long have you worked as a nurse? \_\_\_\_\_

Type of Agency: \_\_\_\_\_

Unit/department: \_\_\_\_\_

Have you attended continuing education/workshops on the topic of Palliative Care?:

(please circle): Yes    No

If yes please describe \_\_\_\_\_

\_\_\_\_\_

Was Palliative Care included in your basic nursing educational program?

(please circle): Yes    No

If yes please describe:

\_\_\_\_\_

\_\_\_\_\_

Would you be interested in attending continuing education on the topic of Palliative Care?

(please circle): Yes    No

If yes what topic(s) would you be most interested in learning more about?

\_\_\_\_\_

## APPENDIX C

# Seeking Registered Nurses



To Participate in a 60-90 minute research  
*Focus Group* on the subject of  
**Palliative Care: Viewpoints from Nurses**  
Must be an RN not certified in palliative care

Contact Nancy Buttry at 618-962-3337 or [nbuttry@siu.edu](mailto:nbuttry@siu.edu). Research conducted under the supervision of Dr. Kathleen Welshimer, Health Education, Southern Illinois University Carbondale

Time: TBA  
When: TBA  
Where: TBA

## APPENDIX D

**Research Project: Palliative Care:****Viewpoints from Nurses**

Researcher:

Nancy Buttry, Doctoral Student in Health Education and Recreation  
*Southern Illinois University, Carbondale*

## Purpose of the Study (Explanation)

The purpose of this study is to describe the perceptions, impact, and meaning of palliative care from the viewpoint of nurses who provide care to patients and their families. Currently there is not a clear understanding of what Registered Nurses in this region know and believe about palliative care. Viewpoints from nurses who provide care will provide a description of palliative care as it exists in this region. The goal is to gain a better understanding of what palliative care means to nurses. The results from this study may be used in academic publications including journals and books.

## APPENDIX E

**Research Project: Palliative Care:  
Viewpoints from Nurses**

Researcher:

Nancy Buttry, Doctoral Student in Health Education and Recreation  
*Southern Illinois University, Carbondale*

Agency Permission Letter

Please indicate permission on agency letterhead for research to be conducted at this agency and send to: Nancy Buttry, 111 County Road 300N, Norris City, IL 62869 or nbuttry@siu.edu.

I give permission for Nancy Buttry to conduct research at this agency on the topic of **Palliative Care: Viewpoints from Nurses**.

I understand that the researcher will interact with nurses who will be asked to participate in a semi-structured interview or focus group on the subject of Palliative Care. The names of any persons included in this study will *not* appear in any papers. This specific agency will *not* be identified. I understand that the information gathered from this study may be later used in conjunction with the publication of academic articles or books.

Name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Position at agency: \_\_\_\_\_

This project has been reviewed and approved by the SIUC Human Subjects Committee. Questions concerning your rights as a participant in this research may be addressed to the Committee Chairperson, Office of Sponsored Projects Administration, SIUC, Carbondale, IL 62901-4709. Phone (618) 453-4533. E-mail: siuhsc@siu.edu

## APPENDIX F

**Research Project: Palliative Care: Viewpoints from Nurses**

Researcher:

Nancy Buttry, Doctoral Student in Health Education and Recreation  
*Southern Illinois University, Carbondale*

Purpose

The purpose of this study is to describe the perceptions, impact, and meaning of palliative care from the viewpoint of nurses who provide care to patients and their families. The results from this study may be used in academic publications including journals and books.

Participation

If you choose to take part in this study, you will participate in a semi-structured focus group/interview lasting approximately one hour. The interview will be audio-recorded and later transcribed so it may be referenced most accurately. The recordings will be destroyed at the completion of the study.

Your Rights

Your participation is *voluntary* and you may withdraw at any time. Please feel free to present questions or concerns to the interviewer at any time before, during, or after the interview. You do not have to answer any questions you do not want to. If there is a question you wish not to answer, please indicate you wish to “skip it”.

Confidentiality

All information gathered from this interview will be kept in a secure file at the researcher’s home. Basic demographic information such as race, age, sex, etc., will be gathered, as well as general background information such as education, general past work experience, and that included in the interview. Only those directly involved with this project will have access to the data. Your name will not be published, and only the researcher will have access to all records. All reasonable steps to protect your identity will be taken.

I  agree to participate in this study.

I  agree  disagree that the researcher may quote me in her paper. I understand that my name would not be used and that no identifying information would be shared.

Thank you for supporting this study. If you have questions please email me at [nbuttry@siu.edu](mailto:nbuttry@siu.edu), or call (618) 962-3337 or you may contact my supervising professor, Dr. Kathleen Welshimer, Department of Health Education and Recreation, SIUC, Carbondale, IL 62901; [welshime@siu.edu](mailto:welshime@siu.edu) or call (618) 453-2777.

---

 Participant signature

Date

This project has been reviewed and approved by the SIUC Human Subjects Committee. Questions concerning your rights as a participant in this research may be addressed to the Committee Chairperson, Office of Sponsored Projects Administration, SIUC, Carbondale, IL 62901-4709. Phone (618) 453-4533. E-mail: [siuhsc@siu.edu](mailto:siuhsc@siu.edu)

## APPENDIX G

**Research Project: Palliative Care:  
Viewpoints from Nurses**

Researcher:

Nancy Buttry, Doctoral Student in Health Education and Recreation  
*Southern Illinois University, Carbondale*

I \_\_\_\_\_ agree to participate in this research project conducted by Nancy Buttry, Doctoral Student in Health Education and Recreation at Southern Illinois University, Carbondale.

The purpose of this study is to describe the perceptions, impact, and meaning of palliative care from the viewpoint of nurses who provide care to patients and their families. The results from this study may be used in academic publications including journals and books.

I understand that my participation is strictly voluntary and that I may refuse to answer any question without penalty. I also understand that I will be involved in a semi-structured focus group/interview lasting approximately one hour. I understand that the focus group/interview will be audio-recorded and later transcribed so it may be referenced most accurately. The recordings will be kept in a secure file at the researcher's home and will be destroyed at the completion of the study.

I understand that any questions or concerns about this study are to be directed to Nancy Buttry, 618-962-3337, [nbuttry@siu.edu](mailto:nbuttry@siu.edu), or Dr. Kathleen Welshimer, Department of Health Education and Recreation, SIUC, [welshime@siu.edu](mailto:welshime@siu.edu) or call 618-453-2777.

I have read the information above and any questions I asked have been answered to my satisfaction. I agree to participate in this activity and know my responses will be audio-recorded. I understand a copy of this form will be made available to me for the relevant information and phone numbers.

I \_\_\_ agree \_\_\_ disagree to be audiotaped.

---

Participant signature

Date

This project has been reviewed and approved by the SIUC Human Subjects Committee. Questions concerning your rights as a participant in this research may be addressed to the Committee Chairperson, Office of Sponsored Projects Administration, SIUC, Carbondale, IL 62901-4709. Phone (618) 453-4533. E-mail: [siuhsc@siu.edu](mailto:siuhsc@siu.edu)

## Appendix H

### **Proposed Script for Focus Group/Interview**

*Consent forms will be distributed, collected, and a copy provided to the participant(s). Consent to audio-record will also be distributed, collected, and a copy provided to the participant(s).*

**For focus groups:**

“Welcome and thank you for participating in this focus group on the subject of Palliative Care.”

**For interview:**

“Thank you for agreeing to speak with me about Palliative Care.”

“The purpose of this focus group/interview is to learn more about nurses’ perceptions related to Palliative Care. As a nurse you are in a unique situation to experience palliative care in your daily work as you provide care for patients and families who are experiencing a life-limiting illness or condition. Currently there is not a clear understanding of what Registered Nurses in this region know and believe about palliative care. Viewpoints from nurses who provide care will provide a description of palliative care as it exists in this region. The goal is to gain a better understanding of what palliative care means to nurses.”

**For focus groups:**

“I would like to remind you that to protect the privacy of focus group members, a pseudonym will be used when coding the transcripts of this focus group. I would also ask that you not discuss what was shared during the focus group with anyone else.”

**For focus groups/interviews:**

“The focus group/interview will last approximately 60-90 minutes and will be audiotaped so that the discussion is recorded accurately.”

“Do you have any questions before we begin?”

## APPENDIX I

**Palliative Care:  
Viewpoints from Nurses  
Focus Group Interview Guide**

1. Tell me what palliative care means to you.
  - How did you learn about palliative care?
  - What does palliative care consist of at your agency?
2. Tell me about your experiences with patients who you feel needed palliative care and did not receive it or chose to pursue aggressive, curative or intensive care.
  - How did you feel about the experiences?
3. Tell me about your experiences with patients who received palliative care.
  - How did you feel about the experiences?
4. What do you see as barriers to palliative care in your experiences?
5. What do you see as rewards to providing palliative care?
6. Is there anything else you would like to share about palliative care that we have not discussed?