

**THE PERCEPTIONS OF ADVOCACY BEHAVIORS IN END-OF-LIFE NURSING
CARE AMONG NOVICE, EXPERIENCED AND EXPERT NURSES**

A Dissertation

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By

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Title of Dissertation: The Perceptions of Advocacy Behaviors
in End-of-Life Nursing Care Among Novice,
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**Submitted in partial fulfillment of the requirements for the degree of Doctor of
Nursing Science.**

Dedication

This dissertation is dedicated to the memory of my mother, Miranda Eden “Edie” Wiest, RN, who was my first nurse educator and inspiration for the care of people nearing end-of-life. Through her work a community was supported and dying was viewed as a beautiful part of life. Her personal end-of-life journey taught the next generation to carry on.

Acknowledgments

The journey to obtain a doctorate is one that can be compared to many other life experiences. One might believe it is a personal passage; however, it is soon apparent that much support is needed to complete each step. The journey is shared with family, friends, colleagues, faculty, and peers. I believe that it was this network of support and God's grace that allowed me to complete my educational process.

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My husband, Marshall, has shared every step with me during my life-long educational journey. Words cannot express my deep gratitude for his unwavering support and love. I would like to offer a special thank you to my children, Jason and Mary, who have shared their mother's time and energy with class time, travel, and writing projects. I could not have succeeded without my family's patience and encouragement. Finally, I am grateful to God, the source of my being and strength.

As a novice researcher, I am especially appreciative for the encouragement and financial support of The Southeastern Pennsylvania (SePA) Chapter of the American Association of Critical-Care Nurses. The award of the SePa Chapter Research Grant for \$1,600.00 served as practical support and acknowledgement of the professional organization's role to promote nursing practice, education and research.

Abstract

Nurses and educators have difficulty describing the steps of advocacy to guide novice nurses. In order to improve the status of end-of-life care, nurse educators need to be cognizant of the advocate role in nursing practice. Benner (1984) writes that caregiving practices do not come naturally, but are skills learned first in families and communities and later in school and work. To overcome the barriers to the practice of advocacy, educational opportunities in schools of nursing and practice settings are essential.

The purpose of this comparative descriptive study was to describe nurses' perceptions of advocacy behaviors in end-of-life nursing practice. The research questions guiding this study explored the perceptions of advocacy behaviors and the supports and barriers to the practice of advocacy in end-of-life nursing care among graduate and registered nurses in acute care settings. A second set of questions identified the differences among novice graduate nurses, experienced and expert nurses in the perception of advocacy behaviors and the supports and barriers to practicing advocacy in end-of-life nursing care in acute care settings.

The use of theory to explore the nature of patient advocacy as a nursing role in end-of-life care provides a guide for nursing education, practice and research. The novice to expert process and the seven domains of a caring practice as they relate to advocacy behaviors (Benner, 1984) provided a framework in which the nurse can move towards becoming an effective patient advocate. This study helps to develop a clearer

understanding of the power of advocacy (Benner) to assist the patient and family to overcome barriers impeding their end-of-life care.

This study used a naturally occurring practice setting of three regional hospitals and provided an excellent opportunity to examine and describe the perceived advocacy practice behaviors in end-of-life nursing care among novice, experienced and expert nurses. The convenience sample consisted of 317 practicing nurses, with the majority reporting frequent contact with dying patients. Practicing nurses completed the 38-item Ethics Advocacy Instrument (Wlody, 1993), including two open-ended questions and a demographic survey, with 33.3% return rate by postal mail.

Participants indicated considerable agreement with perceived advocacy behaviors in end-of-life nursing practice with no significant differences among novice, experienced and expert nurses. Despite the recent emphasis on end-of-life nursing education, practicing acute-care nurses report modest exposure to end-of-life training. The perception of hospital supports was modest with no significant differences among novice, experienced and expert nurses. Three substantial supports to advocacy practice identified by the participants included nurse managers, co-workers and multi-disciplinary services. The study participants described considerable barriers to their advocacy practice including the physician, the patient's family and fear. Novice nurses reported with great frequency that lack of communication and lack of time and/or support served as barriers to their practice.

The major study limitations included the low instrument reliability and limited validity. Other limitations included the non-random, convenience sample with unequal

groups, and the timing of the data collection that might have interfered with measurement of true novice nursing practice.

This study added to the empirical data base and its findings were congruent with the literature in that the majority of nurse participants agreed that they practiced advocacy behaviors, despite the reported barriers. A cross-method triangulation served to strengthen internal validity by measuring the concept of advocacy from two approaches. This study did not confirm an over-all difference in advocacy behaviors among the novice, experience and expert nurse as measured by the APS and ABS combined score. However, it offered insight into the supports and barriers nurses at different skill levels experienced in the practice of advocacy. Nurse educators can use these data to revise teaching-learning methods or add content to better prepare their graduates. Appropriate teaching methods to address differences of opinion and navigation of the hospital system may equip nurses with the communication tools of advocacy and ultimately improve patient care.

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Chapter 1

Advocacy in End-of-Life Nursing Care

The nursing profession has gained professional autonomy over the last five decades and has clearly defined its role as patient advocate (Bernal, 1992; Hewitt, 2002; Mallik, 1997; Segesten, 1993). The integration of professional practice acts, ethical practice statements, social policy recommendations, and definitions of professional nursing, provide the legal and professional support for the nursing role of advocate.

Nursing's Social Policy Statement (ANA, 2004) provides a framework for understanding the nurse's role and obligation to society and those receiving care. It gives a clear account of responsibilities to the public served by the nursing profession. The values and assumptions in which the policy statement is grounded include that the "relationship between a nurse and patient involves full and active participation of the patient and the nurse in the plan of care and occurs within the context of the values and beliefs of the patient and nursing" (ANA 2004, ¶ 7). This definition of nursing practice has evolved from Nightingale and Henderson with the consistent orientation of the promotion of well-being in the people served (ANA). The authority to practice nursing is based on a social contract that acknowledges professional rights and responsibilities by and for the public; therefore, nurses have an obligation to serve on behalf of the patients in their care. Advocacy for the public is an implied role of nursing practice.

The Essentials of Baccalaureate Education for Professional Nursing Practice (AACN, 1998) clearly state that the role of the professional nurse includes advocacy:

Nurses are providers of care. In this role, nurses are patients' advocates and educators. Historically, the nursing role has emphasized partnership with patients - whether individuals, families, groups, or communities – in order to foster and support active participation in determining health care decisions. Patient advocacy is, and will continue to be, a hallmark of the professional nursing role, and requires that nurses deliver high quality care, evaluate care outcomes, and provide leadership in improving care. (p. 4)

The document also describes how nurses recognize that clinical practice is based upon values and ethics as well as science and technology. Ethical decisions must be made within a professional framework to support practice. Therefore, the role of advocacy in nursing practice has underpinnings in ethical decision-making. The AACN document provides a clear directive that professional nursing, from novice to expert practice, includes the hallmark role of patient advocacy.

Ethics is the foundation of nursing practice. The Code of Ethics (ANA, 2001) serves to guide nursing practice to adhere to the ideals and moral norms of the profession. It is a statement of the ethical obligation and duty of every individual entering the profession and is assumed to be non-negotiable. The recently revised Code provides nine statements to guide nursing practice. The third statement: "The nurse promotes, advocates for, and strives to protect the health, safety, and rights of the patient" (ANA, 2001, §3.0), clearly defines advocacy as an obligation to the patients served. The Code of Ethics for Nurses provides a moral and just framework to use in clinical practice and the role of patient advocate is clearly assumed to be a priority of nursing care.

State practice acts and codes also serve as guides for the practice of the advocacy role. For example, the Pennsylvania Code of Nursing Practice states that the general function of the registered nurse is to carry out nursing actions which promote, maintain and restore the well-being of individuals (Commonwealth of PA, 2003, §21.11). The Pennsylvania Board of Nursing recognizes the standards of practice and professional codes of behavior, as developed by the nursing associations, as the criteria for assuring safe and effective practice (Commonwealth of PA, 2003, §21.11). Therefore, according to the licensing agency's standards, nursing has an obligation to the role of patient advocate.

The practice of advocacy and end-of-life care in America has changed drastically in the last century due to the advances in medical technology and science. The leading cause of death has changed from communicable diseases to chronic, degenerative illnesses. The care of the dying has shifted from family and community to experts in the health professions (AACN & City of Hope, 2000; Ferrell, Grant, & Verani, 1999; Haisfield-Wolfe, 1996; Jablonski & Wyatt, 2005; Matzo & Sherman, 2001). Health care institutions have replaced the home as the most common place where death occurs and end-of-life care is more likely to be given by health care professionals than family members.

Nurses spend more time with people who are facing death than any other member of the health care team (AACN & City of Hope, 2000; Badger, 2005a; Haisfield-Wolfe, 1996; Jablonski & Wyatt, 2005). Throughout history, nurses have sought ways to improve the quality of life for individuals, families, and communities during every phase

of life's journey. The value of the nurse's role in insuring quality of life for the patient and family during the dying process cannot be underestimated. Nursing professionals are in key positions to support end-of-life care decisions and advocate for patients and families across all health care settings. Advocacy has been identified as the common thread of quality end-of-life nursing care (AACN & City of Hope; McClement & Degner, 1995; Penn, 1994). Advocacy encompasses pain and symptom management, ethical decision making, competent culturally sensitive care, and caring for people through the death and dying process (AACN & City of Hope; McClement & Degner; Penn). Advocacy is the act of informing and supporting patients and families to make the best decisions for their care (Rushton, 1994). For the purpose of this study, advocacy behaviors in nursing practice are defined as assisting the patient and family to overcome barriers impeding their care path (Wilkie, 2001). A care path includes the plan of nursing care which integrates Benner's (1984) seven domains of a caring nursing practice to support end-of-life care decisions made by the patient.

Statement of Problem

Nurses and educators have difficulty describing the characteristics of advocacy to guide novice nurses. In order to improve the status of end-of-life care, nurse educators need to be cognizant of the advocate role in nursing practice. Benner (1984) writes that care-giving practices do not come naturally, but are skills learned first in families and communities and later in school and work. To overcome the barriers to the practice of advocacy, educational opportunities in schools of nursing and practice settings are essential. Nurses advocate for patients in every practice setting and it is an inherent part

of all professional nursing curricula (Foley, Minick, & Kee, 2002). Nurse educators in baccalaureate programs are challenged to prepare graduates who possess the ability to practice advocacy; however, there is little description in the literature of how nurses learn the advocacy role. Because advocacy is embedded in nursing practice, it is sometimes invisible (Benner, Hooper-Kyriakidis, & Stannard, 1999; Curtain, 1983; Foley et al.; Wlody, 1993).

When nurses advocate for patients, they may face barriers associated with health care systems (Carpenter, 1992; Hewitt, 2002) and professional relationships (Badger, 2005a,b; Brophey, 2001; Curtain, 1983; Ellis, 1995; Grace, 2001; Kohnke, 1980). For example, nurses who work in acute care settings may experience conflict between their loyalties to their patients and their loyalties to the physician and employer (Kohnke). The patient's voice may get lost among the conflicts of the family, physician, agency policy, and colleagues' opinions. Conflicts may result in misunderstandings, confusion, and strained relationships.

The concept of existential advocacy implies that the patient and nurse can freely decide their relationship roles. The nurse attends to the patient during periods of sustained contact, and offers personal care. This trusting, dynamic, interpersonal relationship is a precondition for advocacy. The nurse is engaged in the relationship unifying the experience and providing personal meaning that the illness, suffering or dying is to have for the patient and family (Curtain, 1983; Gadow, 1980; Trandel-Korenchuck & Trandel-Lorenchuck, 1983). The unique knowledge of the patient and common humanity forms the foundation of the nurse-patient relationship. Thus, the nurse is in the ideal position

among health care providers to experience the patient as uniquely human with individual strength and beliefs and use this position to intervene on the patient's behalf. According to Curtain (1983), the end purpose of nursing is the welfare of other human beings.

With proliferation of the scientific knowledge base and technology over the last four decades, nursing roles have expanded to incorporate new technical skills and ethical and care standards that serve to guide practice (Haisfield-Wolfe, 1996; McClement & Degner, 1995). People's attempt to delay death or prolong life through modern technology has complicated care and increased options for end-of-life decisions. Nurses' traditional responsibilities and roles in end-of-life care have expanded to include involvement in issues of advance directives, do-not-resuscitate decisions, and palliative care options (Haisfield-Wolfe).

The disparity between the way people die and the way they wish to die is increasing. The results of a survey (Field & Cassel, 1997; NHPCO, 1996) reveal the majority of adults wish to be cared for at home if terminally ill, but the reality is that less than 29% enroll in home hospice services, leaving the majority of end-of-life care to acute and long-term care institutions. Some institutional cultures impede good care because of their treatment and cure focus, paternalistic care, inadequate decision-making models, and inadequate policies for pain and symptom management (AACN & City of Hope, 2000; Curtain, 1996; Field; NHPCO). The landmark Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT, 1995) serves to confirm the barriers to quality end-of-life care in America's health care institutions. The study demonstrated that for patients who were in the dying process,

discussions and decisions about care were uncommon for patients who were in the active dying process. For example, nearly half of all do-not-resuscitate orders were written in the last two days of life, and in many cases physicians made no change in their treatment patterns (SUPPORT).

Excellent quality end-of-life care depends on the availability of educated health care professionals. Death and dying are touched upon in the core curriculum of most nursing schools, but treatment is often limited to a single lecture, a brief class discussion, or a series of assigned readings (Christopher, 2001). The professional nursing education system fails to prepare graduates for evidenced-based end-of-life nursing practice.

Purpose of the Study

The primary purpose of this study is to describe nurses' perceptions of advocacy behaviors in end-of-life nursing practice in the acute care setting. The comparison of perceptions of advocacy behaviors among novice, experienced and expert nurses contributes to an understanding of the embedded practice of advocacy. In addition, the study identifies perceived supports and barriers to the practice of advocacy related to care for the dying. By disseminating the perceptions of advocacy practice and its perceived supports and barriers in end-of-life care, nurse educators and leaders may gain knowledge to use in educational programs and infrastructures to support the practice of advocacy for the novice, experienced and expert nurses.

Research Questions

The primary research questions guiding this comparative descriptive study were:

1. What are the perceptions of advocacy behaviors in end-of-life nursing care in

acute care settings among novice, experienced, and expert nurses?

2. What are the supports to practicing advocacy in end-of-life nursing care in acute care settings among novice, experienced, and expert nurses?
3. What are the barriers to practicing advocacy in end-of-life nursing care in acute care settings among novice, experienced, and expert nurses?
4. What are the differences among novice, experienced, and expert nurses in the perception of advocacy behaviors in end-of-life nursing care in acute care settings?
5. What are the differences among novice, experienced, and expert nurses in the identification of supports to practicing advocacy in end-of-life nursing care in acute care settings?
6. What are the differences among novice, experienced, and expert nurses in the identification of barriers to practicing advocacy in end-of-life nursing care in acute care settings?

Theoretical Framework

This study focuses on the perception of advocacy behaviors in nurse-patient interactions during end-of-life nursing care. The literature reveals that advocacy, like caring, is a concept that requires theoretical ties before the meaning can be understood (Mitchell & Bournes, 2000). The traditional nursing process is a mere tool with biological, psychological, and sociological underpinnings unless it is based on the nurses' belief and value system (Mitchell & Bournes). The nurse's theoretical or philosophical

view of human beings and their health-illness experience support the context in which the role of advocacy is practiced.

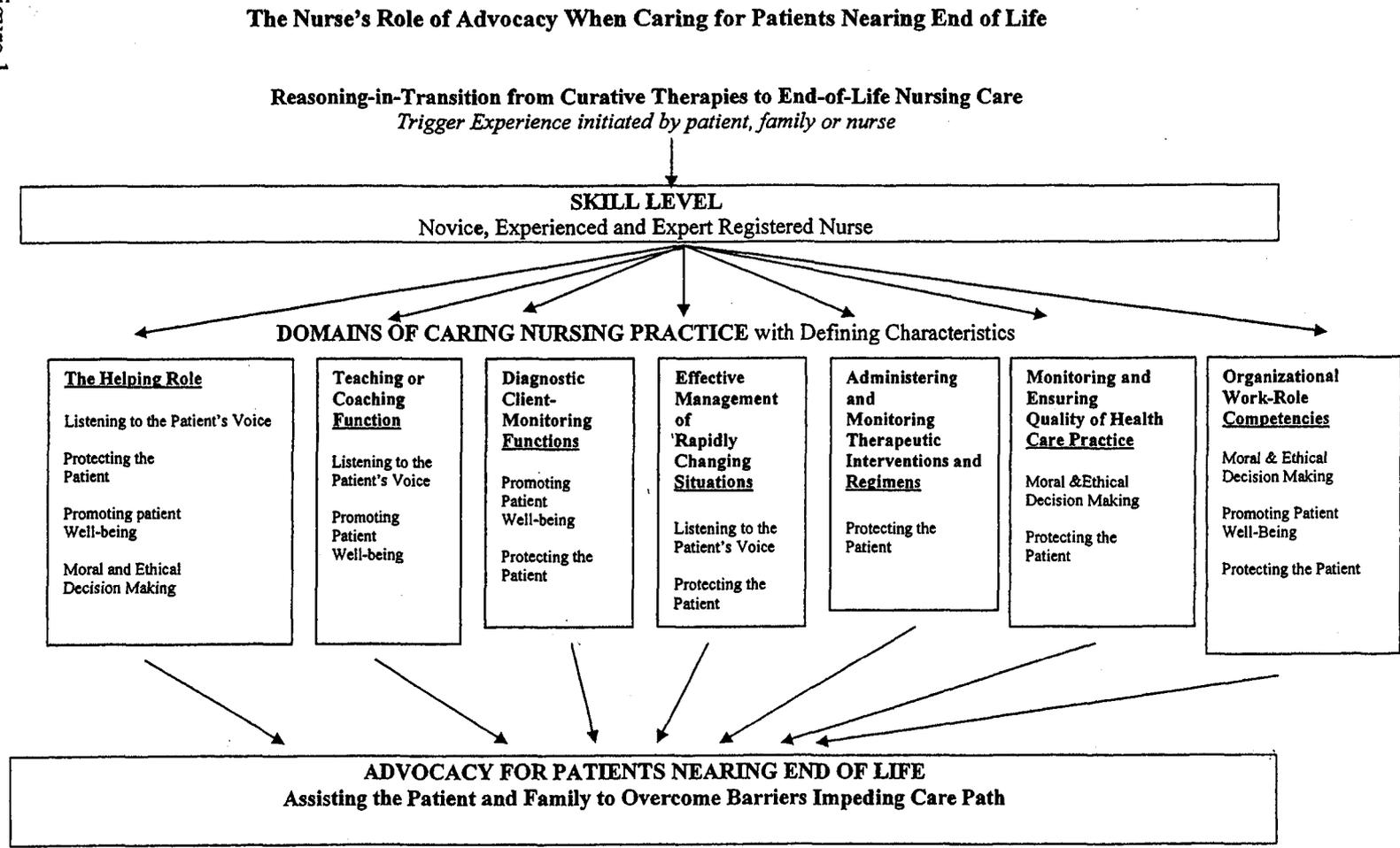
“Theory gives meaning to knowledge to improve practice by describing, explaining, and predicting phenomena. A nurse’s power is increased through theoretical knowledge because systematically developed methods guide critical thinking and decision making...” (Marriner-Tomey & Alligood, 2002, p.11). Patricia Benner’s (1984) theory regarding the progression from novice to expert clinical nursing practice offers common foci and threads related to the advocate role. These include: (a) the relationship between nurse and patient, (b) ethical connections and responsibility, (c) the caring ethic, (d) expert skills, and (e) the relationship between principles and practice.

The novice to expert process Benner (1984) describes provides a framework in which the nurse can move towards becoming an effective patient advocate. Of particular interest are Benner’s seven domains of a caring practice as they relate to advocacy behaviors. These domains include: (a) the helping role, (b) teaching or coaching function, (c) diagnostic client-monitoring functions, (d) effective management of rapidly changing situations, (e) administering and monitoring therapeutic interventions and regimens, (f) monitoring and ensuring quality of health care practices, and (g) organizational work-role competencies (Benner; Benner et al., 1999; Benner & Wrubel, 1989). They relate holistically to the defining characteristics identified in the literature review of the nurses’ advocacy practice performed for this study including: (a) listening to the patient’s voice, (b) protecting the patient, (c) promoting patient well-being, and (d) moral and ethical

decision making. The threads of a caring and excellent practice describe in full what consequences, or desired outcomes, advocacy behaviors should produce.

A conceptual map of Benner's (1984) theory related to the nurses' advocacy behaviors when caring for patients nearing end of life appears in Figure 1. The first step to integrate the behavior of advocacy is to develop a reasoning-in-transition skill. "Reasoning-in-transition refers to practical reasoning where a clinician takes account of gains and losses in understanding a situation" (Benner et al., 1999, p. 569). The person in need of advocacy has been described as vulnerable (Gates, 1995; Penn, 1994; Rich, 1995; Segesten, 1993), powerless, helpless, dependent (Bernal, 1992; Mallik, 1997; Norrie, 1997; Segesten; Snowball, 1996), and unable to speak for one's self (Annas, 1974; Penn; Segesten). A trigger situation such as an illness and/or hospitalization that requires reasoning-in-transition and actions is necessary in order for the act of advocacy to begin (Benner, 1984; Benner, Hooper-Kyriakidis & Stannard, 1999; Penn, 1994; Segesten, 1993). Benner's description of the reasoning-in-transition that is transformed into moving from curative therapies to end-of-life nursing care and caring can be used to explain the trigger experience. Nurses are most likely present and bear closest witness to the patient's and family's plight during the process of trying to understand how to proceed. Finding a way to progress, reasoning-in-transition about the human experience of impending death, may unfold unevenly over time. Clinical decisions, that are made by the family in the context of uncertain, changing situations, and in the midst of suffering and fear frequently need the nurse to run defense for them (Benner), thus triggering advocacy behaviors.

Figure 1
Application of Benner's Theory Related to the Advocacy Role in the Context of End-of-Life Care



Adapted from: Benner (1984); Benner, Hooper-Kyriakidis & Stannard (1999); Wilkie (2001)

The next aspect of Benner's theory (1984) to consider is the nursing practice skill levels of the subjects in this study: novice, experienced, and expert nurses. Each nurse passes through the skill levels of clinical practice. The upward movement from novice to expert demonstrates the change from reliance on abstract principles to the use of past concrete practice experience (Benner). For the purpose of this study, Benner's five skill levels of novice, advanced beginner, competent, proficient and expert were collapsed into three categories: novice, experienced and expert.

The novice and advanced beginner stages of skill acquisition were combined to reflect the practice of a first year graduate nurse in transition from student to registered nurse. Benner believes that students of nursing function at the novice level due to the lack of background experience and lack of discernment between relevant and irrelevant aspects of a clinical situation. The advanced beginner has enough experience to grasp aspects of the situation but is rule guided and relies on the help of those more experienced (Benner). In addition, Benner suggests that nurses at higher levels of skill in one area of practice could be classified at the novice level if placed in a situation in which the "goals and tools of patient care are unfamiliar" (Benner, p. 21). The complexities of end-of-life nursing care places the advanced beginner in unfamiliar situations that require guidance of those more experienced.

In this study, the competent and proficient stages of Benner's (1984) skill acquisition were combined to create the experienced-level nurse. The competent practitioner is described as having an increased level of efficiency and deliberate planning capabilities and the proficient nurse adds the perception of situations as whole

rather than in segments (Benner). Benner writes that experience “does not refer to the mere passage of time or longevity. Rather, it is the refinement of preconceived notions and theory through encounters.....” (p. 36). Even though there is a “leap, a discontinuity, between the competent level and the proficient and expert levels” (p. 37), measurement in time is not reliable or rule governed.

The expert-performer of nursing practice is described as one who no longer relies on a rule or guideline to connect the understanding of the clinical situation to an appropriate action (Benner, 1984). The expert nurse uses background experience to support an intuitive grasp of each situation, and with precision, can zero in on the clinical problem. Expert nursing practice is resource-based, embodies know-how, and sees the big picture, while at the same time, sees the unexpected (Benner).

From the nurse’s skill level emerges the congruency among Benner’s (1984) seven domains of nursing practice (the helping role, teaching, or coaching function, diagnostic client-monitoring functions, effective management of rapidly changing situations, administering and monitoring therapeutic interventions, and regimens, monitoring and ensuring quality of health care practices and organizational work-role competencies) with the four defining characteristics of advocacy behavior (listening to the patient’s voice, promoting patient well-being, protecting the patient and moral and ethical decision-making) discovered in the literature review (Chapter 2). It is believed that the seven domains of nursing practice (Benner) and the defining characteristics of advocacy behavior need to be present and are of equal importance to reach the desired outcome in any given patient situation where advocacy behaviors exist. For the purpose

of this study, the most prevalent of the four defining characteristics of advocacy behaviors described in the literature was matched with Benner's seven domains of nursing practice. And finally, the desired outcome of advocacy is to assist the patient and family to overcome barriers impeding their health-care goals.

Advocacy behaviors are far from a new component of nursing practice. A congruency has been described between Benner's (1984) Novice to Expert Theory and the process of developing advocacy behaviors. As individual nurses set forth on their practice careers, advocacy behaviors will continue to grow. Theoretical frameworks can explain how to assist the nurse to become more effective in the role of patient advocate.

Definitions

Introduction

Theoretical and operational definitions of study variables provided the conceptual meaning and specific focus for measurement for the study (Burns & Groves, 2001). Definitions also served to limit the focus of the study and are provided as follows:

Perception of Advocacy Behaviors in Nursing Practice at End of Life

Theoretical Definition

The theoretical definition of advocacy behavior in nursing practice for the purpose of this study is one that was articulated by Wilkie (2001) in the Toolkit for Nursing Excellence at End-of-life Transition [TNEEL]. It summarizes and implies that all the defining qualities revealed in the literature search are present. It simply states: "Advocacy is assisting the patient and family to overcome barriers impeding their care path" (Wilkie, ¶ 2).

The perception of advocacy behaviors refers to the nurses' view of advocacy concepts and responsibilities. Advocacy behaviors are those behaviors exhibited by nurses to fulfill their perceived obligations to patients (Wlody, 1993). Benner (1984) goes on to say advocacy power removes obstacles or stands along side and enables the patient and family to actively participate in care decisions. The literature review performed for this proposal identifies four defining characteristics of the practice of advocacy: (a) listening to the patient's voice, (b) protecting the patient, (c) moral and ethical decision making, and (d) promoting patient well-being. They are congruent with this study's survey instrument.

Operational Definition

The perception of advocacy behaviors will be measured by the Advocacy Perception and Advocacy Behavior sub-instruments of the Ethics Advocacy Instrument (EAI) (Wlody, 1993). When combined, scores on advocacy perception and advocacy behavior give evidence of a subject's perception of advocacy behavior in end-of-life nursing practice. Higher scores indicate a greater perception of advocacy behaviors.

Novice, Experienced, and Expert Nurse

Theoretical Definition

Benner's (1984) definitions of novice to expert nursing practice offers a model, that in movement through five levels of skill acquisition, the nurses' performance change from a rule-based practice to intuitive thinking. The

performance levels (novice, advanced beginner, competent, proficient and expert) reflect a logical sequence of development. Following Benner's model and premise that skill acquisition moves through stages, the following definitions guided this study:

1. The novice nurse is a graduate of a diploma, associate, or baccalaureate program with a temporary practice permit or registered nurse (RN) license in the first year of professional practice.
2. The experienced RN is a graduate of a diploma, associate, baccalaureate, and/or master's program(s) and has one to five years of full-time practice experience or equivalent part-time professional practice experience.
3. The expert RN is a graduate of a diploma, associate, baccalaureate, master's, and/or doctoral program(s) and has greater than five years of full-time practice experience or equivalent part-time professional practice experience.

Operational Definition

The author-revised demographic data survey of the Ethics Advocacy Instrument or EAI (Wlody, 1993) consists of a variety of questions to gather demographic data (Appendix A). The years of nursing experience for novice nurses is defined as less than one year. The years of nursing experience for experienced nurses is defined as one to five years. The years of nursing experience of expert registered nurses is defined as greater than five years. The demographic data survey also provided each subject the opportunity to identify the level of educational preparation.

Supports

Theoretical Definition

Supports to the practice of advocacy are factors that support the nurse's role to help the patient and family to reach their desired outcomes of end-of-life care. Supports, or facilitators are consistent with Benner's (1984) domains of caring nursing practice and may include a supportive institutional culture and structure (Beckstrand, Callister & Kirchhoff, 2006; Brophey, 2001; Copp, 1986; Ellis, 1995; Georges, Gryphonck, & DeCastle, 2002; Jablonski & Wyatt, 2005; Martin, 1998a), positive personal attitudes (Copp; Martin; Pimple & Schmidt, 2001), knowledge of end-of-life best practices (Benner, 2001; Ferrell et al., 1999), and moral and ethical decision-making competencies (Baldwin, 2003; Brophey; Copp; Hamric, 1999; Kuuppelomaki, 2002; Loverage, 2000; Mallik, 1997).

Operational Definition

Supports were measured by the third sub-instrument, Infrastructure Data, of the EAI (Wlody, 1993). It was designed to identify hospital infrastructure related to supporting the nurses' advocacy practice. A Structure Score (SS) for this section of the instrument (items#29-36) was based on the sum of the number of "yes" responses. The higher the score, the greater the perceived supports in the practice environment. In addition, the instrument has an open-ended question asking what the greatest support(s) are in the practice of advocacy (Wlody, 1993) (Appendix A, item 38).

Barriers

Theoretical Definition

Barriers to the practice of advocacy are factors that interfere with the patient and family's desired outcomes of end-of-life care. They can be internal to the nurse such as anxiety, attitudes, stereotypes and prejudices (Copp, 1986; Georges et al., 2002; Martin, 1998a; Pimple & Schmidt, 2001), or external such as institutional policies and procedures (Brophey, 2001; Copp; Ellis, 1995; Georges; Jablonski & Wyatt, 2005; Martin), interpersonal conflicts (Baldwin, 2003; Brophey; Curtain, 1983; Ellis; Hewitt, 2002), employment risk (Brophey; Copp; Ellis; Georges, et al.; Martin), lack of prepared faculty to teach end-of-life content, lack of textbook information and overcrowded medical and nursing curricula (Christopher, 2001; Grant & Virani, 1999). In addition, inconsistent communication and consensus regarding plan of care among the patient, family, nurse and physician increases barriers to desired patient-centered outcomes (Badger, 2005a,b; Beckstrand, Callister & Kirchhoff, 2006).

Operational Definition

Barriers were measured by the third sub-instrument, Infrastructure Data, of the EAI (Wlody, 1993). It is designed to identify hospital infrastructure related to supporting the nurses' advocacy practice. In addition, the instrument has an open-ended question asking what the greatest barrier(s) are in the practice of advocacy (Wlody, 1993) (Appendix A, item 37).

Assumptions of Study

To guide the process of the study, seven assumptions were made:

1. Advocacy is embedded in nursing practice.
2. Advocacy is an inherent part of all nursing curricula.
3. Novice, experienced and expert nurses advocate for patients in every practice setting.
4. Vulnerable patients are in need of an advocate (nurse or otherwise) across all practice settings and developmental stages.
5. Novice, experienced and expert nurses provide end-of-life care.
6. Barriers interfere with the practice of advocacy in nursing practice.
7. The power of advocacy removes barriers to achieve the patient and family's desired outcomes of end-of-life care.

Significance of Study

As nursing strives to grow as a profession, the practice of patient advocacy continues to expand. This study contributes to the nursing practice and education evidence base by providing insight into the practice of advocacy, the supports and barriers to advocacy in practice, and the educational levels and practice experience. Nursing science is advanced in that the connection of practice, research, and nursing theory is furthered.

End-of-life care issues are not mutually exclusive. Nursing education, practice, and research are interwoven, with one area affecting the other. Increased knowledge of

practice and research provides nursing education with a foundation of knowledge to share with the next generation of nurses.

Nursing Research

The nature of patient advocacy as a nursing role in end-of-life nursing care provided in acute care settings has limited empirical referents. To date, the literature demonstrates that qualitative, phenomenological, and descriptive survey research methods are commonly chosen to describe the role of advocacy in nursing practice. The lack of consistent outcome measurements across multiple studies opens the door for questioning the effectiveness of the advocacy role. Exploring the specific role of advocacy in nursing practice in end-of-life care contributes to the evidence-based literature.

Nursing Practice

Because advocacy is so embedded in nursing practice as to sometimes be invisible (Benner et al., 1999; Curtain, 1983; Foley, et al., 2002; Wlody, 1993), expert nurses have difficulty describing the steps of advocacy. Foley et al. (2002) conclude that most caregiving skills do not come naturally and need to be taught. This study helps to develop a clearer understanding of the power of advocacy to assist the patient and family to overcome barriers impeding their care path.

The demand for end-of-life care will escalate in the future as our elderly population grows and a burdened health care system confronts the cost of chronic and terminal illness (Ferrell et al., 1999). Holistic end-of-life care, which has traditionally been the expertise of hospice programs, must extend to acute and community based

systems. Ferrell and Grant (2001) report that only 50% of nurses discuss end-of-life care options with their terminally ill patients. The conclusion drawn from their studies over the past several years was that hospice professionals know more about end-of-life care options than nurses practicing in other settings. Nurses in acute care settings have less specialization in end-of-life care as compared to hospice nurses; however, the majority of nurses practice in these settings (Ferrell & Grant).

Nursing Education

To influence future end-of-life care, nurse educators need to search for the most effective teaching-learning approach to prepare graduates for care of the dying. A priority identified by the National League for Nursing Priorities for Research in Nursing Education (NLN, 2003) is to develop best practices in teaching and learning. Every graduate of a nursing program in the twenty-first century should have the skill, knowledge and attitudes necessary to provide competent end-of-life care. In addition, Altun and Ersoy (2003) state an expected outcome of nursing education is to know how to protect vulnerable patients at the end-of-life through advocacy.

End-of-life care involves interpretation of complex situations (AACN & City of Hope, 2000; Beckstrand et al., 2006; & Sherman, 2001). In this context, nursing care often requires intuitive judgment. In Benner's (1984) framework, the expert nurse engages in "know-how" knowledge which is difficult to articulate. This tacit knowledge presents a challenge for nurse educators to create nursing curricula and subsequent guidance of novice nurses to effective practice (Copp, 1994).

Nursing Science

This study contributes to nursing science in that it furthers the evidence-base literature grounded in theory. The use of Benner's (1984) *Theory from Novice to Expert: Excellence and Power in Clinical Nursing Practice* expands nursing science. This study will help to provide a clearer understanding of the power of advocacy as described in Benner's seven domains of care. Further, evidence was collected to describe the differences between novice, experienced and expert practice. Theory provides common foci and threads related to the advocate role serving as a link between concepts, empirical evidence and practice. "Theory gives meaning to knowledge to improve practice by describing, explaining and predicting phenomena..." (Marriner-Tomey & Alligood, 2002, p. 11).

Chapter Summary

This chapter provides background considerations and a theoretical framework to guide the exploration of the differences among novice, experienced and expert nurses in their perceptions of advocacy in end-of-life nursing care. The primary purpose of this study was to describe nurses' perceptions of the advocacy role in end-of-life nursing practice. The research questions guiding this comparative descriptive study were designed to identify the perceptions of advocacy behaviors and the supports and barriers to the practice of advocacy in end-of-life nursing care among graduate and registered nurses in acute care settings. A second set of research questions were intended to explore the differences among novice, experienced and expert nurses in the perception of

advocacy behaviors and the supports and barriers to practicing advocacy in end-of-life nursing care in acute care settings.

With the gain of professional autonomy, integration of professional practice acts, ethical practice statements, and legal responsibility to the patient, nurses have assumed their obligation to practice advocacy. Nurses' traditional responsibilities and roles in end-of-life nursing care have expanded to include ethical decision-making and navigating the complex health care environment to achieve patient and family wishes.

The novice to expert process (Benner, 1984) provides a framework in which the nurse can move towards becoming an effective patient advocate and assist the patient and family to overcome barriers impeding their desired end-of-life care. Benner's seven domains of a caring practice serve to frame the defining characteristics of advocacy behaviors identified in the Chapter 2 literature review.

Theoretical and operational definitions provide the conceptual meaning and specific focus for measurement to explore the stated research questions. The defined study variables include: (a) perception of advocacy role in nursing practice at end-of-life; (b) novice, experienced and expert registered nurse; (c) supports to the practice of advocacy; and (d) barriers to the practice of advocacy. Chapter 1 concludes with the exploration of the study's significance for nursing research, practice, education and science.

Chapter 2

Review of Literature

The role of advocacy is far from a new component of nursing practice. As nursing strives to grow as a profession, the practice of patient advocacy continues to expand. This review of literature explores the nurses' role of advocacy in end-of-life care in acute care settings.

A review of the Cumulative Index of Nursing and Allied Health Literature [CINAHL] revealed literature on patient advocacy and end-of-life care published in the last 10 years directly related to patient-care. The Pro-Quest and Dissertation Abstract Search engines were used to elicit additional records. Most were indirectly related to the patient-care situation. Journal articles were found by hand search and referring to the reference list of pertinent articles. The time-span was extended to include advocacy literature from the 1980s due to the expanding social context of the professional nursing role during that decade. Empirical referents are limited, but provide a beginning understanding of how nurses define advocacy and how nurses learn to advocate for their patients.

The review of literature is presented as follows: (a) origins of the term of advocacy, (b) philosophical underpinnings of advocacy, (c) ethical and legal underpinnings of advocacy, (d) characteristics of advocacy, (e) risks and barriers to the practice of advocacy, (f) empirical referents of advocacy, (g) defining characteristics of end-of-life care, (h) empirical referents of end-of-life care, and (i) theoretical framework.

The qualitative and quantitative empirical referents are presented in chronological order as a group to demonstrate the development of the advocacy and end-of-life caring roles.

Origins of the Term of Advocacy

Advocacy is defined by Webster (Merriam-Webster, 2004) as to: (a) summon for counsel, (b) speak in favor of, (c) support and defend a cause, and (d) plead in another's behalf. It is a process (verb) in which an advocate (noun) acts on another's behalf.

Synonyms (Urdang, 1978) frequently used for the process of advocacy include (a) support, (b) backing, (c) joining oneself to, (d) upholding, (e) favoring, (f) arguing for, and (g) standing up for. The Oxford Reference Dictionary of Nursing (Wainwright, 1990) defines patient advocate as:

A practitioner, usually a nurse, whose role is to promote and safeguard the well-being and interests of his or her clients by ensuring they are aware of their rights and have access to information to make informed decisions. (p. 40)

The person in need of advocacy has been described as vulnerable (Copp, 1986; Gates, 1995; Penn, 1994; Rich, 1995; Segesten, 1993), powerless, helpless, dependent (Bernal, 1992; Mallik, 1997; Norrie, 1997; Segesten; Snowball, 1996), and unable to speak with loss of control for him or her self (Annas, 1974; Penn; Segesten). A trigger situation (Penn; Segesten) such as an illness and/or hospitalization that requires decision-making and actions is necessary in order for the act of advocacy to begin.

Grace (2001), Kohnke (1980), Mallik (1997), Millette (1993), Segesten (1993), and Snowball (1996) suggest that the nursing role of advocacy should enable and support the autonomous client. Advocacy is the act of informing and supporting a person so that

he/she can make the best decision. The right of the patient to have all of the information necessary to make decisions is particularly important. Thus, the act of advocacy is two-part: first, to inform and, second, to support. Rushton (1994) goes on to state that advocacy generally acts to safeguard and advance the interests of another. Nurses do not act in the place of the patient; they assist the autonomous patient and family to make decisions. The role includes the actions of advising, sharing information, and offering recommendations to enable patients to make their own decisions. Ellis (1995) states that advocacy is more concerned with representation and communication. Curtain (1983) suggests that it is easier to describe advocacy by what it forbids, rather than what it demands. She states that advocacy precludes coercion, exploitation or manipulation.

The foundation of advocacy is the nurse-patient relationship (Annas & Healey, 1974; Becker, 1986; Curtain, 1983; Gadow, 1980; Kohnke, 1980; Mallik, 1997; Miller, Mansen, & Lee, 1983; Segesten, 1993). The form of the relationship varies because of its dynamic nature. It changes, grows, contracts, and finally ends. The needs of the patient, the knowledge and ability of the nurse, and the practice environment all influence the process of advocacy. Becker describes the act of advocacy as either passive or active. To initiate an active role, the nurse takes action because of the role responsibility and obligation to the patient. The action stem from the nurse's belief and value system. Examples include initiating family and healthcare team conferences to solve care dilemmas and actively seeking opportunities to change hospital policies. The passive advocate role reflects actions that are not deliberately based on the individual nurse's convictions. They may be grounded in the expectations and obligations to the institution.

or societal norms and beliefs. An illustration may include following hospital routines such as visiting hours.

Philosophical Underpinning of Advocacy

Godow (1980) and Trandel-Korenychuck (1983) believe that nursing must be defined in terms of its philosophy of care and not by its roles or tasks. They discuss existential advocacy as a philosophical foundation of nursing. Godow asserts that nurses have a moral philosophical view of 'good' practice. Existential advocacy involves the nurse helping patients discern the unique meaning in the experience of health, illness, suffering or dying. Bishop and Scudder (2003) argue that existential advocacy cannot be the center of nursing practice because most patients do not choose the nurse who cares for them. Since nurses are assigned to patients, the balanced power of the ideal nurse-patient relationship is destroyed.

The contrast between the patient's rights movement and paternalism supplies the context for the philosophy of caring. The concept of advocacy proposed by Godow (1980) is opposite of paternalism. Paternalistic acts and attitudes are those that limit the liberty or rights of individuals for their own interest. Diagnostic tests, medication and treatment regimens are expected if the "good" patient is to follow the doctor's orders. The patient is to submit to the professional's wishes. The nurse's role of advocacy in a paternalistic organization may be reduced to one of a technical advisor, not fully realizing the philosophy of care (Bramlett, Gueldner, & Sowell, 1990; Godow).

The patient's rights movement, or consumerism, was formed out of paternalistic healthcare organizations. It is based upon the principle that freedom of self-determination

is the most fundamental and valuable human right (Bramlett et al., 1990; Gadow, 1980; Trandel-Korenychuk, 1983). The professional, while obligated to act in the individual's interest, is not permitted to influence health care interests in any way. By definition, self-determination means that patients make their own decisions (Gadow). The Patient Bill of Rights (AHA, 1992) and the age of consumerism encourage patients to ask questions about treatments and health care. Patients are more knowledgeable than in past decades about health issues and exert their right to direct and guide treatment.

The philosophy of caring implies that advocacy must resolve the dilemmas of paternalism and consumerism. Nurses are in the best position to overcome paternalism and consumerism because they define its practice philosophically rather than sociologically (Curtain, 1983; Gadow, 1980). The concept of existential advocacy implies that the patient and nurse can freely decide their relationship roles. The nurse attends the patient during periods of sustained contact, and offers personal care. This trusting, dynamic, interpersonal relationship is a precondition of advocacy. The nurse is engaged in the relationship unifying the experience and facilitating personal meaning that the illness, suffering or dying is to have for the patient and family (Curtain; Gadow; Mathes, 2005; Trandel-Korenychuk, 1983). The unique knowledge of the patient and the common humanity form the foundation of the nurse-patient relationship. Thus, the nurse is in the ideal position among health care providers to experience the patient as uniquely human with individual strengths and beliefs and to use this position to intervene on the patient's behalf. According to Curtain, the end purpose of nursing is the welfare of other human beings.

A conflicting view presented by Allmark and Klarzynski (1992) asserts that the role of nurse and advocate are incompatible. In a nursing context, advocacy is seen as the nurse pleading the cause of the patient. They suggest a conflict occurs in the non-mandated nature of the nurse advocate, and in the fact that the nurse attends to a patient's best interest in terms of health, not a cause (Allmark & Klarzynski). The nurses' motive to attempt the practice of patient advocacy is viewed as disingenuous because of the underlying power struggle between medicine and nursing professionals. Allmark and Klarzynski believe that nurses should reject nursing advocacy and embrace alternative means of empowering the patient such as an independent advocacy system.

Grace (2001) notes that the term advocacy as a description of actions on behalf of others is grounded in legal settings and does not fully describe what nurses do. She offers the term 'professional advocacy' that consists of a broader scope of professional practice. Professional advocacy permits a wider view of responsibility in environmental and contextual venues, in addition to facilitating longer-term solutions (Grace). Nursing practice involves care of individuals, families and groups. Advocacy actions may be required at a variety of levels such as national health policy decisions, economic conflicts of interest, person to person miscommunication and institutional barriers.

Ethical and Legal Underpinnings of Advocacy

Nurses have a professional responsibility to practice according to their code of ethics and law. Law and ethics are similar in that they have developed in the same historical, social, cultural and philosophical context (AACN & City of Hope, 2000; Edge & Krieger, 1997). Ethical dilemmas in end-of-life care surround the patient's capacity to

make decisions and communicate wishes (AACN & City of Hope; Dzyacky & Sheldon, 1999). In order to engage in the informed consent process, patients must have the requisite ability to comprehend information, to contemplate options, to evaluate risks and consequences and to communicate decisions. Selected ethical issues identified at the end of life include: (a) the curative intent of a treatment when death is eminent, (b) life sustaining treatments viewed as prolonging suffering, (c) do not resuscitate orders when the patient or family are not in agreement, (d) requests for passive or active assisted suicide, and (e) a proposed treatment causes undue burdens upon the patient or family (AACN & City of Hope; Dzyacky & Sheldon; Edge & Krieger; Ferrell & Coyle, 2005; Fins et al., 1999; Mathes, 2005; Matzo & Sherman, 2001).

Ethics is a branch of philosophy that considers and examines moral life. Ethics and morals refer to conduct, character, and motivations involved in moral acts (Edge & Krieger, 1997; Matzo & Sherman, 2001). The concept of morality is applied in nursing practice and refers to duty, obligation and personal principles of conduct. Values have been called the cornerstone of nursing moral practice (Matzo & Sherman). They are foundational to the notions of good and bad, beneficial and harm. Values influence judgment; therefore, nurses are obligated to go through the process of self-reflection to help identify, consider, and articulate the belief, purposes and attitudes they have that drive their actions. Every nursing act that intervenes in the life of a patient has the possibility of supporting or transgressing some value cherished by the patient (Matzo & Sherman).

The major ethical principles of significance to nurses are: (a) respect for persons and autonomy, (b) beneficence, (c) non-maleficence, and (d) justice. The duties of veracity, fidelity, and confidentiality are moral responsibilities derived from these principles that further guide and direct nursing actions (Edge & Krieger, 1997; ANA, 2001; Mathes, 2005; Matzo & Sherman, 2001; Millette, 1993; Pence & Cantrall, 1990). The most fundamental ethical principle for nursing practice is the principle of respect for persons (Matzo & Sherman; Sanchez-Sweatman, 1997). Respect for persons and the ethic of caring is broader and more abstract than autonomy and self-determination. Respect for persons requires individuals to be treated as unique and given treatment that is respectful of their human dignity. Respect for persons and their decisions incorporates a trusting relationship and access to relevant information. The basic relationship between a patient and a nurse is one of competence, compassion, support and advocacy (AACN & City of Hope, 2000; Matzo & Sherman). The practice of nursing implies respectful relationships and the ethic of caring.

Nurse practice acts, codes, and policy statements uphold and promote the ethical and legal standards of the profession. Advocacy is of legal interest in that nurses are professionals who exercise judgments. They assess when patients should receive information (Sanchez-Sweatman, 1997). They also ensure that patients understand the information provided. The traditional definition of advocacy is grounded in legal parlance. In the lawyer-client relationship the client chooses and retains the lawyer of his or her choice and thereafter the lawyer acts as an advocate. Traditionally patients do not choose their nurses, or ask them to act as their advocates. If patients had a choice they

would not be ill or vulnerable; and therefore, not need an advocate (Sanchez-Sweatman). This is the basis for the assumption that vulnerable patients need advocates.

When a competent patient or designated surrogate decides that a proposed treatment will impose undue burdens such as prolonged suffering, the health care team may be placed in an ethical dilemma based on the patient's right for self-determination. The most common reasons given in the decision to withhold or withdraw therapy are patient choice, undesirable quality of life, when the burden outweighs benefits, and prolonged dying (AACN & City of Hope, 2000; Ferrell & Coyne, 2005; Matzo & Sherman, 2001, Matzo et al., 2004; O'Callahan, Fink, Pitts & Luce, 1995; Tilden, Tolle, Nelson & Fields, 2001; Tilden, Tolle, Nelson, Thompson & Eggman, 1999). Rushton (2004) points out that end-of-life care in children offers additional ethical concerns. Most children cannot make independent health care decisions and parents act as the designated surrogate representing the child's interests.

Brophey (2001) believes the primary concern of an ethical practice is the ability to advocate on behalf of the patient and family. Using the example of a neonatal nurse, she asserts that accountability in professional practice involves acting as a patient representative. Ethical care of a non-autonomous infant derives from ethical theories of good, and not from rights (Brophey). Neonatal nurses attempt to alleviate pain and suffering along with nurturing parents through healthcare decision making processes.

Copp (1986) describes members of vulnerable populations, such as patients in end of life, as individuals or groups who lose power to represent themselves, and their needs, wishes, values and voices. The planning and implementation of nursing care must

covertly and overtly include advocacy for the patient and family, especially in end-of-life circumstances. Alleviating pain and suffering, facilitating decision-making, and communication of the patients' expressed or written wishes are just a few of the daily issues confronting the direct care provider. Advocating for the terminally ill is a prominent part of end-of-life nursing care. It is the nurse who remains by the family and patient to ensure quality of life until death. The bedside nurse can not evade ethical issues (Mathes, 2005).

Copp (1986) continues to delineate a range of vulnerability: (a) individuals of high-risk who sooner or later will become the nurses' concern and care, (b) those who are genetically predisposed to specific diseases, a low birth weight infant, the deprived teenaged mother and the terminally ill; (c) victims of war, famine, poverty and trauma represent a group of previously well-individuals who through circumstances threaten their representative voice; (d) those who are temporarily incapacitated because of trauma, compromised mental health, major stress and any experience that interferes with communication; (e) individuals who have lived decades with birth injuries, hemiplegia, war wounds, blindness or residual damage from diseases are permanently vulnerable; and (f) the elderly due to their decreased functional capacities. According to Copp vulnerable individuals experience increasing powerlessness. Regardless of the setting or circumstances, it is the nurses' responsibility to empower. Types of advocacy include: (a) human advocacy, (b) political advocacy, (c) animal advocacy, (d) moral-ethical advocacy, (e) legal advocacy, (f) spiritual advocacy, and (g) individual and system

advocacy (Copp). Advocacy is an extension of skills nurses already possess; therefore, it is a logical extension of nursing practice.

Sanchez-Sweatman (1997) discusses the nurse-patient relationship in the legal terms of the fiduciary relationship. The word fiduciary means “trust-like” and historically, the common law recognizes tradition and assumes that the nurse-patient relationship falls under the legal tradition of fiduciary. The obligations of the fiduciary are that power is exerted in the dependent’s best interest. The law views health care professionals as having superior knowledge that requires the patient to trust that the knowledge is being used in the patient’s best interest (Sanchez-Sweatman).

The legal risks of the role of advocacy in nursing practice are not well defined but have an effect on practice. Carpenter (1992) points out that information given by nurses allow patients to make informed decisions. While this is admirable in theory, it may result in conflict with the physician who chooses to withhold information. The risk of disciplinary action or loss of employment may seem too high a price for the nurse to bear. Nurses must have knowledge of the law and decide whether they are willing to face the consequences of their practice. For example, the case of Tuma versus the Board of Nursing (Sanchez-Sweatman, 1997) demonstrates that courts have not always passed decisions supporting nurses as patient advocates. Tuma, a registered nurse, was caring for a dying cancer patient when she informed the family of the side effects of chemotherapy, plus mentioned other work being done at another hospital using natural treatments. The family informed the physician about the alternative treatment discussion and subsequently, the physician brought charges against Tuma with the Idaho Board of

Nursing. They found that Tuma had acted in an unprofessional manner because her actions interfered with the physician-patient relationship. The case was overturned at a later date after a review of the nurse's role of communicating health information. This illustrates that the milieus in which nurses' work, particularly the hospital environment, expect loyalty to the institution and physicians. Despite the patient's legal and ethical right to be informed, the patriarchal system served to over-rule basic patient rights. Although the law has frequently viewed professional relationships as fiduciary, this concept has rarely, if ever, been applied to the nurse-patient relationship (Gates, 1995; Sanchez-Sweatman). This gives reason to why nurses fear speaking up for patients even when they are suffering (Gates).

Characteristics of Advocacy

Analysis and synthesis of the findings in the literature reveal the following defining characteristics of advocacy and are summarized as follows: (a) protecting the patient, (b) listening to the patient's voice, (c) moral and ethical decision making, and (d) promoting patient well-being. The meaning of each attribute may be clarified by identifying the correlating antecedents. The antecedents are useful to further define the critical attributes. Table 1 demonstrates the analysis and synthesis process, organizing the defining attributes and essential conditions of advocacy. It also presents the nurses' role of advocacy as central to the role of nursing across multiple settings and patient situations. The four defining characteristics of the concept of advocacy from a nursing perspective appeared over and over again in the literature. The relationship of the

Table 1

Defining Characteristics of Advocacy

| Defining Characteristic | Antecedents | Reference |
|-------------------------|--|---|
| Protecting the Patient | Excellent Nursing Care Scientific Knowledge Base Role and Scope of Practice Excellent Skill Confidence Accountability Presence Compassion | Abrams, 1978; Baldwin, 2003; Bernal, 1992; Brice, 1999; Brophy, 2001; Curtain, 1983; Ellis, 1995; Kohnke, 1980; Loveridge, 2000; Mallik, 1997; Miller et al, 1983; Mitchell & Bournes, 2000; Norrie, 1997; Pence, 1990; Penn, 1994; Rich, 1995; Rushton, 1994; Snowball 1976; Willard, 1996; Zusman, 1982 |
| | Collaboration Navigate organizational system Political savvy | Kuuppelomaki, 2001; Mitchell & Bournes, 2000; Norrie, 1997; Miller et al., 1983; Penn, 1994; Rich, 1995 |
| | Professionalism Know limitations Recognize domino effect Analyze need, consider alternatives Accept patient decision | Annas & Healey, 1974; Bernal, 1992; Georges et al., 2002; Mallik, 1997; Pence & Cantrall, 1990; Rushton, 1994; Snowball, 1996 |
| | Authority and Power Scope of practice Care decisions In-between role Patient's right for truth | Annas & Healey, 1974; Becker, 1986; Bernal, 1992; Curtain, 1983; Mallik, 1997; Miller et al., 1983; Pence & Cantrall, 1990; |

Table Continues

| Defining Characteristic | Antecedents | Reference |
|-----------------------------------|--|--|
| | | Penn, 1994; Rich, 1995; Willard, 1996 |
| Listening to the Patient's Voice | Communication Trust, respect, support Therapeutic Nurse to nurse Nurse to patient/family Nurse to physician Nurse to agency Assisting patients to explore values, preferences and goals Preserving personhood | Abrams, 1978; Annas, 1974; Baldwin, 2003; Becker, 1986; Benner, 1999; Bernal, 1992; Boyle, 1999; Brophy, 2001; Copp, 1986; Curtin, 1983; Ellis, 1995; Gadow, 1980; Georges, 2002; Mallik, 1997; Miller et al., 1983; Mitchell & Bournes, 2000; Penn, 1994; Rich, 1995; Rushton, 1994; Snowball, 1996 |
| Moral and Ethical Decision Making | Conflict Resolution Communication skills Truthfulness Unbiased information Consider alternatives Decision Making Respect patient choices Inform family of rights Identify family decision-maker Identify goals of care from all perspectives Calculated Risk Taking Know culture of environment | Boyle, et al., 2005; Loveridge, 2000; Mathes, 2005; Snowball 1996; Zusman, 1982 Baldwin, 2003; Benner, 1999; Brophy, 2001; Copp 1986; Hamric, 1999; Kuuppelomaki, 2002; Loveridge, 2000; Mallik, 1997; Mathes, 2005; Miller, et al., 1983; Mitchell & Bournes, 2000; Norrie, 1997; Rushton, 1994; Thelen, 2005 Becker, 1986; Brophy, 2001; Copp, 1986; Gadow, 1980; Mallik, 1997; Miller |

Table continues

| Defining Characteristic | Antecedents | Reference |
|------------------------------|---|--|
| | Adversarial role Conflicting loyalties Scope of practice | et al., 1983; Penn, 1994; Segesten, 1993; Rich, 1995; Trandel-Korenychuk & Trandel-Lorenychuck, 1983; Zusman, 1982 |
| Promoting Patient Well-being | Counseling Consoling Holism | Abrams, 1978; Baldwin, 2003; Gadow, 1980; Mitchell & Bourne, 2000; |
| | Quality Assert own rights Restore or maximize the patient's ability to speak for themselves | Rushton, 1994; Rich, 1995; Segesten, 1993; Snowball, 1996; Willard, 1996 |

antecedents to the defining characteristics can be traced directly to the standards of professional practice (ANA, 1995; AACN, 1998; Commonwealth of PA, 2001). While the antecedents may be generalized to many concepts, the cluster of defining characteristics is relative only to the advocacy role.

The patient and family outcomes that are expected to occur if advocacy is practiced by nurses during end-of-life care include: (a) safe care (AACN, 1998; ANA, 2001; Brice, 1999; Curtain, 1983; Ferrell & Coyle, 2005; McClement & Degner, 1995; Miller et al., 1983; Rushton, 1994; Sanchez-Sweatman, 1997), (b) improved quality of life for the patient and family (Baggs & Schmitt, 2000; Copp, 1986; Ferrell & Coyle, 2005; Haisfield-Wolfe, 1996; Segesten, 1993; Tazelaar, 2001), (c) patient autonomy and self determination (ANA; Baldwin, 2003; Becker, 1986; Bernal, 1992; Bramlett et al.,

1990; Georges & Grypdonck, 2002), (d) patient satisfaction (Baldwin; Bernal; Boyle, , 2005; Willard, 1996), (e) dignity of life, (AACN & City of Hope, 2000; Ferrell & Coyle; Matzo & Sherman, 2001), and (f) comfort and minimal suffering (Beckstrand, , 2005; Jablonski & Wyatt, 2005; Loveridge, 2000; AACN & City of Hope; Ferrell & Coyle; Matzo & Sherman). Nurse satisfaction and empowerment are additional outcomes in the practice of advocacy (Badger 2005a,b; Brice; Haisfield-Wolfe; Hamric, 1999; Miller; Mylott, 2005; Pence, 1990; Penn, 1994; Zusman, 1982).

Risks and Barriers to the Practice of Advocacy

The nurse advocate must take risks and be introspective about personal motivation, knowledge and skill. The practice of advocacy requires self-knowledge of one's own biases, stereotypes and prejudices. Practicing from a belief system or philosophical base is imperative to be effective in long-term practice (Brophey, 2001; Copp, 1986; Curtain, 1983; Gadow, 1980; Mylott, 2005). The nurse is engaged in relationships during illness and suffering and uses professional and personal skills to engage in advocacy. This opens the possibility for ineffective practice if the nurse is (a) fearful of pain and suffering, (b) inadequately educated, or (c) constrained by institutional policy or authority of the employer (Boyle, , 2005; Copp, 1986, Martin, 1998; Thelen, 2005).

A risk of nurse advocacy is the danger of being caught in the middle and misunderstood. Individuals who are vulnerable often are in situations highly charged with emotion, confusion and strained relationships between care-givers (Baldwin, 2003; Curtain, 1983; Copp, 1986; Ellis, 1995; Grace, 2001, Martin, 1998b; Mylott, 2005).

Nurses find themselves in-between the conflicts of family, physicians, the agency's policies and nurse colleagues' opinions. These conflicts may cause reprobation from peers, which can take an emotional toll and raise the possibility of a job loss. Novice nurses may have greater difficulty navigating the attitudes and climate of complex care situations due to inexperience or lack of confidence. In addition, a negative consequence of conflicts may include or result in patient discomfort. The literature implies that competition between health care providers in providing the service of advocacy may impose stress and emotional discomfort for patients who are 'in between' (Baldwin; Copp; Kohnke, 1980).

Mylott (2005) argues that nurses are the ones 'in the middle' and offers insight into their unique decision-making opportunities acting as agents of the physician and patient, as well as ones own moral agent. Nurses are expected to be trustworthy team members, equally representing all parties in a hierarchical top-down system while working from the bottom up to meet the patient's needs. Despite the barriers, Mylott is positive that nurses have evolved as independent clinical decision makers who embrace a professional mandate of autonomous ethical action in practice.

Pimple and Schmidt (2001) and Copp (1994) discuss the barriers concerning advocating for the dying. They include the nurses' anxiety, personal death attitudes and a knowledge deficit for the necessary skills to care for the dying patient. They believe that education provides students with knowledge and skill to deliver quality end-of-life care and empowers the student to have the courage and take the risks needed in the practice of advocacy. Georges et al. (2003) identified that the nature of the nurses' end-of-life care

role is shaped by the context of their workplace. The barriers outlined by nurses in their study include: (a) avoiding emotional stress, (b) striving to remain objective, (c) being task oriented as opposed to patient oriented, and (d) working in accordance with agency rules.

Martin (1998a) agrees with Georges et al. (2003) that nurses need to develop more effective coping mechanisms and admit to the stress faced in advocate roles. In a study of ritual action and its effect on the role of the nurse advocate, Martin identified four barriers nurses face in the effective practice of advocacy. They include: (a) professional distance, (b) task orientation, (c) hierarchical structure, and (d) oppressive culture.

Many nurses believe that “standing up for others” is part of their being and does not need to be taught. Advocacy involves the nurse fulfilling the role of a patient representative (Foley et al., 2002). Benner (1984) writes that care-giving practices do not come naturally, but are skills learned first in families and communities and later in school and work. To overcome the barriers to the practice of advocacy, educational opportunities in schools of nursing and practice settings are essential.

Brophey (2001) and Ellis (1995) suggest that a risk the nurse assumes when practicing advocacy is a power struggle between the patient, family, physician, institution and nurse. The nurse may be accused of acting in a paternalistic manner while claiming to be acting on behalf of the patient or family. Nurses are bound by their institutional policies, professional body and medical personnel. The role of advocate may be used to increase areas of responsibility and power (Brophey; Hewitt, 2002). Nurses may

experience tension between providing the best possible care for patients and respecting their autonomy. As in the practice of medicine, nursing is vulnerable to overruling patient wishes and providing more or less care than the patient desires. It can be argued that even in the balanced nurse-patient relationship, nurses are in control by virtue of their knowledge and skill (Hewitt).

Briggs and Colvin (2002) express the nurse's role as patient advocate in end-of-life decision making is well supported in professional position statements; however, in reality there is a significant gap in the amount of formal and continuing education nurses receive on this role. When asked to rank the most important competencies for end-of-life care, Briggs and Colvin report that nurses said the top three were how to talk to patients and families about dying, pain control techniques, and comfort care measures. In addition, the nurses perceive organizational barriers exist, including lack of communication, inconsistent practice patterns, lack of organizational definition of competence expectations, and a lack of adequate role models (Briggs and Colvin).

The State Initiatives in End-of-life Care, a newsletter profiling promising policies and practices in end-of-life care (Christopher, 2001), identifies several barriers to the implementation of broad education to health care providers, subsequently affecting practice. They include: (a) lack of faculty members prepared to teach the end-of-life content, (b) lack of end-of-life content in medical and nursing textbooks, (c) overcrowded medical and nursing curricula, and (d) the interdisciplinary nature of end-of-life content does not easily fit into the structure of most medical and nursing schools.

The risks and barriers to the practice of advocacy in nursing practice specific to end-of-life care as identified in the literature are summarized in Table 2.

Table 2

Risks and Barriers to the Practice of Advocacy

| Risks and Barriers | Reference |
|---|---|
| Institutional policy, cultural restraints, and hierarchical structure | Brophey, 2001; Copp, 1986; Ellis, 1995; Georges et al., 2002; Jablonski & Wyatt, 2005; Martin, 1998a; Mylott, 2005 |
| Personal attitudes, values, stereotypes and prejudices | Copp, 1986; Martin, 1998a; Pimple & Schmidt, 2001 |
| Fear of pain and suffering | Copp, 1986; Martin, 1998a, |
| Knowledge deficit | Badger, 2005a; Benner, 1984; Briggs & Colvin, 2002; Carpenter, 1992; Copp, 1986; Foley et al., 2002; Jablonski & Wyatt, 2005; Martin, 1998a; Pimple & Schmidt, 2001 |
| Ill defined legal precedence | Carpenter, 1992 |
| Nurses' emotional toll due to conflict, caught in the middle, misunderstood, moral and legal distress | Baldwin, 2003; Brophey, 2001; Curtain, 1983; Ellis, 1995; Hewitt, 2002; Mylott, 2005 |
| Strained relationships | Baldwin, 2003; Curtain, 1983; Copp, 1986; Ellis, 1995; Grace, 2001; Martin, 1998a |
| Emotional toll for patients | Baldwin, 2003; Copp, 1986; Kohnke, 1980 |
| Nurse anxiety | Copp, 1994; Georges et al., 2002; Pimple & Schmidt, 2001 |

Table continues

| Risks and Barriers | Reference |
|--|---|
| Task oriented, professional distance | Georges et al., 2003; Martin, 1998 |
| Oppressive culture | Martin, 1998 |
| Lack of consistent communication | Boyle et al., 2005; Beckstrand et al., 2006; Jablonski & Wyatt, 2005; Mylott, 2005 |
| Lack of prepared faculty to teach end-of-life content, lack of textbook information, overcrowded medical and nursing curricula | Christopher (Ed.), 2001; Ferrell, et al., 1999; Jablonski & Wyatt, 2005; Thompson, 2005 |

Empirical Referents of Advocacy

The nature of patient advocacy as a nursing role in end-of-life care provided in acute care settings has limited empirical referents. The following studies provide a beginning base and serve as exemplars of the concept of advocacy.

Segesten (1993) conducted a descriptive qualitative study with 32 "expert" Swedish nurses who were asked to describe situations in which their actions made a significant and positive difference for the patient. The study method included interview and a structured questionnaire (Segesten). The themes of a problem concerning a powerless patient, a plea, and an adversary were exemplified by one or two condensed stories told by each of the expert nurses interviewed. It was concluded by the investigator that a third of the narratives included descriptions of patient advocacy because it demonstrated a high degree of importance. Therefore, patient advocacy in nursing is viewed as a natural part of holistic nursing and of care more than cure. Segesten further described a patient advocacy situation as being triggered when a nurse makes prompt

decisions and takes actions, acts out of conviction, accepts additional work, and takes the risk of being punished.

Segesten's (1993) study had several limitations due to its design and replicability. The study group was not thoroughly described and reliability of the questionnaire was not determined. The instrument was only mentioned once and not described or evaluated. Inter-rater reliability was not determined and the study group did not have the opportunity to review the results. However, this was a beginning attempt to address the practice of patient advocacy and confirms the fact that more studies of this nature are needed.

Millette (1993) explored nurses' preferences for the various models of advocacy as well as the relationship of these preferred models to demographic settings. The three models were: (a) bureaucratic advocacy, where the nurse owes allegiance primarily to the institution and the needs of both patient and nurse are secondary; (b) physician advocacy, in which the doctor is given the chief consideration, and all other factors are subordinate; and (c) client advocacy, in which the client is the primary focus, with all health providers acting together to attain the clients' self-determined goal.

The study participants (Millette, 1993) responded to an advocacy assessment questionnaire and responses to a moral dilemma. The dilemma was a case constructed in a hospital setting in which a physician made an error that was being covered up. The case was chosen because it offered three clear choices for the nurse to act: (a) for the client, (b) for the physician, and (c) for the institution. Two-thirds of the sample ranked the client advocate model over the bureaucratic or physician model, which supported the

study hypothesis. However, the selected actions of the client advocate were rejected by the sample indicating a lack of support for the client advocate model. Significant differences were found in the area of position held in the practice setting and degree of agreement with physician advocacy and bureaucratic advocacy. The subjects in staff positions indicated significantly more disagreement with the physician model than did those subjects with management positions ($p = .04$). Also, subjects in staff positions demonstrated greater disagreement with bureaucratic advocacy ($p = .03$) than did the subjects in management positions (Millette). The study suggests that the concept of client advocacy has great appeal to the practicing nurse; however, its implementation might present problems. Furthermore, these findings indicated a gap between theory and practice or between the ideal and reality.

McClement and Degner (1995) studied the expert nursing behaviors in care of the dying adult in the intensive care unit using a descriptive, exploratory study. The theoretical perspective for this study was based upon the premise that if nurses were to receive systematic education about death with a planned assignment, they would be less likely to withdraw from care of the dying. Skill acquisition and clinical judgment are believed to be cognitive skills that are learned; therefore, identification of expert clinical performance in the care of the dying is the first step in clinical knowledge development.

McClement and Degner (1995) recruited ten expert staff nurses at two different hospital intensive care units. Semi-structured interviews were completed in the respondent's home and lasted from 45 minutes to three hours. Subjects were asked to describe expert nursing behaviors in the care of dying patients and to recall the most

recent incident that they could remember in which a colleague had demonstrated exemplary behavior when caring for dying patients. The interviews were coded to identify essential behaviors. Six categories were identified and described by the principal investigator. The interview descriptions were reviewed by a separate rater and the inter-rater reliability was set at .95. Final descriptions of the six critical nursing behaviors can be summarized as follows: (a) responding during death scene, (b) responding to the family, (c) facilitating the transition from cure to palliation, (d) responding to anger, (e) responding to colleagues, and (f) enhancing personal growth (McClement & Degner, 1995). Nurses' descriptions in this study provided clear examples of critical nursing behaviors needed to give quality end-of-life care in acute care settings. While methodology and small sample size precludes generalizability, the behaviors might serve as a beginning guide for structuring nursing education programs on care of the dying. Finally, the study was limited to nurses caring for the adult patient population in an intensive care unit setting.

Snowball (1996) explored the understanding of the concept of advocacy among 15 volunteer registered nurses from general medical and surgical units in a large teaching hospital in England. An interpretive, qualitative design was used to elicit experiences and perceptions of advocacy. Four categories or themes were identified on the concept of advocacy from the interview process (Snowball, 1996). They include: (a) the therapeutic relationship, (b) sharing a common humanity, (c) the cultural environment of care, and (d) reactive and proactive advocacy. The researcher believed that the findings indicate that the participants moved beyond simple descriptions of advocacy and had developed a

view of the concept that was based on their philosophy of nursing. All of the participants focused on the centrality of the patient to professional nursing practice. The limitations of this study were that it was small scale and exploratory method; therefore, the findings are difficult to generalize.

The literature supports advocacy as an essential component of the registered nurse's professional role, yet experts provide no consistent definition of advocacy. In an attempt to define the role, Foley, Minick and Kee (2000) explored the experiences of military nurses as they engaged in advocating practices. Advocating practices are conceptualized to be embedded in the everyday practices of nursing. Heideggerian hermeneutic phenomenology was chosen as the philosophical framework and method for the study because the investigators believed that the role of advocacy gives meaning to the experience of being human. A volunteer sample of 24 active duty United States Army nurses who were deployed in a peacekeeping military operation in Bosnia and Hungary participated in the study (Foley et al.). Three months after the nurses returned from Bosnia and Hungary, the investigator used a non-structured interview technique to elicit stories about the nurses' experiences when they believed they served as a patient advocate. The transcribed interviews and the interview observational notes comprised the data (Foley et al.). A research team assisted in the data interpretation using the constant comparative method.

The meaning of advocacy to the nurses was found to consist of one overall constitutive pattern – safeguarding, and four themes that constituted the safeguarding pattern (Foley et al., 2000). The four themes of advocating are protecting, attending,

being the patient's voice, and preserving the patient's identity. In all of the narratives, nurses reported situations involving vulnerable persons. Another notable characteristic in the advocacy situation was caring. Caring was indicated by a respect and concern for those for whom the nurses advocated and was fostered by the formation of a relationship between the nurse and patient. For the nurses in this study, advocacy was about safeguarding. They felt a responsibility to protect the patient because they were the healthcare professional that spent the most time with patient (Foley et al.). The findings of this study are limited by the convenience sample, but the importance of the study should not be underestimated. The findings will help the nursing profession begin to develop a common definition of nursing advocacy and these nurses' stories attest to the importance of advocacy in nursing practice.

Building upon their first study, Foley, Minick and Kee (2002) conducted a second study using hermeneutic phenomenological research methods to describe how Army nurses develop the skill of advocating for patients. The study participants (N=62) were asked to tell stories reflecting their experiences during the military operation when they had assumed patient advocacy roles. After telling their stories, they were asked how they believed they had learned skills in becoming the patient's advocate. A research team analyzed the audio-taped transcriptions and field notes using the interpretive method of hermeneutics.

The researchers (Foley et al., 2002) revealed a constitutive pattern of developing advocating practices. The themes emerged as: (a) who I am, (b) watching other nurses interact with patients, and (c) gaining confidence. Several of the participant's stories were

included in the study to clarify the meaning of the themes. The three themes serve to give the nurse educator insight into how novice nurses learn the role of patient advocacy. Most care-giving skills did not come naturally and needed to be taught. Foley and colleagues concluded that nurses began their understanding of advocacy in their families and communities prior to entering nursing school. The three themes identified in this study define methods to integrate learning strategies to promote the advocacy role, for example, reflective journaling, role modeling and practice to gain confidence in role development.

An assessment of health care organizations in La Crosse, Wisconsin (Briggs & Colvin, 2002) exposed significant differences between advance directives and actual end-of-life decisions. A review of 540 adult deaths between April 1995 and March 1996 occurring in the community's two hospitals, six nursing homes and three hospice organizations was performed. Of the deceased adults, 85% had written advance directives and 96% of these documents were present in the medical record. Briggs and Colvin found that decisions made at the end-of-life were consistent with the written directives in 98% of the cases. The significant factor leading to the excellent program outcomes was an educational approach for registered nurses designed to define competencies and broaden knowledge and skills needed for the role of advocate. A community advance care planning (ACP) program, Respecting Choices, was offered to area organizations that included professional training, consumer education and organizational practices that create a culture of shared and informed decision-making and planning for future health care (Briggs and Colvin). An organizational change and documentation procedures were implemented within the system and to encourage and engage nurses in learning more

about the patient's preferences and implementation of the advanced care plan. The assessment investigators reported that the goal to promote patient autonomy and improve the experience with end-of-life care from the patient and nurses' perspective was accomplished.

Nursing education is faced with the challenge of preparing nurses for the practice of advocacy. In a pretest - posttest design, Altun and Ersoy (2003) studied nursing student's tendencies to act as advocates and to respect patient's rights and if the tendencies changed during the educational process. In a university setting in Turkey, 55 students responded to a self-report questionnaire on advocacy during the first semester of the nursing program and again at the end of their four-year program of study. The independent variable involved a course in nursing ethics and the regular clinical rotations. The study was framed in the belief that health care providers have a moral obligation to ensure that patient's rights are upheld. After four years of nursing education, nursing student's tendencies increased significantly ($p \leq .05$) in the beliefs that patients have the right to be self-determining ($\chi^2 = 21.52$), nurses should always tell the truth to patients ($\chi^2 = 14.38$), patients have the right to refuse treatment ($\chi^2 = 16.05$) and health care professionals should be allowed actively to end a dying person's life ($\chi^2 = 18.48$). Most of the respondents in this study expressed that quality of life is the basis for maintaining treatment. A limitation of Altun and Ersoy's study was that it included only a small cohort of nursing students at one international university. The authors wished to determine cause and effect of the ethics course and the regular clinical rotations. In conclusion, the student's increased tendencies to deliver ethical care is weak at best.

In summary, the studies reviewed for the purpose of exploring the nature of advocacy in nursing practice serves to provide a base of empirical knowledge to build this proposal upon. Using qualitative methods, six studies explored nurse's perceptions of the definition of advocacy and the behaviors needed to integrate advocacy into practice. The literature is minimal and tentative. Foley et al. (2000, 2002) demonstrated the strongest studies in design, method and clarity of outcomes. Additional studies with a variety of methodologies are needed to determine how nursing professionals in education, research and practice, can contribute to the evidence-base of advocacy behaviors in end-of-life care.

Defining Characteristics of End-of-Life Nursing Care

Defining end of life is a challenge for health care experts. Since it refers to the interval when overall prognosis is poor, near-term chance of dying is high, and forgoing disease-specific treatments has become a serious option (Finucane, 2004), specific observations or defining characteristics are not clear. End-of-life care is often used synonymously with comfort or supportive care, hospice and palliative care. All terms refer to care that is holistic, attentive to symptoms, mindful of patient goals and separate from disease-specific treatment (Finucane).

During the National Institutes of Health (NIH) State of the Science Conference on Improving End-of-Life Care (2004) experts gathered to present the latest end-of-life research findings. Measuring quality of end-of-life care is challenging because of the inability to accurately prognosticate death and the inability of the majority of dying people to participate in interviews during this stage (Finucane, 2004; Teno, 2004).

Despite the obstacles, health care providers are in dialog to identify outcome variables important to measure quality, healthcare system issues associated with improved or worsened outcomes and processes and interventions to assure a quality end-of-life experience for the patient and family (von Gunten, 2004). Conference experts called for rapid development of a research infrastructure to improve understanding of best practice in diverse groups of end-of-life patients, along with enhanced resources to deliver quality care.

End-of-life care often includes hospice and palliative care principles (AACN & City of Hope, 2000; NIH, 2004). This merger suggests that palliative treatment and support are available in all settings through an illness and dying trajectory. Palliative care seeks to integrate curing with caring to improve quality of life and support the patient's view of a good death (AACN & City of Hope; National Consensus Project, 2004; Rushton, Spencer & Johanson, 2004). The notion of a "good death" or "dying with dignity" in modern American culture includes concepts such as peacefulness, physical comfort, autonomy, preparedness, connectedness with loved ones, awareness, discretion, meaning, and acceptance (Beckstrand et al., 2006; National Consensus Project; Proulx & Jacelon, 2004; Rushton, et al.; Virani & Sofer, 2003; Volker, Kahn, & Penticuff, 2004).

End-of-life care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands the traditional illness-cure model of medical treatment to combine active and compassionate therapies intended to comfort and support, enhance quality of life for the patient and family, and provide opportunities

for personal growth (AACN & City of Hope, 2000; Matzo & Sherman, 2001; National Consensus Project, 2004)

The broad scope of end-of-life, or palliative care, as described in The Last Acts Palliative Care Task Force's (1997) philosophy, improves quality of care for individuals and families. Palliative care provides support and care for persons facing life-threatening illnesses across settings and is based on the understanding that dying is a part of the normal life cycle. The process of dying is recognized as a profound individual and family experience. Excellent care is focused on enhancing the quality of remaining life by integrating physical, psychological, social and spiritual aspects of care. The use of an interdisciplinary team is the key to addressing the many needs of the dying and their families. In addition, to the Last Act's philosophy of care, the American Geriatrics Society (1996) recommends caregivers attend to guarding against inappropriate aggressive treatment near death and work to minimize the financial burdens that treatment places on the family.

The goal of palliative care as described in the Clinical Practice Guidelines for Quality Palliative Care (National Consensus Project, 2004) is to "prevent and relieve suffering and to support the best quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies" (p. 3). Palliative care is operationalized through effective management of pain and other distressing symptoms, while incorporating psychosocial and spiritual care according to patient and family needs, values, belief and culture. Palliative care affirms life by supporting patient and family goals for the future, including their hopes for cure or life-prolongation, as well as their

hopes for peace and dignity through the course of illness, the dying process and death (National Consensus Project, 2004; World Health Organization [WHO], 2002, ¶2).

In a concept analysis of palliative care in the United States, Meghani (2004), identified four attributes of current palliative care: (a) total, active and individualized patient care; (b) support for the family, (c) interdisciplinary teamwork, and (d) effective communication (Boyle et al., 2005). These are congruent with the national organization's definitions and philosophy of quality end-of-life care.

The established and proven model of palliative care at the end of life is hospice care (AACN & City of Hope, 2000; Ferrell, & Coyle, 2005; National Consensus Project, 2004; Zambroski, 2004). The hospice and pain management movements have demonstrated the efficacy of the patient-centered model of interdisciplinary team care and provided the impetus to formalize and promote a broader application of palliative care. There has been an increased demand for services that integrate the well-established philosophy and practice of hospice care to all stages of illness and to every care setting (AACN & City of Hope; Meghani, 2004; National Consensus Project).

Hospice philosophy supports the long-term objective of creating a personalized experience with each patient and family at the end of life. Care does not stop after the death of the patient. Just as the patient's death experience involves the physical, emotional, spiritual and social dimension, the survivor's reaction to loss is also supported by the health care team. Hospice care is directed by the patient's and family's value system. The interdisciplinary team is challenged to deliver care that reflects family choices, wishes and values. Hospice care emphasizes palliative care, which can be as

aggressive as curative care, but with a focus on comfort, dignity, quality of life, closure, and patient and family choice. The hospice philosophy supports the ethical principle of veracity and promotes patient autonomy (AACN & City of Hope, 2000; Ferrell & Coyne, 2005; Hospice and Palliative Nurses Association, 2002; Matzo & Sherman, 2001; National Consensus Project, 2004; Zambroski, 2004).

The scope of end-of-life care has evolved to include a wide range of patient populations for whom alleviation of suffering and improvement of quality of life may be relevant goals (Meghani, 2004; National Consensus Project, 2004). The broadened view of patient populations who may benefit from end-of-life care include: (a) children and adults with congenital injuries or conditions leading to dependence on life-sustaining treatments, (b) persons of any age with life-threatening illnesses where cure or reversibility is a realistic goal but pose significant burdens, (c) persons living with progressive chronic conditions, and (d) seriously and terminally ill patients for whom intensive palliative care is the predominant focus and goal of care for the time remaining.

Empirical Referents of End-of-Life Nursing Care

Increased interest to evaluate progress in end-of-life care and clarification of research priorities is demonstrated by recent national attention. Identified evidence supports the association of patient satisfaction and quality of care with communication, practical support, pain management and enhanced care-giving (Lorenz, Morton, Mularski, Shugarman, Sun, Wilkinson, Maglione, & Shekelle, 2004). The nursing profession is motivated to contribute to the evidence base. The following studies provide a beginning base and serve as exemplars to the practice of end-of-life nursing care.

A qualitative study conducted by Georges, Grypdonck and DeCasterle (2002) explored the perceptions of nurses about their role in palliative care nursing and the problems encountered in practice. The research originated from the desire of the nurse managers to illuminate the problems and frustrations staff nurses felt when caring for dying patients on a palliative care unit in a Netherlands academic hospital. The ward was considered to have more of a medical model of care and nurses felt that they were unable to provide patient-centered care.

The data were gathered through participant observation (n=14) and in semi-structured interviews (n=10) to determine the problems faced when working in a multidisciplinary team (Georges et al., 2002). The perceptions of nurses about the nature of their role as palliative care nurses were shaped by the context of their workplace. Two main reflections emerged from the data and included: (a) striving to adopt a well-organized and purposeful approach, and (b) striving to increase the well-being of the patient. The researchers (Georges et al.) reported that these perceptions are divergent and lead to different approaches to patient care according to one's own reality as a palliative care nurse. The participants seemed to be more attracted to acting according to a well-organized and purposeful approach and adopting a bureaucratic advocacy model rather than a patient advocacy model. The study illustrated some difficulties in applying the patient advocacy model due to attitudes, striving to remain objective, being task oriented, avoiding emotional distress and working in accordance with the rules.

For nurses who strive to enhance patient well-being, it was discovered that they adapted their approach to individual patients (Georges et al., 2002). Strategies to increase

their ability to practice patient-centered care include: (a) adopting a humble attitude, (b) giving attention to patient's experiences, (c) being available, (d) valuing a caring attitude, and, (e) trying to accept and cope with emotional strain. These are congruent with the defining characteristics of the advocacy role outlined in this literature review.

Schwarz (2003) explored how nurses experience and respond to a patient's request for assistance in dying in an interpretive phenomenological study. Ten nurses believed a competent patient had asked them for help in the dying process and participated in two-hour interviews in their homes. Their current employment included hospice home care ($n=4$), care of patients with AIDS ($n=3$), critical care ($n=2$) and care of patients with spinal cord injuries ($n=1$). All 10 nurses were Caucasian, middle-aged and most had advanced nursing degrees.

The findings of the study (Schwarz, 2003) were presented as four major themes: (a) being open to hear and hearing, (b) interpreting and responding to the meaning, (c) responding to persistent requests for assistance in dying, and (d) reflections. Few nurses in this study unequivocally agreed or refused to participate in helping patients die. Most study participants struggled alone and in silence to find another way to respond by providing good end-of-life care and remaining present when patients and families suffered. When the goal of care was to help patients die well, these nurses experienced difficulty identifying a reliable moral line that distinguished among palliative interventions that allowed, hastened, or caused death (Schwarz). They described unspoken understandings and covert agreements with family members, and collusion with physician colleagues. In summary, when the acts of collusion and secrecy became

routine, they undermined the importance of collaboration and consultation found in good end-of-life care.

Studies (Calvin, 2004, Georges et al., 2002, Schwarz, 2003) reviewing the needs of the dying patient have used specified time points rather than following the patients through the last span of their lifetime, until death. Wong, Liu, Szeto, Shama and Chan (2004) offered another approach in their prospective study that used clinical records and nursing anecdotes to examine the health problems encountered by dying patients followed from the point of referral to home care till death. The study took place in a hospital and home care service specializing in palliative care in Hong Kong. Thirty-two subjects with a mean age of 67.3 years and typical diagnosis of cancer were recruited during the study period. The Omaha system of patient classification was used to develop a study instrument encompassing environment, psychosocial, physiological and health-related behaviors with a total of 44 health problems. After each home visit, a nurse documented the client assessment and intervention provided. If a health problem was identified, the nurse would write notes to describe the problem. At the end of data collection, the clinical notes were subject to content analysis by members of the research team.

The four dimensions of environment, psychosocial, physical and health related behaviors were compared using the Friedman test to measure differences between the first, middle and final home visit scores. Findings revealed that patients who were discharged home in general had good environmental conditions including income, sanitation, residence and safe neighborhoods. Social support was also adequate with good

social contact, interpersonal relationships, caretaking and communication with community resources. The common physical symptoms included edema, ascites, dyspnea and pain. They were moderately to mildly severe when the nurse first visited the patients, but improved over the duration of visits due to proper management (Wong et al., 2004). Among the four domains of health behaviors, the psychological aspect brought the most concern to patients, families and healthcare professionals. The commonly observed psychological reactions among the subjects were guilt, stress, fear, anger, anxiety, grief, and spiritual distress. In conclusion, the study demonstrated that the effects of the disease process, treatment and care have impact on a patient's physical and psychological well-being. The limitations to Wong et al.'s study include the small number of only cancer patients in the sample, a mono-ethnic environment which may offer different family structures and values that support home care.

Calvin (2004) utilized a grounded theory approach to explore decisions about end-of-life treatment in people with kidney failure undergoing hemodialysis. When prompted to think about and discuss end-of-life treatments, the 20 study participants (Calvin) chose to focus on living rather than dying. A substantive theory of personal preservation was developed. The theory consists of three phases: (a) knowing the odds for survival, (b) defining individuality, and (c) personal preservation.

Themes that evolved from the patient interviews included knowing and beating the odds, discovering meaning of health for themselves (having faith in a higher force), taking chances, and being responsible. The author concluded that the theory of personal preservation, offered a new conceptualization of the process whereby hemodialysis

patients make decisions regarding end-of-life medical treatments. This is in opposition to the traditional view that advance care planning models should be offered early in hemodialysis treatment plans. The nurse's holistic care that includes advocacy behaviors sustain the personal preservation conceptualization in that it supports the patient and family to make decisions regarding their end-of-life care.

In another study, a retrospective chart review was performed to compare the quality of care provided to a convenience sample of 195 patients who died during a six-month period at a large medical center (Paice, Muir, & Shott, 2004). The researchers defined quality of care by symptom documentation, use of diagnostic and therapeutic procedures in the final 48-hours of life, and determination of advance directives. The data collection form was adapted from the end-of-life chart review developed by the Center to Improve Care of the Dying (Paice et al.).

Symptom distress was prevalent in the study sample (Paice et al., 2004) of patients at the end of life. The most common findings documented included pulmonary congestion (92%), confusion (86%), fever (78%), dyspnea (78%), pain (77%), fatigue (42%), sedation (36%), agitation (32%) and decubitus ulcers (26%). Documentation of success in meeting the emotional needs of the patient and family occurred in 60.3% of the patients. Diagnostic and therapeutic procedures were common in the final 48 hours of life and included intravenous medications, opioids, urinary catheters, antibiotics, blood draws, X-rays and ventilators. Physical restraints were employed in 21.5% of the patients. When compared to patients who had documented pain with those who did not have pain documented in the medical record, there was no difference in opioid dosing (Paice et al.).

Another significant finding of the Paice et al. (2004) study involved the differences in pain and symptom management based on the location where the care was provided. Patients in the palliative care unit were more likely to have symptoms documented, less invasive procedures and less restraints. In conclusion, the researchers suggested areas for improvement in clinical practice where end-of-life care is provided is to aggressively address symptom identification and management, use physical restraints less often, decrease the amount of invasive testing and offer emotional care. The advocacy behaviors of the nurse can make significant contributions to improved patient outcomes, no matter the kind of unit or location (Paice et al.). The retrospective design and reliance upon documentation within medical records provided significant limitations for the study. In addition, the study was confined to one urban tertiary care hospital during a six-month period, limiting the ability to generalize the results.

Badger (2005a) conducted a descriptive study to explore critical care nurses' experiences of moving from cure to comfort-oriented care and to describe the factors that inhibit or facilitate such transitions. The study took place in an 18-bed medical intensive care unit located in the Northeast United States. Focus group interviews, informal conversations and observations served as data collection methods for 24 participants. The analysis included data reduction, data display and drawing conclusions based on Miles and Huberman's (1994) qualitative analysis method. The participants did not describe a clear transition from cure to comfort oriented care during their patient's treatment. End-of-life transitions were viewed as difficult when patient's families had conflicts or were indecisive about terminating treatment. Physicians added to the difficulty when they

offered options that were unlikely to change the patient's progress. The most distressing situations reported by the critical care staff were dealing with younger patients with an acute life-threatening illness and performing futile care on elderly patients.

A descriptive, exploratory study (Wotten, Borbasi & Redden, 2005) described the experience of palliative care nurses on factors influencing care for patients with end stage heart failure. Participants (N = 17) ranged in age from 25 to 55 years and included RNs, clinical nurse consultants and clinical nurse managers in a metropolitan public teaching hospital. Semi-structured one-hour interviews were completed, transcribed and analyzed to extract themes and categories. The themes identified as affecting nurses' ability to provide palliative care included: (a) knowledge of the patient, (b) health system inadequacies, (c) knowledge of palliative care, and (d) difficulties in the provision of palliative care (Wotten et al.).

Beckstrand et al. (2006) collected suggestions from a random sample of the American Association of Critical Care Nurses using a 72-item survey on the perceptions of end-of-life care. The goal was to gain insight for improving end-of-life care in intensive care units (ICU). Of the 861 critical care nurses who responded to the survey, 485 offered suggestions for improving care. Among the respondents, 70% had cared for at least 30 dying patients. The responses were coded and synthesized by a critical care nurse researcher with expertise in qualitative inquiry. A second researcher also performed analysis and the inter-rater reliability was .92.

Providing a "good death" was the major theme identified (Beckstrand et al., 2006) by many of respondents ($n = 128$). Specific suggestions for providing a good death

included facilitating dying with dignity, not allowing patients to die alone, managing patient's pain and discomfort, and knowing the patient's wishes. Additional suggestions included promoting earlier cessation of treatment or not initiating aggressive treatment at all. Effective communication among the health team members and educational initiatives for professionals and the public were also recommended.

Critical care nurses respondents identified several barriers to providing good death (Beckstrand et al., 2006). The most frequently cited barrier was lack of time (n = 72). Staffing patterns and shortage of nurses were perceived as major obstacles when caring for sicker patients and one study participant thought it was imperative that "the nurse caring for the dying patient have that patient as a 1:1 assignment when death was predictably imminent, in order to meet both the patient and family's needs adequately", (Beckstrand et al., 2006, p.40). Communication challenges among patients, families, nurses and physicians (n = 44) and treatments based on physicians' needs rather than patients' needs (n = 24) were identified by the respondents.

Beckstrand et al.'s (2006) study provides excellent insight into the reality of practicing nurses. Unfortunately, these experienced nurses did not think that good deaths were routinely possible while patients were in an ICU. Barriers continue to exist in providing quality end-of-life care in critical care units, and some clinicians seem impervious to change despite the recent evidence on end-of-life care.

The recent studies (Badger, 2005; Beckstrand et al., 2006; Calvin, 2004; Georges et al., 2002; Paice et al., 2004; Schwarz, 2003; Wong et al., 2004; Wotten et al., 2005) reviewed for the purpose of describing end-of-life nursing care and issues surrounding

nursing practice provide a beginning foundation of exemplars to explore behaviors that illustrate the advocacy role. Using the hospice model (National Consensus Project, 2004) as a benchmark, nurse researchers continue to discover the perceptions of nurses regarding their role of providing end-of-life care in a variety of settings and patient populations.

From Novice to Expert: Excellence and Power in Clinical Nursing Practice

Patricia Benner's (1984) work which applied the Dreyfus Model of Skill Acquisition to nursing practice was influenced by Virginia Henderson's definition of nursing. Benner's rich background in practice and research served as a bridge to theoretical thinking. She has studied clinical situations in an attempt to discover and describe the knowledge embedded in nursing practice. She believes that clinical knowledge accrues over time in a practice discipline and there are differences between practical and theoretical knowledge (Marriner-Tomey & Alligood, 2002). Citing Kuhn and Polanyi, philosophers of science, Benner emphasizes the difference in "knowing how," a practical knowledge that may elude formulations, and "knowing that," or theoretical explanations (Benner). She believes that clinical wisdom is more varied and complicated than theoretical information, and that by studying practice, nurses can uncover new knowledge. Benner adapted the Dreyfus Model of Skill Acquisition to clinical nursing practice. The model is situational and describes five levels of skill acquisition and development: (a) novice, (b) advanced beginner, (c) competent, (d) proficient, and (e) expert. Benner applies the model to nursing noting that "experience

based skill acquisition is safer and quicker when it rests upon a sound educational base” (Marriner-Tomey & Alligood, p. 169).

The central concepts and definitions embedded in Benner’s (1984) middle-range theory include the five levels of skill acquisition and development, competence, experience, clinical knowledge and practical knowledge. Table 3 presents Benner’s major concepts and their theoretical definitions.

Table 3

Benner’s Major Concepts and Theoretical Definitions

| Concept | Definition |
|-------------------|--|
| Novice | “No background understanding, context-free rules; difficulty discerning between relevant and irrelevant aspects of the situation” (Benner, 1984, p. 296). |
| Advanced Beginner | “Marginally acceptable performance; coped with real situations; recognizes aspects of situation” (Benner, 1984, p. 291). |
| Competent | “Considerable conscious, deliberate planning; increased level of efficiency” (Benner, 1984, p. 292). |
| Proficient | “Perceives situations as wholes rather than in terms of aspects; performance guided by maxims; intuitive grasp based upon a deep back-ground understanding” (Benner, 1984, p.297). |

Table continues

| Concept | Definition |
|------------------------|---|
| Expert | “Hybrid of practical and theoretical knowledge; deep background understanding clinical situations; develops process of comparing whole similar and dissimilar clinical situations to another” (Benner, 1984, p. 294). |
| Aspects of Situation | “The recurring meaningful situational components recognized and understood in context because the nurse has previous experience”(Benner, 1984, p. 291). |
| Attribute of Situation | “Measurable properties of a situation that can be explained without previous experience in the situation” (Benner, 1984, p. 291). |
| Competency | “An interpretively defined area of skilled performance identified and described by its intent, function, and meanings” (Benner, 1984, p. 292). |
| Domain | “Area of practice having a number of competencies with similar intents, functions and meanings” (Benner, 1984, p. 293). |
| Exemplar | “An example of a clinical situation” (Benner, 1984, p. 293). |
| Experience | “Active process of refining and changing preconceived theories, notions, and ideas” (Benner, 1984, p. 294). |
| Maxim | “A cryptic description of skill performance” (Benner, 1984, p. 296). |
| Paradigm Case | “A clinical experience that stands out and alters the way the nurse perceives and understands further clinical situations” (Benner, 1984, p. 296). |
| Salience | “A perceptual stance or embodied knowledge” (Benner, 1984, p. 298). |

Benner's work delineates the importance of excellent caring practices. She notes that research demonstrates that practice grows through experiential learning and through transmitting that learning in practical settings (Benner, 1999). She identifies 31 competencies which are organized into the following seven domains of a caring nursing practice: (a) the helping role, (b) teaching or coaching function, (c) diagnostic client-monitoring function, (d) effective management of rapidly changing situations, (e) administering and monitoring therapeutic interventions and regimens, (f) monitoring and ensuring quality of health care practices, and (g) organizational and work-role competencies (Benner, 1984; Benner et al., 1999; Benner & Wrubel, 1989). The competencies focus on the whole situation rather than separating it into parts.

Benner identifies caring as central to nursing practice. She expresses that caring and excellence require not only commitment and involvement, but also power (Benner, 1984; Benner et al., 1999). Benner believes that power in nursing practice is gender neutral, abandoning the stereotypical views of coercion and domination. The nurses in her study found safety in their use of power by genuinely caring for their patients. She identifies six different qualities of power associated with caring that include: (a) transformative power, (b) integrative caring, (c) advocacy, (d) healing power, (e) participative/affirmative power, and (f) problem solving. Transformative power involves changing the patient's position from one of receiving care to one of participating in care. The integrative caring practice reinstates the patient into the social environment. With

patient care situations where a prolonged or permanent disability is inevitable, the nurse is instrumental in helping one to maximize ability to continue a meaningful life style.

The nurse using the power of advocacy removes obstacles or stands along side the patient and family to enable them to succeed. The healing power implies that nurses establish a healing relationship and create a therapeutic environment by mobilizing hope in themselves, the staff, and the patient. A healing relationship solicits the patient's internal and external resources and empowers them by bringing hope, confidence, and trust. In using participative/affirmative power, the nurse finds meaning and strength in practice. It is the opposite of distancing oneself to avoid burnout. Finally, a caring practice requires expert, creative problem solving. Problem solving power is developed through meaningful engagement in patient situations. In summary, Benner (1984) writes that nurses have power, though they exert their power from a position of low status in the hierarchy. They are the ones who are on the front lines of practice and know how to work the system.

Benner's theoretical assertions can be summarized in the following statements:

(a) knowledge accrues over time in the practice of an applied discipline (Benner, 1984, p.1), (b) a clinician's knowledge is embedded in perceptions rather than precepts (Benner, p. 43), (c) formal rules are limited and discretionary judgment is used in actual clinical situations (Benner, p. xviii), (d) perceptual awareness is central to good nursing judgment...begins with vague hunches and global assessments to...critical analysis (Benner), and (e) expertise develops when the clinician tests and refines propositions, hypotheses, and principle-based expectations in actual practice situations (Benner, p.3).

In subsequent writings, Benner and Wrubel (1989) identified how the Novice to Expert Theory views the nursing paradigm concepts of nursing, person, health, and environment. Table 4 presents the concepts and definitions.

Table 4

Nursing Paradigm Concepts Defined by Benner and Wrubel (1989)

| Concept | Definition |
|---------------------------|---|
| Nursing | “A caring relationship; an enabling condition of connection and concern” (Benner & Wrubel, p. 4). |
| Person | “A self-interpreting being, defined in the course of living a life; embodied; has an effortless and nonreflective understanding of the self in the world” (Benner & Wrubel, p. 41). |
| Health | “Focus on the lived experience of being healthy and ill; human experience of health or wholeness” (Benner & Wrubel, p. 7). |
| Environment/ Situation | “Engaged interaction, interpretation and understanding; implies that one has a past, present, and future...influences current situation” (Benner & Wrubel, p. 23, 80). |

Benner (2001) and Benner et al. (1999) illustrate how nurses caring for patients in critical care units facing the end of life require clinical and ethical discernment. In their work grounded on the findings of previous ethnographic studies of critical care nurses, stories are used to exemplify complex ideas and ambiguities inherent in caring for the critically ill. Much attention is given to end-of-life care and decision-making. Benner, et al. illustrate how when the patient is dying, critical care nurses must reframe their

intention of the right care for the patient from curative action to palliative interventions. Nurses are the ones who are present, who bear closest witness to the patient's and family's plight during the process of trying to understand how to proceed. Finding a way to progress, reasoning-in-transition about the human experience of impending death (e.g., leaving loved ones, saying good-bye, and finishing one's life) may go at a different pace than reasoning-in-transition about the biomedical decisions (Benner et al., p.375). The patient, family and nurse's understanding of the illness and dying process all unfold unevenly over time.

End-of-life clinical decisions are made in the context of an uncertain, changing situation and many times in the midst of suffering and fear. Patients and families frequently need the nurse to run defense for them (Benner, 1984), thus triggering the advocacy role. The five levels of clinical nursing expertise described by Benner (1984) may respond to the patient and family at different rates and skill. Because the beginner and advanced beginner nurse may not yet sort out what is most imperative, they may need guidelines and expert preceptors to ensure that important patient needs are met. The proficient nurse perceives situations as wholes rather than in terms of aspects (Benner) and are effective in determining priorities of care. They use analytical tools when needed and provide safe and quality care. The competent and proficient nurses are able to work within the seven domains of nursing practice (Benner et al., 1999) and convey advocacy behaviors in most situations. The expert nurse uses transformative power, integrative caring, advocacy, healing power, affirmative power and problem solving to consistently deliver an integrative caring practice.

Summary

The review of literature explored the philosophical and ethical foundations of advocacy in order to identify the nature of advocacy in end-of-life care. The characteristics and domains of quality of end-of-life care were also explored. As nursing strives to grow as a profession, the embedded practice of advocacy continues to expand. The origins of advocacy in nursing practice and professional codes and standards support the nurses' role expansion to include the advocacy role. Most of the literature on the concept of advocacy is philosophical in nature and offers little practical guidance on how the role of advocacy should be interpreted by nurses for the practice and educational settings. For the purpose of this review, literature from the last two and one-half decades was accessed due to the expanding social context of the professional nursing role during the 1980s. The limited empirical literature on the advocacy role in nursing practice opens many possible avenues for research.

The characteristics of advocacy identified in the literature are: (a) protecting the patient, (b) listening to the patient's voice, (c) moral and ethical decision-making, and (d) promoting patient well-being. Many professional skills were identified to support the practice of advocacy including: (a) communication, (b) excellent nursing care, (c) collaboration, (d) conflict resolution, (e) decision making, (f) use of authority and power, and (g) calculated risk taking.

Risks and barriers to the practice of advocacy identified in the nursing literature include: (a) knowledge deficit, (b) institutional policy and cultural restraints, (c) the

nurses' emotional toll of risk taking due to being caught in the middle, (d) employment risk, and (e) ill-defined legal precedence.

Quality end-of-life care includes hospice and palliative care principles guided by patient and family values (AACN & City of Hope, 2000; Finucane, 2004; Lorenz, 2004; National Consensus Project, 2004). Palliative care provides support and care for persons facing life-threatening illnesses across settings and is based on the understanding that dying is a part of the normal life cycle. Domains of quality palliative care include: (a) symptom management, (b) spiritual care, (c) cultural and social aspects of care, (d) and integration of ethical and legal aspects of care.

The practice of advocacy in end-of-life care is an emerging field and evidence-based literature is limited, particularly in acute care settings. The research studies examined included a cross section of methodology and targeted specific groups such as hospital, home care and palliative care nurses in their natural environments. The findings revealed a beginning understanding of nurses' perceptions of their role in end-of-life care.

While there is a growing body of knowledge in end-of-life issues, the research is still in its infancy in terms of rigorous testing and outcome measurement (Lorenz, 2004). Research is needed to understand patient needs, the nurse's perceptions, and the health care system's influence on quality outcomes of end-of-life care. The proposed study of the nurse's behavior of advocacy when caring for patients nearing end of life in acute care settings will add to the knowledge-base.

CHAPTER 3

Methodology

This chapter describes the research design used to study the perceptions of advocacy behaviors and barriers and supports to the practice of advocacy in end-of-life nursing care in acute care settings. The descriptions of setting and sample, instrumentation, procedures for data collection and methods used for data analysis are presented.

Research Questions and Variables

The primary research questions guiding this comparative descriptive study were:

1. What are the perceptions of advocacy behaviors in end-of-life nursing care in acute care settings among novice, experienced and expert nurses?
2. What are the supports to practicing advocacy in end-of-life nursing care in acute care settings among novice, experienced and expert nurses?
3. What are the barriers to practicing advocacy in end-of-life nursing care in acute care settings among novice, experienced and expert nurses?
4. What are the differences among novice, experienced and expert nurses in the perception of advocacy behaviors in end-of-life nursing care in acute care settings?
5. What are the differences among novice, experienced and expert nurses in the identification of supports to practicing advocacy in end-of-life nursing care in acute care settings?

6. What are the differences among novice, experienced and expert nurses in the identification of barriers to practicing advocacy in end-of-life nursing care in acute care settings?

The independent variable was the experience level of registered nurses (novice, experienced and expert). The dependent variables included: (a) the perception of advocacy behaviors, (b) the supports to the practice of advocacy, and (c) the barriers to the practice of advocacy.

Research Design

A comparative descriptive design was used to examine the differences among novice, experienced and expert nurses in the perceptions of advocacy behavior in end-of-life nursing care in acute care settings. Burns and Grove (2005) suggest the comparative descriptive design to examine and describe the differences in variables in two or more groups that occur naturally in a setting. Descriptive studies are designed to gain more information about the characteristics of selected interests as they naturally occur (Burns & Grove). Manipulation of variables does not occur. This design was appropriate to the study's purpose to describe nurses' perceptions of advocacy behaviors in end-of-life nursing practice and their perceived supports and barriers. The limited empirical knowledge-base regarding the practice of advocacy in end-of-life nursing care guided the use of the descriptive study design. Nurse educators and leaders may better understand, teach and provide the infrastructures to support the advocacy behaviors, if clarified.

Setting

The naturally occurring practice setting of three regional hospitals provided the location of this study. A fourth hospital was approached and access was denied due to a study that was currently being conducted on palliative care. The rationale for selecting regional hospitals included the proximity to the researcher's home, the similarity of practice settings and the availability of nurses. All hospitals were located in moderate-sized urban areas of Southeastern Pennsylvania. The hospitals ranged in size from 185 to 800 inpatient beds and offer a full range of inpatient and community-based services. Hospital A reached Magnet Status and Hospital B was pursuing Magnet Status. Hospital C had many nursing quality indicators in place. All hospitals have implemented professional career ladders and a form of self-governance among nursing staff. Hospitals A and B continued to sponsor diploma schools of nursing and hire many of their own graduates.

Sample Selection and Size

Research instruments were distributed to 1000 nurses at three hospitals in Southeastern Pennsylvania. A 33.3% return rate was achieved with 333 surveys returned through the mail. Sixteen surveys were not used because of incomplete or confusing data on the first three sub-instruments, resulting in a final sample of 317 nurses. There were no exclusion criteria for the GN and RN participants. This study included nurses with clinical, advanced practice or managerial positions because of their unique perceptions of the advocacy role.

The convenience sample was drawn from the target population with numbers based on a power analysis estimate (Borenstein, Rothstein, & Cohen, 1997). At least fifty-three participants per experience group (novice, experienced and expert) were needed to reach a moderate effect size ($ES = .25$) and a power of .80. The final sample had 61 participants in the novice group, 69 participants in the experienced group and 186 participants in the expert group. One participant did not indicate years of experience; therefore, not included in an experience group. However, the extra participant was included in the total sample size and final power analysis. Post study analysis with a sample size of 317 established an observed power of .39 based on actual one-way analysis of variance (ANOVA).

The known limitation of the convenience sample included the limited geographical location; therefore, generalization of the findings was restricted. Further, the sample consisted of volunteers who were self-selected, allowing generalization only to this accessible group of nurses. The limitation was acceptable for this descriptive study in that it provided a means of acquiring information in unexplored areas (Burns & Grove, 2005).

Instrumentation

The Ethics Advocacy Instrument or EAI (Wlody, 1993) (Appendix A) is a self-administered 38-item instrument with four sub-instruments. The EAI was developed by Wlody (1993) based on advocacy behaviors defined by the American Association of Critical Care Nurses (1989) and The American Nurses Association Code for Nurses (1985). The advocacy behaviors are congruent with the revised versions of the American

Association of Critical Care Nurses Position Statement on Role of the Critical Care Nurse as Patient Advocate (2004) and The American Nurses Association Code of Ethics for Nurses (2001). The purpose of the instrument is to “explore the perceptions and behaviors of nurses, identify advocacy behaviors and how the educational systems and health care infrastructures support or don’t support those behaviors” (Wlody, p. 89).

The EAI (Wlody, 1993) validation was conducted in two stages. First, the preliminary instrument was reviewed by a national panel of six nurse experts for content validity, clarity and readability. In addition, the panel members completed the instrument and pilot tested the sub-instruments. As a result, minor revisions were completed and a second expert panel was consulted. The revised instrument was piloted for reliability in a group of staff nurses by Wlody. The author confirmed its reliability but was unable to locate the specific data (G. S. Wlody, personal communication, February 14, 2005). Permission for using the EAI in this study was obtained from the instrument’s author Ginger Schafer Wlody (Appendix B). Reliability data from the present study were analyzed and are reported in Chapter 4.

The major themes identified by Wlody are congruent with this study’s literature review and defining characteristics of advocacy. Table 5 illustrates the defining characteristics of advocacy in Wlody’s EAI and the defining characteristics for the role of advocacy in end-of-life nursing care.

The first sub-instrument, Advocacy Perception (Appendix A), contains twenty-five Likert-scale questions related to the subject’s perceptions of advocacy. There are five

possible responses measured on a five-point scale that includes strongly agree (5), agree (4), no opinion (3), disagree (2), and strongly disagree (1). The responses are assigned values and total scores for the sub-instrument can range from 25 to 125. There are seven questions which are stated negatively (2, 3, 8, 9, 15, 18, 23) and were reversed for scoring. The sum of the score comprised the Advocacy Perception Score for each subject with the higher range in scores indicating a greater perception of advocacy.

Table 5

Wlody's Major Themes with Comparison of Defining Characteristics of Advocacy

| Major Themes (Wlody, 1993) | Thacker's Defining Characteristics for the Role of Advocacy in End-of-Life Nursing Care |
|--|---|
| Nurse as mediator | Listening to the patient's voice Moral and ethical decision making |
| Nurse as protector of patient self-determination | Listening to the patient's voice Protecting the patient well-being |
| Nurse as patient rights advocate or representative | Protecting the patient Moral and ethical decision making Promoting the patient well-being |

The second sub-instrument, Projections of Advocacy Behavior (Appendix A), of the EAI is designed to identify subject's projections of advocacy behaviors and consists of three scenarios encompassing characteristic situations with moral conflicts in which nurses find themselves (Wlody, 1993). Each scenario follows with four possible responses including the nurse as a mediator (lowest advocacy level = 1), nurse as

protector of self-determination (moderate advocacy level = 2), and nurse as patient rights advocate (highest advocacy level = 3). The fourth possible response supports a concept that generally conflicts with advocacy (paternalism or non-advocacy behavior = 0) (Wlody, 1993). The subjects are instructed to select only one response and the total score for each subject on the second sub-instrument comprises the Advocacy Behavior Score (ABS). The scores range from 0 (non-advocacy behavior) to 9 (highest advocacy level). The item response by category for the Advocacy Behavior Subscale is displayed in Appendix C. When combined, the scores from the Advocacy Perception Sub-Instrument and Projections of Advocacy Behavior Sub-Instrument can range from 25 to 134, with the higher scores indicating greater advocacy behaviors.

The third sub-instrument of the EAI consists of eight items related to the subject's hospital infrastructure. It includes questions related to the presence of a hospital ethics committee and whether nurses are members of the ethics committee. This group of questions require the subject to check a response of "yes", "no", "don't know", or in some cases, "not applicable". A Structure Score (SS) for this section of the instrument (items #29-36) was based on the sum of the number of "yes" responses. The scores can range from 0 to 8; the higher the score, the greater the perceived supports in the practice environment. The final portion of this sub-scale includes two open-ended questions asking what the greatest barrier(s) and support(s) are in the practice of advocacy (Wlody, 1993). The open-ended questions were analyzed for patterns and frequency of comments by a method of content analysis.

The fourth sub-instrument of the EAI consists of a variety of questions to gather demographic data (Wlody, 1993). The original demographic data form was revised for the purpose of this proposal (Appendix A) to elicit information regarding the participant's experience in care of end-of-life patients. The demographic items include:

1. Gender
2. Age
3. Level of nursing education
4. Years of RN nursing experience in full-time equivalent
5. Years of current area of clinical practice
6. Primary area of clinical practice
7. Functional role/position
8. Employee status
9. Frequency of working with dying patients
10. Participation in training seminars concerning end-of-life care in the last three (3) years
11. Advocacy as part of formal or continuing education

The EAI appeared to be an excellent instrument to measure this study's research questions as illustrated in Table 6 where the sub-instruments are compared to the research questions.

Procedures for Data Collection

Human Subject Protection

After permission from the Widener University Institutional Review Board (IRB) was obtained (Appendix D), permission to conduct this study was confirmed with two hospital IRBs and one deferred to the Widener University IRB (Appendix E). The potential risks or discomforts that subjects may have experienced by participating in this study's anonymous survey were minimal and may have included inconvenience of time and an uncomfortable reflection upon one's practice or certain patient care situations.

There was no direct benefit to the participant; however, a benefit of this study included the expansion of current knowledge of the advocacy practice of nurses which can have significant impact for nurse educators and influence patient care in the future.

The benefits and risks were explained in the introductory letter to each potential subject. Identifying information was not requested and informed consent was assumed by the voluntary return of the survey booklet via mail in an enclosed addressed stamped envelope. There was no participant compensation for this study; however, a bookmark was inserted into each study book for the participants to keep. In addition, a raffle for a \$100.00 gift certificate to a local business was held in each of the three participating hospitals for those choosing to participate in the study. Tear-off tickets were included in each survey booklet with instructions

Table 6

Research Questions and Sub-Instrument of Wlody (1993)

| Research Question | Sub-Instrument |
|---|--|
| What are the perceptions of advocacy behaviors in end-of-life nursing care in acute care settings among novice, experienced and expert nurses? | Advocacy Perception Sub-Instrument Projections of Advocacy Behavior Sub-instrument Demographic Data |
| What are the supports to practicing advocacy in end-of-life nursing care in acute care settings among novice, experienced and expert nurses? | Infrastructure Instrument Demographic Data |
| What are the barriers to practicing advocacy in end-of-life nursing care in acute care settings among novice, experienced and expert nurses? | Infrastructure Instrument Demographic Data |
| What are the differences among novice, experienced and expert nurses in the perception of advocacy behaviors in end-of-life nursing care in acute care settings? | Advocacy Perception Sub- Instrument Projections of Advocacy Behavior Sub-instrument Demographic Data |
| What are the differences among novice, experienced and expert nurses in the identification of supports to practicing advocacy in end-of-life nursing care in acute care settings? | Infrastructure Instrument Demographic Data |
| What are the differences among novice, experienced and expert nurses in the identification of barriers to practicing advocacy in end-of-life nursing care in acute care settings? | Infrastructure Instrument Demographic Data |

to return the raffle ticket via mail in the small envelope inserted into the prepared stamped envelope for the study booklet return. The tickets were identified by a self-selected code and hospital name only. A drawing occurred with the help of each hospital's Vice President of Patient Services or research coordinator to identify the gift recipient.

Data Collection

Permission to approach hospital employees was obtained from each hospital's administrator or research coordinator (Appendix F). After an introductory call, a personal visit was made by the researcher to the designated contact person to describe the study and plan avenues of access to the GN and RN population. Access to the sample was achieved through nurse managers at two hospitals and the research coordinator of the third hospital. The self-contained study booklets included the following items:

1. Cover letter (Appendix G)
2. Demographic Questionnaire (Appendix A)
3. Ethics Advocacy Instrument (EAI) (Wlody, 1993) (Appendix A)
4. Addressed and stamped envelope for return mail
5. Bookmark gift
6. Raffle ticket and instructions

The participants completed the questionnaire during a convenient time at work (break or during class) or home. Two months were allowed for the return of survey instruments.

Data Analysis

Demographic data and the responses from the EAI (Wlody, 1993) were coded and entered into the Statistical Package for Social Sciences, version 12.0 (SPSS, 2004) computer program by the researcher. Access to raw data and summary results during the study process was limited to the researcher, statistician and dissertation committee members. The data were maintained in a locked cabinet in the researcher's home and will be kept for seven years. When data were missing or confusing on questionnaires, these questionnaires were omitted from the sample used for analysis. As this number was small (<5%), pre-established missing data guidelines (Burns & Grove, 2005; Munro, 2004) were not used.

Descriptive statistics were calculated on the sample characteristics and instrument items/subscales including inspecting for normalcy, frequency distribution, mean, mode, standard deviation (SD), and chi square test. Inferential statistics included the comparative calculation of a one-way analysis of variance (ANOVA).

The EAI was examined for reliability for this study by use of Cronbach's alpha coefficient (Burns & Grove, 2005; Munro, 2004). The specific statistical procedures used for each research question are specified in Table 7. Additional analyses was performed on selected demographic variables such as educational levels, frequency of working with end-of-life patients and participation in training seminars concerning end-of-life care to ascertain differences among groups.

A content analysis was performed with the self-report data obtained from the two open-ended questions on the infrastructure instrument. According to Morse (1994), content

Table 7

Statistical Procedures for Study Research Questions

| Research Question | Data Analysis |
|---|---|
| What are the perceptions of advocacy behaviors in end-of-life nursing care in acute care settings among novice, experienced and expert nurses? | Frequency Distribution Mean, Mode and Standard Deviation |
| What are the supports to practicing advocacy in end-of-life nursing care in acute care settings among novice, experienced and expert nurses? | Frequency Distribution Content Analysis |
| What are the barriers to practicing advocacy in end-of-life nursing care in acute care settings among novice, experienced and expert nurses? | Frequency Distribution Content Analysis |
| What are the differences among novice, experienced and expert nurses in the perception of advocacy behaviors in end-of life nursing care in acute care settings? | One-way Analysis of Variance |
| What are the differences among novice, experienced and expert nurses in the identification of supports to practicing advocacy in end-of-life nursing care in acute care settings? | Content Analysis |
| What are the differences among novice, experienced and expert nurses in the identification of barriers to practicing advocacy in end-of-life nursing care in acute care settings? | Content Analysis |

analysis is appropriate for text data and involves categorizing each word or phrase with labels that reflect the data or words. Two hundred and fifty-three participants (79.8%) supplied one to several narrative statements or word phrases identifying supports and barriers to their advocacy practice. All comments were read from beginning to end before re-reading and highlighting on the original instrument. Then, the highlighted ideas or word phrases were transferred to a summary worksheet. Texts were divided into idea categories and a selection of phrases representative of the ideas were determined (Burns & Grove, 2005; Miles & Huberman, 1994; Morse; Wilson, 1993). The combination of words and phrases with the rich description and conceptualization of the open-ended text data added depth to the study analysis. Word and phrase counts were performed to compare the frequency of the concepts in each group of subjects (novice, experienced and expert) and then combined to report aggregate data. Specific counts in each experience group were not reported due to the over-lap of categories and the inability to confirm the contextual meaning with individual participants. In order to arrange and think about the more textually embedded data, a chart was constructed for data display. Drawing conclusions required consideration of what the data meant in the context of acute care practice and of what the data implied with respect to the research question. An expert in qualitative research provided direction and input in all phases of the data analysis and concurred with the final outcomes.

Chapter Summary

This chapter discussed the comparative descriptive research design and its use in this study. The population, sample and setting described a naturally occurring practice

environment in which nurses from all experience levels are employed. Procedures for data collection using a self-administered survey instrument (EAI) distributed to nurses in three regional medical centers were discussed. Information on the instrument's development and content was provided. The instrument was constructed to yield scores related to advocacy perceptions, projected advocacy behaviors, infrastructures present, barriers and supports to advocacy and demographic information. Two open-ended questions were included to further describe barriers and supports within the infrastructure system. Data analysis included descriptive and inferential statistical procedures. A content analysis on the data obtained from the open-ended questions was conducted.

CHAPTER 4

Findings

This chapter presents findings of this study on the perceptions of advocacy behaviors and barriers and supports to the practice of advocacy in end-of-life nursing care in acute care settings. The demographic characteristics of the sample and analysis of findings for each research question are reported. In addition, the results are presented from the comparative viewpoint of novice, experienced and expert nursing practice.

Demographic Description of Nurse Participants

From the total convenience sample ($N = 317$) of practicing nurses in three Southeastern Pennsylvania community hospitals, 305 nurses reported ages that range from 20 to 73 years, with a mean age of 37.6 ($SD = 12.1$) years. The participants ($N = 317$) were 98.1% female ($n = 311$) and 1.9% male ($n = 6$). For the 313 respondents that addressed this item, the mean number of years as a professional nurse was 11.9 ($SD = 10.88$) with a range of .10 to 43 years. Nearly half (47.1%) reported a Diploma in Nursing as their highest level of education; only one-fifth (21.2%) held a Bachelor of Science degree (see Table 8). Not all participants identified demographic data; therefore, the sample varies in reported numbers.

Respondents' primary areas of clinical practice ($N = 314$) were medical-surgical (47.5%) and critical care units (23.9%). The majority reported their practice position as staff nurses (89%) working ($N = 316$) full time (76.9%). Table 9 identifies the reported clinical practice area, practice position and employee status of the sample.

Table 8

Highest Level of Nursing Education (N = 312)

| Level of Nursing Education | Frequency | Percent |
|---------------------------------|-----------|---------|
| Diploma in Nursing | 147 | 47.1 |
| Associate Degree in Nursing | 91 | 29.5 |
| Baccalaureate Degree in Nursing | 66 | 21.2 |
| Masters Degree in Nursing | 7 | 2.2 |

Nearly 60% reported the frequency of working with dying patients as “often”, while 30.6% reported that they rarely worked with dying patients. Forty-one percent reported participation in training seminars concerning end-of-life care in the last three years and nearly 76% indicated that the concept of nursing advocacy has been a part of their formal or continuing education. Table 10 summarizes these data.

Demographic Comparison of Novice, Experienced and Expert Nurse Participants

Frequencies, means, standard deviations, chi-square tests, and one-way analysis of variance (ANOVA) were calculated to determine if there were any differences in demographic characteristics among expert ($n = 186$), experienced ($n = 69$) and novice ($n = 61$) nurse participants. One-way analysis of variance (ANOVA) revealed expected significant differences among the three groups in years of experience ($F = 421.9$; $df = 1$; $p = .001$) and age ($F = 327.1$; $df = 1$; $p = .001$). A chi square test of independence revealed further significant differences in the practice positions ($\chi^2 = 12.78$; $df = 6$; $p = .047$). As

Table 9

Area of Clinical Practice, Practice Position and Employee Status

| Area, Position and Status | Frequency | Percent |
|---|-----------|---------|
| Primary Area of Practice (N = 314) | | |
| Medical-Surgical/Step-Down | 149 | 47.5 |
| Critical Care | 75 | 23.9 |
| Inpatient Obstetrics/Pediatrics | 17 | 5.4 |
| Ambulatory Care | 12 | 3.8 |
| Other | 61 | 19.4 |
| Practice Position (N = 317) | | |
| Staff Nurse | 282 | 89.0 |
| Management | 18 | 5.7 |
| Clinical Specialist | 3 | 0.9 |
| Other | 14 | 4.4 |
| Employee Status (N = 316) | | |
| Full Time (> 30 hours) | 243 | 76.9 |
| Part Time (< 30 hours) | 60 | 19.0 |
| Per Diem Hospital Pool | 11 | 3.5 |
| Other | 2 | 0.6 |

experienced nurses' ages increased, their practice positions changed. Novice nurses were more likely to hold entry-level staff positions in acute care settings, whereas experienced nurses held a variety of positions. As the nurse progresses in skill and professional development, expanded opportunities in leadership and education are available.

Additional significant differences among novice, experienced and expert nurses were found in advocacy education ($\chi^2 = 19.72$; $df = 2$; $p = .001$), the area of practice ($\chi^2 = 39.42$; $df = 8$; $p = .001$), primary employee status ($\chi^2 = 13.02$; $df = 6$; $p = .043$) and

Table 10

Frequency of Working with Dying Patients, End-of-Life and Advocacy Education(N = 317)

| Work with Dying Patients, Education | Frequency | Valid Percent |
|--|-----------|---------------|
| Frequency of Working with Dying Patients | | |
| Daily | 20 | 6.3 |
| Often | 190 | 59.9 |
| Rarely | 97 | 30.6 |
| Never | 10 | 3.2 |
| Participation in Training Concerning End-of-Life Care in the Last Three Years | | |
| Yes | 130 | 41 |
| No | 187 | 59 |
| Concept of Advocacy a Part of Formal or Continuing Education | | |
| Yes | 240 | 75.7 |
| No | 77 | 24.3 |

educational level ($\chi^2 = 20.26$; $df = 6$; $p = .002$). The experienced (88.4%) and novice (88.5%) nurses reported that the concept of advocacy had been a part of their formal or continuing education. Novice nurses primarily work in medical-surgical and step-down units (70.5%) and were employed full-time (93.3%) at a greater percent than the experienced and expert groups. The educational-level differences among novice, experienced and expert nurses was demonstrated in the higher percentage of diploma

graduates in the expert (53.3%) and novice groups (50.8%). A summary of the data is presented in Appendix H.

Findings Related to Research Questions

Question 1: What are the perceptions of advocacy behaviors in end-of-life nursing care in acute care settings among novice, experienced and expert nurses?

Advocacy Perception Scores (APS) ranged from 76 to 111 ($N = 317$) out of a possible 125. The mean score was 91.42 ($Mdn = 91$; $SD = 6.04$). The total score for each subject in the second sub-instrument comprised the Advocacy Behavior Score (ABS). The ABS ($N = 317$) ranged from 4 to 9 out of a possible 9 with a mean of 7.57 ($Mdn = 8$; $SD = 1.07$).

The reported combined scores on the APS and ABS instruments among all participants ranged from 83 to 118 out of a possible 134, with a mean of 98.99 ($Mdn = 99$; $SD = 6.16$), indicating a large agreement with perceived advocacy behaviors in nursing practice. Table 11 displays the APS and ABS scores for the study participants.

Table 11

Mean Scores of Perception of Advocacy Behaviors (N = 317)

| Sub-Instrument | Range | Mean | <u>SD</u> |
|----------------------------------|--------|-------|-----------|
| Advocacy Perception Scores (APS) | 76-111 | 91.42 | 6.04 |
| Advocacy Behavior Scores (ABS) | 4-9 | 7.57 | 1.07 |
| Combined Scores (APS plus ABS) | 83-118 | 98.99 | 6.16 |

Question 2: What are the supports to practicing advocacy in end-of-life nursing care in acute care settings among novice, experienced and expert nurses?

Research Question 2 centers around the perceived supports to the advocacy role in end-of-life nursing care. Participants were asked to respond to eight structural items in their hospital work environment. The mean Structure Score was 3.68 with a range of 0 to 6 ($SD = 1.39$) indicating a moderate perception of structure support. It was noted that many of the participants did not know if their hospital had a collaborative practice committee or forum for discussion. Forty-seven percent of the participants answered item #34 with “unknown”. Table 12 portrays findings related to specific support structures in the hospital environment.

An additional open-ended question served as an opportunity for the participant to express opinions regarding the nurse as a patient advocate when caring for patients nearing end of life. Two hundred and fifty-three participants (79.8%) supplied one to several narrative statements or word phrases identifying supports to their advocacy practice. Participants reported several supports to advocacy practice in end-of-life nursing care including nurse managers, co-workers, and multi-disciplinary team support. Additional supports to advocacy practice included communication, relationship with patient, family, nurse knowledge, and nurse beliefs and compassion.

Nurse Manager and Co-Worker Support

Across all experience categories of novice, experienced, and expert nurses, the nurse manager and co-workers were identified as supports to the practice of advocacy with the highest frequency. Participants listed brief statements or words simply stating

“supportive nurse managers,” “nurse manager is always there,” “nurse manager,” or “fellow nurses”, “co-workers,” and “peers.” Two nurses expressed: “If [the] MD is not listening, RNs can always go to the nurse manager who will help [their] voice be heard” and “strong influence [of] leadership for patient advocacy.” Other participants wrote: “I can always ask for help from my co-workers to help achieve goal” and “[the] nursing

Table 12

Support Structures in the Hospital Environment (N = 317)

| Item Number Description | Number of “Yes” Responses | Percent |
|---|---------------------------|---------|
| 29. My hospital has ethics committee | 307 | 96.8 |
| 30. Nurse representative on hospital Ethics Committee | 241 | 76 |
| 31. My hospital has a nursing Ethics Committee | 47 | 14.9 |
| 32. I am a member of hospital Ethics Committee | 5 | 1.6 |
| 33. I am a member of nursing Ethics Committee | 0 | 0 |
| 34. My hospital has collaborative practice forum for discussion | 147 | 47 |
| 35. My hospital allows nurses to bring concerns to hospital Ethics Committee | 237 | 74.8 |
| 36. When disagreements occur, I pursue my hospital’s mechanism for dispute resolution | 183 | 57.7 |

team supports each other.” The study participants clearly looked to their nursing peers and managers to help in their advocacy role for the complexities of end-of-life nursing care.

Multidisciplinary Team Support

Many nurse participants identified members of the health care team as supportive to their individual practice of advocacy. Social and Chaplain Services most frequently appeared with statements or words: “social worker,” “social service department,” “hospital chaplain,” “pastoral care department,” and “spiritual care”. A smaller number of study participants identified the physician as a support to their advocacy practice by simply writing: “MD,” “some MDs,” and “MDs, if they listen to patient’s needs.” Respondents across all experience levels recognized the importance of the multidisciplinary team support in their end-of-life nursing care.

Communication

According to many respondents, communication was key in their practice of advocacy. Communication among nurses, patients, families, physicians and other members of the health care team was mentioned. Phrases or words that offer examples of communication support are: “good rapport,” “good MD interaction,” “being a good listener”, “able to voice concerns,” “allow patients to express themselves and their needs,” “we must explain in terms the patient understands so they can make wise decision,” “strong treatment team and communication,” “my willingness to challenge physicians openly and discuss care with patient and family,” and “frequent open communication.” The value of communication was expressed by many participants.

Other Supports: Nurse Beliefs and Compassion, Relationship with Patient, Nurse Knowledge, and Family

Many nurse participants believed that personal values, knowledge, and compassion for their work also supported the practice of advocacy. Statements made by nurses included: “knowing that I am doing the right thing,” “my personal beliefs about life and God,” “help patient deal with illness...,” “years of experience as a human-being and as a nurse,” “the nursing staff’s involvement in patient’s care,” “my background, belief and experiences,” and “being there for your patient and trying to help them.” According to some respondents, another support to advocacy practice was the satisfaction of having a relationship with their patients. Simple words or phrases to illustrate patient relationships included: “direct patient care,” “support patient’s wishes,” “being there for your patient and trying to help them,” and “knowing my patients.” This study illustrates the nurse’s compassion and belief in the work of patient care. Nurse knowledge and education were included as support by some study participants. Simple phrases such as “my education,” “my knowledge,” and “school education” were noted.

Nurses identified the patient’s family as a support to the end-of-life process. Families were perceived as helpers with communication and decision-making. Nurses wrote in phrases that identified the family as support such as “family support,” “support person available 24/7 to help with conflict,” and “well informed patient and family to help with decision making.” The pivotal role of patient’s family members was recognized by the study respondents. Communication between patients’ families and the healthcare team was identified as a positive attribute in the end-of-life process.

Question 3: What are the barriers to practicing advocacy in end-of-life nursing care in acute care settings among novice, experienced and expert nurses?

A second open-ended question served as the opportunity for study participants to express the barriers experienced in their advocacy role when providing care to end-of-life patients. Two hundred and fifty-three participants (79.8%) supplied one to several narrative statements or word phrases identifying barriers to their advocacy practice. The three most frequent barriers to the practice of advocacy identified among the study participants included the physician, family and fear. Additional categories identified were lack of communication, lack of knowledge, lack of time, and lack of hospital support.

Physician

The complex physician-nurse relationship surfaced in the many responses related to physicians. Three sub-categories were noted and include: (a) personal traits, (b) difficulty with end-of-life care issues, and (c) communication. Specific areas that the study participants identified related to physicians and the perceived personal traits included: “as a nurse, my opinions are minimized,” “patient believes that MD knows all,” “lack of discussion with end-of-life issues prior to patient illness,” “lack of respect for nurse and suggestions,” “MD indifference to end-of-life issues,” “MD beliefs and expectations,” and “egotistical attitude.”

Additional responses related to physicians revolve around the nurses’ perception that physicians have difficulty with end-of-life issues. Examples include: “lack of discussion with end-of-life issues prior to illness,” “uncomfortable with issues,” “outdated ideas,” “see death as a personal failure on their part and are uncomfortable

dealing with these issues as a result,” “on-call MD doesn’t deal with problem,” “MD’s inability to stop the lab tests and allow nature to take course,” and “MD doesn’t utilize hospice.”

A third data category that surfaced related to the physician included communication processes. The nurses’ perception that ineffective communication is common was illustrated by the following comments: “lack of communication between multiple physicians and staff,” “not having my voice heard when trying to speak to the MD,” “not sure what the doctor communicated,” “reluctant to discuss issues,” “lack of clear written communication,” and “lack of listening”. Nurses responded with a high-level of frequency to the issues surrounding the physician’s practice traits, difficulty with end-of-life care issues, and communication.

Family

Nurse participants identified family members as both supports and barriers to the care of their loved one. Responses that illustrate the family as a barrier to care include: “lack of knowledge,” “lack of preparation related to end-of-life issues,” “unrealistic expectations,” “dysfunctional families,” and “[the] inability to cope.”

Fear

According to many participants, fear served as a barrier to advocacy behaviors among nurses in all experience groups. Examples of fear included: “intimidation by physician,” “physician may get mad at RN for stepping over the line,” “being minimized by physician and fellow nurses and supervisors,” “labeled as trouble-maker by staff and physicians,” fear of being sued by family,” “afraid to confront doctors,” “RN caught in

the middle and feels uncomfortable supporting the patient,” and “the don’t rock the boat attitude of nurses.” The study participants did not provide insight into their perceptions of consequences of their fear, only that fear got in their way of advocacy behaviors.

**Other Barriers: Lack of Communication, Lack of Time and Hospital Support,
Lack of Knowledge**

Other barriers identified by the study participants included poor communication among team members, families and patients. One nurse identified that conflict could be avoided by simple written notes in the patient’s chart that reflected the plan of care or advanced directives. Another participant shared that open communication is the core of patient care. One nurse expressed frustration in her practice about the lack of time for caring: “inadequate staffing that hinders giving the needed time to counsel or console.” Other nurse participants identified the need for educational, hospital and community support to address end-of-life issues: “lack of education for nurses and doctors,” “lack of community education,” “lack of knowledge about legal aspect,” and “hospital protocols, legal issues, paternalistic medical behavior and too much red tape.” Participants in all study groups shared the concern that lack of communication serves as a barrier to the practice of advocacy in end-of-life nursing care. Furthermore, the nurse participants shared their insight that lack of time and support influenced their ability to use therapeutic communication skills to achieve all of their roles in quality patient care.

Question 4: What are the differences among novice, experienced and expert nurses’ perception of advocacy behaviors in end-of-life nursing care in acute care settings?

The separate and combined scores of the APS and ABS for nurses in the three groups of novice ($n = 61$), experienced ($n = 69$) and expert ($n = 186$) nurses were analyzed for Means and Standard Deviations. The mean scores were very similar among groups. Table 13 presents the findings of the score comparisons. ANOVA revealed no significant differences in the perceptions of advocacy behaviors as measured by the APS, ABS or combined scores among novice, experienced and expert nurses.

Table 13

Mean Scores of Perception of Advocacy Behaviors Among Novice, Experienced and Expert Nurses (N = 316)

| Group | <u>n</u> | Range | Mean | <u>SD</u> |
|---|----------|--------|--------|-----------|
| Advocacy Perception Scores (APS) | | | | |
| Novice | 61 | 77-108 | 92.66 | 6.86 |
| Experienced | 69 | 76-106 | 90.64 | 5.09 |
| Expert | 186 | 76-111 | 91.34 | 6.05 |
| Advocacy Behavior Scores (ABS) | | | | |
| Novice | 61 | 6-9 | 7.62 | 1.03 |
| Experienced | 69 | 5-9 | 7.61 | 1.01 |
| Expert | 186 | 4-9 | 7.54 | 1.10 |
| Combined Scores | | | | |
| Novice | 61 | 85-116 | 100.28 | 6.84 |
| Experienced | 69 | 83-113 | 98.25 | 5.28 |
| Expert | 186 | 83-118 | 98.88 | 6.19 |

Question 5: What are the differences among novice, experienced and expert nurses in the identification of supports to practicing advocacy in end-of-life nursing care in acute care settings?

The mean score for the Hospital Structure (SS) was higher for expert nurses ($M = 3.78$) than novices ($M = 3.57$). Interestingly, it was higher for novices than experienced nurses ($M = 3.46$). Table 14 displays the Mean scores on the Hospital Structure Score among novice, experienced and expert nurse participants.

Table 14

Mean Scores on the Hospital Structure Score (SS) Among Novice, Experienced and Expert Nurse Participants (N = 316)

| Experience Group | <u>n</u> | Range | Mean | <u>SD</u> |
|------------------|----------|-------|------|-----------|
| Novice | 61 | 1-6 | 3.57 | 1.47 |
| Experienced | 69 | 0-6 | 3.46 | 1.53 |
| Expert | 186 | 0-6 | 3.78 | 1.30 |

However, using a one-way ANOVA, there was no significant difference among novice, experienced and expert nurse participants in identifying hospital structure supports as measured by the third sub-instrument.

The open-ended question asking study participants to identify supports in their roles as patient advocate provided additional insight into the differences among novice, experienced and expert advocacy practice in end-of-life nursing care. Appendix I displays a cross case matrix (Miles & Huberman, 1994) of the most frequently reported supports

to advocacy practice among novice, experienced and expert nurses. All three groups reported a strong agreement among the top three supports: (a) nurse manager, (b) co-worker, and (c) the multi-disciplinary team. The experienced and expert nurses reported with greater frequency than the novice nurses did the importance of communication, relationship with the patient, nurse beliefs and compassion, and family.

Question 6: What are the differences among novice, experienced and expert nurses in the identification of barriers to practicing advocacy in end-of-life nursing care in acute care settings?

The open-ended question asking study participants to identify the greatest barrier(s) in their role as patient advocate provided additional insight into the differences among novice, experienced and expert advocacy practice in end-of-life nursing care. Appendix J displays a cross matrix (Miles & Huberman, 1994) of the most frequently reported barriers to advocacy practice among novice, experienced and expert nurses. All three groups reported with great frequency the perceived barriers of physician traits and physician communication. The expert nurse group added the insight that physicians have difficulty related to end-of-life issues. Novice nurses responded with great frequency that lack of communication and lack of time and/or support served as barriers to their practice. All three groups reported that fear is a barrier to their end-of-life nursing care.

Auxiliary Analysis

Descriptive statistics, chi square, and ANOVA were used to determine differences in the perceptions of advocacy behaviors in end-of-life nursing care based on the

participants' educational levels and primary areas of clinical practice. Analysis of the data revealed that there were no significant differences in the perceived advocacy role measured by the total score of the APS and ABS among participants holding an associates degree ($n = 92$; $M = 99.33$; $SD = 6.54$) diploma ($n = 147$; $M = 98.50$; $SD = 6.11$), or baccalaureate degree ($n = 66$; $M = 99.82$; $SD = 5.68$). Further examination revealed a 2-point increase in the Mean scores of the combined APS and ABS in nurses working in medical-surgical units ($n = 149$; $M = 99.52$; $SD = 6.24$) over nurses in the critical care units ($n = 75$; $M = 97.51$; $SD = 6.33$). However, this difference was not significant.

Significant differences among nurses participating in training seminars concerning end-of-life care in the last three years were revealed in the perceived advocacy role measured by the total score of the APS and ABS ($F = 13.46$; $df = 1$; $p = .001$). Forty-five percent of experienced nurses and 42.5% of expert nurses reported having had end-of-life education in the past three years while only 31.1% of novice nurses reported this experience. Further cross-tabulation analysis revealed that baccalaureate educated novice nurses ($n = 10$) did not report end-of-life education more often than their colleagues with diploma or associate education (Table 15). In addition, a significant difference was found among nurses who reported the role of nursing advocacy taught in formal or continuing education within the past three years ($\chi^2 = 19.72$; $df = 2$; $p = .001$). No differentiation was made between advocacy education in the formal academic setting or continuing education setting. The novice and experienced nurses reported greater frequency of advocacy education (88.5% and 88.2% respectively) than

Table 15

Comparison of Educational Levels of Novice Nurses and End-of-Life Education (N = 61)

| Education Level | <u>n</u> | End-of-Life Training | |
|----------------------|----------|----------------------|----|
| | | Yes | No |
| Associate Degree | 20 | 8 | 12 |
| Diploma | 31 | 8 | 23 |
| Baccalaureate Degree | 10 | 3 | 7 |

expert nurses who graduated from schools of nursing more than five years ago (66.4%).

Reliability Estimation

Cronbach's alpha internal consistency reliability of the Ethics Advocacy Instrument's Advocacy Perception (APS) and Advocacy Behavior (ABS) scales was computed. The 25-item Advocacy Perception Scale (APS) had a standardized Cronbach's alpha coefficient of .35 ($N = 317$). When combined with the 3-item Advocacy Behavior (ABS) scale, a Cronbach's alpha coefficient of .35 ($N = 317$) resulted. Cronbach's alpha internal consistency reliabilities obtained in this study cannot be compared to previous studies using the Ethics Advocacy Instrument due to the unavailability of precise reliability measurements (G. S. Wlody, personal communication, February 14, 2005). The reliability of the instrument in the present study was low.

Chapter Summary

This chapter has described the findings of perceptions of advocacy behaviors, barriers and supports to the practice of advocacy in end-of-life nursing care in acute care settings. The demographic characteristics of the sample were presented and the six study questions answered with statistical analysis. Additional analysis were performed on the demographic data and the reliability of the instrument was reported.

The convenience sample ($N = 317$) of practicing nurses worked in one of three hospitals in Southeastern Pennsylvania. The average participant was female (98.1%) with a mean age of 37.6 years. The majority of participants was staff nurses (89%), educated by a hospital-based diploma program (47.1%) and practiced in the acute care units of medical-surgical (47.5%) and critical care (23.9%). The majority of study participants reported the frequency of working with dying patients as “often”.

The perceived advocacy behaviors in end-of-life nursing care was measured by combining the scores of the Advocacy Perception (APS) and Advocacy Behavior (ABS) Sub-Instruments. The reported combined scores among all participants ranged from 83-118 with a mean of 98.99 indicating high agreement with advocacy behaviors in nursing practice. There were no significant differences in the perception of advocacy behaviors among novice, experienced and expert nurses.

Upon review of the supports to advocacy practice, a mixed report was revealed. The Mean Structure Score was 3.68 for the study participants out of a possible score of 8, uncovering a below average perception of hospital support structures. There was no significant difference among novice, experienced and expert nurse participants in

identifying hospital structure supports. However, the mean score for Hospital Structure (SS) was higher for expert nurses compared to novices. Two hundred and fifty-three participants supplied one to several narrative statements or word phrases identifying supports to their advocacy practice. The three most common supports to the practice of advocacy identified were peers, nurse managers, and multi-disciplinary team members. The study participants noted that the most frequent barriers to their advocacy practice included fear, the physician, and the patient's family. Novice nurses responded with greater frequency that lack of communication and lack of time/support served as barriers to their practice of advocacy in end-of-life nursing care.

Differences were revealed in the perceived advocacy role measured by the total score of the APS and ABS among nurses participating in training seminars concerning end-of-life care in the last three years and nursing advocacy taught in formal or continuing education.

CHAPTER 5

Discussion, Conclusions and Recommendations

The primary purpose of this study was to describe nurses' perceptions of advocacy behaviors in end-of-life nursing practice in the acute care setting. This chapter presents a discussion and interpretation of the findings and the conclusions followed by the limitations of the study, and implications for nursing practice, research, education and nursing science.

Discussion and Interpretation of the Findings

Demographic Characteristics of Sample

The demographic characteristics of the study participants are similar to the documented demographic characteristics of the Pennsylvania and National Registered Nurse Workforce (HRSA, 2004; PA Department of Health, 2002; PSNA, 2005). The average study participant was female (98.1%) with a mean age of 37.6 years. The majority of the participants were staff nurses (89%), educated by a hospital-based diploma program (47.1%) or an associate degree (29.5%). The predominant level of training for RNs employed in Pennsylvania is the hospital diploma (35%) and bachelor's degree (34%). By comparison, data from HRSA National Nurse Sample Survey reveals that nationally, the predominant level of education was the associate degree (37%) followed by the bachelor's degree (33%) (PA Department of Health, 2002). The average number of years of professional nurse experience was 11.9 with a range of .10 to 43 years. The large numbers of diploma and associate degree prepared nurses reflect the suburban and rural work force of Pennsylvania. The congruency between published

demographic characteristics of Pennsylvania nurses and the demographics of this sample serve to strengthen the external validity of the findings (Burns & Grove, 2005; LoBiondo-Wood & Haber, 2006).

Work with Dying Patients, Advocacy and End-of-Life Education

The care of the dying has shifted from family and community to experts in the health professions (AACN & City of Hope, 2000; Badger, 2005a; Ferrell et al., 1999; Haisfield-Wolfe, 1996; Matzo & Sherman, 2001) and health care institutions have replaced the home as the most common place where end-of-life care occurs. Badger reports that caring for dying patients was ordinary, rather than extraordinary in a study performed with nurses in medical intensive care units. This study's participants supported the literature in their reported frequency of working with dying patients as "often" (59.9%) or "daily" (6.3%). However, in spite of the frequency of caring for dying patients, only 41% of the study participants report involvement in training seminars concerning end-of-life care in the last three years. The participants who received education on end-of-life nursing care scored significantly higher on the APS and ABS combined scores ($F = 13.46$; $df = 1$; $p = .001$) than those who did not; therefore, education may positively influence perceived advocacy behaviors in end-of-life nursing care.

Death and dying are addressed in the core curriculum of most nursing schools, but are often limited to a single lecture, a brief class discussion, or a series of assigned readings (Christopher, 2001). The experienced (44.9%) and expert (42.5%) nurses reported greater frequency of end-of-life education than novice (31.1%) nurses who

graduated from schools of nursing within the past year. Further analysis revealed that baccalaureate educated novice nurses did not report greater end-of-life education than their colleagues with diploma or associate education. This finding contradicts the recent emphasis on end-of-life education in schools of nursing (Altun & Ersoy, 2003; Ferrell et al., 1999; Matzo & Sherman, 2001; Thompson, 2005) but might indicate that practicing nurses are gaining access to end-of-life education such as provided by the End-of-Life Nursing Education Consortium [ELNEC] (AACN, 2004; AACN & City of Hope, 2000; Thompson, 2005).

Advocacy education was evident in formal or continuing education for 75.7% of study participants. Novice (88.5%) and experienced (88.2%) nurses reported greater frequency of advocacy education than expert (66.4%) nurses. The literature supports that advocacy is an essential component of the nurses' professional role (ANA, 2004; ANA 2001; AACN, 1998; Foley, Minick & Kee, 2002, 2000); however, one-fourth of the study participants did not acknowledge advocacy education. Study results further support the need for advocacy education in that a significant difference between participants who reported advocacy education and those who did not ($F = 22.34$; $df = 1$; $p = .001$) was discovered for participants' APS and ABS combined score. Those participants who received advocacy education have a greater perception of advocacy behavior.

Research Question #1

Regarding the perceptions of advocacy behaviors in end-of-life nursing care the study participants' large agreement with perceived advocacy behaviors in nursing practice is consistent with nursing's professional practice acts, ethical practice statements,

social policy recommendations and definitions of professional nursing (AACN, 1998; ANA, 2004; ANA, 2001). There may be several reasons to support this finding. Ethics is the foundation of nursing practice and the role of advocacy has underpinnings in ethical-decision making. Nurses and educators have difficulty describing the steps of advocacy to guide novice nurses (Foley, Minick, & Kee, 2002) and may not emphasize the advocacy role or ethical decision-making process. The practice environment may not support independent thinking, especially when it questions the status quo. In addition, the practice environment may not realize or “label” the number of patients nearing end-of-life and have not placed a high priority on the specific needs of nursing care. In order to improve the status of end-of-life care, nurse educators need to be cognizant of the advocate role in nursing practice and nurse administrators need to create environments to support advocacy.

Research Question #2

The study participants scored below average ($M = 3.68$) on the Structure Support Sub-Instrument. Forty-seven percent of the participants did not know whether their hospital had a collaborative practice committee or forum for discussion and only 57.7% noted that when a disagreement occurs, they would pursue the hospital’s mechanism for dispute resolution. The sub-instrument content may lack validity and be one reason for the low mean score. Two questions centered on the existence of an ethics committee specifically for the nursing staff. Due to the current interdisciplinary nature and complexities of patient care, hospitals may utilize a one-committee structure for ethical

concerns. With that said, it is still unfortunate that the majority of study participants did not know they had a forum for discussion when complex issues arise.

An additional open-ended question served as an opportunity for the participant to express opinions regarding supports to the nurse as a patient advocate when caring for patients nearing end-of-life. The three noteworthy supports identified were peers, nurse managers, and multi-disciplinary team support. This may be explained by the need for nurses to obtain or expand their professional confidence after the formal education process. Briggs and Colvin (2002) identified a significant gap in the amount of formal and continuing education nurses receive on the role of patient advocate; therefore, nurses look for the support of peers, nurse managers and health care team members to guide them in role development. Patient advocacy is viewed as a natural part of holistic nursing (Segesten, 1993) and the complex situations nurses find themselves in require a dependence upon each other and the more experienced healthcare providers. It is consistent with Benner's (1984) work in that clinical wisdom is more varied and complicated than theoretical information and requires development over time. Nurses form natural relationships with colleagues in the clinical setting that allow continued skill acquisition and development.

Other supports recognized include the nurses' personal beliefs and compassion, patient-nurse relationships, the patient's family, the nurses' knowledge-base, and communication. The high number of responses to the open-ended question suggests that nurses have much to say about their practice of advocacy in end-of-life nursing care.

Supports, or facilitators, are consistent with Benner's (1984) domains of caring nursing practice. The natural relationships with colleagues in the clinical setting allow continued skill acquisition and development in the: (a) helping role, (b) teaching or coaching function, (c) diagnostic and client monitoring functions, (d) effective management of rapidly changing situations, (e) administering and monitoring therapeutic interventions and regimens, (f) monitoring and ensuring quality of health care practices, and (g) organizational work-role competencies. This study's identified supports of the nurse manager, co-worker, and multi-disciplinary team member may illustrate the supportive institutional culture and structure supports discussed in the literature (Badger, 2005; Brophey, 2001; Copp, 1986; Ellis, 1995; Georges, et al., 2002; Martin, 1998). The nurses' knowledge of end-of-life best practices (Benner, 2001; Ferrell et al., 1999) is also consistent with previous findings. Another support identified in the literature included positive personal attitudes (Copp, Martin, Pimple & Schmidt, 2001). This study's respondents identified personal beliefs and compassion as a perceived support to their practice of advocacy. The language of positive attitudes was not used, but one may draw comparisons that compassionate care is based on a positive outlook and attitude. Moral and ethical decision-making competencies (Baldwin, 2003; Brophey; Copp; Hamric, 1999; Kuuppelomaki, 2002; Loverage, 2000; Mallik, 1997) were identified in the literature as foundational to advocacy practice in end-of-life nursing care; however, very few of the study's respondents identified decision-making as a support to their advocacy practice.

Research Question #3

A second open-ended question served as the opportunity for study participants to express the barriers experienced in their advocacy role when providing nursing care to end-of-life patients. The three sizeable barriers identified among the participants included the physician, the patient's family, and fear. Other barriers listed were lack of communication, lack of knowledge, lack of time, and lack of hospital support. It is interesting to note that the respondents identified family as a support and barrier. Further review of the data revealed that the family was a barrier when there was lack of knowledge or preparation related to end-of-life issues and unrealistic expectations. Possible reasons for the nurses identifying physicians and family as barriers may be the nurses' lack of decision-making (Baldwin, 2003; Brophy, 2001; Curtin 1983; Ellis, 1995; Hewitt, 2002; Mylott, 2005), empowerment (Brophy; Copp, 1986; Ellis; Georges; et al., 2002; Jablonski & Wyatt, 2005; Martin, 1998a; Mylott), and communication skill development (Boyle et al., 2005; Beckstrand et al., 2006; Jablonski & Wyatt, Mylott) . The culture of acute care nursing in some hospitals may not support the time and advanced skill needed to resolve complex issues at the staff nurse level. In addition, nurse educators may not initiate strategies to develop these skills, instead focusing on task-oriented procedures and knowledge. Thus, nurses may be lacking in the necessary preparation to fulfill their role as patient advocate.

The identified barriers are not surprising within the context of the three regional hospitals used for this study. Many participants were diploma graduates and have been in practice greater than five years. Long-time affiliation with hospitals is common and many

nurses stay for employment after diploma education. The hospital cultures are changing, most notably with the movement to Magnet status, but stem from years of patriarchal hierarchy. It will take time to achieve shared governance and nurse empowerment in these environments.

The barriers identified by this study's participants are consistent with the literature. Barriers to the practice of advocacy are factors that interfere with the patient and family's desired outcomes of end-of-life care. They can be internal to the nurse such as anxiety, attitudes, lack of knowledge, stereotypes and prejudices (Copp, 1986; Georges, Gryphonck, & DeCastle, 2002; Martin, 1998a; Pimple & Schmidt, 2001), or external such as institutional policies and procedure (Brophey, 2001; Copp; Ellis, 1995; Georges et al.; Martin), and interpersonal conflicts (Baldwin, 2003; Brophy; Curtin, 1983; Ellis; Hewitt, 2002). This study's respondents did not use the language of employment risk (Brophy; Copp; Ellis; Georges, et al.; Martin); however, they identified fear as a frequent or most frequent response (see Appendix J).

These results confirm the findings of other recent studies (Badger, 2005; Beckstrand et al., 2006) in that barriers to a "good death" continue to exist and that nurses have much to say about quality patient care. The results also provide information for further discussion and inquiry.

Research Question #4

There were no significant differences in the perceptions of advocacy behaviors among novice, experienced and expert nurses as measured by the APS, ABS or combined APS and ABS scores among novice ($n = 61$), experienced ($n = 69$) and expert nurses ($n =$

186). Benner (1984) believes that clinical knowledge accrues over time in a practice discipline and there are differences between practical and theoretical knowledge. The study groups of novice, experienced and expert were derived from Benner's major concepts and theoretical definitions. The novice nurse is one with "no background understanding, context-free rules; difficulty discerning between relevant and irrelevant aspects of the situation" (Benner, 1984, p. 296). In this study, the novice nurse was one who had worked less than one-year. The time-frame may have influenced the level of expertise, placing some of the novice group in the level of competent or proficient. A better approach could have been to measure advocacy behaviors prior to graduation. In addition, novice nurses may have answered the study instrument in a theoretical way, not yet experiencing confrontations or being positioned in the middle of a dispute. Another explanation of the finding may be that the practice environment cultivates non-advocacy behaviors; therefore, experienced and expert nurses responded to the study instrument in a realistic way. Perhaps the longer one practices in an environment with moderate empowerment, the more chance there is for complacency to occur. In contrast to Benner's model, the motivation to change and "stand up" for personal beliefs of advocacy is lowered.

Research Question #5

There was no significant difference among novice, experienced and expert nurse participants in identifying hospital structure supports as measured by the third EAI sub-instrument; however, the mean score for the Hospital Structure Supports was higher for expert nurse participants than novice nurse participants. The open-ended question asking

study participants to identify supports in their role as patient advocate provided additional insight into some differences among novice, experienced and expert advocacy practice in end-of-life nursing care. Experienced and expert nurses reported with greater frequency than the novice nurses the importance of communication, relationship with the patient, nurse beliefs and compassion, and family. They were able to reach beyond the day-to-day work challenges to see the inter-related concepts of communication, relationships and personal beliefs.

These findings may be explained in that experienced and expert nurses have the confidence, maturity and life experience to navigate interpersonal and structural systems. Access to the nurse manager, interdisciplinary teams and hospital structure and policies such as the ethics committee requires a “hybrid of practical and theoretical knowledge” (Benner, 1984, p. 294) that the expert nurses have developed. This is congruent with the theoretical process of skill acquisition outlined by Benner.

Research Question #6

The open-ended question asking study participants to identify the greatest barrier(s) to acting as a patient advocate provided additional insight into the differences among novice, experienced and expert nurses. All three groups reported with great frequency the perceived barriers of physician traits and physician communication. The expert nurse group added the insight that physicians have difficulty related to end-of-life issues. Novice nurses responded with great regularity that lack of communication and lack of time and/or support served as barriers to their practice. All three groups reported that fear is a barrier to their end-of-life nursing care.

There may be several reasons that account for these findings. One possible explanation may be that novice practice involves an orientation period. Hospital infrastructure, policy, and procedures are complex and overwhelming. Novice nurses practice from theoretical knowledge (Benner, 1984) and need time to establish proficiency and communication patterns. Other explanations may include that expert nurses are involved in policy-making for clinical practice and have established lines of communication.

The importance of the expert nurse group identifying that physicians have difficulty relating to end-of-life issues cannot be underestimated. This finding is congruent and has been documented in other studies (AACN & City of Hope, 2000; Badger, 2005a; Beckstrand et al., 2006; Carpenter, 1992; Brophy, 2001; Georges et al., 2002; Kohnke, 1980; SUPPORT, 1995). It has been identified that all members of the health care team need additional education on the many issues surrounding end-of-life care. This study's responses by the expert nurse group supports Benner's (1984) theory in that expert nurses use integrative thinking skills. They could look beyond the physician behavior and identify the need for education.

Carpenter (1992), Gates (1995), and Sanchez-Sweatman (1997) shed a possible light on why all three nurse groups responded with great frequency that fear was a barrier to advocacy behaviors in end-of-life nursing care. The legal risks of the role of advocacy in nursing practice are not well defined but have an effect on practice. If nurses advocate for their patients such as sharing information to make informed decisions, conflict may occur with physicians. The risk of disciplinary action or loss of employment may seem

too high a price for the nurse to bear. Patriarchal systems may serve to over-rule basic patient rights, despite the patient's legal and ethical right to be informed. This gives reason to why nurses fear speaking up for patients even when they are suffering (Gates). In a culture of physician dominance nurses may have great difficulty navigating the attitudes and climate of complex care situations (Brophey, 2001; Copp, 1986; Ellis, 1995; Georges et al., 2002; Jablonki & Wyatt, 2005; Martin, 1998a; Mylott, 2005). The study sample included nurses who work at hospitals that continue to offer diploma schools of nursing and hire the majority of their own graduates. Nurses are bound by their institutional policies, professional body and medical personnel. Decades of hierarchical communication patterns and decision-making influence nurses' behavior and a change in work-place culture will be slow.

Conclusions

The following conclusions are presented based on the findings of this study:

1. Acute care nurses care for dying patients on a routine basis.
2. Despite the recent emphasis on end-of-life nursing education, practicing acute-care nurses report modest exposure to end-of-life training.
3. There is large agreement with perceived advocacy behaviors in end-of-life nursing practice.
4. End-of-life nursing education and advocacy education positively influenced perceived advocacy behaviors when caring for end-of-life patients as measured by the APS and ABS combined score.

5. The identified supports to the practice of advocacy center on nurse managers, co-workers, and multi-disciplinary services.
6. Experienced and expert nurses report with greater frequency than novice nurses that communication, relationship with patient, nurse beliefs and compassion, and family support the practice of advocacy.
7. The major reported barriers to the practice of advocacy included the physician, family and fear for all groups.
8. Novice nurses reported with great regularity that lack of communication and lack of time/support served as barriers to their practice of advocacy.
9. Novice, experienced, and expert nurses do not significantly differ in their perceptions of advocacy behaviors.
10. The Ethics Advocacy Instrument did not achieve an acceptable reliability for this study.

Limitations

The major limitation of this study was the low instrument reliability measure. There is limited validity of the EAI and the reliability measurement ($\alpha = .374$) was below generally acceptable levels (Burns & Grove, 2005; LoBionno-Wood & Haber, 2006; Munro, 2004). Instrument reliability testing examines the dependability, consistency, accuracy and comparability of the instrument. Instrument internal consistency requires the assumption that the instrument items designed to measure selected variables are all measuring the critical attribute and nothing else (Burns & Grove). Therefore, the EAI instrument's reliability permits questions on the justification of performing analysis on

data from the instrument. Advocacy, as well as many other phenomena studied in nursing, may involve changes with different situations and over time. If one's perception of advocacy behaviors changes, the instrument's reliability may not reflect a stable or reliable measure. The decision to use data from the EAI was based upon the changing nature of advocacy and the sufficient power achieved in the study sample. However, the results of perceived advocacy behavior as measured by the EAI should be regarded with caution. In addition, participants in this study may not have responded accurately to the items of the Ethics Advocacy Instrument, a self-report survey.

A second limitation is the inability to generalize study findings beyond this sample. The sample was a nonrandom, convenience sample drawn from three hospitals in Southeastern Pennsylvania. The sample reflects Pennsylvania's workforce characteristics; however, diploma schools of nursing do not exist in the majority of the United States. Two of the three hospitals hired many of their own diploma school graduates. The limited geographical location serves to restrict the findings.

Another limitation was the uneven sample groups. Burns and Grove (2005) suggest that the more unequal the group sizes, the smaller the effect size; therefore, the sample must be larger. A preliminary power analysis indicated that 53 subjects per experience group (novice, experienced and expert) were needed to reach a total sample size of 159 with a moderate effect size ($ES = .25$) and a power of .80. Post study analysis with a sample size of 317 established an observed power of .39 based on actual one-way analysis of variance (ANOVA). The uneven experience groups and below generally

acceptable level of instrument reliability may have contributed to low power and lower statistical conclusion validity.

The timing of the data collection might have interfered with measurement of true novice nursing practice. Participants were placed in the novice experience group with one to 12 months of clinical practice (M years = .64; SD = .45). The optimum time for data collection would have been in the early summer during new graduate orientation or even prior to graduation.

Implications for Nursing Research

While there is a growing body of knowledge of the advocacy role in end-of-life issues, the research is still in its infancy in terms of rigorous testing and outcome measurement. This descriptive study contributed to the base of evidence related to the practice environment. This study had similar results and is congruent with the literature in that the majority of nurse participants agreed that they practiced advocacy behaviors, despite the reported barriers. The identified supports to the practice of advocacy centered on other nurses and team members, while at the same time addressed personal beliefs and patient relationships.

This study provides the opportunity for instrument development to measure perceived supports and barriers to the practice of advocacy consistent with Wilkie's (2001, ¶ 2) definition of advocacy: "...assisting the patient and family to overcome barriers impeding their care path." The qualitative data findings, along with existing literature can guide the process of tool development. Seventy-nine percent of the respondents felt the need to add one to several narrative statements identifying supports

and barriers to their advocacy practice. These statements can help formulate items for a new instrument. Once defined, the individual items measuring perceived supports and barriers of advocacy behaviors in end-of-life nursing care can be evaluated for validity and tested for reliability. New knowledge derived from rigorous and consistent measurement allows for testing across populations and generalization of the findings.

This study contributes to the body of knowledge and opens the door for further questioning of the effectiveness of the advocacy role. A cross-method triangulation (Burns & Grove, 2005) served to strengthen internal validity by measuring the concept of advocacy from two approaches. Most studies measuring the concept of advocacy have been qualitative in nature.

Recommendations for Further Research

The researcher recommends further research on this topic including:

1. Address the study questions using a larger sample from a wider geographical area with an instrument demonstrating acceptable reliability measures.
2. Develop a quasi-experimental design with an educational treatment on evidenced-based end-of-life nursing care with a focus on the role of advocacy.
3. Develop a quasi-experimental design with an educational treatment on how to teach advocacy with a focus on the supports to advocacy behaviors.

4. Consider the timing of data collection for the novice experience group. It may be best to collect data shortly prior to graduation.
5. Expand the sample to long-term care facilities.
6. Use other qualitative methods such as interviews or focus groups for data collection.
7. Continue the use of experience group comparison, but consider changing the operational definition of the novice nurse.
8. Consider the use of Benner's (1984) five experience group categories.
9. Continue to refine the EAI to reach greater reliability or develop another valid and reliable tool to quantify advocacy behaviors in end-of-life nursing care.
10. Develop a valid and reliable quantitative instrument to measure supports and barriers to the practice of advocacy.

Implications for Nursing Practice

The demand for end-of-life care will continue to increase as our elderly population grows and a burdened health care system confronts the increase in chronic and terminal illness (Ferrell et al., 1999). With the majority of nurses practicing in acute care settings (HRSA, 2004), this study's findings may serve as a baseline assessment to guide staff development education and hospital infrastructure policies. Supports to the practice of advocacy may be enhanced in the practice environment by continued communication skill development. Additional programs to strengthen collegial relationships among nurse

managers, co-workers, and multi-disciplinary team members will serve to enhance the supportive environment.

It is known that patient advocacy is viewed as a natural part of holistic nursing practice and nurses take actions out of conviction and the risk of being punished (Segesten, 1993) and that advocacy has great appeal to the practicing nurse; however, its implementation might present problems (Millette, 1993). McClement and Degner (1995) and Snowball's (1996) work demonstrated examples of nursing behaviors needed for the role of advocacy. These behaviors include: (a) responding to the family and colleagues, (b) responding to anger and the cultural environment, (c) enhancing the therapeutic relationship, and (d) facilitating the transition from cure to palliation. Foley et al. (2000, 2002) contributed to the understanding of the meaning of advocacy in nursing practice by identifying the four themes of the safeguarding pattern: (a) protecting, (b) attending, (c) being the patient's voice, and (d) preserving the patient's identity. Further study gave insight into how nurses develop the skill of advocacy. The emerging themes included: (a) who I am, (b) watching other nurses interact with patient, and (c) gaining confidence.

In this study, nurses reported with great frequency the physician and patient's family as barriers to their practice of advocacy. With this finding, one may conclude that practicing nurses and their healthcare colleagues need further communication skill development. Poor communication, intimidating behavior and mistrust contribute to poor patient outcomes. Ensuring that nurses are provided with the education, competency, and rewards to effectively negotiate the conflict-laden end-of-life issues would dramatically alter the culture and work environment (AACN, 2005; Baggs & Ryan, 1990; Baggs &

Schmitt, 2000). Appropriate methods to address differences of opinion and navigation of the hospital system may equip nurses with the communication tools of advocacy.

Communication and decision-making skills to help the nurse deal with multi-disciplinary members of the health-care team will only serve to improve end-of-life care. Another implication for the practice environment is to improve communication among physicians, nurses, and family. Different care foci and patient outcome goals serve as barriers to teamwork; therefore, opportunities for care conferences and simple listening may reduce this reported barrier. Educational interventions on end-of-life care options and communication strategies for nurses, physicians, patients and families may ultimately facilitate improved patient care.

In order to fulfill their role as advocate, nurses must be involved in making decisions about patient care. As the single constant professional present with hospitalized patients, nurses offer much expertise in data management and are the vital link to the entire multi-disciplinary team (AACN, 2005). This is congruent with Benner's (1984) framework in that she acknowledges this role in the domains of a caring nursing practice.

Hospital infrastructures may be well established; however, if the nurse at the bedside does not know what resources are available or how to access them, the infrastructure is ineffective. Nurse managers, clinical nurse specialists, and staff development educators can positively effect the end-of-life nursing care of their patients by sharing information regarding the available resources to support complex patient-care conditions and encourage the nurse to use them. In addition, the constant attention and

support by formal process and structures foster joint communication and decision making (AACN, 2005).

Holistic end-of-life care has traditionally been the expertise of hospice programs (Ferrell et al., 1999), but must extend to acute and long-term care facilities. This study was consistent with Briggs and Colvin's (2002) finding that the nurse's role as patient advocate in end-of-life decision making is well supported in position statements; however, in reality, there is a significant gap in the amount of formal and continuing education nurses receive on this role. Nurse educators and managers can use these findings to plan educational programming for direct-care providers.

Implications for Nursing Education

To influence future end-of-life care, nurse educators need to search for the most effective teaching-learning approach to prepare graduates for care of the dying. Every graduate of a nursing program in the twenty-first century should have the skill, knowledge and attitude necessary to provide competent end-of-life care. In the last five years, textbooks have improved end-of-life nursing care content and nurse educators have had the opportunity to increase their knowledge and teaching methods (AACN & City of Hope, 2000; Copp, 1994; Matzo & Sherman, 2001). The results of this study revealed that novice nurses did not report with greater frequency receipt of advocacy or end-of-life education. Nurse educators can use these data to revise teaching-learning methods or add content to better prepare their graduates. Teaching-learning strategies such as role play, narratives, reflective journaling and case study can offer substantial support professional role development and advocacy behaviors.

The care of the dying has shifted from family and community to experts in the health professions with nurses spending more time with people who are facing death than any other member of the health care team (AACN & City of Hope, 2000; Ferrell et al., 1999; Haisfield-Wolfe, 1996; Matzo & Sherman, 2001). End-of-life nursing care involves interpretation of complex situations and requires intuitive judgment (AACN & City of Hope; Matz & Sherman). This tacit knowledge presents a challenge for nurse educators to create nursing curricula and subsequently guide novice nurses to effective practice (Copp, 1994). The extension of the End-of-Life Nursing Education Consortium (ELNEC) opportunity (AACN & City of Hope), inclusion of integrated and direct content and clinical practice in basic nurse educational programs, and expansion of end-of-life experiences for practicing nurses are just a few suggestions on how to help nurses offer improved end-of-life care.

Implications for Nursing Science

Benner's (1984) Theory from Novice to Expert: Excellence and Power in Clinical Nursing Practice provided a useful framework for this study to contribute to the understanding of how the power of advocacy was practiced by acute care nurses in end-of-life care. The nurse using the power of advocacy removes obstacles and supports the patient and family to enable them to succeed. Benner writes that nurses have power, though they exert their power from a position of low status in the hierarchy. This study contributed to the clinical wisdom that future educational and hospital structure interventions can be based upon. This study's participants identified supports to their advocacy practice as peers, nurse manager and multi-disciplinary team members. This is

consistent with Benner's (1984) work in that clinical wisdom is more varied and complicated than theoretical information and requires development over time. Nurses form natural relationships with colleagues in the clinical setting that allow continued skill acquisition and development.

The two, open-ended questions on the EAI survey instrument served to gather clinical knowledge from practicing nurses. The method and results demonstrated congruence with the findings "that communicating to critically ill patients and families is a complex process filtered through fears and hopes and across levels of education and understanding. It is little wonder that patient questioning and listening for patient understanding is so fraught with misunderstandings and fragmentation" (Benner, Hooper-Kyriakidis & Stannard, 1999, pp. 371-372).

End-of-life clinical decisions are made in the context of an uncertain, changing situation and many times in the midst of suffering and fear. The levels of clinical nursing experience described by Benner (1984) may respond to the patient situation at different rates and skill. This study did not confirm an overall difference in advocacy behaviors between the novice, experienced and expert nurse as measured by the APS and ABS combined score; however, it offered insight into the supports and barriers nurses of each skill level experience in the practice of advocacy. Modifying Benner's five experience groups (novice, advanced beginner, competent, proficient, and expert) to only three experience groups (novice, experienced and expert) may have also served to decrease the model's clarity in the area of skill acquisition and development, competence, experience, clinical knowledge, and practical knowledge.

Results of this study also established some support for the model proposed in Figure 1 (p. 11). The first step to integrate the behavior of advocacy is to develop a reasoning-in-transition skill. The study participants' identification of supports and barriers to their practice of advocacy demonstrated the struggle Benner (1984) explains in her work. It refers to the practical reasoning where a clinical situation moves from curative therapies to end-of-life nursing care and caring. This can be used to explain the trigger experience. Clinical decisions, that are made by the family and patient in the context of uncertain, changing situations, and in the midst of suffering and fear frequently need the nurse to run defense for them (Benner), thus triggering advocacy behaviors.

The domains of a caring nursing practice were demonstrated in all nurse experience levels (novice, experienced and expert) to assist patients to overcome barriers impeding their care. The EAI served to capture all of Benner's (1984) seven domains of practice and this study's four defining characteristics of advocacy behavior (listening to the patient's voice, promoting patient well-being, protecting the patient, and moral and ethical decision-making). This study supported the belief that the seven domains of nursing practice (Benner) and the defining characteristics of advocacy behavior discovered in the literature review (Chapter 2) are present and of equal importance to reach the desired outcome in any given patient situation where advocacy behaviors exist. Study respondents provided further illustration of these complex roles in their responses to the open-ended questions related to supports and barriers to the practice of advocacy.

Summary of the Study

This comparative descriptive study using a naturally occurring practice setting of three regional hospitals provided an excellent opportunity to examine and describe the perceived advocacy practice behaviors in end-of-life nursing care among novice, experienced and expert nurses. The convenience sample consisted of 317 practicing nurses, with the majority reporting frequent contact with dying patients. Practicing nurses completed the 38-item Ethics Advocacy Instrument (Wlody, 1993), including two open-ended questions and a demographic survey, with 33.3% return rate by postal mail.

Participants indicated considerable agreement with perceived advocacy behaviors in end-of-life nursing practice with no significant differences among novice, experienced and expert nurses. Despite the recent emphasis on end-of-life nursing education, practicing acute-care nurses report modest exposure to end-of-life training. The perception of hospital supports was average with no significant differences among novice, experienced and expert nurses. Three substantial supports to advocacy practice identified by the participants included nurse managers, co-workers and multi-disciplinary services. The study participants described considerable barriers to their advocacy practice including the physician, the patient's family and fear. Novice nurses reported with great frequency that lack of communication and lack of time and/or support served as barriers to their practice.

The major study limitations included the low instrument reliability and limited validity. The decision to use data from the EAI was based upon the changing nature of advocacy and the sufficient power achieved in the study sample. The second limitation

was the inability to generalize study findings beyond this sample. The sample reflects Pennsylvania's workforce characteristics; however, diploma schools of nursing do not exist in the majority of the United States. Other limitations included the non-random, convenience sample with unequal groups and the timing of the data collection that might have interfered with measurement of true novice nursing practice.

This study added to the empirical data base and its findings were congruent with the literature in that the majority of nurse participants agreed that they practiced advocacy behaviors, despite the reported barriers. A cross-method triangulation served to strengthen internal validity by measuring the concept of advocacy from two approaches. Nursing practice can benefit from the study findings. Appropriate methods to address differences of opinion and navigation of the hospital system may equip nurses with the communication tools of advocacy. Communication and decision-making skills to help the nurse deal with multi-disciplinary members of the health-care team will only serve to improve end-of-life care.

The results of this study revealed that novice nurses did not report with greater frequency receipt of advocacy or end-of-life education. Nurse educators can use these data to revise teaching-learning methods or add content to better prepare their graduates. Evidenced-based teaching-learning strategies such as role play, narratives, reflective journaling and case study can offer substantial support for professional role development and advocacy behaviors. And finally, nursing science was supported in that the study contributed to the clinical wisdom that future educational and hospital structure interventions can be based upon. This study did not confirm an over-all difference in

advocacy behaviors between the novice, experience and expert nurse as measured by the APS and ABS combined score. However it offered insight into the supports and barriers nurses at each skill level experienced in the practice of advocacy.

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Appendix A

Survey Instrument and Participant Packet

Introduction to Survey

Nurses advocate for patients in every practice setting. Because advocacy is so embedded in nursing practice it is sometimes invisible. **The purpose of this survey is to explore the role of advocacy when caring for patients nearing end of life.** Even though you may have never cared for a dying patient, fill out the survey with the intent or thought of caring for a patient who is terminally ill or in the dying process.

For the purpose of this study **advocacy is defined as “assisting the patient and family to overcome barriers impeding their care....”** (Wilkie, ¶ 2).

Please do not include your name or identifying information anywhere on the return survey.

Ethics Assessment

Ethics Perceptions

Items 1 – 25 relate to your perceptions. Please respond to the following questions by indicating your level of support and placing the appropriate number in the space before each item. Please remember, there is no right or wrong answer!

| STRONGLY AGREE | SOMEWHAT AGREE | NO OPINION | SOMEWHAT DISAGREE | STRONGLY DISAGREE |
|-------------------|-------------------|---------------|----------------------|----------------------|
| 5 | 4 | 3 | 2 | 1 |

When caring for a dying patient:

- ___ 1. In my practice, advocacy means that nurses should support what the patient wants, rather than what the physician wants (in the event of a difference of opinion).
- ___ 2. It is more important to be loyal to my institution, than to my individual patient.
- ___ 3. Nurses should not be involved when treatment decisions are made about patient care.
- ___ 4. Nurses strive to protect patients from direct harm.
- ___ 5. The primary role of a nurse is as patient advocate.
- ___ 6. I should support my patient's right to their beliefs, even if I don't agree.
- ___ 7. Patients have the right to make health care decisions for themselves.
- ___ 8. During decision making it is not proper or right for me to interfere, even if to support what the patient really wants.
- ___ 9. In my practice setting, the physician is the central (most important) decision-maker.
- ___ 10. Nurses must occasionally take risks themselves to protect patients from harm.
- ___ 11. In my practice setting, the patient is the central (most important) decision-maker.
- ___ 12. It is my foremost duty to protect the patient from harm.
- ___ 13. It is my duty to act as mediator between patients and health care team (the doctors and others) only when I feel it is necessary.
- ___ 14. My actions or behavior affect the "ethical environment" where I work.
- ___ 15. When patients are unable to participate in making their own health care decisions, physicians have the greatest responsibility to make these decisions for them.

| STRONGLY AGREE | SOMEWHAT AGREE | NO OPINION | SOMEWHAT DISAGREE | STRONGLY DISAGREE |
|-------------------|-------------------|---------------|----------------------|----------------------|
| 5 | 4 | 3 | 2 | 1 |

- ___ 16. Advocacy behaviors in nursing support the concept that patients have the right to make decisions for themselves.
- ___ 17. When patients are unable to make decisions for themselves, the nurse is responsible to assist in identification of decision-makers.
- ___ 18. Nurses are not permitted to interfere if they disagree with physician decisions in my hospital.
- ___ 19. I have an obligation to myself to maintain my moral integrity.
- ___ 20. When I am unable to support the patient's view, I am able to transfer the patient's care to another nurse.
- ___ 21. I believe that I have a responsibility to create an environment which supports patient values and advances patient goals.
- ___ 22. As a part of my assessment, I try to determine patient preferences, values and beliefs.
- ___ 23. If I have a reason to believe the patient does not understand information relevant to a decision, it is not my role to bring it to the attention of the physician or others.
- ___ 24. I believe that I am legally empowered to act as a patient advocate.
- ___ 25. I am aware of laws and regulations in my state which support my role as a patient advocate.

Ethics Case Studies

In this section there are three scenarios. Please read the scenario, then respond to the questions by selecting the response that fits the actions you most likely would take in that situation. Please remember, there are not right or wrong answers.

26. JB is a 30 year old male admitted to the hospital immunodeficiency unit with diffused lymphadenopathy, shortness of breath and persistent cough. Diagnostic studies revealed the lesions to be Kaposi's Sarcoma and chest x-ray confirmed pneumocystis carinii pneumonia. Personal history revealed JB to be a sexually active homosexual male, living with his lover for three years. The clinical picture suggested an advanced stage of AIDS.

JB's condition deteriorated over two weeks and he was transferred to the ICU. Weight loss, fever and diarrhea continued as well as increasing respiratory difficulty. Bilateral lung consolidation finally resulted in intubation and mechanical ventilation. The patient originally had been coherent and alert, but as his condition declined, he was no longer able to communicate with staff. As his prognosis worsened, the physicians reported that his rapid deterioration and failure to respond to therapy suggested little hope. Further aggressive treatment appeared futile.

The team suggested contacting JB's family, particularly since JB had not completed an advanced directive, living will, or similar declaration. The family visited the hospital infrequently, as JB's parents had difficulty in dealing with his illness, since they had not known of his homosexuality until this hospitalization. They had been very supportive of JB when he was alert and able to communicate but now they have requested that no aggressive treatment be initiated, including CPR.

The request not to have aggressive treatment is in direct opposition to what JB's lover Tony has requested. Tony stated that he and JB discussed this quite openly and he is requesting that "everything" be done. "JB asked me not to let them give up trying", he said. He insisted that JB remain full code and that aggressive treatment continue. The physicians feel that JB's case is futile, but they are concerned about the conflict between the family and the lover. You, as JB's nurse have mixed emotions regarding the extent of treatment. Other staff members have conflicting opinions about the right course of action.

As JB's nurse you checked the chart and noted that it was documented when JB was first admitted by another nurse that JB wanted aggressive therapy, despite the futility of his disease.

As his nurse you would:

- a. Speak with the social worker about the case.
- b. Do nothing particular, leaving the decision to the doctors.
- c. Call a team meeting (physician, nurses, pharmacists, social workers, etc.) to talk about the patient's rights and what should be done.
- d. Contact the attending physician to discuss the documentation regarding JB's wishes.

27. You work in the emergency room of a private hospital. An eighteen year old Hispanic girl is admitted after the car she was driving crashed and hit a four year old girl playing on the sidewalk in front of her home. The child is dead on arrival. Resuscitative efforts have failed. The driver, Maria, has no driver license or insurance, and is acting as if she were high on drugs.

Maria's condition seems stable, but injuries to her left arm reveal trauma to the brachial nerve and artery. Because she seems stable and has no insurance, the emergency room physician determines that she can be transferred to the county hospital. Maria is shouting obscenities at the staff and yelling that she wants to leave because she has an "appointment". You see that circulation to her left hand is compromised. You express concern because of the time delay you know the patient faces in the County ER. A co-worker recommends that you "stay out of it".

What would you do?

- a. Do nothing further as you already expressed your concerns.
 - b. Chart your findings and call your supervisor.
 - c. Make a referral to Behavioral Health to request their assistance.
 - d. Talk to the Emergency Room physician again about your concerns.
28. A seventy-five year old female, Miss Farley, has been a patient in your ICU several times before. She has had multiple operations for cancer of the liver, but each time she has come through the procedure fine, and the surgery has extended her life. Miss Farley is a retired nurse and has always had a positive attitude toward her illness. She is the type of patient that nurses like to care for, because she is so appreciative.

The last palliative procedure did not go well and she needs more surgery. Her diagnosis and prognosis is discussed with her by the physician while you are in the room changing the patient's dressings. During the next few hours Miss Farley becomes increasingly withdrawn and somewhat tearful. She tells you that she has changed her mind and that she wants no further surgery, no antibiotics, no TPN, no food and no resuscitation. She states that she "has lived a wonderful and happy life" and that you should "take care of this with the doctors for me". She says, "I know that you'll help me, "in a sad and poignant voice. What are your reactions, feelings about this situation? What does the patient really mean? Do the patient's wishes conflict with your values? If Miss Farley were twenty-five years old would you feel the same way?

As Miss Farley's nurse you:

- a. Clarify Miss Farley's concerns, document your discussions in the medical record, and call the Chief Surgical Resident (or attending physician) to discuss the problem immediately, or as soon as feasible.
- b. Refer the case to the chairman of the Ethics Committee to be discussed at their next monthly meeting.
- c. discuss the problem with your roommate as she has had several classes in "right to die issues".
- d. Raise your concerns at the afternoon team conference and allow the group to become involved.

Infrastructure Data

Please respond to these questions by placing an X in one appropriate space before each item. These questions pertain to the hospital you are in today.

Response choices include: YES, NO, UNK (unknown), or NA (no applicable).

| | Yes | No | UNK | NA |
|---|-----|----|-----|----|
| 29. My hospital has an ethics committee | | | | |
| 30. There are nursing representatives on the hospital ethics committee | | | | |
| 31. My hospital has a nursing ethics committee | | | | |
| 32. I am a member of the hospital ethics committee | | | | |
| 33. I am a member of the nursing ethics committee | | | | |
| 34. My hospital has a collaborative practice committee or forum for discussion (a committee of nurses and doctors who discuss issues of mutual concern) | | | | |
| 35. My hospital allows nurses to bring concerns or issues before the hospital ethics committee | | | | |
| 36. When disagreements occur, I pursue my institution's mechanism for dispute resolution | | | | |

Supports and Barriers to the Role of Advocacy

The next two questions provide the opportunity for you to express your opinion regarding the nurse as a **patient advocate when caring for patients nearing end of life.**

37. As a nurse, what do you see as the greatest barrier(s) to acting as a patient advocate?

38. What do you see as supports in your role as patient advocate?

Appendix B

Permission for Use of Ethics Advocacy Instrument

October 4, 2004

Karen S. Thacker, RN, MSN, CS
Doctoral Candidate at Widener University

[REDACTED]
Sinking Spring, PA [REDACTED]

Dear Karen,

You have my permission to use the Ethics Advocacy Instrument (EAI) developed for my dissertation in 1993. I understand you will be using all four sub-scales with minor adjustments to the demographic information in the following dissertation study:

The Differences between Novice, Experienced and Expert Graduate and Registered Nurses in the Identification of Facilitators, Barriers and Perceptions of Advocacy Behaviors in End of Life Practiced in Acute Care Settings

Please share the results of your research upon completion.

Sincerely,

[REDACTED]
Ginger Schaefer Wlody, RN, EdD, FCCM
Acting QMO, VISN 18
Mesa, Arizona

Adjunct Professor, ASU College of Nursing
Tempe, Arizona

Appendix C

Item Response by Categories of Advocacy Behaviors

Item Response by Categories of Advocacy Behaviors (Wlody, 1993)

| Item | Response | Advocacy Behavior | Score |
|------|---|---------------------------------|-------|
| 26a | Speak with social worker about the case | Mediator | 1 |
| 26b | Do nothing particular, leaving the decisions to the doctor | Non-advocacy behavior | 0 |
| 26c | Call a team meeting (physician, nurses, pharmacists, social workers) | Protector of self-determination | 2 |
| 26d | Contact the attending physician to discuss the documentation regarding JB's wishes | Patient's rights advocate | 3 |
| 27a | Do nothing further, as you already expressed your concerns | Non-advocacy behavior | 0 |
| 27b | Chart your findings and call your supervisor | Protector of self-determination | 2 |
| 27c | Make a referral to Behavioral Health to request their assistance | Mediator | 1 |
| 27d | Talk to the Emergency Room physician again about your concerns | Patient rights advocate | 3 |
| 28a | Clarify Miss Farley's concerns, document your discussion in the medical record, and call the Chief Surgical Resident (or other attending physician) to discuss the problem immediately, or as soon as feasible. | Patient rights advocate | 3 |
| 28b | Refer the case to the chairman of the Ethics Committee to be discussed at their next monthly meeting | Mediator | 1 |
| 28c | Discuss the problem with your roommate as she has had several classes in "right to die issues" | Non-advocacy behavior | 0 |
| 28d | Raise your concerns after the afternoon team conference and allow the group to become involved | Protector of self-determination | 2 |

Appendix D

Widener University Institutional Review Board Permission



Widener University

Office of the Provost

Memorandum

To: Karen Thacker, RN, MSN

From: Dr. Barbara Patterson
Chairperson, Widener University Institutional Review Board

Date: September 7, 2005

RE: Protection of Rights of Human Subjects Review

This letter serves to inform you that your research, **“The Perceptions of Advocacy Behaviors in End of Life Nursing Care Among Novice, Experienced and Expert Nurses”(#34-05)** has been reviewed and **approved** by the Widener University Institutional Review Board (IRB) for the protection of rights of human subjects. You may begin data collection as proposed in your application.

If, for any reason, the approved research data collection method changes significantly, you are required to notify the IRB, in writing, of such changes. Please, remember that the IRB committee and Widener University accept no responsibility for liabilities associated with this study. Ultimately, responsibility rests with the investigator.

The approval of this study is in effect for one year from the date of approval and is eligible at that time for renewal. Upon completion of the study, a final written report of the research is to be submitted to the IRB.

The members of the IRB extend their best wishes for your successful completion of this research project. If you have any questions, please call me at [REDACTED] Thank you.

[REDACTED]

Barbara Patterson, PhD, RN

CC: Dr. E. Bayley

Widener University, One University Place, Chester, PA 19013-5792
t: 610-499-4106 f: 610-499-4108 www.widener.edu

Appendix E

Hospital Institutional Review Board Permission Letters



November 3, 2005

Karen S. Thacker, DNSc (c), RN
[REDACTED]

RE: The Perceptions of Advocacy Behaviors in End-of-Life Nursing Care Among Novice, Experienced, and Expert Nurses

Dear Ms. Thacker:

On October 18, 2005, Susan Sample representing the Chairman of the Institutional Review Board of the Lancaster General Hospital conducted an expedited review of the above-mentioned protocol (dated September 6, 2005), and a full waiver for consent and HIPAA authorization. In addition, the survey that will be completed by participants was reviewed. Pursuant to 45 CFR 46.110 and 21 CFR § 56.110, this review revealed no more than minimal risk to subjects. Therefore, expedited approval of the protocol is granted. Based on review of this protocol, Ms. Sample assigned the protocol a low risk level. The IRB approval is effective for the period of October 18, 2005 through October 17, 2006.

Continuing review of the protocol will be conducted at intervals commensurate to the degree of risk but not less than once a year. Based on the risk level assigned to the protocol, continuing review will occur once a year. As the principal investigator you will be required to submit a request for continuing review at least 60 days prior to the expiration of the current approval.

This project is to be conducted in accordance with all federal regulations governing human subject research, as well as the policies of Lancaster General Hospital and the IRB.

If you have any questions regarding this letter or the IRB, please feel free to contact me at [REDACTED].

Sincerely,

[REDACTED]
Jeffrey T. Cope, MD
Chairman, Institutional Review Board

JTC:tp

Medical and Dental Staff Office

Lancaster General Hospital • 555 North Duke Street P.O. Box 3555 • Lancaster, PA, 17604-3555
(717) 544-5090 • Fax (717) 544-5107 • www.LancasterGeneral.org

The Reading Hospital and Medical Center



Harry Ramsey, MD, Chair
 A. George Neubert, MD, Co-Chair
 Sharon House, RN, Project Manager
 SueAnn O'Buck, Secretary
 FWA # 00003110

IRB Office
 N Building, Ground Floor
 610-988-5082/5083
 Fax 610-988-5081
 IRB Reg. # 00002156

Institutional Review Board

September 28, 2005

Karen S. Thacker, RN, MSN, DNSc(c)
 [REDACTED]

RE: The Perceptions of Advocacy Behaviors in End of Life Nursing Care Among Novice, Experienced and Expert Nurses

Dear Ms. Thacker,

I have reviewed the above captioned research proposal and determined that it meets the requirements for exemption found in the Code of Federal Regulations Title 45, Part 46, Section 46.101(b)(2). The basis for this determination is this project involves the use of anonymous survey procedures. The data collected cannot be linked to the subjects and therefore any disclosure of the data outside of the research could not reasonably place the subjects at risk of criminal or civil liability or damage to their financial standing, employability or reputation.

The above determination was based on the information provided. Changes to the research plan may alter its exempt status and should be reported to the IRB.

Should you have any questions regarding this matter, please do not hesitate to contact me at 610-374-4404 or Sharon House, RN in the IRB Office at [REDACTED].

Sincerely,
 [REDACTED]

Harry E. Ramsey, Jr., MD
 IRB Chairman

HER:sh
 c: IRB Office.

St. Joseph Medical Center

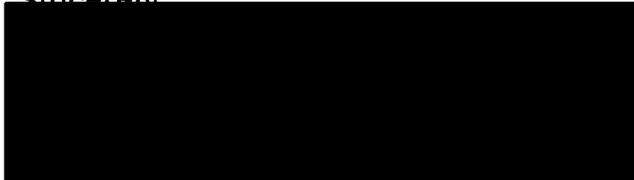
June 23, 2005

Karen S. Thacker, DNSc (c), RN


Dear Karen,

You have permission to conduct your doctoral dissertation research study "The Perceptions of Advocacy Behaviors in End-of-Life Nursing Care Among Novice, Experienced and Expert Nurses" at St. Joseph Medical Center. You may have access to our nursing staff through the staff nurse educators and unit managers.

I understand that you will have full approval from the Widener University and St. Joseph Medical Center's Institutional Review Board does not need to review before proceeding. Since the research project involves nursing opinion but no patient specific data we can do defer to the opinion of the university IRB and I will be the administrator of record.

Sincerely,


Debra H. Stavarski
Vice President, Clinical Services
Chief Nursing Officer

DHS/dek

Appendix F

Permission to Conduct Research from Hospital Administrators



July 7, 2005

Karen S. Thacker, DNSc (c), RN



Dear Karen,

You have tentative permission to conduct your doctoral dissertation research study "The Perceptions of Advocacy Behaviors in End-of-Life Nursing Care Among Novice, Experienced and Expert Nurses" at Lancaster General Hospital. You may have access to our nursing staff through the nursing research committee representatives.

I understand that you will have full approval from the Widener University and Lancaster General Hospital's Institutional Review Boards before proceeding with this study.

Sincerely,



Susan Sample MSN, CRNP
Co-chair Nursing Research Committee
Program Manager Cardiothoracic Surgery

The Reading Hospital and Medical Center



Donna F. Weber
Vice President/ Nursing
Telephone: 610-988-8244

July 12, 2005

Karen S. Thacker, DNSc (c), RN
[REDACTED]

Dear Karen,

You have permission to conduct your doctoral dissertation research study "The Perceptions of Advocacy Behaviors in End – of – Life Nursing Care Among Novice, Experienced, and Expert Nurses" at The Reading Hospital and Medical Center. You may have access to our nursing staff through the staff nurse educators and unit managers.

I understand that you will have full approval from the Widener University and The Reading Hospital and Medical Center's Institutional Review Boards before proceeding.

Sincerely,
[REDACTED]

Donna F. Weber, RN, MSN
Vice President Nursing

Appendix G

Correspondence to Study Participants Cover Letter

Dear Colleague,

You are invited to participate in a study of the role of advocacy in end-of-life nursing care. The primary purpose of this study is to add to the knowledge base about the nurses' perception of the advocacy role in end-of-life nursing practice. This research study is a part of my doctoral work at Widener University School of Nursing.

If you decide to participate, you will complete the four parts of the study booklet attached to this letter. The first part asks that you rate your agreement to 25 statements regarding your ethics perceptions. The second part involves reading three patient scenarios and identifying the one response you most likely would take in that situation. The third area asks some questions about your hospital. Two open-ended questions are included regarding the supports and barriers in your role as patient advocate. The final portion asks for demographic information.

The amount of time needed to complete this survey should be 15-20 minutes. You may complete this survey when it is convenient for you. Anonymity will be assured. All surveys are number coded to remove the possibility of identification or any connection with individual nurses. Survey booklets will be destroyed after completion of the study.

Your decision whether or not to participate is totally voluntary. A decision to not participate will not prejudice your future relations with your hospital. If you decide to participate, you are free to discontinue at any time without prejudice and throw the study booklet away.

You indicate your voluntary agreement to participate by completing and returning the survey booklet in the self-addressed, stamped enveloped provided. There may be no direct benefit of participating in this study; however, information obtained in this study may benefit nursing education and practice by adding to our scientific knowledge base.

Potential risks are minimal. You may experience some emotional discomfort when reflecting on your nursing practice or certain patient care situations.

You are not directly compensated for participation in this study; however, a raffle for a \$100.00 gift certificate to Boscovs will be drawn. Please complete the raffle ticket included in your study booklet. To maintain your anonymity, provide a code on the raffle ticket you will remember. Your staff development department will be notified of the winning "code" in October.

The Widener University Institutional Review Board has approved this study for solicitation of participants. If you have any questions about the rights of study participation you may call Dr. Barbara Patterson, Chair of Widener University Institutional Review Board at [REDACTED].

Thank you in advance for your cooperation. Your professional opinion is greatly valued. If you have any questions, please contact me at the email or phone number below.

Sincerely,

Karen S. Thacker, RN, MSN DNSc (candidate)

[REDACTED]

Appendix H

Comparison of Educational Level, Practice Area, Employee Status and AdvocacyEducation Among Expert, Experienced and Novice Nurses

| Educational Level, Practice Area Employee Status and Advocacy Education | <u>N</u> | Frequency | Valid Percent |
|---|----------|-----------|---------------|
| Educational Level | | | |
| Expert | 186 | | |
| Diploma | | 97 | 53.3 |
| Associate | | 40 | 22 |
| Baccalaureate | | 39 | 21.4 |
| Masters | | 6 | 3.3 |
| Experience | 69 | | |
| Diploma | | 19 | 27.5 |
| Associate | | 31 | 45.6 |
| Baccalaureate | | 17 | 25 |
| Masters | | 1 | 1.5 |
| Novice | 61 | | |
| Diploma | | 31 | 50.8 |
| Associate | | 20 | 32.8 |
| Baccalaureate | | 10 | 16.4 |
| Practice Area | | | |
| Expert | 183 | | |
| Medical Surgical/Step Down | | 65 | 35.5 |
| Critical Care | | 44 | 24 |
| Inpatient OB/Pediatrics | | 12 | 6.6 |
| Ambulatory Care | | 11 | 6 |
| IV Team | | 9 | 4.9 |
| Case Management | | 7 | 3.8 |
| Administration | | 3 | 1.6 |
| Radiology/Endoscopy | | 3 | 1.6 |

Table continues

| Educational Level, Practice Area Employee Status and Advocacy Education | <u>N</u> | Frequency | Valid Percent |
|---|----------|-----------|---------------|
| Experience | 69 | | |
| Medical Surgical/Step Down | | 40 | 58 |
| Critical Care | | 21 | 30.4 |
| Inpatient OB/Pediatrics | | 2 | 2.9 |
| Ambulatory Care | | 1 | 1.4 |
| Other* | | 5 | 7.2 |
| Novice | 61 | | |
| Medical Surgical/Step Down | | 43 | 70.5 |
| Critical Care | | 10 | 16.4 |
| Inpatient OB/Pediatrics | | 3 | 4.9 |
| Other* | | 5 | 8.2 |
| Employee Status | | | |
| Expert | 186 | | |
| Full Time | | 134 | 72 |
| Part Time | | 41 | 22 |
| Experienced | 69 | | |
| Full Time | | 53 | 76.8 |
| Part Time | | 14 | 20.3 |
| Novice | 61 | | |
| Full Time | | 56 | 93.3 |
| Part Time | | 4 | 6.7 |
| Advocacy Education | | | |
| Expert | 186 | | |
| Yes | | 124 | 66.7 |
| No | | 62 | 33.3 |
| Experience | 69 | | |
| Yes | | 61 | 88.4 |
| No | | 8 | 11.6 |
| Novice | 61 | | |
| Yes | | 54 | 88.5 |
| No | | 7 | 11.5 |

*other examples = cancer unit, operating room, utilization review, case management

Appendix I

Most Frequently Reported Supports to Advocacy Practice Among Novice,
Experienced and Expert Nurses

| | Novice (<u>n</u> = 61) | Experienced (<u>n</u> = 69) | Expert (<u>n</u> = 186) |
|------------------------------------|----------------------------|---------------------------------|-----------------------------|
| Nurse Manager | XXX | XX | XXX |
| Co-Worker | XXX | XXX | XXX |
| Multi-Disciplinary Team Support | XX | XXX | XXX |
| Communication | X | XX | X |
| Relationship with Patient | X | X | XX |
| Nurse Beliefs and Compassion | X | XX | X |
| Family | X | X | XX |
| Nurse Knowledge | X | X | X |

XXX = most frequent responses ($\geq 25\%$ of respondents)

XX = frequent responses ($\geq 15\%$ of respondents)

X = less frequent responses ($\geq 10\%$ of respondents)

Appendix J

Most Frequently Reported Barriers to Advocacy Practice Among Novice,
Experienced and Expert Nurses

| | Novice (<u>n</u> = 61) | Experienced (<u>n</u> = 69) | Expert (<u>n</u> = 186) |
|--|----------------------------|---------------------------------|-----------------------------|
| Physician: Personal Traits | XXX | XXX | XXX |
| Difficulty with End- of-Life Issues | X | X | XXX |
| Communication | XXX | XXX | XXX |
| Family | X | XX | XX |
| Fear | XXX | XX | XXX |
| Lack of Communication | XXX | X | X |
| Lack of Time and Support | XX | X | X |
| Lack of Knowledge | X | X | X |

XXX = most frequent responses ($\geq 25\%$ of respondents)

XX = frequent responses ($\geq 15\%$ of respondents)

X = less frequent responses $\geq 10\%$ of respondents)