

A GOOD DEATH: THE EXPERIENTIAL ETHICS OF NURSING

by

JUDITH L. HOLD

STEPHEN TOMLINSON, COMMITTEE CHAIR

BECKY ATKINSON

KARL HAMNER

AARON KUNTZ

DOUGLAS MCKNIGHT

A DISSERTATION

Submitted in partial fulfillment of the requirements
for the degree of Doctor of Education
in the Department of Educational Leadership,
Policy, and Technology Studies
in the Graduate School of
The University of Alabama

TUSCALOOSA, ALABAMA

2013

Copyright Judith L. Hold 2013
ALL RIGHTS RESERVED

ABSTRACT

During end-of-life care, nurses face ethical dilemmas on a daily basis with minimal operative scholastic preparation and professional expertise. The diverse source of ethical quandaries includes patient care issues related to legalities, inappropriate medical interventions, social roles, and professional and personal values. Ethical discourse in end-of-life care occurs within institutions where policies, professional relationships, and economic factors constrain ethical reflection. Thus, it is imperative that ethical education take into account the professional and social context of nursing, in addition to traditional teachings focused on many principles and theories, codes of conduct, and legal ramifications.

The purpose of this research was to explore how experienced nurses' successfully resolved day-to-day ethical dilemmas during end-of-life care. This study utilized narrative analysis to analyze data generated from one-on-one interviews with six hospice nurses. The semi-structured interviews were conducted in two phases. Using core story creation, several different ethical dilemmas were identified divulging struggles with key stakeholders. Thematic analysis was then used to create three main themes: *Ethics within Practice*, *Ethical Knowledge*, and *Ethical Solutions* discussed within the framework of situational context, deliberations, and ethical actions.

The results gained from this research provide information on how to improve nursing ethics education through the use of narratives of experienced nurses. The nurses used in this research told their stories depicting a keen awareness of ethical conflicts situated by contextual factors including social, political, and personal issues. Their deliberations were informed through

formal, experiential, and intuitive knowledge creating a sense of phronesis as they negotiated the right course of actions. The nurses solved ethical predicaments by either following rules or choosing acts of resistance. It is my contention that the results of this study will empower practicing nurses and nurse educators to appreciate and incorporate context and different forms of knowledge to inform ethical discourse. We can utilize the experienced nurses' wisdom to improve nursing ethics education which ultimately translates to providing better deaths for patients.

DEDICATION

This dissertation is dedicated to hospice nurses who work hard and strive to give patients a good death. They were my inspiration throughout this study.

ACKNOWLEDGMENTS

I wish to acknowledge the faculty members who have guided me throughout my research. Stephen Tomlinson's, my committee chairperson, encouragement and wisdom was invaluable throughout this research endeavor. Through his guidance, I exceeded my own expectations to achieve my potential as a novice nurse researcher. I am also indebted to my committee members, Becky Atkinson, Aaron Kuntz, Karl Hamner, and Douglas McKnight for their expert advice. Thank you.

My gratitude extends to my colleagues and friends who have been instrumental in helping me with this research project. Their words of support were reassuring and comforting to help me to proceed with my research.

Last but not least, this research would not have been possible without the support of my family who never stopped encouraging me to persist. Thank you for your patience and understanding.

CONTENTS

ABSTRACT	ii
DEDICATION	iv
ACKNOWLEDGMENTS	v
LIST OF TABLES	x
I INTRODUCTION	1
Statement of the Problem.....	11
Significance.....	14
Summary	15
II CONTEXT OF THE STUDY: LITERARY AND THEORETICAL FRAMEWORK.....	16
Research in End-of-Life Care	16
Good Death	17
Nurse’s Role during End-of-Life Care	25
Ethical Dilemmas during End-of-Life Care.....	30
Consequences of Ethical Predicaments	39
Nursing Education	41
Theoretical Framework.....	51
Situated Knowledge	51
Epistemology and Power Structures	56
Nurses’ Knowledge.....	62
Summary	66

III METHODOLOGY	68
Narrative Inquiry.....	68
Participants.....	70
Generation of Data.....	73
Data Analysis	75
Ethical Considerations	78
Establishing Rigor.....	79
Summary	82
IV DATA ANALYSIS RESULTS	83
Dilemmas	83
Nurse Ellen’s Dilemmas	84
Nurse Leslie’s Dilemmas.....	90
Nurse Chris’s Dilemmas.....	98
Nurse Darlene’s Dilemmas.....	103
Nurse Amy’s Dilemmas.....	113
Nurse Mary’s Dilemmas.....	116
Thematic Analysis	122
Situational Context.....	123
Theme One: Ethics within Practice.....	124
Summary of Situational Context.....	147
Deliberations	153
Theme Two: Ethical Knowledge	153
Summary of Deliberations	159

Ethical Actions.....	163
Theme Three: Ethical Solutions.....	163
Summary of Ethical Actions.....	168
Findings Related to Research Questions.....	173
Research Question 1	173
Research Question 2	176
Research Question 3	178
Research Question 4	179
Research Question 5	182
Summary of Chapter IV.....	184
V SUMMARY, FINDINGS, AND RECOMMENDATIONS.....	186
Overview of the Study	186
Implications.....	188
Situational Context.....	188
Deliberations	191
Ethical Actions.....	194
Implications for Nursing Education.....	195
Policy Considerations	202
Suggestions for Future Research	203
Summary	206
REFERENCES	208

APPENDICES:

A	PRE-DETERMINED LIST OF INTERVIEW QUESTIONS	224
B	IRB APPROVAL LETTER.....	226
C	INFORMED CONSENT FORM/AGENCY PARTICIPATION.....	228
D	INFORMED CONSENT FORM/AUTHORIZATION TO PARTICIPATE.....	230
E	THEMES AND SUB-THEMES CONCEPT MAP	232

LIST OF TABLES

1	Demographics and Experiences of Participants.....	72
---	---	----

CHAPTER I

INTRODUCTION

During end-of-life care, nurses face ethical dilemmas on a daily basis despite minimal scholastic preparation and little professional expertise. The diverse range of ethical problems include patient care issues related to legal mandates, inappropriate medical interventions, social norms, and professional and personal values. Moreover, ethical discourse related to end-of-life care occurs within institutions where policies, professional relationships and economic factors constrain reflection. Consequently, ethical situations are embedded in an environment of power, emotions, and efficiency. This atmosphere conducive to nurses behaving as passive, contractual employees of a healthcare institution inevitably undermines ethical outcomes. There is little debate that nursing ethics education has not been effective in empowering nurses to be self-directed and accountable in ethical decision making when faced with ethical dilemmas during end-of-life care. To prepare nursing students to make sound moral judgments, academic training is needed in the theory and practice of ethical discourse. It is imperative that ethics education take into account the professional and social context of nursing, in addition to traditional teaching focused on principles, codes of conduct, and legal ramifications.

The importance of teaching ethics to nursing students cannot be underestimated as members of the profession desperately need to know how they should act in problematic situations. Ethical knowing must guide nurses' conduct. Indeed, the American Association of Colleges of Nursing recommends that nursing students be well versed in ethics (American Association of Colleges of Nursing [AACN], 2008; Garity, 2009). There is broad agreement that

ethics education should assist nurses in their decision making through achieving objectives including supporting ethical aspiration, facilitating recognition of ethical dilemmas, and enhancing understanding of ethical issues (Begley, 2006; Lin, Lu, Chung, & Yang, 2010; Vanlaere & Gastmans, 2007). Yet despite consensus on the importance of ethics education in the nursing curricula, ethics has not been a required course in most undergraduate programs (Park, 2009). Most nursing programs use an integrated teaching model incorporating ethics education throughout the curriculum. As a result, theory is diluted and topics on nursing ethics are not allotted sufficient time within a well-planned and delivered curriculum. To complicate the issue, most nurse educators are not sufficiently versed in nursing ethics to successfully guide nursing students (Woods, 2005).

Nurse educators utilize a code of ethics as a framework to teach ethical discourse to nursing students. Primarily, a professional code of ethics is a set of rules to enhance decision making by providing a framework of practices, attitudes and behaviors that are to be assumed by practitioners (Hussey, 1996; Pattison, 2001). Yet, is looking up a set of rules an effective venue for making moral decisions? The code is taught as a tool to guide nursing actions; however, it cannot stand on its own. For a code of ethics to function as an applied tool of moral theory, nurses must understand underlying ethical theory and principles to practical problems. Moreover, nurses are expected to blindly adhere to the profession's code of ethics by ignoring their own values, beliefs and more importantly experiences. According to modern Western philosophy, the ethical person is one who has free will and reason to assess principles and courses of action. Therefore, the ethical nurse would act freely and autonomously to uphold universal ethical principles such as beneficence, autonomy, non-maleficence and justice. On one hand, actions dictated by codes mask independence and preclude judgment and on the other hand, the use of

general terminology and abstract ideology are subject to misinterpretation. In short, codes of ethics embody many flaws which hinder the nurses' development of ethical discernment and accountability (Tadd et al., 2006).

While codes of ethics are introduced to nursing students during their professional education, ethical codes and related policies also follow them in practice. In the face of proliferating ethical issues, healthcare organizations have issued policy statements to support healthcare professionals including nurses and patients in ethical decision making (Mylott, 2005). In the *Code of Ethics for Nurses with Interpretive Statements*, the American Nurses Association (ANA, 2001) acknowledged the ethical responsibilities of nurses. Traditionally, the nurses' code of ethics functioned as an ethical framework for nurses, providing them with guidelines for responding to moral issues in healthcare. For example, the third code: "The nurse promotes, advocates for, and strives to protect the health safety and rights of the patient" (ANA, 2001) clearly highlights the importance of ethical conduct. Additionally, the American Association of Colleges of Nursing's *Essentials of Baccalaureate Education for Professional Nursing Practice* emphasized the importance of ethics in nursing education (2008). Ethics is cited as an essential competency as evidenced by the statement "ethics is an integral part of nursing practice and has always involved respect and advocacy for the rights and needs of patients regardless of setting" (AACN, p. 27). But while these statements reflect what the nursing profession demands of its members, questions remain as to their effectiveness in directing nursing practice.

Because the nursing profession demands ethical behavior from its constituents, nursing education includes ethics in the curriculum yet falls short in its' deliverance. In addition to incorporating the Code of Ethics as a teaching tool, ethics education is frequently taught as a theoretical subject precluding experiential knowledge (Begley, 2006). Nursing education needs a

way to incorporate experience inherent in practical situations with ethical principles. Integrating Aristotle's approach to ethics with a focal point on experience can be a valuable tool in nursing ethics education. Aristotle (1998) emphasized the fundamental differences between theory and practice with each possessing unique types of knowledge. Therefore, practical and theoretical knowledge are learned differently. Theoretical knowledge, which is frequently employed in teaching ethics, is focused on understanding, not application. Knowledge based on theory has a sole form of existence which cannot be altered. On the other hand, knowledge in the practical realm is based on experiences contextualized within social interactions. As an alternative to teaching theoretical knowledge in nursing ethics education, embracing practical knowledge is essential to foster moral insight and know-how.

Nowhere is it more important to include Aristotle's concept of practical knowledge than issues related to end of life ethics. Practical knowledge in contrast to theoretical knowledge is an experienced based knowledge as opposed to the latter which concerns itself with science and unchangeable universal truths (Saugstad, 2002). Furthermore, practical knowledge is based on experiences contextualized within social interactions with the outside world. *Techne* and *phronesis* have to do with acquiring practical expertise through the selection of specific knowledge discourses (Aristotle, 1998). *Techne* addresses the acquisition of a skill with awareness of underlying principles while *phronesis* is the knowledge of ethics incorporating an understanding of best course of action for a particular occurrence. Furthermore, *phronesis* depends on experience to reach the right conclusion at the right time utilizing right rationales and arguments. It is applicable to nursing as nurses rendering end-of-life care need to make sound moral decisions through acquiring sufficient experience in interpreting ethical discourse. Applying *phronesis* to nursing facilitates the process of making wise clinical judgments using

clinical reasoning over time in a contextualized situation (Melnyk & Fineout-Overholt, 2011). More specifically, phronesis involves making ethical decisions along with sound clinical judgments based on a mutual trust relationship between patient and family. Thus, phronesis involves “making moment-to-moment judgments about what ought to be done, what is good and right, and what is possible” (Chinn & Kramer, 2004, p. 5). I argue that end-of-life care is impeded if nursing ethics education prizes theoretical knowledge over other ways of knowing, such as phronesis.

Another key reason to revamp nursing ethics education in end-of-life care is the changed way people die in the United States as a result of improvement in healthcare (National Institute of Health [NIH], 2004). Today, death is more likely to occur in old age from chronic diseases (Hardwig, 2009). In fact, of the 2.4 million people who die each year in the United States, 1.8 million are older than 65 years of age (Institute of Medicine [IOM], 2003). Furthermore, the incidence of chronic illnesses, debility, and dementia has proliferated as peoples’ lives are protracted. People tend to delay death or prolong life through medical technology. Many individuals now fear that death may come too late and take too long as their lives become void of quality (Hardwig, 2009).

The experience of dying today differs from what it was 100 years ago (Walter, 2003). Historically, most people died a quick death from accidents, infectious diseases, childbirth, or war. Moreover, the place of death has been transformed from an intimate setting to a public venue. At the beginning of the 20th century, people died primarily at home where family, clergy and the community had an active role (Aries, 1974). Nowadays the location of death has shifted to the hospital, where physicians have become gatekeepers and nurses caregivers. According to Walter (2003), most people today die in the hospital with their bodies attached to machines by

tubes and wires surrounded by hospital personnel rather than families. What is more, the dying process often spans over several years.

Nowadays, nurses play a vital role in assisting dying patients to make decisions by caring for patients and their families through the dying process. In addition, nurses are patients' advocates to ensure that comprehensive needs of the dying are met. Many obstacles, however, hinder a patient's wishes including how nurses perceive their role in end-of-life care situations and knowing how to intervene on behalf of the patient (Ulrich et al., 2010; Van Bruchem-van de Scheur et al., 2008). In addition, advances in science and technology have complicated the dying process by giving patients more diverse options while simultaneously disempowering patients as their agency is denied or more likely ignored (Bendle & Cook, 2001). Thus, the growing complexity of the healthcare system has placed more responsibility on nurses for ethical decision making. As a result of these obstacles, nurses are encountering an increasing number of ethical dilemmas in clinical practice during end-of-life care (Izumi, 2010; Mylott, 2005). Nurses need to have an understanding of ethical discourse to empower them to make sound moral decisions during end-of-life care. Sadly, the majority of nurses do not have the needed ethical awareness and thus suffer guilt or confusion as a result.

One of the most challenging tasks for nurses is caring for dying patients. This has been complicated by power structures within modern medicine. As nurses, we view the dying patient as an integrated human being with not only physiological needs but spiritual and emotional concerns. However, the medical model of cure dominates healthcare delivery by focusing on the patient's physiological activities and attempts to prolong life utilizing scientific and technological advances. Therefore, for the dying patient, the diagnosis of a terminal illness is equated with curative endeavors and waiting to die. Dying has moved from the moral domain to

a highly technical realm (Bendle & Cook, 2001). Historically, the dying process shifted from a spiritual, community event to a secular, medical occurrence dictated by the medical establishment. My contention is that traditional values derived from religious, philosophical and traditional sources have been usurped by power, specifically bio-power. In fact, bio-power has created an obstacle for nurses to negotiate ethical discourse at the end-of-life.

The work of Foucault offers a relevant discourse to the integration of power, specifically bio-power, into the current phenomenon of death. Foucault (1965) correlated power to an event as something that happens rather than an object to be possessed and passed from one to another. According to Foucault, power is an arbitrary system formed within interactions of engagement. Furthermore, Foucault demonstrated how the concept of power is connected with that of knowledge. He contended that during the 18th and 19th centuries, social institutions including the church, the military, prisons, schools, and medical clinics became a part of a power establishment conceded by privileged knowledge. This remains relevant in today's medicalized services. Knowledge is created as a consequence of relationships formed through interactions within power structures and this serves as an instrument of power. These rules of power create a specific ideology or knowledge base (Foucault, 1979).

As a result of bio-power, death has become a medicalized event resulting in the extensive regulation of the body with unquestioning mission to preserve life and avoid death. Garry (2001) defines medicalization as a form of dominating social control causing damage to lives of marginalized people. Specifically, medicalization entails an essential reallocation of emphasis on the dying process from a spiritual domain to a technical venue. Thus, unable to cope with death and connotations of failure, doctors impose their own form of subjugation upon the body. Consequently, life-prolonging medical technologies, such as feeding tubes and respirators

became venues for achieving control over bodies. The patient becomes a confined entity signifying the struggle between physician and nature and ceases to be treated as a social being. Even the hospital's appearance and demeanor is that of a prison-like structure for the dying, as it shelters patients in an enclosed, restricted, and hidden place from the rest of functional society. Within walls of the hospital, medicalization of death prevails resulting in dehumanized treatment of the dying. In the meantime, hospitals changed from being the place to die to places to rescue one from death.

Untoward and ironic outcomes occur as death became stigmatized as a phenomenon to be avoided at any price. The practice of medicine brought about regulations to subjugate the dying body, but did so at a cost. For example, attempts by legislatures, lawyers, clergymen, physicians, and philosophers to define death have been elusive and dependent on available medical technology. Connors (1980) discussed how the broad definition of death reinforces the medicalization of the dying process. The medical professional's ability to 'bring back to life' is precipitated by medical procedures such as cardiac catheterization, surgery or administration of medications. These medical interventions may temporarily elude death yet sacrifice a quality of life that prolongs a painful and anguished dying process. The patient whose heart has been shocked and medicated back into a sinus rhythm often survives with extensive brain damage and needs invasive life support measures. In fact, the effects of medical treatment and dominance of bio-power actually increase illness and death (Conway, 2007). It produces iatrogenic effects by reducing individual autonomy and increasing patient dependency on the medical establishment. As a result, ethical decisions at end-of-life have become contextualized within an atmosphere dominated by medicalization.

Do we know how to die well? The concept of a good death is a recent phenomenon in the United States. During the past 20 years, there has been an emphasis on a good death (Department of Health, 2008; National Council for Palliative Care, 2006). In 1997, the Institute of Medicine (IOM) defined a good death as one that is “free from avoidable distress and suffering for patients, families and caregivers; in general accord with patients’ and families’ wishes; and reasonably consistent with clinical, cultural and ethical standards” (p. 4). Ideally, the concept of a good death refers to the death a person would choose for him or herself. Although the definition of a good death is subjective, research discloses common domains that characterize a good death (Steinhauser et al., 2000). Physical comfort, communication, preparation for death, completion of social and emotional tasks, contributing to others, and affirmation of the whole person are themes repeated in different research studies (Emmanuel & Emmanuel, 1998; Smith, 2000; Tong et al., 2003; Vig, Davenport, & Pearlman, 2002). In addition, most of the literature recognizes the importance of biomedical, cultural, psychological, social and spiritual components within these themes (Sheehan, 2000; Steinhauser et al., 2000; Tong et al., 2003; Vig et al., 2002). Dying is not solely a physiological event but a holistic endeavor.

Even though we have knowledge on how to create a good death, numerous obstacles prevent its occurrence including power structures and lack of education. Nurses are dominated by the medical establishment often rendered powerless to exert their professional expertise. Nursing education is another hindrance preventing a good death. Nurses are frequently taught that dying patients are objects to be repaired not persons being helped to die a “good death.” It is my contention that nursing education curricula does not adequately incorporate ethical discourse during end-of-life to affect a good death. Consequently, nurses lack knowledge to make sound

ethical decisions at the end of life within the context of an environment dominated by controlling power structures.

It is my intention to employ a feminist epistemology to enhance the understanding of ethical challenges faced by experienced nurse during end-of-life care. Within a feminist discourse, situated knowledge advocates an “embodied vision” challenging mainstream epistemological claims of objectivity (Haraway, 1988). Knowledge that is “situated” recognizes and incorporates one’s position while taking into account the geographical, social, and political context of the knower (Haraway, 1988). Situated knowing espouses to knowledge being embodied and positioned socially, culturally, racially, sexually, and politically (Ford, 2007; Haraway, 1988; Lang 2011). I chose a feminist perspective as it brings a unique lens to exploring local knowledge of nurses caring for the dying as it allows for focusing on social and political contexts of power structures undercutting ethical discourse in a profession inhabited largely by women.

Nurses’ are situated knowers in that they incorporate their experiences, practices, and circumstances to produce a unique realm of knowledge. There are four ways in which knowers are situated inclusive of the knower’s historical location, location within specific social and linguistic contexts, creativity in the construction of knowledge, and affectivity, commitments, enthusiasm, desires and interests (Code, 1991). The interplay of these four ways of being, are situated in fluid and constant movement to produce dynamic knowledge that changes over time. The feminist perspective of situated knowledge lends to the nurse’s understanding of the interplay of ethical reflections and the dying process within an historical event, and as a current phenomenon within social and linguistic contexts, and constructed, subjective knowledge.

Situated knowledge complements the arguments of Patricia Benner (1991) on her advocacy of narratives to inform ethical practice. Ethical expertise is experientially learned through transmitting narratives of practical situations. Benner (1991) espoused to the significance of stories situated within a community to inform ethical comportment. Thus, first person narratives of practice positioned within social, historical and political contexts offer interpretive phenomenological studies of ethical discourse. Furthermore, nurses' stories reveal the unique knowledge of the author through unraveling feelings and meanings that can be translated into ethical reasoning. In fact, Benner claimed that clarity in ethical discourse is dependent on the situated knowledge of the nurse and patient. Nurses need to tell their stories to shape our ethical comportment by sharing learned ways to navigate between social structures that may impede ethical know-how. It is my contention that these narratives, stories of experienced nurses, can be used to inform practice to enhance ethical reasoning.

Statement of the Problem

On a day-to-day basis, nurses are confronted with ethical dilemmas during end-of-life care negatively affecting patient outcomes. An affective apprenticeship of ethical comportment and formation should render the nursing student with the knowledge and skills to make ethical decisions and solve problems (Benner, Sutphen, Leonard, & Day, 2010). "Nurses need the skill of ethical reflection to discern moral dilemmas and injustices created by inept or incompetent healthcare or by an inequitable healthcare delivery system" (Benner et al., 2010, p. 28). Yet, practicing nurses do not feel adequately prepared to deal with ethical discourse during end-of-life care in part due to lack of education and experience. Thus, it is my argument and the focus of

this study that nursing ethics education fails to prepare students to adequately make sound ethical decisions during end-of-life care.

Focusing on the problem, several research questions related to ethical discourse during end-of-life care become evident.

1. What are experienced nurses' insights to the nurse's role in ethical dilemmas during end-of-life care?

2. What are the available recourses to the experienced nurse in end-of-life care to assist with ethical decision making?

3. What are the challenges faced by the experienced nurse in ethical decision making during end-of-life care?

4. What are the insights of experienced nurses on the effect of ethical decisions during end-of-life care on patient outcomes?

5. How do the contextual (institutional, personal, professional, social, legal) factors influence ethical decision making during end-of-life care?

After examining the literature and my findings, I was then able to address the following question: "How can experienced nurses' narratives depicting successful resolution of day-to-day ethical dilemmas during end-of-life care inform nursing ethics education?" The answers to these questions may guide the education of nurses in ethical discourse during end-of-life care. These narratives employed as a form of experiential learning can be an exemplary venue to the understanding of ethical reasoning.

In order to research these questions, I conducted a qualitative inquiry analyzing the narratives of experienced nurses involved in end-of-life care. A qualitative study supports the inclusion of the experienced nurses' knowledge as situated knowers to inform nursing ethics

education. Specifically, narrative inquiry was used due to its capacity to render life experiences in relevant and meaningful ways. Connelly and Clandinin (1990) related narrative inquiry as the storied accounts of daily life and as a means of characterizing the phenomenon of human experience. Thus, a narrative inquiry is a collaboration in which mutual storytelling unfolds between researcher and participants as the inquiry proceeds. I believe that an engaged dialogue on the experiences of practicing nurses during end-of-life care can inform nursing ethics education and ultimately the advancement of skillful ethical comportment.

The study was conducted in a hospice milieu in a metropolitan city in the Southeastern United States. The hospice services clients in their private homes, long-term care, and assisted living institutions. Registered nurses with different educational backgrounds are employed to coordinate the care of dying patients. The registered nurses manage care of 10 to 12 hospice clients, most of whom are elderly with a terminal illness. The participants were recruited using purposeful sampling because they can “purposefully inform an understanding of the research problem and central phenomenon in the study” (Creswall, 2007, p. 125). Six hospice nurses with 2 or more years of working exclusively with dying patients were selected to participate in this qualitative research study. Using experienced participants to share their knowledge base ensured that they had bypassed the novice and advanced beginner stage as depicted by Benner (1984).

Data were collected using individual interviews, field notes, and observations at a convenient locale for participants. Open-ended questions served as a guide for the interview process. These questions were obtained from a review of the research literature. In addition, research questions were designed to encourage participants to recount experiences of ethical discourse in their practice. Narrative interviews consisted of two parts, as proposed by Bertaux and Kohli (1984). The first interview supported an extensive narration by the participant during

which I restricted my comments to promote the flow of the storytelling. The second part of the interview involved more purposeful questions to seek clarification of topics introduced in the first interview and asked questions related to educational preparation for ethical decision making. All interviews were audiotaped and transcribed to capture the participants' stories.

Data analysis in narrative inquiry can employ several different approaches as there is no standard methodology (Kelly & Howie, 2007). I chose two narrative methods to analyze data generated from the interviews. Core story creation, as described by Emden (1998), was used as a means of reducing full-length stories to shorter stories. I then created themes by using thematic analysis (Braun & Clark, 2006). Thus, core story creation and thematic analysis were both effective in deriving common threads of meaning and significance in the nurses' narratives.

Significance

This study will have important implications for nurses, dying patients and their significant others, and nurse educators. Through sharing nurses' narratives that depict ethical practice during end-of-life care, nurses can learn an array of ways to exemplify and reflect on their ethical concerns, and refine their understanding of ethical discourse. This study will help nurses explore how to bridge the gap between ethical concepts, epistemic discourse, and professional practice as the nurses' narratives can serve as exemplars for nursing ethical practice. Foremost, nurses can be empowered that their situated knowledge is uniquely constructed to enhance sound ethical decision making during end-of-life care.

This study will also provide insight on how to improve ethical discourse in nursing education. Nurse educators will be able to use this information to develop the curriculum to include situated knowledge of ethical comportment during end-of-life care. Narratives from

experienced nurses can be instrumental in transforming the nursing students' understanding of day-to-day ethical decisions during end-of-life care. In addition, this study addressed the epistemology of situated knowledge in the classroom itself. In nursing ethics education, teachers and nursing students should be held responsible for their knowledge construction in a learning environment void of oppression and power.

The most important beneficiary of this study is the dying patient and their significant others. Patients are dependent on nurses as their caregivers to meet their physical, spiritual, and psychological needs during end-of-life care. Nurses are entrusted to make sound ethical decisions to render the dying patient a peaceful, good death. Furthermore, a good death is individualized as there is no right way to die. Ethical dilemmas during end-of-life care may preclude a patient's desires from being incorporated into the healthcare plan. This study will advance the quality of end-of-life care by providing knowledge on ethical discourse to affect positive patient outcomes.

Summary

Nursing education needs to apprise nursing students to make sound ethical decisions during end-of-life care. It is my contention that narratives of experienced nurses are an effective pedagogy in end-of-life care. The voices of experienced nurses constitute valuable 'situated knowledge' about how nurses interpret their practice contextualized in social and political frameworks. To this end, nurses equipped with ethical discourse can help actualize a good death for dying patients concluding in a momentous rite of passage.

CHAPTER II

CONTEXT OF THE STUDY: LITERARY AND THEORETICAL FRAMEWORK

In this chapter, I explore the scholarship and theoretical frameworks supporting this study on the efficacy of nursing ethics education to prepare future nurses to make sound ethical decisions during the dying process. The purpose of the literature review is to identify a) the parameters of a good death, b) the nurse's role during end-of-life care, c) ethical dilemmas confronting nurses while caring for the dying, d) negative effects of ethical discourse, and e) nursing education's efforts to teach ethics. The theoretical context supports my contention that a nurse's knowledge is unique and valuable particularly to nursing ethics education. I use a feminist perspective valuing the worth inherent in individual knowledge to examine the various barriers, including power structures, in acknowledging the significance of situational knowledge.

Research in End-of-Life Care

This literature review sets the stage for my study by presenting evidence to support the ineptness of nursing ethics education to adequately prepare nursing students to make operative ethical decisions during end-of-life care. First, it is necessary to examine the goal of end-of-life care, which is to render a good death for patients. I begin with an analysis of research studies related to the constituents of a good death. Next I review various roles, some of which are obscure, assumed by nurses in orchestrating a good death. In their efforts to create a good death, nurses are confronted with numerous ethical dilemmas. Thus, ethical predicaments are explored in terms of prevalence, the nurse's role as patient advocate, and nurse's professional

relationships with physicians. The negative consequences resulting from ethical quandaries including stress and moral distress are also explored. I conclude the literary context by looking at nursing education's efforts to promote the concept of a good death and equip nurses with moral know-how through courses on palliative care and ethics.

Good Death

The literature related to cultural and societal views of a good death, religious and philosophical perspectives of death, and death in art and literature reveals how the concept of a good death has emerged in modern western civilization. Once the notion of dying well gained attention of healthcare professionals, end-of-life research was generated to obtain perspectives of a good death from caregivers, healthcare providers, and patient's viewpoints. A good death became the ultimate goal for many patients and caregivers yet healthcare providers often struggle with delivering a good death versus medical intervention directed toward cure.

Art and literature. What is a good death? Inherent in this phrase are two words: good and death. *Random House Webster's College Dictionary* (1991, p. 444) defined good as "being positive or desirable in nature" or "having the qualities that are desirable." The dictionary defined death as "the termination of life" (1991, p. 333). Therefore, a good death can be thought of as a desirable termination of life.

In the middle ages, a good death was celebrated in art and literature as "ars moriendo" meaning the art of dying (Aries, 1974). Death marked the salvation of the soul, neither ending nor beginning, but part of the life cycle. *Everyman* (Van Laan, 1963), one of the greatest medieval dramas, explored the doctrine of salvation and its relation to death. In *Everyman*, death

was viewed as a dignified journey, not involving physical pain, but with emphasis on fostering a reckoning with God. The Dance of the Dead painted on a cemetery wall in Paris in 1424 revealed each character dancing with his or her own death throughout the life span (Smith, 2000). The proverbial death as being a part of life was well-depicted in this famous painting.

Death was a common subject in 19th century literature. It was the major theme of Emily Dickinson's and William Cullen Bryant's writings (Atkinson & Atkinson, 1993). Harriet Beecher Stowe's *Uncle Tom's Cabin* (as cited in Atkinson & Atkinson) depicted a good death in the mid-1800s. As little Eva dies, "the large clear eyes rolled up and fixed . . . earth was past and earthly pain . . . a bright, glorious smile passed over her face and she said, brokenly, 'O! love--joy--peace!' gave one sigh, and passed from death into life" (p. 86). Thus, in the 19th century death was still considered as an integral part of life and familiar.

Religious and philosophical. The perception of a good death has always been of keen interest to humankind. The ancient Greeks equated a good death with euthanasia. Actually, euthanasia stems from two Greek words: "eu" which translates as good and "thanatos" meaning death (Mystakidou, Parpa, Tsilika, Katsouda, & Vlahos, 2005). Today, euthanasia is associated with a death that is perpetuated or accelerated with the help of medicine. However, ancient Greek society equated a good death with euthanasia that came upon a person naturally as the result of time, aging, or a divine gift. In fact, a good death was considered a heroic alternative to a life of pain, despair, or remorse. As Plato noted in the *Phaedon*, the philosopher Socrates chose hemlock instead of exile as an act of a good death (Mystakidou et al., 2005). Socrates expressed no anxiety about dying because death frees the soul from the body. In fact, Socrates dies content and admonishes his followers for crying.

With the advent of Christianity, the concept of a good death took on a new connotation. In fact, the death of Jesus depicts the ultimate anti-good-death story (Walters, 2004). Jesus not only is portrayed as not wanting to die but dies with a sense of abandonment by his friends. The unpleasant details of death are revealed as a stark reality in the death of Jesus. Thus, death became associated with suffering and sacrifice.

Death literature in the Middle Ages warned individuals of their sinful nature making a good death a remote possibility. “Therefore, just as sin came into the world through one man, and death came through sin . . . so death spread to all, because all have sinned” (Rom 5:12). Christians became familiar with the idea of redemptive suffering. Suffering became a test of faith and hence, if incorporated into death, did not necessarily signify the exclusion of a good death as it would in modern times. Christianity did not define a good death in clinical terms but spiritually in which there is salvation of the soul and redemption of one’s sins (Guroian, 2004).

In the mid-19th century, the decline of Puritan religion prompted a shift in attitudes of a good death from a religious emphasis to secular overtones. Secularizing death was a gradual phenomenon accelerated by specific historic events. Laderman (1996) claimed the Civil War in the United States assisted in normalizing usage of medical interventions during the dying process. During the Civil War, there was an acceptance of medical interference to prevent infection and spread of disease among wounded soldiers. The reality of the battlefield robbed the human body of religious symbolism in the dying process (Laderman, 1996).

In the 20th century, death became shameful and forbidden. Relatives and friends surrounding the dying person had a tendency to conceal the gravity of their condition. Between 1930 and 1940, the secularization of the dying process accelerated (Aries, 1974). This change was due to the displacement of the site of death from home to the hospital. Dying in the hospital

became a technical phenomenon in which physicians strived to obtain an acceptable death while focusing on treatment and cure. Aries described an acceptable death as one that can be tolerated by survivors. Thus, in the early 1900s, a good death did not provoke strong emotions in the survivors and they were spared embarrassment.

In defining a good death, religious norms vary widely. From a Christian viewpoint, Sheehan (2000) asserted three essential components of a good death. Medical care needs to be put in proper perspective and not be the focus of dying. Secondly, dying well means sensitivity to the church. According to Sheehan, the third most important attribute of a good death is equated with living well with God. The Hindu religion has a very particular notion of a good death. Walter (2003) asserted that dying on the floor with family members praying and chanting signifies a good death for a Hindu. The Tibetan Buddhist correlates mindfulness with dying well (Rinpoche, 1992). Mindfulness is freedom from a tense or distracted state bringing one a heightened awareness of the moment.

Cultural and societal. In many early tribal societies, death was accepted as a part of life (Walter, 2003). To interfere with the occurrence of death was considered blasphemous (Smith, 2000). Death of one member of the tribe affected the family, community, and the entire society that together ensured that death was managed according to tribal religious rites. In these tribal societies, the religious leader actualized a good death, and everyone in the community had a script. Thus, a good death was attended, and revered and, most importantly, tribal societies did not permit interference with the dying process.

Recently the concept of a good death has emerged into the spotlight of Western civilization. Contemporary Americans want to remain in control, fear pain and aloneness, and

desire protection from a highly technical death (Byock, 1997). The Institute of Medicine (1997) defined a good death as one that is “free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients’ and families’ wishes; and reasonably consistent with clinical, cultural and ethical standards” (p. 4). Furthermore, Byock (1997) asserted that there is no definitive blueprint for a good death. Defining attributes of a good death and how it can be achieved is vital information to obtain so that its deliverance can be actualized. Thus, empirical support for what defines a good death has emerged into current research literature.

Research literature. Research studies and literature reviews have explored definitions of a good death from perspectives of healthcare providers, caregivers, and healthcare recipients. In fact, several studies compared viewpoints of healthcare professionals, significant others, and patients. Healthcare professionals, caregivers, and patients often have different criteria defining a good death resulting in tensions affecting the delivering of end-of-life care. Attributes defining a good death may be dependent on an individual’s role during the dying process. For example, physicians’ concerns center on medical processes while nurses, caregivers, and patients focus on patients’ experiences during the dying process. This section describes research studies related to describing a good death from diverse participants.

Physicians. Steinhauser et al. (2000) studied attributes of a good death as understood by the patient, healthcare provider, and caregiver. This qualitative study utilized focus groups and in-depth interviews. Participants identified six components of a good death: pain and symptom management, preparation for death, concrete decision making, completion, contributing to

others, and affirmation of the whole person. However, Steinhauser et al. (2000) found that physician's perspective of a good death focused on the biomedical while patients and families defined a broader range of influential factors.

Good et al. (2004) conducted a qualitative and quantitative study using semi-structured interviews and self-administered attitudinal surveys to 163 internists in two major medical centers in the United States. Three major themes emerged framing parameters for a good and bad death from physicians' perspectives. Time and process were paramount to include whether death was expected. Medical care was also deemed significant including the appropriateness of end-of-life decision-making processes. Effective communication was the third factor influencing death often associated with efficacious medical care and a good death. Many physicians did not have long term doctor-patient relationships which hindered communication. It is important to note that the physicians' narratives were dominated by discussions on technologies chosen, interventions implemented and constraints of medical decision making.

Nurses. Hopkinson and Hallett (2002) explored the understandings of a good death as voiced by 28 nurses caring for dying patients in the hospital. Data were collected by means of a single open interview. The nurses were asked to discuss patients who had died or were expected to die. For the group of nurses studied, the characteristics of an ideal death included symptom control, peace, dignity, and expectations enabling preparation. The findings, however, suggested that there were also personal understandings of a good death supporting the concept of a "personally ideal death." A personally ideal death recognizes that the beliefs and values of each individual influence definition of a good death. Hopkinson and Hallett (2002) concluded that

there was a need for empirical evidence related to patients' perspectives on domains of a good death.

Griggs (2010) conducted a qualitative study to ascertain community nurses' perceptions of a good death. Seventeen community nurses involved in end-of-life care were interviewed to identify their views on key components to a good death. Eight themes associated with a good death were identified: symptom control, patient choice, honesty, spirituality, professional relationships, effective preparation and organization and provision of seamless care. A good death is feasible when all eight elements are in place. Several challenges including lack of necessary medication and resources, ineffective professional relationships and lack of teamwork were identified as detriments to a good death.

Beckstrand, Callister, and Kirchoff (2006) conducted a research study to improve end-of-life care in intensive care units. A random sample of 1,409 critical nurses, who were geographically dispersed, was sent a 72-item questionnaire on their perceptions of end-of-life care and a good death. The survey included a request for suggestions on ways to improve care at the end-of-life. Responses were received from 861 critical care nurses offering suggestions on improving end-of-life care focusing on a good death. Barriers to providing a good death included nursing time constraints, staffing patterns, communication obstacles, and treatment decisions based on physicians' needs. Proposals for providing a good death included emphasizing dying with dignity; not permitting patients to die alone; symptom management; complying with patients' wishes regarding end-of-life care; promoting cessation of treatment at an opportune time; and effective communication. Again, it should be emphasized that this research studied the healthcare providers' perceptions of a good death.

Patients and caregivers. There are studies that have explored attributes of a good death based on perspectives of individuals who will be or are recipients of end-of-life care. Vig et al. (2002) conducted a qualitative study of 16 geriatric patients' insights regarding characteristics of a good death. In describing a good death, participants identified multiple themes such as no pain, quick, being prepared, and no suffering. Moreover, participants provided different explanations of why given themes contributed to a good death. The researchers concluded that older patients should be asked specific questions about their end-of-life choices and the reasons for these choices.

Mason (2002) conducted a qualitative study on non-professionals' perspectives of a good death using storytelling as a methodology. Participants were asked to describe two stories about deaths of people known to them. One story was to be related to a good death and the other was a less desirable death experience. Participants were 20 people: 10 hospice daycare patients and 10 relatives of individuals who had died in hospice. What emerged was a multi-dimensional and dynamic meaning of a good death. Three frames of reference were identified within which participants' understood death and dying: an acknowledgement of tension and paradox, contextualization within the life lived, and an attitude of flexible realism. Furthermore, participants' comprehension of a good death was pragmatic suggesting contentment to get as near as possible to what is desired in the dying process. Mason suggested that the term "good enough death" was more appropriate to use than "good death" as it conveyed existence of negotiation of goals due to limitations and complexities within the dying process.

A few studies examined defining a good death from the perspective of individuals from diverse culture or ethnic backgrounds. Tong et al. (2003) researched common domains for a good death taking into consideration cultural differences. Tong conducted a qualitative study

using 129 participants (patients and caregivers) assigned to 29 focus groups to obtain views about death and dying. Physical comfort, burden on family, location and environment, presence of others, prolongation of life, communication, completion and emotional health, spiritual concerns, cultural concerns, and individualization were common themes that emerged from the study. There was a significant distinction between minority and non-minority views of what constitutes a good death. Important differences were apparent in areas of spiritual and cultural concerns, and individualization.

A qualitative research study by Seymour, Bellamy, Gott, Ahmedzai, and Clark (2002) focused on the elderly person's perception of a good and bad death. Thirty-two participants selected from six community groups were divided into eight focus groups. Key themes related to pain and comfort, morphine, making an easy passing, fears related to pain, and euthanasia were introduced into the focus groups as topics for discussion. Participants expressed a good death to be one in which morphine and terminal sedation was used to promote a comfortable and quiet end to life. Moral and social concerns, however, were intertwined with the usage of medical modalities to promote peaceful dying. Further research was suggested to enhance the awareness of the elderly person's perspective related to medical practices toward life's end.

Nurse's Role during End-of- Life Care

The nurse's role during end-of- life care is eclectic yet often ambiguous to nurses and other healthcare providers. To better understand this role, I first discussed meanings of related terms including end-of-life care, palliative care, and hospice care to avert any confusion. I then proceeded to deliberate on the nurse's role while caring for the dying beginning with a discussion on nurses' confusion as to their responsibilities. The various roles of the nurse during

end-of-life care including symptom management, rendering emotional support, promoting dialogue among all stakeholders, and participating in decision-making processes are explored.

End-of-life care. The term end-of-life care is often used interchangeably with palliative care and hospice care. In fact, all three terms are equated with a dignified and peaceful death yet significant nuances separate them. Palliative care is appropriate over the continuum of chronic illnesses in conjunction with curative treatment. Thus, palliative care is crucial at the end of life but should not be limited to terminal care (Coyle, 2005). Hospice care is a programmatic model for the delivery of palliative care at the end of life (Meghani, 2004). It is a benefit covered by both private and public insurers. In the United States, the hospice Medicare benefit has been offered as an alternative to curative care. On the other hand, end-of-life care centers on care delivered in close proximity to a patient's expected death (Coyle, 2005). Most importantly, the relief of suffering through the deliverance of holistic care is the key goal of hospice care, end-of-life care and palliative care.

Nurse's role. Several research studies focused on nurses' confusion as to their role during end-of-life care. Van Bruchem-van de Scheur et al. (2008) conducted a quantitative study to investigate the role, perceptions, responsibilities, and problems of nurses assisting with making end-of-life decisions. Questionnaires from 1,179 nurses employed in hospitals, home care organizations, and nursing homes were analyzed. Of the nurses who responded, 23% disagreed with physicians' decisions during end-of-life care but failed to act. More alarmingly, nurses were insufficiently aware of their responsibilities during end-of-life care. Reinke et al. (2010) found similar results of role confusion when they surveyed 717 registered nurses to determine their

viewpoints on underutilized skills during end-of-life care. Using qualitative and quantitative methodologies, results rendered concerns regarding undefined nursing roles compounded by ineffective communication amongst health team members. Thus, what exactly is the nurse's part in end-of-life care is not frequently known to the nurse adversely affecting patient care.

Much of the focus of end-of-life care has centered on nurses' roles in symptom management toward the end of life. The *Compendium of Position Statements on the Nurse's Role in End-of-Life Decisions* (ANA, 1992) stated that promotion of comfort is the primary goal for nurses caring for dying patients. The assessment of symptoms and control of pain are key nursing responsibilities to assure maximal comfort. To assess end-of-life core competencies and associated educational needs, White and Coyne (2011) piloted a descriptive study with members of the Oncology Nurses Society in four states. Symptom management was declared the number one priority nursing intervention during end-of-life. A similar research study was conducted to assess core competencies deemed most important by members of Hospice and Palliative Nurse Association (HPNA) (White, Coyne & White, 2012). A validated survey was sent to 4,022 HPNA members with a return rate of 31.2%. Symptom management was again considered the prime competency followed by pain control in delivering nursing care to dying patients. Uncontrolled symptoms at the end of life can ultimately forfeit a good death for the patient (Glasberg, Eriksson, & Norberg 2008).

To meet the needs of dying patients, nurses must be proficient in rendering emotional support to patient and family members (Haraldsdottir, 2011; Jackson & Dixon, 2011). In fact, results from a study based on ethnomethodology revealed that hospice nurses resorted to routinized care centered on comfort rather than engaging with patients' emotions regarding their imminent death (Haraldsdottir, 2011). Another research study focused on how direct care

community health nurses in the United Kingdom provide emotional support during end-of-life care (Law, 2009). Using grounded theory methodology, data were gathered from nine nurses, nine patients, and four family caregivers through semi-structured interviews, observations, and communication through email. The findings revealed five categories of core behaviors affecting participants: dying world, outside world, entering dying world, maintaining connections, and bridging worlds. The nurses met patients' emotional needs by assisting them to bridge between the dying world and outside world by minimizing feelings of isolation, yet nurses did not feel adequate in catering to their emotional needs. If nurses do not feel equipped to deal with complex needs of dying patients, nursing education must respond by helping nurses provide emotional support during the dying process.

Several research studies have focused on the nurse's role in communication during end-of-life care (Efstathiou & Clifford, 2011; McMillen, 2008; Reinke et al., 2010, White & Coyne; 2011; White et al., 2012). Nurses are ideally suited to facilitate effective communication due to their close proximity to patients, family members, and physicians. Communication was cited as a central competency for nurses to render effective care for the dying terminating in a good death (Efstathiou & Clifford 2011; Reinke et al., 2010; White & Coyne, 2011; White et al., 2012). In fact, effectual communication with family members is imperative in preparing for end of life (Steinhauser et al., 2000). Patients and family members viewed quality communication as central to successful end-of-life care (Royak-Schaler et al., 2006). Thus, nurses are positioned to employ effective communication strategies to enhance sharing of information and identify preferences associated with a good death. Yet several barriers impede communication including physician disinclination and nurse's uneasiness (Royak-Schaler et al., 2006; Schulman-Green, McCorkle, Cherlin, Johnson-Hurzeler, & Bradley, 2005). McMillen (2008) conducted a constructivist

grounded theory study to explore experiences of eight critical care nurses in assisting patients with communicating their end-of-life decisions. One theme that emerged from the data included the nurse's role as a communicator. Responsibilities within this role included planting the seed through effective communication, supporting the family, and being the patient advocate. Thus, communication is integral to the nurse's role in end-of-life care inclusive of being an advocate for the patient. Successful communication is key to promoting efficacious decisions during the dying process.

The nurse's role during decision making processes can range from giving emotional support, providing information, assessing patient's needs and preferences, and patient advocacy. Furthermore, decisions at the end-of-life involve complex entities such as withdrawal of treatment, chosen place to die, artificial hydration and nutrition, and symptom management making effective decision making a crucial task in providing for a good death. An analysis of eighteen qualitative research papers published between 1997 and 2007 revealed a strong relationship between shared decision making inclusive of patient input and a good death (Frank, 2009). In the Netherlands, a descriptive study was conducted to study nurses' views on their role in decision making processes at the end of life (de Veer, Francke, & Poortvliet, 2008.) Results revealed that nurses prefer to be involved in decision making procedures by initiating the process and involving families yet increased clarity about their role is needed. Nurses can also play a significant role in decision making by sharing knowledge and identifying patients' needs (Hildén & Honkasalo, 2006; Smith, 2000). It is the nurse who can empower patients and families to participate in decision making at the end-of-life. However, shared decision making is often impeded due to the nurses' preparedness, confusion related to patient advocacy role, and

conflicts between physicians and nurses (Hildén & Honkasalo, 2006; Mahon, 2010). These impediments prevent sound decision making and often lead to ethical dilemmas.

Ethical Dilemmas during End-of-Life Care

End-of-life care results in many ethical dilemmas for the nurse. Different contextual scenarios can create ethical dilemmas such as withdrawal of treatment, artificial hydration and nutrition, and aggressive symptom management. An ethically difficult situation is viewed as one in which the nurse knows the right action but cannot pursue it or uncertainty about the correct course of action (Soderberg & Norberg, 1993). My discussion, however, focuses on nurses and their role and responsibilities during end-of-life care. Accordingly, I organized this section by the topics of ethical dilemmas, the nurses' roles as patient advocates, and nurses' conflicts with physicians.

Prevalence of ethical dilemmas in end-of-life care. End-of-life care results in many ethical challenges especially for nurses. Several research studies have focused on the prevalence of ethical issues when caring for the dying in a healthcare setting. The results are strikingly similar. A survey of ethical challenges in Norwegian nursing homes reported on the occurrence and nature of ethical dilemmas (Gjerberg, Førde, Pedersen, & Bollig, 2010). Questionnaires were sent to 766 nursing homes in Norway with a 60% response rate. Results revealed that the majority of ethical challenges focused on prolongation of life. Breaches in patients' autonomy, lack of adequate resources, and disagreement with family members were also cited as ethical concerns by nursing staff. Another research study involved an analysis of focus group interviews from 50 Norwegian generalist nurses from four hospitals and three long-term care institutions

(Schou, Alvsvag, Blaka, & Gjengedal, 2008). Results revealed that nurses' concerns focused on establishing good practice by prioritizing patients' and families' needs which were often complicated by inadequate resources and ethical intricacies. The patients' families also created unique ethical dilemmas for the nurse while the patient was viewed as the object of routinized care. In another research study, 32 nurses were asked to reflect on memorable experiences with dying patients (Izumi, 2010). The interviews were interpreted using a hermeneutical approach: paradigm cases, exemplar cases, and constant thematic analysis. Paradigm cases, depicting a sense of goodness, were used to identify nurses' ethical practices. Involvement with patients and engagement are important to paradigm cases. The nurses' stories were contrasted with paradigm cases to reveal four levels of nursing practice: ethical, distressed, unethical, and uncertainty. These results revealed the importance of nurses' abilities to reason through ethical concerns as well as the embodiment of these apprehensions. In yet another study, Pavlish, Brown-Saltzman, Hersh, Shirk, and Rourke (2011) utilized questionnaires based on the Critical Incident Technique (CIT) to collect data on ethical dilemmas, nursing interventions, and patient outcomes from 91 nurses. Although the study did not target end-of-life care, nurses' major ethical concerns were related to quality of life by questioning benefits of aggressive treatment during the dying process. Promoting patient autonomy was the second key ethical conflict faced by participants. This goal was often usurped by family members' wishes. Furthermore, most nurses expressed regret in witnessing unnecessary suffering and pain. Some nurses described their ethical duties as solely related to symptom management. The authors concluded that nurses' abilities to negotiate ethical concerns have not kept pace with the plethora of advanced treatment options offered to patients. In conclusion, during end-of-life care ethical issues arise pertaining to prolongation of

unnecessary treatment, exercising patient autonomy, lack of adequate resources, family conflicts, and confusion as to the nurse's role.

Patient advocacy. Being an effective advocate for the patient is an imperative nursing responsibility. Virginia Henderson, a renowned nurse theorist, described advocacy as nurses helping “people do what they would ordinarily do for themselves to maintain health, recover from illness, or die a peaceful death when persons lack the strength, will, or knowledge to care for themselves” (Henderson, 1961, p. 41). Moreover, there is a clear mandate that nurses should act as patient advocates. The *Code of Ethics for Nurses with Interpretive Statements* (American Nurses Association, [ANA], 2001) acknowledged ethical responsibilities of nurses to function as patient advocates. The third code states “The nurse promotes, advocates for, and strives to protect the health safety and rights of the patient” (ANA, 2001). Advocacy is a key role for nurses warranting further discourse especially as it pertains to self-determination during end-of-life care.

Autonomy, a central concept in patient care, is promoted through advocacy. In the context of healthcare, autonomy can be seen as the right to make decisions or self-determination of rights, such as the right to accept or refuse treatment (Beauchamp & Childress, 2001). Furthermore, patient autonomy ensues when nurses empower patients to make decisions based on all available knowledge. Through the role of patient advocacy, the nurse promotes autonomy through rendering information and offering emotional support (Kohnke, 1982). Thus, promoting hopes of patients and families through incorporating their preferences into end-of-life care plans is an essential element of advocacy. Nurses are ideally situated to guide patients' and listen to their concerns as physicians often lack time or possess an intimidating demeanor interfering with effective communication (Breier-Mackie, 2001; Thacker, 2008). Do nurses, however, take

advantage of their opportunistic stance to promote autonomy during the dying process and advocate for patients?

When nurses advocate for patients, they may face several barriers associated with lack of education, societal needs, or professional relationships (Hewitt, 2002; Kirsch, 2009; Thacker 2008). Due to demands of the advocacy role during end-of-life care, nurses may struggle due to poor advocacy skills (McSteen & Peden-McAlpine, 2006). In a comparative descriptive study to reveal acute care nurses' perceptions of nursing advocacy behaviors in end-of-life care, one quarter of the study's 317 participants did not have advocacy education (Thacker, 2008). Furthermore, there is little description in the literature on how nurses learn the advocacy role (Thacker, 2008). The advocacy role is complex necessitating equilibrium between societal and individual needs (Kirsch, 2009). Societal and third party influences the use of limited resources and necessity to conserve cost which further complicate the intricacies of optimal advocacy (Bailey, 2011). Despite patients' suffering, conflict may ensue if nurses advocate for patients. Nurses have been fearful to speak out for patients due to intimidation from physicians and the negative effects it may have on their career (Hewitt, 2002; Thacker, 2008). Thus, patriarchal systems within institutionalized medicine promote an atmosphere of fear and intimidation effecting nurse advocacy.

There can be a thin line between advocacy and paternalism, especially in end-of-life care (Breier-Mackie, 2001; Zomorodi & Foley, 2009). Paternalism occurs when a patient's preferences, decisions, or actions are denied out of concern for the patient's well-being (Breier-Mackie, 2001). Some argue that medical paternalism can only be justified when beneficence, doing no harm, is applied or when autonomy or personal rights are not violated (Bassford, 1982). Yet, when physicians substitute their judgments for medical interventions that are best for

patients, autonomy is displaced with paternalism. While it may be true that physicians possess the knowledge and expertise to direct medical treatment at the end of life, patients' desires and needs may be sacrificed in the process. So who knows best which treatment modality to pursue: patient or physician? Patients who are confronted with dilemmas of autonomy versus paternalism often do not verbalize their needs due to intimidation by the doctor's perceived power or the doctor's lack of time to listen to them (Breier-Mackie, 2001; Hall, 2003). In fact, fear and power are often used to encourage patient compliance or selection of a particular way of treatment (Cowling, Shattell, & Todd 2006; Hall, 2003). Since roles of nurses are often intimate and personal, it could be argued that nurses' obligations are to weigh ethical principles, such as beneficence and autonomy, in order to determine where advocacy ends and paternalism begins. Nurses are in the ideal position to be mediators by knowing the patient best and many times having better communication skills than physicians (Breier-Mackie, 2001). Yet, nurses do not always speak up for patients due to fear and intimidation (Hewitt, 2002; Thacker, 2008). Nurses and patients are negatively affected by threads of paternalism woven throughout the healthcare system.

Two key questions plague healthcare providers and patients during end-of-life care. Who is the primary decision maker? What is the principal focus of end-of-life decisions: cure versus care? Physicians maintain the most influence in not only decisions regarding medical treatment at the end-of-life but also whether hospitalization is warranted. In a qualitative study analyzing 108 interviews from staff members in 11 hospitals, the predominant consensus was that the physician controlled treatment options at the end-of-life (Larochelle, Rodriguez, Arnold, & Barnato, 2009). Physicians, who have a decisive role, must shift from a curative model of care to a focus on quality of life (Breier-Mackie, 2001). Yet, physicians often have difficulty changing

directions as their beliefs and attitudes, socialized by their education and the healthcare institution, affect their decisions related to end-of-life care. A quantitative study of physicians revealed their hesitancy to relinquish curative treatment for dying patients (Duke & Northam, 2009). As a result of the healthcare provider's role in end-of-life care, the preferences of patients and families may not be taken into account usurping the patient's sense of autonomy.

Many healthcare professionals strive to conquer death through making death a medicalized event (Garry, 2001). Medicalization can be seen as a method by which human problems are viewed and treated as medical problems (Sadler, Jotterand, Lee, & Inrig, 2009). Through medicalization, normal human conditions such as menopause, dying and unhappiness are transformed into medical conditions to be treated with medications and technological advances. Death is a prime example of how a human problem becomes a medical entity. Death was not always treated as a medical event but reflected a spiritual, inevitable journey to a preferred, utopia destination (Aries, 1974). Today, technology has brought the ability to control death but at a financial and emotional cost. The use of life sustaining technology such as ventilators, feeding tubes, and hemodialysis has increased over the past 30 years for Medicare recipients in their last year of life (Barnato, McClellan, Kagay, & Garber, 2004). Furthermore, it is still not quite clear how the impact of medicalization has impacted the role of the nurse (Syme & Bruce, 2009). Nursing care emphasizes evidenced based practice focusing on care that has measurable outcomes. Thus, nursing roles inherent in advocacy, emotional support, and listening become a lesser priority in end-of-life care as they are not measurable. Attention to physical signs and symptoms rather than relief of spiritual and emotional distress have become the focus of nursing care brought about by medicalization of the

dying process (Clark, 2002). Thus, the nurse may be more attuned and comfortable alleviating physical discomfort than advocating for holistic nursing care of the dying patient.

Conflicts between physicians and nurses. The literature on physician-nurse relationships suggests a complex association which can accentuate ethical discourse. Disputes amongst healthcare professionals can disrupt patient care adversely affecting patient outcomes during end-of-life care (Duke & Northem, 2009; Frank, 2009). Conflicts between physicians and nurses during end-of-life care are centered on prioritization of treatment, nondisclosure of diagnosis, and hierarchal and power relations (Frank, 2009).

Prioritization of treatment has resulted in adversarial encounters between physician and nurses. Is aggressive treatment such as mechanical ventilation, chemotherapy, feeding tubes, and hemodialysis a viable option for the dying patient? Physicians may be ill equipped to deal with caring for the dying as their education is devoted to diagnosis and cure rather than care at the end of life (Dickinson, 2012; Duke & Northam, 2009; Gibbins, McCoubrie, & Forbes 2011). A grounded theory study using observation and semi-structured interviews from 29 clinical nurse specialists disclosed their frustrations with physicians' reluctance to forgo curative treatment for dying patients in an acute care setting (Willard & Luker, 2006). The healthcare providers' focus on prioritization of treatment and routine care complicated further by their aversion to palliative care overshadowed patients' autonomy. A quantitative study by Hilden, Louhiala, Honkasalo and Palo (2004) replicated these results when 44% of the nurses believed active treatment for dying patients continued too long. Medical and nursing care needs to be patient-centered yet nurses and physicians have different goals for outcomes of end-of-life care. It all goes back to patient preferences, educating patients as to their options so that an informed decision is generated. Once that decision is disclosed, who will advocate for the patient? It should be the nurse, but as

discussed previously, advocacy may not be an easy task especially if healthcare professionals have different objectives in end-of-life care. Thus, the nurse may feel trapped in a professional web of choosing the correct ethically bound course of action.

Over the past decades, there has been a change in the practice of disclosing a terminal illness from concealment to a more acceptable approach (Krisman-Scott, 2000). Yet even today this change is not absolute and the practice still remains unclear as to its prevalence. Nurses often find themselves in the middle as their nursing care is often hampered by the patient's lack of information. An ethnographic research design was used to explore the experiences on elderly patients and nurses caring for them in a hospital setting (Costello, 2001). Findings revealed that physicians used a paternalistic approach selecting to withhold information from patients yet inform the relatives of the patients' imminent death. Consequently, nurses experienced many problems related to offering emotional and spiritual support due to these disclosure practices.

Power dynamics between nurses and physicians highlight the power inequality that exists between men and women in social, political institutions. Nurses, predominately women, often feel powerless in a rigid hierarchy dominated by male physicians (Sirota, 2007). In a qualitative study of 42 nurses in four different nations, nurses expressed a sense of powerlessness (Malloy et al., 2009). Many of the nurses' voices were silenced irrelevant to their education background viewing physicians as most powerful within the institutional hierarchy. The other problem that exists is one in which nurses in subordinate positions have crucial knowledge yet are not taken seriously (Kagan, Smith, Cowling, & Chinn, 2010; Mackintosh & Sandall, 2010). Moreover, physicians and nurses are employed in institutions possessing a masculine connotation shaping institutional policies and practices (Mackay, 2004). Thus, power issues inherent in healthcare are

closely linked with gender which necessitates looking at gender as a form of reference shifting the focus away from the individual to social and political forces.

Nurses can exercise their power through acts of resistance (Kagan et al., 2010; Peter, Lunardi, & Macfarlane, 2004). Through challenging the status quo, nurses are empowered to speak out to create changes in policies and practices. In actuality, nurses need to break unproductive rules to achieve best patient outcomes. In an analysis of nursing literature between 1990 and 2003, acts of resistance were seen in nurses challenging power inequalities through speaking up, confrontation, reporting to higher authorities and whistle-blowing (Peter et al., 2004). Yet, institutions' and physicians' reactions to acts of resistance led to punishment and loss of employment as well as conflict resolution. Furthermore, moral implications are inherent in acts of resistance (Peter et al., 2004). In ethical scenarios, nurses need to resist by not submitting to aversive power entities to ensure that the best ethical course of action is upheld. Resistance can be viewed as a moral act entailing an analysis of power structures to generate new knowledge to halt power imbalances. Nurses need to be equipped on ways to analyze power which is best accomplished by incorporating a framework for scrutinizing power structures within healthcare into the nursing curriculum.

The power relations between nurses and physicians may be unduly influenced by how each profession approaches moral concerns. By virtue of their gender, nurses (who are mostly female) address ethical dilemmas through a feminine perspective. Typically, women's lives are linked to nurturing and caring for the dependent members of society. Relevant to their life experiences, women have developed values and morals centered on caring relationships (Gilligan, 1977). Women not only know themselves through their connectedness with others but their relationships guide actions. In fact, Noddings (1984) argues that caring inherent in

relationships is the basis for ethical decision making. “One must meet the other in caring. From this requirement, there is no escape for one who would be moral” (Noddings, 1984, p. 201). Thus, it is not adherence to principles that legitimizes moral actions but rather the “degree to which the action was rooted in caring” which provides an understanding of the feminist approach to ethical concerns (Noddings, 1984, p. 53). Men may use a feminine approach to moral questions yet are more inclined to make ethical decisions on the basis of anticipated consequences (utilitarianism) or principled reasoning (deontology). In ethical discourse, the adherence to ethical principles may be difficult for nurses to appreciate while an understanding of caring relationships is more relevant to their life experiences.

Consequences of Ethical Predicaments

Ethical quandaries create negative effects not only for nurses but patients are also adversely affected. During end-of-life care, ethical dilemmas may adversely alter patient outcomes. In addition, nurses may succumb to stress and moral distress ultimately emanating in leaving the nursing profession (Ulrich et al. 2007; Ulrich et al. 2010). Thus, diverse consequences of ethical dilemmas are discussed in relation to its effects on the patient and nurse.

Forfeiting a good death. During end-of-life care, patients face adverse effects due to ethical quandaries which render a good death impossible (Gjerberg et al., 2010; Peter et al., 2004). A good death, as previously explored, is based on patients’ preferences, a highly individualized endeavor that needs to be communicated to all participants. Patients need to be in control of their own death yet the end stage of life is often plagued with patients struggling with retaining some form of autonomy (Castledine, 2010). Due to nurses close proximity to patients,

nurses are placed in the role of advocate to act as guides, liaisons, and supporters during the dying process (McSteen et al., 2006). Yet end-of life care spurs ethical dilemmas leaving nurses ill equipped to be effective advocates. Nurses find themselves confined by power entities usurping their knowledge base as well as their voices. Thus, dying patients may be left without a voice of their own and succumb to others' definitions of a good death or futile medical care focused on cure precluding a good death.

Nurses' stress and moral distress. Nurses may experience stress in everyday practice not just end-of-life care. Using descriptive statistics, cross tabulations, and Pearson correlations, Ulrich et al., (2010) analyzed 422 questionnaires from nurses in four states. The nurses identified five stressful issues in delivering nursing care on a daily basis. These challenging concerns included the nurse's role in protecting patients' rights; patient's self-determination and informed consent to treatment; nursing staffing patterns; patients' advance care planning; and surrogate decision making by significant others. Additional apprehensions were unethical practices of healthcare professionals; breaches of patient confidentiality or right to privacy; and end-of-life decision-making. Many nurses reported a sense of powerlessness with minimal influence on outcomes. This sense of powerlessness fits the definition of moral distress where one knows the right action but cannot pursue an effective course action due to institutional constraints. The authors concluded that nurses face ethical challenges while providing quality care on a daily basis. To retain nurses, targeted ethics-related interventions that address caring for an increasingly complex patient population were recommended.

Nurses who feel morally responsible but are unable to change what is happening often experience moral distress. Prolonging the dying process is an example. In a qualitative study

using narrative analysis, Robichaux and Clark (2006) interviewed 21 critical care nurses from seven facilities. The study's results revealed three themes: protecting the patient; presenting a realistic picture; and experiencing frustration and resignation. The nurses believed their responsibility was to protect the patient from technological intrusion. In addition, presenting a realistic picture to the patient about the potential for recovery was the nurse's obligation. Frustration focused on not being able to affect a patient's situation was a common experience reported by nurses which culminated in job resignation. This feeling of frustration caused nurses to feel anger and despair, common emotions in moral distress. The expert critical care nurse, however, demonstrated the ability to advocate for vulnerable patients even if outcomes were not influenced. In general, most nurses experienced anguish during the patient's transition from curative to end-of-life care which has been duplicated by other studies (Calvin, Lindy, & Clingon, 2009; Vanderspank-Wright, Fothergill-Bourbonnais, Brajtman, & Gagnon, 2011). It is important to note that moral distress can negatively affect job satisfaction and cause nurses to leave the profession (Ulrich et al., 2007).

Nursing Education

Nursing education faces several challenges to provide quality education in an ever changing healthcare environment. We should move beyond educating future nurses to be competent and safe with an emphasis on evidence-based practices to developing practical wisdom, which Aristotle named phronesis. Nursing education needs to be in the driver's seat instead of trying to keep pace. Nowhere is this more important than in the field of ethics education during end-of-life care. After all, patients only have one attempt at achieving a good death, it cannot be redone. Nurses are pivotal in helping patients achieve a good death. Does

nursing education adequately prepare them to exercise practical wisdom during end-of-life care? Thus in this section, I explore nursing education's attempts to integrate death and dying and ethics education into the curriculum cultivating a sense of phronesis.

Death and dying education. The Institute of Medicine (IOM) reported on the need to improve end-of-life care through educating nurses (1997). A 121member committee critiqued the dying experience, compiling a 418-page report on the dismal national state of affairs pertaining to dying in America. Findings revealed that too many people die in pain and experience distress during the last days of life. In addition, significant legal, economic and educational barriers were identified. The Institute of Medicine recommended educational curricula changes be implemented in the healthcare professions. Consequently, the Robert Wood Johnson Foundation (RWF) initiated Last Acts, a national campaign to improve the dying experience (Pace & Lunsford, 2011). Last Acts rated each state's ability to provide quality end-of-life care which further proved that patients had a slim chance of actualizing a good death. Thus, the evidence was in supporting the necessity to improve end-of-life care and one way to accomplish this feat was through education.

It became evident that nursing education needed to be revamped to include end-of-life care into the curricula. A review of nursing textbooks for the inclusion of end-of-life care substantiated the dearth of information on the dying process in nursing education. Textbooks used in undergraduate nursing curricula were analyzed from the late 1990s and early 2000s for end-of-life content (Ferrell, Virani, Grant, & Juarez, 2000; Kirchoff, Beckstrand, & Anumandla, 2003). Results revealed that textbooks had minimal (2%) to no content on the nurse's role during the dying process. Due to deficiencies in the education of healthcare

professional on end-of-life care, the American Association of Colleges of Nursing (AACN, 2001) established 15 nursing competencies to include in baccalaureate education to assist nurses in actualizing a good death for their patients. Other efforts were initiated to improve end-of-life education in nursing schools which included a national education program. Incorporating the 15 nursing competencies, the End-of-Life Nursing Education Consortium (ELNEC) curriculum was developed through the joint efforts of AACN and the City of Hope National Medical Center. Using a “train the trainer” model to entice nursing faculty, ELNEC’s curriculum provides modules on knowledge, skills and teaching strategies to improve end-of-life care. Thus, nurse educators have the tools. But are they being used?

Education in end-of-life care in undergraduate curricula has increased over the past 30 years but to what extent? In the 1980s, 80% of baccalaureate nursing programs had death and dying integrated into courses but still students had minimal exposure (Dickinson, 2007). Due to the initiatives of IOM and AACN, nursing schools have made accelerated efforts to include end-of-life nursing care in the curriculum. In 2006, data gathered from 410 nursing schools revealed that over 90% of students receive some form of education on end-of-life care yet the average number of hours was less than fifteen (Dickinson, 2007). Furthermore, Dickinson (2006) conducted a quantitative study to compare nursing end-of-life education in 1984 to 2006. Remarkably, the results revealed slight changes in 2006 most notably in an increase in the number of offerings on end-of-life care. Even though there is a distinctive focus on how we die, nursing education has more to do to disseminate knowledge on end-of-life care so that patients’ preferences are actualized.

To date, there have been few research studies to validate the educational outcomes of including end-of-life care in the nursing curricula. A descriptive study of nursing alumni over a

6-year span revealed that a standalone course on end-of-life care was beneficial in preparing future nurses to care for dying patients (Todaro-Franceschi, 2011). Findings also suggested that it is not enough to solely offer electives on end-of-life care which precludes a majority of students. A quasi-experimental study supports the importance of providing end-of-life care to nursing students to improve death and dying knowledge (Whitehead, Anderson, Redican, & Stratton, 2010). Moreover, attitudes toward death and dying can be positively swayed through education (Barrere, Durkin, & LaCoursiere, 2008). It is also noteworthy that content related to end-of-life care has been incorporated in nursing licensure examination by the National Council of State Boards of Nursing. Despite these educational endeavors, which are meager at best, nurses continue to feel inadequately prepared to care for the dying (White & Coyne, 2011; White et al., 2012). Nursing education has not stepped up to the plate perhaps due to reluctance to forgo the medical model of cure.

Ethics education. The importance of teaching ethics to nursing students cannot be underestimated as members of the profession need to know how they should behave. In fact, the American Association of Colleges of Nursing has recommended that nursing students be well versed in ethics (Garity, 2009). Ethics education should assist nurses in their decision making through achieving objectives including supporting ethical aspiration, facilitating recognition of ethical dilemmas, and enhancing understanding of ethical issues (Lin et al., 2010).

Although, there is a consensus as to the importance of ethics education in nursing curricula, ethics has not been a required course in most undergraduate programs (Park, 2009). Most nursing programs use an integrated teaching model incorporating ethics education throughout the curriculum. As a result, nursing ethics may not be allotted sufficient time within a

well-planned and delivered curriculum. To complicate the issue, most nurse educators are not well versed in nursing ethics to successfully guide nursing students (Woods, 2005). Despite the discrepancy of faculty qualifications, content hours, and emphasis on ethics education, the nursing profession endorses the need to prepare students with an ethical awareness and know-how.

The teaching methodology of ethics in nursing education needs to be more effective in instilling a sense of ethical know-how (Brien, Legault, & Tremblay 2008; Garity, 2009; Mooney, 2005; Sellman, 2009). Primarily the two conventional approaches to nursing ethics education are to integrate principles of right action and to focus on virtue ethics (Lin et al., 2010). Nurse educators have emphasized that nursing ethics education should be based on real situations including the narratives of expert clinicians (Benner, 1991; Lin et al., 2010). In addition, the teaching of ethics needs to integrate ethics, legal, and health policy while incorporating innovating teaching strategies including case studies, ethical decision making models, and debate (Garity, 2009). Teaching strategies should also address the affective domain on learning ethical issues during end-of-life care. Emotionally impacted learning activities such as reflection have a substantial effect on learning ethical decision making (Brien et al., 2008). The inclusion of intellectual exercises is imperative to emphasize open-mindedness as the nurse needs to be aware of the possibility that more knowledge is needed or that one might be wrong (Sellman, 2009). In summary, the teaching of everyday ethical comportment in nursing requires an openness of learning to include effective teaching strategies.

Ethics needs to be taught in a way that moral aptitude and social responsibility is facilitated. To this end, teaching nursing ethics requires that we move beyond teaching codes of ethics and moral principles to analysis of institutional barriers and how to challenge these

impediments (Peter et al., 2004). As nurses, we have an obligation to be concerned with power structures which interfere with our ethical behaviors. We get caught up in the medical model of diagnosing and cure which precipitates power by making judgments and categorizing people as normal versus abnormal (Kagan & Chinn, 2010). Spiritual and emotional needs so often overlooked in a good death are therefore placed in the periphery. Power dynamics between nurses and physicians also influence our actions (Kagan & Chinn, 2010; Mackintosh & Sandall, 2010; Malloy et al., 2009; Sirota, 2007) and how we make ethical decisions. Turiel (2002) reminds us that a key to understanding relationships is to address concerns of oppressed individuals and the nature of their relationship with those in the higher social hierarchy. Thus, as nurses we need to be taught how to analyze judgments and expectations of people in opposing segments of power polarities. Furthermore, conflicts emerge from social interactions and social practices emanating from the dynamic power relationships of inequalities. People in power often have a sense of entitlement which restricts freedom of others. In an attempt to make the social system more just, people in subordinate social positions engage in acts of resistance to make the world more righteous (Turiel & Perkins, 2004). Nurses need to be taught how to analyze power and participate in acts of resistance to assure that their voice is heard while their expertise is acknowledged.

Incorporating Turiel's Domain Theory into nursing ethics education would be advantageous for understanding how moral codes conflict with personal and social mores of action. Turiel (2002) distinguishes between concepts of morality, and other domains of social knowledge, such as social convention and personal choice. Each of the three domains applies different principles based on a cognitive sphere of influence with inherent normative values. For instance, actions within the moral domain are guided by principles of how individuals ought to

treat one another. The moral domain is structured by concepts of harm, welfare, and fairness regardless of the nature of existing social rules. Comparatively, actions related to social convention promote efficient functioning of social groups and institutions through agreed upon modes of conduct within a social order. Thus, conventional rules are somewhat arbitrary as they are contextualized within cultural norms and power structures. The domain of personal autonomy entails an understanding of self and others based on concepts of autonomy and individuality. Evolution into a stable sense of self and personal freedom is the ultimate outcome of the personal domain. Since ethical dilemmas take place within the context of society, nurses' analyses about the right courses of action require negotiations between moral reasoning, social convention and personal autonomy. Nurses need to have an awareness of power structures affecting social and personal domains.

Learning to be a good practitioner of moral convictions requires teaching for the purpose of developing phronesis, practical wisdom. Aristotle (1998) refers to phronesis as the practical knowledge of ethics with an understanding of what is the best course of action for a particular occurrence. Phronesis or practical wisdom is the "capacity to act with regard to the things that are good or bad for man" (Aristotle, 1998, p. 142). To best appreciate the contextual significance of phronesis, I offer a synopsis of Aristotle's thoughts on the development of moral character.

In the *Nicomachean Ethics*, Aristotle (1998) discusses knowledge in the context of a more general discourse on ethics. For Aristotle, the central focus on ethics revolves around the pursuit of eudaimonia (a good life) with reference to social, political and theoretical premises (Sellman, 2009). During this endeavor, humans search for the highest good. Thus, the question is 'what type of person should I become' which is achieved through the acquisition of virtues. In turn, virtues are seen as high-quality characteristics which facilitate the achievement of

happiness through sound reasoning. Being virtuous, however, does not translate into happiness as virtues have to be actualized.

Aristotle (1998) views virtues as either intellectual or moral. Intellectual virtues are learned through instruction while moral virtues are acquired through repetitive practice or habituation. The intellectual virtues, such as wisdom and understanding, are achieved through teaching over time whereas moral virtues are embodied overtime. Furthermore, intellectual virtues inform a person of the concepts of a just act while moral virtues are concerned with actually doing a just act for the right reasons. Aristotle makes it quite clear that moral virtues cannot be taught. One achieves moral virtues such as generosity and self-control through evaluating daily acts or habits over a lifetime. Moral virtues are achieved by doing altruistic acts throughout life to the culmination of “acting virtuously out of the love of the virtue itself” (McKnight, 2004). Therefore, a person who has moral virtue conscientiously behaves in the right way by choice and as a manifestation of a fixed disposition.

According to Aristotle (1998), there are five intellectual virtues that can be taught to an individual. First, scientific knowledge or *theoria* is an intellectual virtue which has to do with eternal truths through reasoning. Second, practical skills or *techne* entail the performance of a procedure by utilizing correct reasoning. Third, practical wisdom or *phronesis* incorporates doing the correct act at the right place and time. Fourth, intuition is instrumental in understanding principles underlying scientific truths. Fifth, wisdom is an intellectual virtue which is a combination of scientific knowledge and intuition permitting the acquisition of the highest truths. Is nursing teaching these virtues? Certainly nursing education is teaching theory and skills but is nursing education geared toward teaching *phronesis*?

An Aristotelian perspective offers insight into nursing knowledge as Aristotle asserts there are two divisions of knowledge: theoretical knowledge and practical knowledge. In fact, Aristotle focused on fundamental differences between theory and practice with each possessing unique types of knowledge (Saugstad, 2002). Furthermore, practical and theoretical knowledge are learned differently. Theoretical knowledge is focused on understanding, not application. It has a sole form of existence which cannot be altered. Moreover, theoretical knowledge is scientific, definitive and universal with relevance to *theoria* (Saugstad, 2002). Contemplation is associated with theoretical knowledge with the divine objective of being more God like (Aristotle, 1998). Knowledge in the practical realm, however, is not a certainty as it is subject to change. Furthermore, practical knowledge is based on experiences contextualized within social interactions with the outside world. *Techne* and *phronesis* have to do with acquiring practical expertise through selection of specific knowledge discourses. Certainly, nursing as a practice profession incorporates theory to support and guide its practice and *techne* through the acquisition of specific nursing skills.

Nursing students need to be taught how to draw on *theoria*, *techne*, and *phronesis* to integrate them into practice. The *phronetic* nurse arrives at the correct conclusion at the right time, on the basis of accurate arguments (Saugstad, 2002). According to Aristotle, insight along with experience is needed to achieve *phronesis* as it entails wise and unwise actions (Kristjansson, 2005). A nurse using *phronesis* deliberates about the ethically correct nursing action in a particular situation. Adequate opportunities for acquiring practical wisdom through experiential learning should be provided in nursing curricula to enhance ethical discourse. Experience with different patients in a variety of contextualized environments fosters sound clinical judgments. Nursing students and novice nurses, however, need support in formulating

ethical reasoning as their experience is limited. Reasoning through a specific patient's situation is a key component of the way nurses' use knowledge. James, Andershed, Gustavsson, and Ternstedt (2010) conducted an ethnographic and hermeneutic study to examine different forms of knowledge nurses use to determine how nurses construct knowledge. The results of this study indicated that nurses intertwined knowledge forms of *theoria*, *techne*, and *phronesis* as no knowledge form was dominant. Nursing students need to be given sufficient opportunities to articulate reasons for chosen nursing actions based on ethics, clinical reasoning and relationships with the patient and family.

Another way to develop *phronesis* in nursing ethics education is through helping students to become open minded and emulate others who practice *phronesis* (Sellman, 2009). Students should be educated on how to be open to the wide realm of possibilities in an ethical dilemma including how to cultivate metacognition. To this endeavor, nursing students need to know that it is acceptable to not know everything yet important to be aware of what knowledge is lacking. Intellectual activities, asking the right questions and analyzing situations from multiple points of views are teaching strategies to enhance open mindedness. The nursing student needs to learn how to engage and integrate theory and practice through creating supportive and opposing arguments to substantiate different outcomes. In addition, nurse educators need to be exemplars of *phronesis* by practicing open-mindedness as pedagogy (Sellman, 2009). Empowering students so that their voices are heard develops *phronesis* and active resistance. Through encouraging debates and contrary viewpoints, and welcoming students' objections as a form of ethical discourse, educators teach for *phronesis* and how to actively resist. Thus, teachers of ethics need to demonstrate by their actions *phronesis*, practical wisdom, through role modeling open mindedness and active resistance.

Theoretical Framework

In the theoretical framework, I examined feminist epistemology and critical social theory as lenses to understand ethical discourse as faced by nurses during end-of-life care. To establish a rationale for incorporating feminism and critical social theory into this study, a theoretical foundation will be presented in three parts. First, I argue that a feminist viewpoint of situational knowledge holds significant possibilities for viewing nurses as favorably positioned within their practice by challenging the pervasively influential positivist position. It is my contention that knowledge is an artifact of social manipulations embedded within power structures. Thus, a discussion pursues on how a feminist perspective on epistemology embedded within critical social theory is influenced by social, cultural and political contexts of power structures. A summary follows of the development of nurses' knowledge including experiential ways of knowing as advocated by Patricia Benner. In closing, the theoretical framework supports my contention that nurses' knowledge is valuable to the discipline yet often not appreciated by healthcare professionals, including nurses, due to preset notions that scientific knowledge prevails. Thus, the theoretical context gives power to the voices of my participants by exposing truths embedded within social and political structures.

Situated Knowledge

From a feminine perspective, the question brought before us focuses on truth to our knowledge. The conventional consensus, positivism, asserts that the authenticity of knowledge is derived from the natural sciences anchored in the belief that the world can be known in its entirety from an objective stance (MacKenzie, 2011). As hailed by many feminists, positivism thwarts the efforts of social scientists to scrutinize social phenomenon. Over the past few

decades, feminist scholars have challenged the traditional definitions of knowledge bound in scientific webs as being disembodied and unmarked (Code, 1991; Haraway, 1988; Harding, 1991). Thus, the argument centers on the need for social sciences to have a social epistemology rather than a positivistic approach. Situated knowledge enters into the discussion claiming that no person or group can profess to a detached unbiased viewpoint even in scientific inquiry as all assertions are made from an individual stance (Code, 1991; Haraway, 1988; Harding, 1991).

Claims to the authenticity of true knowledge are entrenched in positivism. Auguste Comte in his *Course de Philosophie Positive* (1830-42/1853) claimed that authentic knowledge was the result of observations affirming a personalized interpretation of reality. Comte coined the term positivism warning about making claims beyond our observations. Positivism, however, has taken on a different connotation to mean that there is a sole reality of knowledge centered in natural sciences, focused on scientific methodology yet independent of human influence (MacKenzie, 2011). David Hume, an 18th century philosopher, is considered one of the fathers of positivism as reflected in his writings about the relationship of the senses and reason (Hume, 1747/1907). In the 1920s, a group of scientists, mathematicians, and philosophers, known as Vienna Circle, were strongly influenced by Hume. Content with the knowledge of observed regularities, they advocated for the scientific method as the sole means to establishing knowledge. In the years that followed, the positivist point of view, as adhered by the Vienna Circle, became revered by scholars who wanted to be associated with the preeminence of positivism (Ayer, 1959).

Over the past 50 years, positivism has been challenged based on two contentions (Goldenberg, 2005). The first centers on the impossibility of being entirely objective in one's research, void of beliefs and values. Isn't data handled and manipulated only to be analyzed by

humans? Inherent in interpretations are our perceptions of observations intermixed and reflecting personal beliefs and values. Then, there is the question of theory choice. Frequently, data can be attributed to several theories yet the theory chosen is subject to the researcher's own biases and laden with the culturally guarded researcher's preferences. These criticisms of positivism are similar to objections put forth by feminist scholars to knowledge formation (Code, 1991; Haraway, 1988; Harding, 1991).

In my argument for the validity of situated knowledge, it is imperative that I address natural scientists' appeal to objectivity as the capstone of authentic knowledge. Objectivity is an important assumption within natural sciences that equates to bias free knowledge through avoiding associated emotional, cultural and social perspectives of the individual. Thus, the revered scientific method has been constructed to foster objectivity by eliminating social and individual values (Harding, 1991). Objectivism itself offers a distorted view of the natural sciences as scientists' beliefs and values are ignored yet effect their research methodology and analysis. Harding (1991) contends that real science is rooted in the scientific method restricted by testing formulated hypotheses derived from supposedly disengaged, neutral scientists. Even in natural science inquiry, the questions chosen to explore cannot be void of objectivity. While filtering into the social sciences, objectivity creates a moral insensitivity, a numbness distancing the knower from the known.

Several feminist scholars have challenged traditional claims to the authenticity of knowledge asserting that knowledge should not be seen independent of the knower (Code, 1991; Harding, 1991; Haraway, 1988). Feminists advocate for an embodied knowledge that is situated in time, place and person asserting that we only know our world from our specific locations within it. Knowing people demands a unique way of knowing which accounts for the

situatedness of the knowing subject and the knower. Knowledge that is “situated” recognizes and incorporates one’s position while taking into account the geographical, social, and political context of the knower (Haraway, 1988; Haraway, 1991). The concept of situated knowledge challenges the positivist position that places the knower outside the situational context. Situated knowing espouses to knowledge being embodied and situated socially, culturally, racially, sexually, and politically (Ford, 2007; Haraway, 1988; Harding, 1991; Lang, 2011).

Donna Haraway made significant contributions to the literature of situated knowledge. Haraway’s (1991) early work on primate biology was significant in delineating the constructs within situated knowledge. She contended that behavior of primates was not only highly gendered but reflected the researcher’s posture and attitude toward primates. Incorporating these revelations, Haraway called for a dogma of objectivity that not only integrates different forms of knowledge but takes into account political, social and cultural stance of the knower. She advocates for an “embodied vision” challenging mainstream’s epistemology’s claim for objectivity which is a posture from within as opposed to abandoning our minds to a disengaged stance (Haraway, 1988). Haraway (1988) argued “for the view from a body, always a complex, contradictory, structuring, and structured body, versus view from above, from nowhere, from simplicity” (p. 589). Thus as defined by Haraway, situated knowledge is embodied by permitting the knower to engage in “webs of connection” while subjecting the knower to take an ethical stance.

In creating a dynamic feminist epistemology, Code (1991) focused on gender while advocating for a compromise between objectivity and subjectivity which she termed “mitigated relativism.” She maintained that completely denying any objectivity also negates reality, even if it is socially constructed. Mitigated relativism is committed to realism while guarded by

objectivity and “capable of taking subjectivity, accountability, and a range of perspectives seriously into account by refusing the tyranny of ideal objectivity, universality and gender neutrality” (Code 1991, p. 251). Objectivity grounded in relativism takes into account what is in our heads intermingled with reality of our experiences. Yet Code took situated knowledge a step further to argue that epistemology is gender specific necessitating a primary focus for feminism. There are four ways in which knowers are situated inclusive of the knower’s historical location, position within specific social and linguistic contexts, creativity in the construction of knowledge, and affectivity, commitments, enthusiasm, desires and interests, all influenced by one’s gender (Code, 1991). The interplay of these four ways of being situated is in fluid movement to produces a dynamic feminist epistemology that changes over time.

Harding (1991) took on a unique stance by arguing for the orthodox notion of objectivity to be more rigorous by maximizing objectivity. She encouraged moving away from “value neutral objectivity” and “judgmental relativism” to a “strong objectivity” (Harding 1991, p. 142). Inherent in a strong objectivity is acknowledgment for grounding of knowledge in historical and social contexts and to “transform it into a systematically scientific resource” (Harding 1993, p. 58). All objects of knowledge are socially constructed, even nature, through their cultural significance and socially constructed meanings within scientific community. In Harding’s (1993) argument for a “strong objectivity,” she claimed that the subject of knowledge must be “considered as part of the object of knowledge” to account for their social uniqueness of each (p. 69). Thus, the social situatedness of the knower along with the object of knowledge are used as resources to maximize objectivity. Harding (1993) contended that strong objectivity cannot be attained by eliminating oneself from the world, but by recognizing our situated whereabouts and being reflexive of our social position.

Harding believed that it should be our goal as feminist researchers, not to justify truth claims, but to enable different forms of knowledge to emerge. Harding (1991) argued for a feminist standpoint epistemology that acknowledges the world as socially and politically constructed, consisting of numerous perceptions and realities. Harding's interpretation of standpoint theory examined marginalized people as the starting point for thought. She claimed that actions of individuals in the higher hierarchy create limitations in self and worldly knowledge on other persons who are in the subordinate economic, social and political stratification. Thus, energies should be aimed at uncovering social processes that entail inequities in historical diversity, subjugated perspectives, and standpoints. She called for a reinvention of ourselves as "Other" to think from the perspective of more than one life, especially individuals that are marginalized. Thinking from the position of the other permits biases to be uncovered relocating ourselves into another's standpoint which is the crux of Harding's take on the Standpoint Theory.

Epistemology and Power Structures

Inherent in formation of knowledge is acceptance of ideas as being closely aligned with power structures. In considering the affiliation between power and creation of knowledge, it is apparent that specific ideas become prominent due to the influence of the power structures of a given society. Michael Foucault (1926–1984), an influential French philosopher viewed knowledge as being created to serve the interests of people in power while mirroring the objective of facilitating power.

Michael Foucault (2002a) described how power has changed over the centuries from a single authority figurehead to a conglomerate of power structures within society. Furthermore, he

defined power as a positive force contrary to the repressive overtones as conceptualized by Marx. Yet, power does not belong to a privileged class exercised on lower socioeconomic strata nor to an authority figure but power filters through all relationships. Foucault articulated how power “reaches into the very grain of individuals, touches their bodies and inserts itself into their actions and attitudes, their discourses, learning processes and everyday lives” (Foucault 1980, p. 39). Thus, power is pervasive surrounding our being as individuals act on behaviors of others to produce changes.

Power operates on several platforms including what Foucault terms bio-power, power over life. Foucault (1965, 1979) claimed that bio-power was formed at the end of the 18th century as a new type of medicine which focused on statistics. Information rendered from numerical figurations sanctioned bio-power to manage births, deaths, reproduction, and illnesses of a society through emanating and categorizing knowledge to affect the health of a society. Bio-power, Foucault argued, was the way in which institutions such as the government and medicine exert control over people to guide conduct or behavior to promote a better life. Thus over time, human beings have relinquished control over their health and bodies to power relationships within social regimes. Since the 18th century, Foucault’s concept of bio-power continues to be a dominant force within the healthcare industry. Bio-power influences the healthcare of a society through creating a specific ideology and secured knowledge base contained within power structures. Consequently, I contend that the exertion of bio-power has mostly removed life and death decisions from the domain of the competent individual into the hands of peripheral decision-makers exercising immense influence over the body creating a plethora of ethical discourse.

Bio-power exists within the alliance of two focal points: anatomo-political and bio-political (Foucault 2002b). Anatomo-political (discipline of the body) creates a power structure that normalizes citizens into self-regulating subjects who followed the standards for health, propriety, and productivity. For example schools, prisons and hospitals were among the institutions that worked to mold bodies and thoughts of individuals to generate conformity. Thus, bio-political (population management) polices the health of populations by using statistics to project random or plausible events that are predicted to happen in a given population. These statistics demarcated the norm while representing current ideology.

Bio-power created new ways of thinking, new knowledge closely aligned with the birth of human sciences. In the 19th century, human sciences emerged to establish a set of norms to standardize behaviors. Thus, a distinct body of information was created which categorized behaviors and thoughts on a continuum from deviant to desirable. This knowledge set was revered by individuals specifically professionals, to include nurses, which granted them a unique authority to uphold a homogenous society. Thus over time, individuals relinquished control over their bodies to power relationships found in the nurse-patient and physician-patient liaison. Docile bodies were constructed through exercising power that exploited bodies by turning them into a useful workforce (Foucault 2002b). Healthcare professionals basked in their scientific knowledge base securing it from mediocrity by creating a privileged source of knowledge known as bio-power.

Michel Foucault further articulated how knowledge was created for the benefit of power (Foucault, 1980). Foucault aligned knowledge as situated within an historical context emanating time sensitive, paradigmatic ideas. He believed that knowledge and power were intertwined. ‘‘Each society has its regime of truth, its ‘general politics’ of truth: that is, the types

of discourse which it accepts and makes function as true . . . (and) the status of those who are charged with saying what counts as true'' (Foucault 1980, p. 131). Thus, those in powerful positions are able to assert the truths as they know it. Foucault's notion of power relies on the construction of knowledge which is utilized and promoted within diverse discourses (including medicine and nursing) to rationalize and validate the conduct of individuals. Consequently, a capillary system of power is produced in which individuals and groups internalize and act on fabricated truths. More specifically, Foucault (1980) describes subjugated knowledge and popular knowledge, the former being that which becomes inundated under a surface of functionalist order and the latter referring to disqualified knowledge of people low in the hierarchy. Popular knowledge should not be confused with commonsense knowledge: popular knowledge is 'a particular, local, regional knowledge, a differential knowledge incapable of unanimity and which owes its force only to the harshness with which it is opposed by everything surrounding it' (Foucault 1980, p. 82). Thus, knowledge was seen as an instrument of power emerging from power relationships.

According to Foucault (1980), examination, normalizing judgment, and hierarchal observation are important venues in the use of knowledge to establish prominent power structures. In addition to measure knowledge, examination is used to create a norm or standard for others to uphold. Through examination, desired characteristics are compensated and strengthened. Normalizing judgment involves the maintenance of the status quo through conformity. Compliance to a socially accepted norm is reinforced through punishments and rewards. Hierarchical observation permits those in a higher power position to have an eclectic view. Foucault's proclaimed three instruments that serve to maintain existing power structures is evident in nursing epistemology as discussed in the forthcoming paragraphs.

Although there are major differences between critical social theory and Foucault's work, there are several notable parallels. Both stances recognize knowledge as contextually produced predisposed to power entities. Similar to Foucault's notion of power and knowledge, critical social theory views knowledge within a social, economic, and historical context organized around power and oppressive forces (Agger, 2006). Critical social theory is a conglomerate of different theoretical frameworks including critical theory, postmodernism, feminist theory and multiculturalism (Agger, 2006). In fact, Agger delineated seven criteria for a theory to be considered a critical social theory including the opposition of positivism; the endorsement of progress through determined political and social actions by increasing awareness of present oppression; supporting the argument that domination is structural; enhancing the awareness of the power of individual and collective agency to challenge the consciousness of false ideology inherent in power structures; supporting the argument that social change begins with alteration in day-to-day existence; and focusing on persuasive alliances between social structures and everyday life. To foster enlightenment and emancipation, critical social theorists advocate for the augmentation of knowledge through critical understanding of social and historical contexts of power structures while abrogating positivist methods.

Feminist theory often uses critical social theory in scrutinizing systems of power and knowledge (Daly, 1978; hooks, 1984). In particular, radical feminists concur that power structures discourage new knowledge from surfacing (Doering, 1992). The oppression of women is paramount to radical feminists generated from a male dominant society. Knowledge emanates from privileged male hierarchy exercising social control over women. Women's ways of knowing are not thought to be credible as they deviate from the empirical model as evident in studying the historical construction of nursing knowledge.

Critical theory, feminism and Foucault serve as a foundation for this research by creating an awareness of the current truths and dominating structures that interfere with the nurse's ethical discourse during end-of-life care. The process of identifying prevailing ideologies and their effect on nurse's professional conduct may aid in creating a new self in which the nurse is empowered. Furthermore, Foucault's concept of emancipation asserts that the individual must become aware of the current set of truths influencing behavior and create a new way of being and acting. As relates to nursing practice during end-of-life care, current ideology focuses on the medical model of cure prevailed by physicians. Nurses need their own set of truths focused on the holistic patient not a physical entity. In addition, critical social theory and Foucault's ideology support the need for nurses to analyze power structures to discern their influence on nursing practice, specifically ethical discourse during end-of-life care. For, example, we have already seen how the nurse may be reluctant to advocate for the patient due to fear of negative consequences. Power intimidates the nurse securing a decisive position in the lower strata of the power hierarchy dominated mostly by the male physician.

In nursing, power reigns within a gendered space of male dominance. Contributing to the subjugation of nurses is the class difference between physicians and nurses. Hierarchical power structures are prevalent as the physician is the leader of the healthcare team exercising patriarchal authority. Power created a unique reality and rituals for truth in nursing as nursing became dominated by the patriarchal realms of medicine and institutional bureaucracy. To further explore how power is an instrumental barrier to nursing, the effects of power on nursing knowledge will be explored.

Nurses' Knowledge

Nursing knowledge illuminates the development of unequal power relationships between nursing and medicine. Historically, gender, finances and education were culprits to advancing the status of nurses (Aita, 2000). For nurses trained under the Nightingale model, obedience, sacrifice and discipline were key attributes to being a 'good' nurse (Borsay, 2009). Nursing was viewed as women's work supervised and directed by the male dominant world of medicine. Character not skill was revered in the nurse. The physician was not to be questioned but obeyed. It is important to remember that in the infancy of nursing, women did not have a social role outside the home (Borsay, 2009). Nursing was seen as an extension of the nurturing female role. Complicating the issue of establishing a credible profession plagued by women was the lack of funding (Stein, 1998). In the United States, hospital run nursing schools often exploited nursing students through promulgating a system of free servitude to adequately staff the hospital wards. To compound matters, educating nurses in a university setting was protested by the medical regime as medical education swiftly moved to that arena during the first half of the 20th century (Stein, 1998). The notion that nurses are to be 'trained' while physicians 'educated' is sadly relevant to modern day. Thus, imbalanced power affiliations were created with physicians triumphing at the expense of the creation of an exclusive nursing knowledge base.

Nursing leaders of the 19th century, including Isabel Robb and Lavina Dock, strived to make nursing a profession by transforming nursing into a scientific entity (Aita 2000, Rush 1992). Nurses, however, were not privileged to scientific knowledge as their role was to make the patient comfortable and clean. Medicine unhampered and eagerly incorporated the sciences into their discipline. Hence, the medical model emerged as depicted as the "anatomical, physiological and biochemical malfunction as the causes of ill-health and encourages a disease-

orientated approach to care that stresses the structure and function of the body . . . rather than the uniqueness or integrity of the individual” (Aggleton & Chalmers, 2002, p. 28). Continuing into the first half of the 20th century, nursing was not seen as a true profession signified by not being privileged to revered scientific epistemology.

During the mid-20th century, the nursing profession’s continual struggle to embrace and incorporate positivism prevailed. Nursing no longer posed a threat to medicine permitting nursing to become a scientific discipline (Cody, 2000). Nurses in the 1950s delivered nursing care based on scientific methods but yet the humanistic aspect of care was ignored. In nursing journals published during 1947 through 1960, articles focused on science and technology (Aita, 2000). Some nursing leaders, however, expressed concerns that an emphasis on scientific methodology may be detrimental to shaping nursing knowledge. Thus, nursing knowledge was torn between an emphasis on positivism or humanism or more accurately plagued with how the two venues could peacefully exist within nursing epistemology.

Meanwhile, nursing knowledge became infused with “disciplinary power” as examination, normalizing judgment and hierarchical observation infiltrated into nursing (Doering, 1992). Traditionally, nursing examinations have focused on rationales behind tasks and skills rather than analytical thinking (Doering, 1992) thus limiting the scope of nursing knowledge. Nursing education, even today, places undue importance to nursing skills creating rigid standards in the form of normalizing judgment. Nursing tasks have to conform to a stringent set of rules without any room for divergence or creativity. Thus, resourcefulness and imagination is stifled while nurse educators proclaim their frustrations in enhancing critical thinking. Critical thinking is contextual in nursing education certainly not relevant to the acquisition of skills.

Nurses have gradually come to the realization for the need for nursing knowledge embedded in experiential and intuitive knowledge. It is only within the past three decades, that nursing knowledge has strayed from scientific endeavors to include other ways of knowing. Carper (1978) proposed a divergence from the empirical knowledge to four patterns of knowing to shape nursing practice and education. These patterns of knowing were empirics, ethics, esthetics, and personal. Akin to positivism, empirics focuses on the objective and data that is quantifiable and verified through scientific methodology (Carper, 1978). Ethical knowing was described as being affiliated with moral duty and obligation, facilitating correct moral judgments and decisions. Esthetics is considered the art of nursing requiring the nurse to see the entire patient scenario from an evaluative perspective which incorporates the outcome of creative interventions. According to Carper (1978), personal knowledge involves a cognizance of self and others in an existential relationship characterized by subjectivism. Carper's ways of knowing were revolutionary for the time period challenging the hold of empiricism on the creation of nursing knowledge.

Experience is another way of knowing that has relevance to the practice of professional nursing and specifically this research endeavor. Benner (1982) used the Dreyfus Model of Skill Acquisition to obtain an understanding on the role of experience to nursing practice. The Dreyfus model proposes that one passes through five levels of proficiency while developing a particular skill: novice, advanced beginner, competent, proficient and expert (Dreyfus & Dreyfus, 1986). Each level builds on the level before it as the novice gains knowledge, skills and experience. It takes approximately 5 years to move through the five stages from novice to expert but the expert level is not always achieved nor guaranteed.

The Novice to Expert Theory, as applied to nursing, depicts the role of experience in developing expertise in nursing (Benner, 1982). Throughout the novice to expert model, the practitioner is learning through experience yet it does not factor into decisive actions until more advanced stages. For example, novices consistently find themselves in novel situations and therefore must rely on “context-free” rules to guide their judgments and actions. The advanced beginner begins to incorporate contextual aspects learned from previous experience yet is still heavily dependent on rules to guide actions. The competent practitioner begins to problem solve by being cognizant of all the rules yet exercising judgment when applying them to specific situations. The competent nurse, relying on past experiences, is able to foresee long range goals and plans and incorporate them into patient care. The proficient nurse, steered by experience, knows how to modify plans to expected anticipated events. Maxims, nuances of a situation, are used to guide the proficient nurse. Then there is expert practitioners who have extensive experiences which guide their actions. Experience used in the acquisition of expertise is described as “not the mere passage of time or longevity; it is the refinement of preconceived notions and theory by encountering many actual practical situations that add nuances or shades of differences to theory” (Benner, 1982, p. 407). The expert nurse is not guided by rules or maxims, yet has an intense understanding of the situation enveloped in an intuition.

The experiential way of knowing in nursing practice was articulated by several nurse scholars (Benner, 1982; Benner & Wrubel, 1982; Burnard, 1992). Experience can be defined as knowing through repeated exposure to situations leading to refinement of earlier ideas and thoughts (Benner, 1982; Benner & Wrubel, 1982). Burnard (1992) described experiential knowing in the context of an interpersonal relationship saying it was the subjective and emotional aspect of the relationship leading to knowledge and that experiential knowing is

personal, distinctive, and difficult to put into words. Benner (2000) believed “knowing that” was the focus of Carper’s work and not “knowing how” gained from experience. Experiential knowing leads to intuition, the incommunicable or tacit way of knowing. Furthermore, phronesis is acquired through experience. Through experiential learning, phronesis is developed as the expert practitioner engages in practical reasoning that takes into account changes in the clinical situation while being engaged and attentive. Expert practitioners do not just engage in knowledge application yet draw on past experiences to create an embodied expertise specific to the clinical situation.

The truths in the stories of nurses are an important source of knowledge which should be revered. After all, in Greek, Medieval and Renaissance cultures, the main venue for moral education was telling stories (MacIntyre, 1985). Nurses’ stories can add moral perspectives to ethical dilemmas as narrators unfold experiences situated within social and political context. The nurse speaks from within, an embodied vision, connected to all the different nuances inherent in the story. The nurse at the bedside of the dying patient thinks from the position of the other, the patient, transforming knowledge. Yet, for nurses to claim a unique knowledge base, the oppressive nature of nursing must be radicalized so that their knowledge can be recognized as not only valid but revolutionary.

Summary

The literary and theoretical framework supports this study on how the narratives of experienced nurses can inform nursing ethics education during end-of-life care. A review of the literature reveals that a good death, while a recent phenomenon in Western civilization, is an imperative objective for many patients. Moreover, there are common domains that define a good

death but yet physician's goals center on the physical aspects of care while nurses and patients focus on a more holistic approach. During end-of-life care, nurses expressed a lack of know-how to care for the complex needs of the dying. Consequently, nurses, ill-equipped to effectively confront the many ethical dilemmas presented during end-of-life care, are frustrated experiencing stress and moral distress. Several barriers, including power hierarchies and the medicalization of death, preempt nurses from executing an influential role in end-of-life care. Nursing education has made efforts to include end-of-life care and ethics into the curriculum but yet nurses continue to lack the recourses to aid patients in achieving a good death. To empower nurses, an analysis of power structures including discourse on active resistance should be included in nursing ethics education. In addition, nurses' unique knowledge, expressed through narratives of their own experiences, should be revered as an imperative source of pedagogy. To this endeavor, nursing ethics education needs to include the perspectives of Aristotle to encourage the development of phronesis, practical wisdom, in future nurses to cultivate the expertise identified by Benner. Thus, the teaching of ethics in nursing education needs to step up to the plate so that more dying patients can actualize a good death.

CHAPTER III

METHODOLOGY

This research focused on the experiences of hospice nurses in confronting ethical dilemmas at the end-of-life as a rich source of data to inform nursing ethics education. A narrative inquiry was used due to its capacity to render life experiences in relevant and meaningful ways. In this chapter, I discuss narrative inquiry, participants, data generation and analysis strategies, and methodological rigor.

Narrative Inquiry

Connelly and Clandinin (1990) related narrative inquiry as the storied accounts of daily life and as a means of characterizing the phenomenon of human experience. In narrative inquiry, the focus is on the recount of the story as a succession of events that are significant to the speaker or audience (Moen, 2006). For this research, the audience is nurse educators and practitioners. My goal was for storytelling to unravel as nurses convey their experiences confronting ethical dilemmas during end-of-life care. In this light, these narratives serve as a medium for getting inside the nurses' minds to explore their realms of reference and comprehension. Knowledge was constructed through the articulation of these nurses' stories as they recounted their experiences. In essence, this research used narrative inquiry to endow nurses' experiences with meaning to generate a way of knowing (Emden, 1998).

Through incorporating narrative inquiry in my research design, attention was drawn to nurses as situated knowers whose knowledge can inform nursing ethics education. As these

nurses told their stories, they conveyed how they entered the world of patients, understood it, and responded to the demands of that world. The nurses' concerns, fears, and hopes were disclosed while telling their stories. Their personal narratives uncovered meanings and feelings that shed light on their personal, contextual, and relational knowledge (Benner, 1991). Nurses, in general, have an engaged knowledge of patients that allows for understanding and compassion, a foundation for embodiment. According to Benner (1991), embodiment acts as a moral source in everyday ethical comportment. Nurses not only possess an embodied knowledge but also a relational knowledge developed through everyday practice (Wright & Brajtman, 2011). The integration of these forms of knowledge assists in situating nurses to create a framework for ethical discourse. Narratives can best capture nurses' unique knowledge on ethics through direct access to their engaged reasoning as revealed in their stories (Benner, 1991). The nurses' situatedness, as revealed in their dialogues, has everything to do with their ethical practice.

Narrative inquiry on ethical discourse focuses on stories as told by nurses not on texts that are independent of participants. Therefore narratives occur within a social context so when nurses tell their stories they are not isolated from their environment or their humanness. Contextuality is key to narrative inquiry as the narrator is connected to the social environment. Context enfolds a specific text yet is a separate entity while co-existing in a symbiotic union (Hansen, 2006). Foucault (1980) reminds us that we live in a space embedded in settings, objects, and social interactions. In erasing social forces along with the nurses' culture, race, and gender silence permeates. Their stories need to be heard in context as it is not only important who tells the story but to position their stories within a social framework. It is important to acknowledge the social processes that produced the nurses' responses. I believe that narrative inquiry fostered a nested dialogue on the experiences of practicing nurses during end-of-life care.

Using narratives in healthcare research has become increasingly accepted as a methodological choice for improving healthcare and education as well as studying social phenomena (Elliott, Gessert, & Peden-McAlpine, 2009; Galbraith, Hays, & Tanner, 2012; Hernandez & Anderson, 2012; Hsu & McCormack, 2012; Kear, 2012; Stanley, 2008). My intention is to use narratives to inform and transform nursing ethics education. The sole knowledge of ethical principles does not translate into proficient everyday ethical practice. Learning to relate ethical theories and principles to practice depends on prior experience. Nurses learn skillful ethical practice best through dialogue transmitted through a group of practitioners (Benner, 1991). Telling engaged stories rather than abstract theorizing is a viable means to transmit knowledge. Thus, narrative accounts where nurses obtained new knowledge or felt good about their practice demonstrates moral discourse (Benner, 1991). It is my contention that narratives reflecting ethical expertise informed through experiences fosters a dialogue to inform ethics education by creating a bridge between ethical theory and practice.

Participants

This study was conducted in a hospice milieu in a metropolitan city in the Southeastern United States. Hospice denotes a public agency or private organization providing palliative and supportive care to persons terminally ill and to their families. End-of-life care is directed and coordinated by the hospice care team primarily in patients' private homes including long-term care facilities and assisted living institutions. A team approach, comprised of physicians, registered nurses, social workers, chaplains, and volunteers is the basis for hospice care. Regardless of ability to pay, hospice care is provided to the patient and to the patient's family

under a written care plan established and periodically reviewed by the patient's hospice care team (Georgia Department of Community Health, 2009).

Within the context of hospice, registered nurses have several responsibilities as they aid in managing care for 10 to 12 hospice clients with terminal illnesses. The registered nurse conducts a comprehensive assessment identifying needs of the patient as well as the capability of the family unit in meeting these needs. A plan of care is established with the input of the patient, patient's family unit, and patient's caregivers. The scope and frequency of hospice team members' services to meet needs of the patient and the patient's family unit are included in the care plan. In addition, the registered nurse provides continuing education for the patient and the patient's primary caregiver regarding progression of the patient's illness and care needs. Thus, the registered nurse in hospice care has a key role in coordinating and managing healthcare for dying patients.

In this study, participants were registered nurses employed as hospice nurses who were recruited using purposeful sampling. I selected participants because they "purposefully inform an understanding of the research problem and central phenomenon in the study" (Creswall 2007, p. 125). Potential participants were identified by the administrative staff of the hospice. Once permission was obtained from the Executive Director of the Hospice, a brief presentation of the proposed research was presented to hospice nurses at their bi-weekly meetings. Hospice nurses interested in participating in the study or seeking more information were provided with contact information. Method of data collection, the informed consent process, protection of confidentiality, and the participant's freedom to withdraw from the study at any time were thoroughly explained to potential participants.

Six hospice nurses expressed interest and were selected to participate in the study. They each had 2 or more years of experience working exclusively with dying patients. See Table 1 for a summary of the participants' demographics and experiences. The purpose for these criteria is to ensure that participants have bypassed the novice and advanced beginner stages of nursing practice as depicted by Benner (1982). Competent, proficient and expert nurses have multifaceted knowledge based on extensive experience on which to interpret new situations (Benner, 1982). The number of participants was determined to ensure a continuum of competent, proficient, and expert nurses to synthesize coherence in the narratives. In conclusion, the narratives of six experienced nurses offered a venue for comparison within a rich knowledge base.

Table 1

Demographics and Experiences of Participants

	Ellen	Leslie	Chris	Darlene	Amy	Mary
Years of Nursing Experience	24 years	28 years	38 years	18 years	30 years	20 years
Years of Hospice Experience	8 years	13 years	3 years	4 years	10 years	14 years
Education level	Baccalaureate of Nursing	Baccalaureate of Nursing	Associate Degree in Nursing	Baccalaureate of Nursing	Masters of Science in Nursing	Associate Degree in Nursing
Race/Ethnicity	Caucasian	Caucasian	Caucasian	Asian	African American	Caucasian
Hospice Role	Triage Nurse	Case Manager	Case Manager	Case Manager	Case Manager	Case Manager

Generation of Data

In this research study, I saw the interview as a means to produce new knowledge rather than a data collection exercise. Through interviewing the nurses, narratives were constructed that depicted the nurses' experiences with ethical dilemmas during end-of-life care. Open ended questions were so designed to prompt participants in telling their experiences. My goal was for participants to contribute their own ideas and to narrate their personalized stories of ethical discourse by means of sharing their knowledge. In narrative interviews, the narrator constructs a particular self, displaying a unique identity constructed within a cultural context (Riessman, 1993). I strived to bring recognition to the nurses' professional identities influenced by feelings and emotions yet situated within social and political understandings about death and ethics. The interviews were so designed for the nurses to divulge their expertise sharing a specific yet contextualized knowledge base.

I incorporated an ethnographic approach in interviewing as the focus of my research was contextualized. Social context surrounds and influences nurses' experiences with ethical dilemmas during the dying process. Narrative research often focuses on the text while ethnography is attuned to the contextual influence of the meaning inherent in the text (Pink, 2010). Relying solely on written texts for my data would evade making observations regarding the context in which texts are produced. It was my intention to use sensory ethnography interviews to enrich dialogues by conceptualizing them as a multisensory event and by attending to the nurses' treatments of their senses (Pink, 2010).

In realizing the need for sensory awareness, I incorporated two features to ensure attunement to the senses: reflecting on the senses during the interview process and emplacement.

A multisensory interview was created through inquiring how the participants attended to the treatment of their senses. Throughout the interview process, I asked specific questions to elicit the nurses' reflections on how they use their senses in their practice. For example, I asked questions such as "What are the sounds that you heard" or "Describe the odors present in the room." Through asking these seemingly simple questions, the nurses relayed how they characterized their own experiences, values, and morals through attending to their senses. The nurses were able to tap into their sensory memories providing insight into their emotions and feelings. Therefore, the interviews were so designed to probe the participants to use their vision, smell, and touch as sensory modalities contributing to their understandings of ethical decision making during end-of-life care.

Emplacement was achieved through my proximity to caring for the dying as being a hospice nurse enabled me to move through and be in and part of an environment with participants. Pink (2010) viewed emplacement as "the relationships between bodies, minds and the materiality and sensoriality of the environment" (p. 25). Understanding the sensory experiences of the nurses was enhanced through having partaken in similar worlds. I have engaged in similar situations to the participants' experiences and realities thus creating an emplaced ethnographic quality to the interviews (Pink, 2010). My parallel experiences constructed a venue for sharing embodied understandings through incorporating the senses. As a researcher, I was able to align my sensory experiences with the participants' senses. Thus, I created a process of movement through the narratives drawing on my familiarity with shared embodied experiences, emotions, and ideas during end-of-life care. It is through engaging in comparable activities and environments of the nurses that I came to know and understand their stories. In summation, viewing the interview as a process bringing together not solely emotions

and experiences but the sensory creation of the environment offers a means for understanding the interview as an emplaced encounter.

The narrative interview consisted of two parts, as proposed by Bertaux and Kohli (1984). The first interview supported an extensive narration by the participant during which I guided the interview through questions and prompting to elicit their verbal, experiential, emotional, social, and sensory encounters (Appendix A). The second part of the interview involved more purposeful questions to seek clarification of topics introduced in the first interview and ask questions related to the educational preparation for ethical decision making. All interviews were audiotaped and fully transcribed by me within 48 hours of the interview. The prompt transcription aided in accuracy in capturing the participants' stories.

Hand written field notes were used to further generate information as to the influences of the context from which nurses told their stories. I made a brief written record of my impressions by jotting down key words and phrases after each interview. These jottings jogged my memory to construct evocative descriptions of the interview. Immediately after leaving the interview, field notes were written up.

Data Analysis

Data analysis in narrative inquiry can employ several different approaches as there is no standard methodology (Kelly & Howie, 2007). Polkinghorne (1995) attested to two different methods of analyzing narrative data: paradigmatic analysis of narratives and narrative analysis.

In paradigmatic analysis of narratives, categories are produced from the data analysis using paradigmatic analytical procedures to ascertain common elements across the database (Polkinghorne, 1995). In narrative analysis, data is analyzed through synthesizing actions,

events, and happenings to produce stories as the outcome of the research process (Polkinghorne, 1995). I incorporated a paradigmatic analysis to determine broad themes and subthemes throughout the data set but also used narrative analysis to synthesize the data into specific ethical dilemmas.

In this study, the narrative inquiry combined two different strategies. To determine dilemmas faced by participants, I used core story creation as described by Emden (1998). Using core story creation, I reduced full length stories to shorter stories to form concrete narratives depicting ethical predicaments. To elicit moral dilemmas faced by each nurse, I used the following steps as illustrated by Emden (1998):

1. I read the interview transcripts several times including listening to tape recordings of interviews. This allowed me to be aware of voice tones, inflections, pauses, and silences to best understand content. I was able to relive the interview, reflect on content, and write down any new ideas or comments.

2. I deleted all of my questions and comments from the interview transcript.

3. I deleted all words that detracted from the key idea of each sentence. I was careful to ensure that the integrity of the stories remained intact as specific dilemmas were unfolded.

4. I read the remaining text to ascertain that dilemmas within the stories made sense.

5. I repeated steps 3 and 4 until only the central ideas remained in each dilemma, making sure that all key ideas were retained. I was very careful to ensure that the dilemmas were true to their narrative form.

6. I returned the core story (dilemmas) to participants for verification at the second interview. None of the participants requested any changes to their stories.

Initially, I planned to use core story creation and emplotment as a means of identifying themes in the dilemmas (Emden, 1998). I chose, however, to inform my data analysis through a more deliberate and rigorous thematic analysis as outlined by Braun and Clarke (2006). I was also apprehensive that using only dilemmas to generate themes may miss important data. Thus, using the entire data set, I employed the following steps to create themes:

Step 1 Becoming Familiar with the Data: I read the entire transcripts several times comparing them to audio recordings. This allowed me to become familiar with the data once again. As recommended by Braun and Clarke (2006), I made notes regarding sections of data that I felt were significant. In this step, my goal was to become familiar with the data which was successfully accomplished.

Step 2 Generating Initial Codes: Being familiarized with the data, I then provided initial codes within each participant's transcript. Given my study was driven by research questions and grounded in a theoretical framework, the themes were theory driven (Braun & Clarke, 2006). Coding was done manually on the computer, electronically highlighting specific data excerpts and designating relevant codes beside each selection. I worked systematically through each data set giving an equal amount of attention to all data items, coding for "as many potential themes/patterns as possible" (p. 89). To preserve context, I left the surrounding data for each code intact. I coded data extracts for as many different themes as relevant. After all the data were coded, I collated them within each code. The correlation between codes across data sets provided a long list of different codes reflective of all the data.

Step 3 Searching for Themes: All of the codes were reviewed and sorted so that groups of related codes either formed main themes, sub-themes, or were discarded if not relevant. Through sorting the codes into themes, I created a thematic map, effectively outlining the interrelationship

between each of the themes and sub-themes generated from the codes (Braun & Clarke, 2006). At the conclusion of step three, my initial thematic map housed four broad themes and 13 subthemes, each associated with one of the broad themes.

Step 4 Reviewing Themes: In this phase, my task was to refine the themes. I reviewed all of the codes within each theme to determine if there was enough supportive data and if any similar themes should “collapse into each other” (Braun & Clarke, p. 91). First, I readjusted locations of any codes that did not fit within a given theme to ensure that each theme formed “a coherent pattern” (Braun & Clarke, p.91). Second, I reviewed each theme by collapsing or removing themes that were unsubstantiated or lacked distinction. I also removed themes that were not relevant to the research question. The resulting thematic map included three broad themes and nine subthemes.

Step 5 Defining and Naming Themes: I examined the data extracts for each theme and organized them “into a coherent and internally consistent account, with accompanying narrative” (Braun & Clarke, 2006). I looked at each theme to determine its relevance to the research questions and their relationship to other themes. At the end of this step, I was clearly able to define and name themes.

Ethical Considerations

The main ethical considerations for this study are informed consent, confidentiality, and anonymity. An informed consent form (Appendix C and D), which included permission to interview, audiotape, and publish the findings, was obtained from all participants and the hospice agency. Included in the consent form is a statement that participants could withdraw at any time, refuse to answer questions, and ask questions. The participants’ rights, as depicted in the consent,

were reiterated at the beginning of each interview. Signed consent forms were obtained before the first interview.

Confidentiality and anonymity of participants was ensured by participants choosing a pseudonym to be attached to the transcribed interviews and data analysis. Transcribed interviews and data were coded with the pseudonyms and maintained in a locked cabinet. Access to the transcribed interviews was limited to myself. Lastly, this proposal was submitted to The University of Alabama's Institutional Review Board (IRB) for ethical review (Appendix B). All recommendations by the IRB were implemented.

Establishing Rigor

Rigor is the means by which research is determined to be legitimate, worthy of contributing to the knowledge base. The question of rigor has perplexed qualitative researchers for the past three decades (Emden & Sandelowski, 1998; Finlay, 2002; Jootun, McGhee, & Marland, 2009; Koch & Harrington, 1998; Lincoln & Guba, 1985). Without rigor, qualitative research may be rejected as a science (Morse, 1999). Lincoln and Guba (1985) suggested four tailored criteria for qualitative research: credibility, dependability, confirmability, and transferability, I question their relevance in this study that embraces objectivity. These four operational techniques have been assumed to support the rigor that should be evident in qualitative research. Yet, establishing rigor can be laced with positivist notions of objectivity as I grapple with concepts such as transferability and truth to knowledge. My contention is that there are many truths to knowledge. Furthermore, I do not expect my findings can be replicated or transferability as they are unique to the social context of this study. Qualitative research as a joint effort between the researcher, participant, and the relationship between the researcher and

participant cannot be duplicated as it is socially constructed (Finlay, 2002). I am not rejecting the idea of rigor but questioning how to best frame its relevance in this study.

According to Streubert and Carpenter (1995), rigor is of utmost importance in qualitative research to ensure that the participant's information has been accurately represented. Creswell (2007) identified eight key strategies for establishing rigor and recommended that qualitative studies use at least two of them. His approach offers a practical synthesis of recommendations from other authors. The key strategies are prolonged engagement and persistent observation, triangulation, peer review or debriefing, negative case analysis, reflexivity (clarification of researcher bias), member-checking, thick description, and external audits. To establish rigor, this study utilized primarily reflexivity but also member checking.

I employed reflexivity as a key means for ensuring rigor in this study. Finlay (2000) explained reflexivity as the process by which researchers scrutinize their own motivations, assumptions, and interests to the subject matter. It is through reflexivity that the researcher practices ongoing self-critique and self-appraisal (Koch & Harrington, 1998). Reflexivity also relates to the degree of influence the researcher exerts on the study (Jootun et al., 2009).

I used reflexivity as a tool for establishing validity in qualitative research yet also as a means for guiding the research process (McCabe & Holmes, 2009). Often reflexivity entails bracketing to put aside one's beliefs to minimize subjectivity before the research commences. Bracketing often has a negative connotation as the researcher attempts to be neutral. The premise of my research relates to the impossibility of being totally detached undercutting any positivist connotations. Yet I do believe it important to reveal my own motives and interests in nurses' abilities to make ethical decisions at the end-of-life to help inform my research.

As a hospice nurse, my main role is to care for the dying and be an advocate for patients and their families. I have witnessed that many patients are not well-educated and rely on the medical establishment to guide their choices. Despite extensive efforts to improve care of the dying, I have found that patients still encounter a prolonged death with mental and physical anguish. The medical professional's ability to "bring back to life" is precipitated by medical procedures such as cardiac catheterization, surgery, or the administration of medications. These medicinal interventions may temporarily elude death at the cost of a life that prolongs a tortuous dying process. Furthermore, I assert that death is often dehumanizing and disempowering due to power structures and emotions that interfere with the dying process. Most significantly, patriarchal power has created a venue in which the medicalization of death ensures that death is administered in an industrial and mechanical fashion. Thus, reflecting on my research and understanding how my own values and view may influence the findings adds credibility to the research.

As a qualitative researcher, I acknowledge that any findings are the result of my interpretation. I used reflexivity as an advantage revealing my connection with the social and professional world of nurses with dying patients. This association permitted me to read between the lines with a unique ability to understand with a keen sensitivity. I can construct meaning which may not be apparent to the outsider. I intend to use reflexive analysis as I write my field notes, before and after each interview, to unravel meanings.

To member check, the core story creations depicting ethical dilemmas were provided to the research participants for validation at the second interview. The second transcriptions were emailed to the participants. No alterations were deemed necessary by the participants to include in the transcriptions.

Summary

This research study utilized narrative analysis as a qualitative research approach to explore how experienced nurses make ethical decisions during end-of-life care. Data were generated from one-on-one interviews with six hospice nurses. The semi-structured interviews were conducted in two phases. Core story creation and thematic analysis were utilized to generate commonalities and differences within the narratives. The rigor of the study was enforced through threading self-critique and self-analysis throughout the research process. Ethical standards to ensure anonymity and confidentiality were implemented to protect the participants' rights.

CHAPTER IV

DATA ANALYSIS RESULTS

The purpose of this study was to explore experienced nurses' successful resolutions of day-to-day ethical dilemmas during end-of-life care inform nursing ethics education. This chapter focuses on the analysis and interpretation of the data. The dilemmas are presented first to foster an appreciation of each nurse's moral struggles. Following this, I present my discussion of the thematic analysis of their narratives framed within discussions of situational context, deliberations on how to solve the conflicts, and actions taken by the nurses to resolve the dilemmas. This sequential framework situates the three main themes and nine subthemes to best understand how the nurses faced and solved ethical dilemmas. In addition, information from the ethnographic interviews is highlighted throughout to position the data in a social context. Last, the results were used to answer the research questions.

Dilemmas

Each nurse shared their stories as they recounted numerous ethical dilemmas some from the past others from currently challenging situations. These dilemmas were captured during the initial interviews and revisited during follow-up meetings for clarification purposes. To depict the essence of the dilemmas, "core story creation" was employed (Emden, 1998). Using core story creation, I reduced the full-length stories to shorter stories to form distinctive dilemmas. During the process, I read the interviews several times to become familiar with the content. I

then deleted all of my questions and comments from the interview and all words that detracted from the key idea of each sentence. Then, I read the remaining text for sense. I repeated deleting all distracting words until only central ideas remained in which the product depicted specific dilemmas. I was careful not to delete too many words because it is important that the essences of the quandaries are captured in the storytellers' own words. The following are the ethical dilemmas experienced by each nurse through core story creation.

Nurse Ellen's Dilemmas

Ellen and I met in the quiet room in the public library. She is a graduate of a 4-year program with a baccalaureate degree in nursing. Ellen has been a practicing registered nurse for 24 years, the past 8 years in hospice. She was employed as a hospice case manager for a little more than year before she became a triage nurse for hospice. The role of the triage nurse involves guiding patients and their families after office hours on her mobile. Ellen addresses their concerns through either giving information or sending a nurse to assess the situation. Sometimes Ellen has to make a visit to the patient but mostly she problem solves via cell phone. She also serves as a valuable resource by advising the field nurses who visit hospice patients. If Ellen has any concerns herself, there is an administrator available for guidance.

Ellen addressed four specific dilemmas during her conversation with me. Interestingly, she did not refer to the ethical principles or the American Nurses' Association Code of Ethics when telling her story. Yet each dilemma was superimposed with ethical principles and/or violations of the code of ethics. During the interview, Ellen did admit to taking an ethics class but confessed to not remembering any information. Ellen resolved ethical dilemmas by prioritizing the needs of the patient to trump any other agenda and by doing "what was right."

The first predicament was actually a patient she cared for at the beginning of her hospice career. She told the story of a middle aged man on hospice because he had lung cancer yet the disease was never confirmed through medical technology. The patient, Mr. X, thought he was told he had lung cancer so he repeated this information whenever going to the emergency room or to a physician. The medical professionals never validated his claims. He was erroneously placed on hospice for allegedly having a life-threatening illness. To be eligible to elect hospice care an individual must be terminally ill with a medical prognosis supporting a life expectancy of six months or less if the illness follows its normal course. The employer did not want to discharge the patient from hospice services due to financial reasons. Thus, the conflict centered on Ellen doing what was best for the patient despite receiving contradictory instructions from the employer.

So I had one patient, years ago now. Mr. X had a diagnosis of lung cancer and he was medicated for that; and we had him on for months. Then he tried to apply for some kind of SSI (social security income) benefit. And when he applied for the SSI benefit they came back to him, and they said that in his file they really couldn't find anything that said he had a terminal diagnosis so that they could put him on disability and give him SSI. So they had asked that they get some kind of X-ray and results and that he go to one of the government contracted physicians. So when he went to this government contracted physician, it ended up that they found that this man didn't have lung cancer . . . he didn't have any kind of cancer. He had an ulcer. So I took that to my boss, and her remark was: "We're not in the business of discharging patients." So I had to come up with some way to get this person his life back.

And I was told that I really was not partner to the information that SSI had gotten unless Mr. X was going to let us do that. He was hooked on the medication because he was in a lot of pain, and so he was on a lot of morphine. So he was at a point where he wasn't sure he really wanted to come off (hospice) and I had to figure out what I could do for him to benefit him to make him feel better to get him off without doing something against company policy to get him off.

So he did end up going to his attending (hospice) physician who submitted the results that ended up letting us know his chest x-ray was clear. And then (I had to) have the physician write an order to discharge the patient without me asking him to do it. And then getting him (the patient) into a drug rehab, home rehab program.

So the dilemma was, how to get a patient back his life, even though my boss was saying, “We’re not in the business of discharging patients.” That was my dilemma. That was a big dilemma, but it worked out. He ended up going on a decreased fentanyl patch, and he went on some methadone . . . because he was getting some pretty hefty doses of morphine for that pain. And it ended up to be an ulcer.

When I came off the case, I stayed in contact with him. He was okay. He was my first home patient for me to manage. I would always be for the patient versus I lose my job. If I was to find information on him and didn’t bring it out, or didn’t bring it to light and it had repercussions for the patient. Let’s say it was something as simple as that he had a negative chest x-ray. What if I withheld that information and let him die? Continue on hospice and lose his life over it? That doesn’t go along with doing the right thing in nursing. We have to bring that out regardless of how your employer feels.

Ellen’s second dilemma focused on the nurse’s role in hospice care as dictated by the employer. Ellen recounted the story of a hospice patient who was on a large dose of morphine yet her pain levels were not diminished. The hospice nurses suspected an addiction problem believing administration was not active in finding a solution to the patient’s increased need for Schedule II controlled substances, which have a high potential for psychological and physical dependence. Apparently, narcotics were missing in the patient’s home resulting in the nurses visiting the patient daily to supply the Schedule II medication. The nurses expressed concern not wanting to be part of the problem by aggravating the patient’s possible addiction versus implementing an effective resolution. The employer, however, informed the nurses that they had to care for the patient by supplying the controlled substances on a daily basis.

A patient is on with us for a diagnosis that’s not a necessarily an approved hospice diagnosis. And she gets medicated with hefty doses of morphine--injectable, veinously--that we draw up and have delivered to her home every day. She gets a total of a hundred milligrams of morphine every day. I think that’s a lot. That’s a boo coo lot. But it doesn’t work. But yet, we keep ordering medications for her, sending nurses out to draw the medications up because at some point there were some medications missing. So we stopped just delivering the medications. We have our pharmacy deliver the medications to the house, then the nurse comes behind, makes a visit, takes medications out of the packet, puts them into a lock box that has a code on it that only the hospice nurses know, and then the hospice nurse, every day, makes a visit to this patient and draws up all these syringes of morphine, so this patient who has a PICC (Peripherally Inserted Central Catheter) line can inject herself with the morphine--she’s got Ativan, too. So she gets a

certain number of syringes filled every day. But she always gets the same number of syringes filled. She always uses all of them, and she always rates her pain at a 10. And so we've had a number of nurses who won't go there now, because they say we're not really doing anything--we're not managing her pain; we're just feeding an addiction. But as a triage nurse, I have to get that call from the patient that says my nurse hasn't come to fill my syringes yet. And yet, when I talk to her, you can't even understand what she's saying. It's like she's had this boatload of meds and she can't even tell you what's wrong with her.

She calls probably 15 times in a row, and then I have to make a decision. Well, is sending the nurse out to this house to see this patient to fill these syringes for this patient that is just addicted and we're feeding into it, really the priority--or is the priority sending the nurse somewhere else where she really needs to go. I deal with that every weekend.

And then we have a few nurses that have already made that decision that they're not going to go to that patient's house, and who have been reprimanded by the company and been told that you have to go. And those nurses will say, "I don't believe that this is the right thing." I think this is a bad choice that we do this. And if I was to be put in that same situation, if it came down to if I had to become the runner (the nurse that goes to the house to see the patient), I wouldn't do it either. So that's an ethical dilemma, too.

You know why are we giving this patient 100 milligrams of morphine every day? She still rates her pain a 10. It's not effective.

The third dilemma had to do with whether medicating a patient for pain would do more harm than good. The patient had a chronic, debilitating disease affecting his neurological functioning. He could no longer breathe on his own requiring a mechanical respirator. Yet the patient elected to be a "full code" meaning that if his heart or breathing stopped, cardiopulmonary resuscitation (CPR) would be done by the healthcare professionals. The dilemma focused on whether to medicate him for discomfort which may have adverse effects resulting in his heart or breathing stopping requiring cardio-pulmonary resuscitation. The administrator advocated for medicating the patient but Ellen feared there may be adverse repercussions. Ellen decided to consult with respiratory therapy and solved the dilemma.

We have a man who's a full code, he's on a vent (ventilator), and he has ALS (amyotrophic lateral sclerosis). He was feeling very short of breath, like he was suffocating. And you couldn't lay his head down. You couldn't almost go even 45 (degrees). He almost had to go total 90 (degrees). And his wife was calling. He was

spitting up green stuff. And she thought he had an upper respiratory infection. And she wasn't really sure what she wanted to do. And for us, it was just medicate him. But if we medicate him, he's a full code. And if we get him really super comfy, we might be putting him in a situation where, respiratory-wise, he's not going to function well. I'm not really sure what the settings on his vent (ventilator) were. Well, it ended up being that we ended up calling the respiratory therapist and bringing them in. And instead of having to medicate this individual, like we were told to do (by administration), we brought the respiratory therapist in, had a consult with them, and tweaked his vent settings, and immediately got rid of his shortness of breath and feeling like he was going to die right there.

But they (administration) really just wanted us to medicate him to get him comfortable. That would have thrown him into a situation where he might not have been able to breathe very well on his own. But they wanted us to medicate him even more, but we chose not to do that. So we called the respiratory therapist so he wouldn't get into a code situation. We just said why don't we just call the respiratory therapist? And they (administration) said yes, go ahead and call him, and then his comfort levels improved after that versus the medication. Of course, the whole thing was being on hospice and being a full code, especially cardiac and ALS patients.

The fourth dilemma involved a conflict with what the family desired for the dying patient versus hospice's protocol of promoting comfort. The family wanted antibiotics although the patient was actively dying implying that death was imminent. The patient was no longer able to swallow necessitating the antibiotics to be given rectally. Rectal administration of medications entails turning the patient and inserting the medication into the rectum which often results in discomfort while compromising the patient's dignity. Ellen utilized her senses in describing the patient rendering some insights into how the patient appeared to the family and healthcare professionals. She concluded the story by stating that medical treatment was ineffective as the patient died despite the antibiotics.

I had to go out and see somebody that was probably dying. I put them on a watch (watch status means the hospice nurse will contact or visit the patient frequently). They (family) wanted to try everything before he died even rectal antibiotics. I just thought you really want to do this for a person who's dying. But that's the family's choice. That's what they wanted to do. So that's what we did. It was their last attempt. A lot of it is what they (patients) want to do. And what their families want. So that's what they want to do, so that's what you do. Because it's for the patient.

I saw this patient who had a hyperextended neck. He was really pale. His mouth was dry. His lips were dry. He was mouth breathing. His eyes were open. His pupils were pinpoint, and they were fixed. He was stiff and he was rigid. He was in an attempted fetal position, but he had a broken hip. And his feet were starting to mottle, and they were discolored and cool to touch. And he had that smell about him. And he had a dry diaper, and it hadn't been wet for over 24 hours. And that smell from his breath was kind of deathly. And they (family) were questionable. They were trying to be optimistic. You could sense that they wanted him to get better especially the wife sitting there. They had been married 40 something years.

And she was sitting there, and she kept saying, "Can we do this?" And he was a DNR (do not resuscitate). And he was a CVA (cerebral vascular accident) from I don't know how long ago. But I think he had a urinary tract infection and we were giving him Cipro (an antibiotic). And regardless of the fact that he was dying, they (family) wanted everything done for him. They wanted me to give him those antibiotics rectally, and they wanted them twice a day, and they wanted to continue that long-acting MS-Contin (morphine) along with breakthrough Roxanol (a quick acting morphine) and all that he needed.

He died two days later. And they gave him those Cipro tabs rectally the whole time. I wasn't there but I just went out there and saw him that one night when we were short (staffed).

To summarize Ellen's dilemmas, three predicaments focused on conflicts with the employer and one predicament centered on conflicts with the family. The first scenario involved a patient who was on hospice services inappropriately as he was not qualified according to hospice guidelines. Ellen devised a solution congruent with the patient's best interests yet was acceptable to the employer. In fact, each ethical dilemma was resolved by prioritizing the needs of the patient to trump any other agenda. The second case of the nurses ineffectively caring for a patient who may have been on hospice to obtain Schedule II drugs was resolved by some, but not all, of the nurses refusing to visit the patient. The nurses believed that they were harming the patient by not addressing the patient's addiction needs. The third dilemma with the patient on a respirator was settled by consulting with another discipline to resolve the patient's respiratory symptoms. Administration advocated giving medication which may have potentially harmed the patient. The fourth case focused on the family's goals interfering with a peaceful death for the

patient. Unfortunately, this dilemma was resolved by the patient's death. Yet, Ellen kept the patient in the forefront of prioritizing nursing interventions as she did with all the ethical dilemmas that she recounted.

Nurse Leslie's Dilemmas

I interviewed Leslie in a quiet room in the county's art building. Initially, she received an associate degree in nursing but pursued her education to obtain a baccalaureate degree in nursing from a religious-based university. Similar to Ellen, she did not refer to the code of ethics or the moral principles in her stories. Leslie, however, attributed her education as having a profound influence on her current practice. She stated she incorporated what she learned from a death and dying course into her current nursing practice. Frequently she poses the question "Are you extending your loved one's life or are you extending his death?" to significant others; a question she learned from her professor. This inquiry aided families to situate their decisions using a different perspective. Leslie reminded me, however, that her baccalaureate nursing education was frequently based on a spiritual foundation.

Leslie was passionate while recounting seven ethical dilemmas precluding the patient from a good death. Leslie has been a practicing registered nurse for 28 years, 13 of which had been as a hospice case manager. Leslie's job duties include visiting patients in their place of residence one or two times a week to manage their symptoms and coordinating care with the other hospice disciplines. Educating significant others is also an integral part of her job responsibilities. Leslie was quite animated while telling stories of day-to-day ethical occurrences which caused personal frustration and disillusionment as she attempted to manage these cases to a successful fruition.

Leslie's first dilemma focused on a conflict between a stakeholder's goals and the best course of action for the patient. In this scenario, the stakeholders are the staff members at a Long-term care Facility (LTCF) who deliver daily nursing care to the patient. The facility's nurses expressed concern that the patient was too noisy disturbing the other residents. The staff at the LTCF wanted to medicate the patient with tranquilizing drugs to calm her yet Leslie feared that these medications may be too sedating resulting in further patient decline.

I have a patient who is doing a lot of yelling right now. She's not in pain. We've figured that out. And she will be yelling and yelling and yelling, and we'll go to her and we'll hold her hand and go, "What's the matter?" And she goes, "Nothing."

So basically, she's vocalizing and she's yelling, but she's not doing it because of pain, because of anxiety, or anything else. The facility that she is in wants us to medicate her--to give her Ativan to essentially shut her up. I have a very hard time doing that and I'm not going to do it at this point because right now she's still eating. She's still able to verbalize some things. If you ask her, "are you in pain" she'll say "no" or what have you. If I start medicating her to quiet her down for staff convenience then I am interfering with her right to be not medically restrained. While I understand what the staff is saying, I also understand that I have a duty to this patient . . . to keep her not medically restrained; however, I also feel that anxiety and yelling and that sort of thing can be a type of suffering.

Suffering is not just the pain issue. There could be spiritual suffering. There could be all kinds of suffering; however, she doesn't seem to be suffering at this point. And so I can't justify, in my mind, medicating her.

What I'm going to do is I'm going to contact the family and I'm going to have a heart-to-heart with the daughter and see where she is with all of this. And if she is okay with me trying a very small amount of Ativan or Xanax or Valium or something like that--just to take the edge off, but not to actually sedate her, then I would be okay with that. But I also have to know where the family is. And one of the things that I don't want to put them on hospice and we're going to start giving them Ativan and morphine and all these other drugs until they become comatose; and that's not right.

The second dilemma Leslie recounted focused on conflicts with her employer. Leslie is adamant about managing the patients' symptoms successfully yet the hospice agency will not pay for effective pain relief medications. Only medications that are on the hospice formulary are paid for by the hospice. Leslie described how she puts forth maximum effort to get the hospice

agency to pay for a particular medication through education. Yet she felt it necessary to resort to deceitfulness while the company was contemplating her request for the pain medication. Leslie justified her actions, however, by meeting the patient's need for pain control.

Now, the other issue that I have with end-of-life care, in terms of symptom management, is pain. And there is a point where if you just go with the cheap stuff, which is liquid morphine, then sometimes you have to go all the way up to the edge of actually causing them to go into respiratory shutdown before you get the pain managed. However, if you can combine some of the other medications with it, and specifically things like steroids, or some of the more expensive pain management issues such as pumps, the pain can be managed so that the patient is still alert and talking.

And sometimes, I get resistance from the company that I work for because it (the medication) is not in the formulary. So the ethic part comes into, "Who am I supposed to be taking care of? The patient? Or the bottom line of my company that I work for?" And it's very difficult. And there have been many times when I've been so vocal about it that I've actually gotten in trouble from the company, not from my families.

And many times, I have to think that I know this will be better for them, in terms of pain control, but I'm not going to say anything because then that will set up the family for expectations that I can't fulfill. And that is very hard, especially if I know something would work better that is not on the formulary.

I have a perfect example. There is a medication that you can use that you spray up your nose, and it's usually used for osteoporosis. It actually helps at a certain dose repair micro fractures in the bone. And it's not a narcotic. But it's really good for pain control because it heals these micro fractures that a lot of patients with bone cancer get. I know it works. It's been everywhere in the literature that it works but I can't get it through my company, because it's not on the formulary, even though it only costs \$120 a month. Now, that kind of stuff makes me crazy because I am for patient care and for symptom relief.

So what I have done is I've gone out on this campaign with my company. Bringing in info on this stuff and showing how it's really better to use this for the people that it does work. It doesn't involve narcotics, and we would use less narcotics, which means we would use less stuff for constipation and less stuff for all of this other stuff. To show that it's money well spent. And so I think we're on the verge of being able to use it. But it's been a slog. And I feel that I shouldn't have to work that hard to get medication for my patient.

And so what I've done is I have stretched what could be considered the truth and say, "Okay. This person has osteoporosis" and get this medication ordered through the family's (insurance) for osteoporosis, so they're getting it and we (the hospice) is not paying for it. Their insurance is paying for it because it's not hospice related. So

ethically, I feel like I'm on the right path, in terms of getting the patient's symptoms controlled. But I also fight with the fact that I'm not really representing the true condition of the patient because I have to lie to get a medication for them that really and truly we should be paying for. You know we really should be paying for this spray for pain control rather than me having to go in the back door and have the insurance or the family pay for this spray instead.

Leslie's third ethical dilemma revolved around conflicts with the hospice physician who wanted to order diagnostic tests. In end-of-life care, diagnostic procedures are not routinely ordered because the ultimate goal focuses on patient comfort rather than treatment. Leslie believed the physician was fearful of a lawsuit so ordered diagnostic tests although treatment was rarely initiated. Leslie sounded her frustration by making the analogy of "boxing fox" as she "fights" for the patient's right to a peaceful death without being prodded by painful, unwarranted diagnostic procedures.

I work in a long-term care facility with the doctor at that long-term care facility but he's also the hospice doctor where I work (at the hospice). And he is very concerned about being sued. And he is always wanting to order things, labs especially. "Let's do a CBC (complete blood count). Let's do a CBC with diff." Let's do a multitude of different lab things. Just pick one. And I am like, "No. What are we going to do with this information?" "We've got to know what it is" (as retorted by the physician). "Why? Are we going to do an intervention? Or if the blood count is low, are we going to give them blood?" "No, we're not" (as retorted by the physician). "Then, let's not do it. Let's not stick this man." Because when you know what something is, the implication is you're going to have to do something about it.

So he (the physician) has a very difficult time with that even though he's a hospice doctor. He still has a hard time wrapping his brain around sometimes doing nothing is the most ethical decision possible. He'll want x-rays. The family has already said they don't want any antibiotics, so why are we going to do an x-ray? "Well, to see if he's got pneumonia" (per the physician).

But we're not going to do anything. So let's not do anything. And that is the ethical decision to just keep this person comfortable, and the family is comfortable with it; so, please, let's not do this. And it has been an uphill slog because a big, big thing that's happening is nutrition. It's perfectly normal for somebody who is at the end stage of dementia to stop eating, or to eat less, and they start losing weight. That's part of the thing. He'll want to put them on Megace or Remeron or something to boost their appetite. And then he'll order this stuff, and then I'll call the family, and the family's like, "No. I

don't want this." Then I have to go back to him (the physician) and say, "Look, the family is saying no."

His modus operandi is to order it and then have the family say no. That way he is covered so that he doesn't get sued. Where, my modus operandi is not to bring it up at all unless the family expresses concern. Because it's part of the dying process.

And he's not the only one. I mean, there are lots of doctors who do this. Or order medications that are really not appropriate anymore i.e. cholesterol medication. "Well, you know, they're cholesterol is really high" (per physician). "But they have end-stage cancer. They're going to be dead in three months, do we really care?" And I say that, but that doesn't mean that I don't care that they're going to be dead in three months; but you have to at some point talk about the elephant. And I have to go, "Do we really care about their cholesterol?" as he's ordering cholesterol labs. We don't care about their cholesterol anymore. Let them eat cake. Let them eat whatever they want.

So it's very hard. Because a lot of times I feel like boxing fog, you can keep hitting at it, but you're just going to go right through. And sometimes I feel with the medical doctors that I really have to do that and fight for the patient. Because they are doing things that, in a hospice context, are totally inappropriate anymore.

The next dilemma that Leslie described centered on giving bad news. She discussed how the physician may recommend hospice services yet the patient and significant others are not aware that the patient is dying from a terminal disease. Leslie rendered the excuse that the patient and family may have been given the information but were unable to process it due to their anxiety. Nevertheless, this does present an ethical dilemma focusing on who should give the "bad news" and when should it be initiated.

The other totally inappropriate thing that I find a lot well, not a lot, but more than I would really like, is to get a patient who the doctor has not told the patient that they're dying. And then we go in there and the patient, if they're alert and oriented, or even the families don't know that they're terminal. And then I'm going in there saying, "Well, I'm a hospice nurse."

And that's why I learned over time to say, "What do you think hospice is? What is your knowledge base for hospice?" Because if they tell me it's for somebody who's dying then I'm like, "Oh, good." Sometimes they tell me, "Oh it's for extra help, because I need extra help." Then I know I'm going to have to start at the very basement of hospice care, hospice teaching, supporting the family, supporting the patient. And I have other people help me with this; the chaplain, social worker, and all that. But it still comes

down to the case manager and the nurse. Sometimes, we're the ones saying, "Well, your dad is dying of cancer, right?" And they're like, "No. The doctor didn't say that."

And maybe the doctor did and they didn't hear it. That's very possible because I know that when you get bad news you shut down. But that, to me, is a barrier in care. Because then, I have to start from a place where they think the family member is getting better to no, they're really not. And what are we going to do about it?

Pain management and the stopping of life sustaining treatment is another ethical dilemma as Leslie related the case of a patient who no longer had the desire to live. The excruciating pain caused the patient to consider stopping the gastric tube feedings that were keeping her alive. Leslie used her knowledge to accurately assess the pain so that appropriate symptom management could be initiated. Leslie expressed personal satisfaction in her ability to manage the symptoms successfully which gave the family more time to process the impending death. Leslie, however, stated that she would have concurred with the patient's wishes to halt artificial nutrition if the patient made the decision for reasonable motives.

I have a patient who has a neurological disease. And all of her muscles are locking up. She's contracted. She's fed by a G-tube (gastic tube that is surgically inserted into the stomach). She, in one day, went from being able to stand to having her left leg and her left arm totally contracted.

She was screaming in pain when I got her. And, of course, we did the morphine thing and all of that kind of stuff. And I was sitting with her, and her husband was crying. And I'm like, "What am I missing? What am I missing?" And then I noticed that her pain, when she was crying out, was episodic. I'm going, "This woman is having muscle spasms."

So I put her on some medication for muscle spasms. Prior to this, she was going to stop her feeding because she could not bear the pain anymore. Her quality of life was awful, and she was ready to go. She was ready to die. I put her on the muscle spasms meds. Almost immediately her pain stopped. That was three weeks ago. She's still alive. She has made no comment, no mention, about taking her tube feeding out.

We now have time to work with her husband to get him to the point where he will be okay, more accepting of her death. So, she hasn't died yet, but this is an excellent outcome because her symptoms are controlled.

And I would have been okay with her decision to stop feeding, don't get me wrong. If she wanted to do that, I would have supported that. But her decision was being made out of the absolute pain she was in. Now, her pain is totally controlled. She's getting up in her Geri chair and all of this kind of stuff. And her family is now having time to cope with this.

So that's a wonderful thing for me. I mean, I feel very good. I feel very successful that I got this benefit, that she's doing this.

Leslie described another dilemma where patients were referred to hospice services too late in their disease process. It should be noted that a physician must make the referral to hospice services concurring that the patient has six months or less to live if the disease follows its usual course. When late referrals occur, the nurse does not have the time to educate the patient and family about hospice services and philosophy including comfort measures. In this scenario, the family was not sufficiently prepared for the impending death resulting in erroneously blaming the hospice professionals for the patient's demise.

When we have a finite amount of time to do this, like two or three days, it can be a real disaster. And one situation that I had, we got the pain, sort of, controlled. And he was one of those that had bone cancer. And bone cancer is horrible, horrible, horrible. And so we had to give him a lot of narcotics; of course, that made him very drowsy, almost lethargic, to try to give this pain control. Well, all the family saw was because this was all so new to them, the diagnosis was new to them, we were giving him drugs and then he died; so we killed him.

And that's hard because I know that we did not kill him, that the cancer killed him. But from the family's point of view, looking at us and what we did, they're like, "Hospice killed my dad. Hospice gave him morphine and now he's dead." Because they never had time to assimilate the whole cancer issue and the fact that daddy was terminal. And that's hard. That's hard. That's hard.

I'll be at Wal-Mart or someplace. And somebody will come up. And 95% of the time, 98% of time people (say), "Oh we had hospice. You guys are angels." Then, I have the other 2% come up and go, "Well, you know, we had hospice and they killed my dad. They gave him morphine. They killed my dad." And almost always, it's a situation like that.

Leslie's final dilemma was more complex involving several conflicts focused on family dynamics and the patient's rights. In this case, the patient has a healthcare agent, the son, who is

not acting in the best interests of the patient. While competent, patients can elect a healthcare agent to make healthcare decisions when they are no longer capable. The DPAHC (Durable Power of Attorney for Healthcare) is a legal document that designates a healthcare agent who is not empowered to make decisions on behalf of the patient unless the patient is deemed incapable of informed consent. When that occurs, the healthcare agent has access to confidential medical records and can make decisions about forgoing treatment, autopsy, and disposition of the patient's remains. The agents' decisions, however, must be consistent with the patients' wishes.

I have a patient that when I first got him he was really very ill and dying, and then he got better. And then he went through a situation on Monday. He went to sleep and he wouldn't wake up, and his O₂ (oxygen) sats (saturation) was dropping into the 60s (supposed to be in the 90s), and he was cheyne stoking (irregular breathing seen at the end-of-life), and he was kussmauling (rapid shallow respirations), and his blood pressure was all over the place.

He was out for 4 days with nothing to eat, nothing to drink. His 'doctor' son came up to see him and goes, "Yes, dad's dying." So we told the other son, who's out of state, daddy's dying. Well, daddy woke up Friday morning and asked for breakfast, and he's still alive.

That son (from out of state) is so angry that daddy is still alive. It is just unreal. So really, that non-death was a bad outcome because they're still talking to this son in Colorado. And he's the POA (Power of Attorney). I mean, he got so mad at me that he fired me from being on his dad's case because I misrepresented him things. I didn't know what was going on. Even though, his brother, the doctor also said this. So it wasn't until a couple months ago that he rehired me because he didn't like the nurse that replaced me. So I'm better than whatever. The son still expresses his upset-ness that his daddy did not die last fall.

And so, no antibiotics, no interventions, we've dropped all of his meds (medications) except for his pain medication. Daddy's still alive and son is very unhappy. So I don't know if that's a negative outcome or not. The patient seems pretty happy. I really think it's the son's issue.

But that's an example of how things could be so discordant when it comes to care. The man (patient) had a really bad boil on his back that was oozing puss and stuff. And I had to talk him (DPAHC) into letting me give the man antibiotics because his idea was that he wanted his dad to go septic and die.

Ethically, I couldn't do that. And it's one thing to not treat pneumonia because of aspiration. You know, it's one thing not to do that or not to give fluids because they can't swallow anymore. I'm okay with that. But to have somebody have an oozing, pussy boil on their back and not do anything to treat that. Because that is extremely painful, I couldn't do that.

I talked the son into it. We cannot let this man suffer like that. Because he couldn't even sit up in his wheelchair. So I said, "Is that going to keep his life longer? It isn't going to make things longer for him. But he's in a lot of pain, and I cannot allow him to be in a lot of pain." If the son had absolutely said no, I don't know what I would have done. Called the "doctor" brother, maybe? That gets into a lot of ugliness, because it's going behind the other brother's back.

But that would have been hard for me had he not agreed to do it. Because ethically, you just can't do that. You just can't let somebody be in pain that way, for something that's so easily fixed.

In summary, Leslie's seven ethical dilemmas focused on struggles with the employer, the physician, and other stakeholders such as the patient's family and staff at a long-term care facility. Each of these conflicts stood in the way of delivering a good death for the patient which was Leslie's ultimate goal. The employer's financial interests impeded successful symptom management for the patient. In the long-term care facility, the stakeholders' goals were based on the rules and regulations involving the good of the whole by medicating a noisy, disturbing patient so as to not disturb the other residents. Stopping treatment which may cause death was another dilemma which was resolved by Leslie's astute assessment skills. Lastly conflicts with the physician involved three separate scenarios focused on treatment, giving bad news and late referrals to hospice. As seen with Ellen, Leslie always had an untarnished depiction of the patients' best interests when negotiating these dilemmas.

Nurse Chris's Dilemmas

Chris and I met in a room in the hospice facility after a hospice interdisciplinary meeting. She graduated from an associate degree nursing program that encompasses 3 years of course

work offered at most community colleges. The associate degree nursing program does not offer in-depth coursework in the physical and social sciences, nursing research, community health, and nursing management as the baccalaureate nursing programs. Similar to Ellen and Leslie, Chris did not refer to the Code of Ethics or any moral principles learned during her nursing education. In fact, she did not find her education to be helpful in her current practice of solving ethical dilemmas.

Chris has been a registered nurse for 38 years mainly working in hospital settings. She began working as a hospice case manager 3 years ago. She visits patients and their significant others in their homes which may be an Assisted Living Facility or Long-term care Facility. Her job responsibilities include the management of the patients' physical, emotional and spiritual symptoms through coordinating care with other hospice disciplines. Chris explained that she was resigning from her current hospice position to accept a job in an oncology clinic where she "didn't have to take work home."

In the first dilemma, Chris described conflicts within the patient's family circumventing the patient's wishes from being actualized. She frequently described herself as "being in the middle" because not all the family members were on the "same page." Such a situation caused lapses in consistent and effective nursing care as all the stakeholders' goals were different. It was important to Chris for all participants to have similar objectives as she did not want to negotiate the patient's preferences from a disadvantaged position. In this dilemma, the central issue focused on stopping life supporting treatment. Chris was instrumental in the conflict's resolution through educating all the stakeholders; rendering emotional support; and coordinating the efforts of all hospice team members.

There was one situation whereby the family dynamics, the patient had married for the second time. Children from the first marriage hated their stepmother; which was the

patient's wife of 25 years. The patient's wife wanted one thing. The children wanted another. The hospice team felt very caught in the middle. And whose allegiance? It was very difficult to determine. We wanted to not be in the middle. And it was hard not to because the children kept calling us and pulling, which was a very difficult spot to be in. And I felt that was an ethical concern. And I thought we were all on board, initially, in talking about end-of-life care. And the daughter completely started screaming and crying with me on the phone one day. And I realized at that point that she was not on board. And at that moment, I realized that we all needed to be on the same page.

We basically backed up. And I talked with the wife and let her know that it was the patient's decision. Because the patient was actually the manipulator. When he was with his children, he wanted to live. When he was with his wife, he was ready to go. So we discussed that the patient was going to have to make the decision, and that we would have to work with him. And when he was ready, then we would assist him. In the meantime, we would be of whatever assistance to all family members in whatever capacity we could, but not necessarily talk about end-of-life care until everyone was on board with that.

And it actually worked out really well once we got to that point. And we did have a family discussion, and it revolved around, mostly, stopping dialysis which was a major dilemma. It wasn't like stopping an antibiotic or not starting an antibiotic. It was, "Do you stop something that we know within a week or so will cause death?"

The children wanted him to continue dialysis. The wife did not want to if the patient didn't want to. He, of course, switched whoever he was around. But he eventually decided not to.

It was a team effort. We had the chaplain and the social worker and I were working very closely so that we were all on board with how we would treat this family, in particular, the children, because they were very divisive. They wanted us to be on their side or at least not be on the wife's side. So if they could catch us saying one thing different they wanted that to happen. And by us teaming up together to make sure that we were not teaming up against the children, but making sure we were all consistent with what our goals were, I think helped us to provide better care.

Once that decision to stop dialysis was made, and the entire family was okay with that. And I see that we assisted or worked very hard on that case. And I do not think they would have ever gotten to that decision without us there. I really see that the entire team worked very hard with that family. And they would have never gotten to that point. They would have probably killed each other, and then more ethical concerns.

The second dilemma is comparable as it involved conflicts within the family yet the crux of the conflict centered on exercising the Power of Attorney for Healthcare (DPAHC). The DPAHC becomes effective when the patient is no longer mentally competent. While recounting

the dilemma, Chris did not refer to an actual case but described this scenario as being a general ethical concern for her.

If the patient is awake and alert and can make their own decisions, they should make those decisions. And often, the families do not understand this; they want to jump in and make decisions.

And it's very difficult to tell a family member that they're not the power of attorney. They are not the legal representative. And even if they were, the patient is still awake and alert and able to make their own decisions.

I have run across that on numerous occasions where certain family members do want to take control, but the one that is truly in charge is taking a backseat and does not want to be in charge; and that makes it very difficult for us. Because we have to go by the POA.

Chris described another ethical predicament in which the patient needed to be effectively medicated to reduce aggressive behavior. The patient's son, however, did not want any sedating medication. The staff at the facility, where the patient resides, refused to intervene on the patient's behalf for fear that the patient's son would become angry and move the patient to another facility. The hospice's nursing assistant, whose job is to bathe the patient, was fearful of getting hit by the agitated patient. Chris confided that she felt caught in the middle between the nursing aide, facility staff and the patient's son. She did find an effective solution beneficial to the patient which satisfied everyone involved in the case.

I do have a situation where a patient needs to be medicated. A dementia patient requires medication. The wife is actually the power of attorney with the son's assistance because the wife does have dementia herself. And the patient is very . . . I don't want to say combative, but very oppositional. And because he's a dementia patient, he doesn't let go. Once he grabs your arm, you, literally, have to peel him off. And he does bite. He does hit. And we've had a CNA (certified nursing assistant) that's ready to resign over him or wants another facility. And the son is adamant that he will not be on any antipsychotic medications. And the facility refuses to intervene because they want the bed filled. And they see it as our problem.

And me, I'm caught in the middle. Because I have a CNA that wants me to do something to keep her from getting hit. And I have a staff member at the facility who sees it as my problem because she wants her bed filled. And she wants to be on the side of the

son, the person who makes the decisions for the patient. And the patient is very aggressive at times.

What I have done, we've talked with the director of the facility. And we are trying some different approaches with the patient. It's a lot more time, but I feel like it's worth it.

And we're teaching the CNA different ways of approaching the patient. Kneeling down so that she can see him at eye level. Often, when she approaches him, and he's sitting and she's standing, that gets him in an aggressive mood right there. That helps a little bit, certainly not completely, but it is working some. Working with him in a very slow, calming voice. It takes twice as long, three times as long, but I think the CNA is willing to do that in place of getting hit. So it's working, somewhat. So we'll see how it goes.

Our CNA that we provide from hospice, she has four patients at the facility. And, as with any caseload, you try to do your best to get all the patients showered before breakfast, or at least get them to the table with their face washed and their teeth brushed. And if you hurry, with any of the patients, with a dementia patient, you take the risk that you will stimulate aggressive behavior. And that's what happens with him.

So that's what we're trying to alleviate. And by working with him very slowly, or maybe even not brushing his teeth before breakfast. Maybe cutting out some of the activities so that we can work with him on a lot slower pace. That's what we're trying.

Chris described another dilemma that emanated from conflicts of interest with the facility staff where the hospice patient resides. She referred to the administration of the assisted living facility as being manipulative through promising patients' families nursing and medical care that the hospice team cannot deliver. Chris stated that due to unbalanced power structures the best treatment regimen for the hospice patient was in jeopardy of being exercised. She found a peaceful course of action through educating the staff at the assisted living which as she stated "buys time" before an effective solution can be implemented.

We find ourselves, in particular in assisted living facilities, and the competition there among the hospice agencies is fairly substantial. And I find, often, that the Executive Directors (ED) promises the families certain things that they feel are appropriate medically, and it's not necessarily. And they have promised that when I show up I will order certain medications, for example, antibiotics, and the sense is, "If you don't we'll just call another hospice." That is a big concern for me because I feel like the patient is caught in the middle. And I am the patient advocate. And if I don't do what the ED

(Executive Director) wants, they'll call another hospice. If I do, then I feel like I've betrayed myself and what my judgment is.

And I often wonder why we're in there if the ED is allowed to have that much power. And that is a difficult situation that I have not found any answers to. But what I have done as each situation comes up, I've tried to work with the ED and just explain to them the nursing medical reason for not doing what she wants, and mostly just stalling, a technique that let's just wait and see. The patient might need an antibiotic. We may do them more harm than good by putting them on antibiotics; and then when they truly need one, it won't work. And you can buy some time that way.

I had one the other day that wanted to put a patient who had been ill for three weeks with the flu on Tamiflu. She didn't bother to look in the PDR (Physician Desk Reference) to see about Tamiflu, but she had promised the family we would start the patient on Tamiflu. So we didn't review that. I was able to dissuade her of that and she was fine.

But there are some situations that you really feel caught. And that threat of, "If you don't do what I say. If the CNA isn't here by 7 o' clock, I'll call the other hospice and they'll have a CNA here at 7 o' clock," those are very difficult, I think, for the hospices to deal with. Because there are certain things you don't have control over. And you can do your very best, and it may or may not be good for them.

In summary, Chris recounted four ethical dilemmas centered on conflicts with the patients' families and staff members at a facility where the patient resides. Specifically, the impasses involved conflicts within the family itself, appropriately exercising the DPAHC, and medication administration for symptom control. In two of the scenarios, the goals of the facility conflicted with the hospice philosophy of effective symptom management to relieve physical and mental suffering. Chris often repeated how she felt "caught in the middle" voicing frustration in effectively solving the dilemmas. The patients' interests were always paramount yet Chris sought peaceful solutions that would appease all involved.

Nurse Darlene's Dilemmas

Nurse Darlene has 18 years' experience as a registered nurse, most of which has been hospital-based in intensive care. She has a baccalaureate education in nursing. Darlene did

attribute an ethics class in a baccalaureate program as being advantageous to her practice yet when asked specifically what was learned she could not recall. She could not remember any particulars from the many case scenarios reviewed in the ethics course. Darlene did not mention any moral principles when she stated that she could not remember anything about the ANA Code of Ethics.

Darlene and I met at the hospice facility itself after the interdisciplinary meeting. Darlene was quite passionate in her discussion of eight dilemmas. She has 4 years of hospice experience caring for dying patients and their families in the home care setting. Similar to Leslie and Chris, her work responsibilities are to minimize the patients' physical, emotional and spiritual symptoms through synchronizing care with other hospice disciplines.

The first dilemma centered on a patient's spouse who did not want to forego aggressive treatment even though it was not in the patient's best interest. The patient was an elderly gentleman whose wife continued to seek aggressive treatment even though the patient had a terminal disease. Hospice philosophy is directed toward palliative care and improving quality of life. Darlene believed that the wife's insistence on curative treatment rather than palliative care was compromising the patient's quality of life.

I have a family that continues to do aggressive therapy, we're talking physical therapy, going to the doctors all the time. They have a specialist, and he is terminal. And I don't think he's really going to be with us that much longer; but, maybe, to the family, it just offers them extra comfort to know that they're doing the best they can. And it's just husband and wife. They have no children together. They have been married about 50 years. So I kind of understand where she's coming from. But it's hard to deal with and trying to tell her, "Okay. He's not feeling well. Try not to push him." He had a bad case of kind of the flu over the week. And he has physical therapy every day. And I said, "Is he still doing that?" And she's like, "Yes. You know, we want to do this and that."

They're in their 80s. Almost 90 years old. And I said, "Is there any way that you could just kind of give it a rest for this week maybe until next week until he gets his strength back or he can breathe better?" And she's like, "Well, okay."

When families are fighting they are being a barrier to the care, you have to speak up for the patient. And that's hard to do sometimes. Because sometimes patients don't want to do it because they don't want to fight with their family. They don't want to do something against their family; so it's very tricky. You just got to learn it through experience.

The next dilemma involved several struggles between the hospice nurse and the family.

Darlene discussed a case she managed where the caregiver, who happened to be the granddaughter, resented caring for the patient. The situation was so ominous that Adult Protective Services needed to be contacted due to issues of possible neglect or abuse. The patient did enter a nursing home where she could be better cared for but even so ethical issues surfaced surrounding the denial of effective pain medications for the patient. The granddaughter did not want the patient medicated with morphine routinely although it relieved her pain symptoms. Darlene circumvented this situation by requesting that the physician order the morphine to be given whenever necessary. Then she asked the facility nurses to give the medication routinely twice a day. Thus the physician's order was consistent with what the granddaughter wanted yet the order was implemented to the patient's advantage.

We've had families fighting with you about morphine or medicating patients. Not really, maybe fighting, but trying to control the situation, saying, "Well, I don't want my dad to be drowsy. I don't want my dad to feel this way. You're medicating him too much. And he might die sooner."

But it's a tough call sometimes. And also, sometimes patients you see them having symptoms; so you want to treat it, and families go against it, they decline it. They say, "No." I have one patient right now that she moans and groans every time she's moved. And she's a demented patient. She's in her late 80s. The granddaughter was taking care of her at home. And there was actually an issue in there of almost like a neglect or abusive relationship. Because she says how much she hated her grandmother, but that she took care of her. She's the only one that can take care of her and the father doesn't care.

So the granddaughter took over. And the father pays for everything. But, apparently, maybe the father didn't have any more funds or something. So the granddaughter, is like, "Well, I have to work; so now, I don't want to take care of her. I can't stand it. I think if I stay taking care of her, I might hurt her."

There was a time we called the social worker. We had to get adult protective services involved. The granddaughter was not really feeding her like she's supposed to be feeding her or doing anything with her. So this lady was down to 86 pounds, at home. And she was bedbound and didn't go anywhere.

When I went to visit her, the patient and the granddaughter, she said, "My grandmother had a fall, and I called 911." It was a story she told me. And she says, "Well, she was in the bathroom." I'm thinking, "What is she doing in the bathroom? She's supposed to be bedbound. She's on diapers. What's she doing in the bathroom?"

Come to find out, the granddaughter opened up and said, "Well, I had to call 911 because she had soiled herself. And I was so upset with her that I called 911, put her in the toilet, and pretended like she fell. So that the rescue people would pick her up and take her with them to the hospital. And I will leave her there. I don't want any contact with her anymore. I'll just let her go there by herself, and don't call me anymore."

So what happened, eventually, we got help with social work and looked for a nursing home for this lady, for our patient. And to tell you the truth, she's gained weight. She's 92 pounds now. And she's more alert. And she's more interactive. She's still demented and nonverbal but she's improved.

And she (granddaughter) fights with me about medication because she was fighting with me recently about pain medicine. I said, "Well, you know, she's demented. She can't speak. We need to medicate her; at least once every morning, and once at night. It would give her comfort." And then the granddaughter is like, "She doesn't need it."

Now, where does my being an advocate come in there? I can't fight her. The facility is the one I'll talk to. So I'll say, "Okay. You guys, do you give her medication and all? Because we still have it as a PRN (when necessary) med (medication). The pain medicine." And I say, "Why don't you guys start to give it to her in the morning and then one at night?" And they do tell me they do give it to her, morning and night even though the granddaughter says no.

I mean, that really bugs me. It makes me feel like I really don't believe her (the granddaughter). She acts like she really cares. But in the back of my mind, I think, "Oh, yes. But I know better. I know what you've done before--the history of this family."

So it makes me feel it's unethical--it's an ethical question. Because I have my feelings, too, in there, my values and the way I've seen things happen; and then, all of a sudden, she acts like she's the caregiver now.

I have to set aside my feelings and do everything the right way. And that means still updating her on what's going on. I have to be very impartial and not judge.

The next dilemma is also a depiction of conflicts between the nurse and the family. In this case, the caregiver kept feeding the patient even though the patient was not capable of swallowing. Darlene's attempts at educating the daughter regarding nutrition at end of life went unheeded. The caregiver also was not accepting of the other hospice team members, resulting in a scenario where the patient's wishes were in jeopardy of not being honored. Darlene was not able to effectively resolve this dilemma although hospice team members were employed to assist the patient's daughter.

I had a patient one time with PSP (progressive Supranuclear Palsy). It's a parasupranuclear, it's a paralysis. It's a neurological disease. They get contracted towards the end of their life. They can still see you. And they may even be able to understand you. They may even have the lockdown syndrome or lockout syndrome, to where they hear and understand everything, but they can't move anymore. They're so paralyzed. Their muscles get so rigid.

The daughter kept feeding her Ensure (liquid supplement). And I kept telling the daughter, I had to be nice to her. But I had to tell her.

Like maybe three or four days before she was dying, I said--Because I've already seen the changes. I had her for a few months, maybe two or three months, and then I started seeing changes. And I told the daughter--"Try not to feed her anymore. If you do, she may just drown. Because she's so paralyzed. I'm sure her throat is paralyzed." And the daughter kept spooning Ensure into her mouth.

And so, maybe three days later, I heard back from the daughter screaming. She was hysterical on the telephone. And she says, "I killed my mom. I think I killed my mom."

I went to her house, looked at the patient. I said, "Well, what were you doing?" She goes, "Well, I was feeding her the Ensure." And I was thinking to myself, "this lady must have been gone for at least a couple of hours by the time I got there because she's got that glazed over look anyway. So you can't really tell. She looked half dead when I was taking care of her."

And the daughter was making comments, screaming and hysterical, and going, "I think I finally killed her. I finally killed her."

That's what she was telling me. I kept reassuring her. "Don't talk that way. You did your best care you could to your mom." But in my head, I was thinking, "Oh, my God. You finally killed your mom."

I was very sympathetic with her. I was giving her support. And I was like, “No, don’t talk that way. You did a great job taking care of your mom.” And I mean, she did in her own way?

I think it’s just families get that way about feeding. And I was thinking to myself, “Oh, my God. Woman, you finally killed your mother.” But, of course, I couldn’t berate her and judge her and tell her anything of that. But it was in my mind?

Ended up they refused social work the whole time. I had to call the social worker- -I think she’s met the lady one time. And then they said, “No. We don’t need a social worker”.”

I had to call her because they wanted to donate the body to science because of her illness. It’s so rare. And she couldn’t get nobody to accept her. Because, apparently, before you donate, the patient themselves have to sign a paper that says I want to donate my body.

You can’t do it for them. You can’t do it post-mortem. You have to do it way before. And she started calling everybody, and nobody would take her body. So they didn’t have any (funeral) arrangements. And I didn’t have this lady very long. So I didn’t have time to push for social workers. And the lady was so controlling about everything. She wasn’t very nice, and she hated us. They didn’t like our company. Because things were going a little bit bad at that time because we had all these changes going on. So things were slipping through the floor and things were just not getting done.

In the next dilemma, Darlene focused on conflicts with the hospice company in which her goals were different from those of the employer. In the first part of her account, Darlene spoke to the general concept of how she needed to abide by company policy. She then gave an actual case which portrayed her frustration for not delivering the care she believed was warranted. Darlene was told by administration to discontinue ‘continuous care’ whereby the hospice provides professional personnel to care for the patient when death is imminent. To be reimbursed by Medicare, the hospice must show that there was a crisis necessitating the need for continuous care. To place an individual on continuous care, there must be a physician’s order and documentation that continuous care is necessary to appease a volatile situation. When continuous

care is initiated in the home, this particular hospice contacts an outside healthcare agency to provide 24-hour care given by licensed practical nurses. While the nurse case manager continues to oversee the case, other hospice personnel also visit the patient. Given these provisions, Darlene thought her expertise was not respected as her pleas to provide continuous care went unheeded. Ultimately the patient was placed back on continuous care but Darlene believed that the family went through unnecessary turmoil.

Because I'm a case manager, but I answer to people who are higher than I am. So I've had issues to where I've had somebody higher up that tells me, "Well, discontinue continuous care. Get her out." Do this. Do that. It bothers me as a nurse because I think that I have enough experience and expertise, and professionalism. But I think I can make that decision myself. You don't know my patient. A case manager would say, "Hey. You're not in the field. I'm in the field. These are my patients. If anything happens to them, ultimately, I am responsible. Not you. Because you're in the office. All you think about is numbers." And it shouldn't be that way.

I think that people who are up there should be very conscious and very supportive of field nurses because what we do is probably the most important thing. Because we're the first contact with patients. We have to answer to families. We're the ones that have to tell them why we have to pull out continuous care, and why they have to find a caregiver at the last minute, and why we have to pull out when their loved one is dying right there and then. Probably not even but a few hours left.

It's hurtful. Sometimes, and you're not supposed to, sometimes I do take it personally. And I do get a little bit passionate about it; so I will fight about it, and I will push it, and I will push it to all the way until I get my way. Because I feel like, "Hey, that's my decision. If you have a problem with it, let's talk about it later; but for now, let's talk about the patient. That is my first priority.

They preach that to you in nursing. When you were taking an NCLEX test, what's the first thing you got to do? Think of the patient. And, you know, it's the truth. Even in real life. When you take care of your patients, think of the patient. That's ultimately your goal is to get the patient taken care of. Families and people around could be either a source of support for you, or they could be actually against you. They could be a barrier for your care. So you just have to be very careful and make the right choices. I think I know it in my heart, maybe. Because I think nursing is a calling.

Let's say my boss says, "No. Let's discontinue continuous care." If I see the need to be there, first, I would make sure I talked to the families, talk to the patient but mostly the families. I will try to reassure them that we will do our best. Try to give the families

the support that they need. And if they have all the information they need to make decisions. Make sure that they have that.

And then I always try to inform them and say, "Okay. This is the worst case scenario. This is something that we may have to do. Would that be something that you can handle?" For example, I'll say, "if your family member is comfortable, and we've got them calmed down, medication is working, and there's somebody in the family that can give medications, we may have to pull out our nurses." And just make sure we educate whoever's going to be taking care of them, and continue to monitor.

And then, once I do that, then I know that I would have to fight for it with the boss. I'll say, "You know what? I think this patient has so and so much time." Because I've had the patient when he came in, he was a cardiac patient, but he was on respite. They wanted to move him to CC (continuous care) but take him home from an inpatient unit. And I said, "Well, if we do that, we have to do CC." So they (administration) said, "Okay. Fine." These are the things that I should have had a say so because I see him. He's my patient. But I didn't have a say so. It was out of my hands.

Because whoever was on top kept wanting to make the decisions and pushing me for it. And I didn't know the patient very well; so I was, "Okay. Fine." So after having either one or two days in respite, he (the patient) goes straight into CC at home. After 24 hours, they (administration) wanted me to take him off CC. Okay, we're talking about somebody that has symptoms. They wanted me to take him off CC after 24 hours being at home without seeing the patient. It was me. I was the one in charge. And find a caregiver to take care of him, at the last minute. After there was already issues before we admitted him about the caregivers.

He had two sons, but they were both estranged from him. So they never took care of him. One of the sons was a little closer; so he was the one that was making the decisions for his dad. But he (the patient) was a real cardiac patient--I mean, short of breath, and taking Lasix, taking all the meds for swelling. And I couldn't believe that they were doing that to him. Before he got discontinued off of CC, I assessed him. I pulled out stuff for morphine. Because finally, the son said, "Okay." And you know how bad I felt about telling the son you need to find a caregiver because by 7:00 tonight we won't be here? You know how bad that makes me feel? That's like we're dropping his dad who is very sick. Very sick. And I kept telling everybody, "We need to keep him on CC."

The caregiver has already said, "We'll take care of him." So I said, "Okay. Fine." I'll go pull out all my morphine so that it's not in a vial so they could medicate. Well, you know, these people are just CNAs (certified nursing assistants). I don't even think they are LPNs (licensed practical nurses) or they're not used to giving morphine, like total care. They're not used to that.

So they took on the care, and then complained about it. They said, "This is a CC case. You should have never gave it to us." That's what I've been trying to tell

everybody, but nobody would listen to the nurse. They wanted their way. So at the end, I said, “You know what, I’m not signing off on it.”

I called the on-call nurse and said, “If you want to sign off on his care for CC, you come here, and you write the order because I can’t write an order ahead of time to say discontinue patient at 7 p.m. when I’m already off by 5:00. That’s not legal. And I don’t feel comfortable. What if there was something that happened between 5:00 and 7:00” I’m not making that decision. So I never made the order. So I called the on-call nurse and said, “You want to do it, you can do it yourself.” This was when we were having problems with weekend nurses. So I finally said, “I’m not doing it.” So I didn’t, I never signed off.

Well, come to find out the LPN (licensed practical nurse) was medicating this patient every hour, 20 milligrams of morphine because he was so restless and agitated. So by the time the CNA visiting nurse came over there, he was out of it; which was the way it should have been.

But the thing was she (CNA) couldn’t tell the difference between him dying or just sleeping. So by the time I got there, he was totally out of it--unresponsive. And I was very upset about that case. Because I said that should have been totally a CC case. And this is like 24 hours. We’re talking about 24 hours. How bad can it be to take care of somebody on continuous care for 24 maybe even 48 hours?

He died that night. He died at 7 p.m. that night, and or the next day. I can’t remember if I put him back on CC, I think I did put him back on CC for 24 hours afterwards. The CNAs were only there for a short period. And so administration is like, “You know what, I don’t care what everybody else says. I give you the order. Go ahead and put him on CC.” I said “okay.”

Why should it be such a struggle? Why would you give me a hard time about taking care of my patient the right way? Why do I have to fight with the family and stress them out? It’s bad enough that, you know, he’s dying. And to stress the family out to look for caregivers at the last minute, that’s just bad nursing right there. So I’m just glad we caught it last minute. But I was telling them, “Why is that such a struggle? It’s not supportive of my decision. It’s telling me that I’m not good enough to make a decision to do that. And that’s not right.” I know when I’m wrong. If I made a wrong decision I’ll say “Okay. Fine. Okay. You’re right.” But if I’m pushing for it and fighting about it, screaming and hollering on the phone, that’s what I had to do.

I was so upset. I was so upset about that case. I reported it, actually. I reported it to corporate. Because I decided that’s not right. It’s micromanaging me. And making me make the wrong decisions that I don’t feel is right. To me, that’s an ethical decision. And I felt like I fought for it enough; but maybe not hard enough. I don’t know.

Sometimes you feel like maybe, I didn’t do well enough. It makes you feel like you’re a bad person because you listen to somebody else. They try to control you.

Darlene also voiced frustration with physicians but did not provide any specific scenarios. She related how the physician is not seen as part of a treatment team but instead is seen as an adversary constituent, almost an obstacle. The discord between physicians and nurses results in day-to-day ethical dilemmas affecting the nurse's role as an advocate for the patient.

Probably the biggest part to being a nurse is just being an advocate. Because when you're not in nursing, you think that the doctor is really your partner. Let's just say you have a nurse, a doctor, and a patient. You always thought that the nurse and the doctor should be on one side and the patient on another. That's how you feel when you're the patient. So I always try to make sure, as a nurse, to let the patient feel like I am with him, not with the doctor. Because I just feel like doctors don't get down to the level of the patient--most of the time, anyway. Some do. And that's really amazing when they do that. But not all of them do because they don't have time usually. And, maybe, they just don't have that manner or something.

But nurses, we're trained to do that. We're supposed to be trained to be at the patient's level. So even when you're educating, or you're telling them what to do, you got to go down to the patient's level; so that's part of being an advocate. Being the spokesperson for them when they can't talk.

You feel like you got to empathize. What are you going to do if you were in their shoes? So when they always ask me a question, I always say, "Well, if it was me that had this, this is what I would do." And it kind of helps them understand a little better that you're with them. You're really on their side. You're not on anybody else's side.

The nursing and medical care of a hospice patient who resides in a healthcare facility or assisted living facility is governed by several different agencies' regulations. Hospices must comply with Federal, State and local laws which dictate eligibility, conditions of participation, covered services and payment. In addition to hospice regulations, the specific guidelines of an assisted living or long-term care facility must be honored. Darlene voiced concern how these regulations interfere with providing quality services jeopardizing optimal patient outcomes.

Because I heard that there was a new regulation now that they're trying to pass in Georgia about discontinuing antipsychotics unless you have these three major diagnoses; which is Parkinson's, Tourette's, and I forgot what else. Because those are the only three things that they have diagnosis (where) antipsychotics is allowed. So now they're saying that people with dementia, you got to discontinue Seroquel and Risperdal, all those medications. And you're like, "No way."

So that's another thing. We're battling, it's not just things that happen personally, but worldwide scale and nationwide scale. It's a lot of different things out there. It's just a matter of weeding out what's really important, I guess.

In summary, Darlene discussed six ethical concerns involving family members, the employer, physicians and agency regulations. Three ethical dilemmas involved different family conflicts in which the patients' wishes were not being honored or the patients' care was not optimal in promoting quality of life. Darlene recounted distressing conflicts with her employer in which she believed her expertise was being ignored and that she was being "controlled." In addition, physicians were definitely an obstacle in caring for the hospice patient as were agencies' regulations. Darlene zealously recalled these dilemmas yet throughout emphasized the course of action best for the patient.

Nurse Amy's Dilemmas

Amy and I met in the room in the county's library. Amy has been a registered nurse for 30 years. Over the past 10 years, she has been employed as a hospice case manager coordinating the multidisciplinary care of home hospice patients while managing their physical and emotional symptoms. Amy is currently pursuing her doctorate degree in healthcare and possesses a Master's Degree in Nursing Science.

Amy stated that her education was helpful in solving day-to-day ethical dilemmas but mainly focused on her post-baccalaureate education. She referred to a graduate level course on the end-of-life needs of different cultures and cultural barriers affecting end-of-life issues. She did not give any specific ethical knowledge learned in the course. Amy also did not refer to the Code of Ethics or the moral principles when she discussed the ethical dilemmas.

Amy's first ethical dilemma focused on the family wishes being in conflict with those of the patient. In this scenario, the patient did not want cardio-pulmonary resuscitation (CPR) yet the family did want the patient to have aggressive treatment. After Amy educated them on the pros and cons, the family eventually respected the patient's wishes

I think one of the issues that I've had to decide on was whether to let the patient's family intervene, because the patient did not want resuscitation or anything of that nature. And the family wanted that because they think he could have survived a little longer. And I spoke with the family, talked with them, we sat down, went through the papers, went through all of that, but it still was a hard core. Towards the end of it, however, they decided that would be the best route for their dad, because he did not want to be resuscitated. He just wanted to let go and just end it all. So that was one of the issues.

In the next predicament, Amy rendered a specific case in which the family's treatment goals differed from the patient's desired outcomes. In this scenario, Amy discussed a veteran who was dying of cancer. His daughters were not able to come to realization that their father was dying, while the patient was accepting of the fact. This scenario also revolved around the merits of doing CPR, which the patient desired, and the daughters were adamantly against. Amy resolved the conflict by educating the daughters.

I recently had a patient and he was an army veteran. And with army veterans they need to be doing and not people doing for him. So he was one of my patients. He came onboard. We admitted him for cancer. And I walked him through death. He was given 2 months to live. He didn't want anything done, but his two daughters wanted to save his life. He had lung cancer and it was metastasized; and at some point he was going to go. However, as his nurse, I kept the momentum. I kept him going. And he didn't do anything unless I said. He would not listen to his girls because they see the other side, and he's seeing death. But his problem was, "When is it going to happen?" Because there was days when he was down. There were days when you go and he was chirpy. And there were days when he was "How long? How much longer?"

But, for the girls they were doing everything to keep their dad alive. They didn't quite understand the disease process. So I went in one day, and I called a meeting with them and the chaplain and the social worker. We were all there. And we explored what were their concerns: Why is that they're finding it hard to let go? And their mama died a year ago. So that was coming up to the anniversary of their mom. So for them, it was hard to see they're just losing their mom, and now losing their dad to cancer. The mom had cancer as well.

So we sat down and we talked. And they said, “We want to do everything to save him.” So I said to them, “Yes, we could save him. But what are we saving? What quality of life is he going to have? He’s going to be writhing in pain. He won’t be eating. He will be skin and bones.” And I just gave them a picture of what he’s going to look like in another couple of months.

And I told them, even though the doctors gave him a few months to live, we’re not God. It’s only God who determines life. They said, “I don’t know. We don’t know. We still cannot let go of my father.” So we chatted and I left. And I said, “You guys just think about it, and I’ll be back in a couple of days. Think about it, and let me know what the decision is.”

Went back that Friday, and at this point, he was dwindling down. He was, literally, going down. And they watched him. And he was in pain. And at this point, he didn’t even want to take the pain medication. For him, he just wanted to let go. But the daughters still think that we needed to do something. So we talked. And I said, “Have you guys decided? Look at your dad at this point. This is the quality of life that you’d want him to have for next couple of months?” This can play out very long. So I stressed that to them. And, you know, they were crying. They started to cry and stuff like that.

And I’m like, “Okay. You guys just need to make the decision. If you do not want full code, this is the time to decide. You’re looking at your dad. He doesn’t want to take any pain medication. He just wants to let go. Are we going to keep him in misery keeping him in misery and have him prolong this pain that he’s going through without pain medication?” They stepped out and I guess they talked about it; and they came back in. And they decided no. They no longer want to prolong his life. And if this is what it is, this is what it is.

And I said, he was an Army veteran. For them, pain is not a problem. They’ve seen so many deaths, have gone through so many pains already, that to him; the pain that he’s going through right now is tolerable in his mind. But you could tell he was writhing in pain.

The next dilemma Amy experienced while a nurse in a Neonatal Intensive Care Unit (NICU). She told about a situation in which the parents did not want to stop aggressive treatment although medical experts stated there was nothing more that could be done for the infant. Amy brought in her own personal experience as a mother of a child who was born prematurely to solve this predicament.

Another issue was when I worked in a NICU (Neo Natal Intensive Care Unit) unit with a baby. The family thought that there was just everything that we could possibly do to save a premature baby’s life, which was not possible. So in that incident, we had to make the

decision, the staff, including myself, that we cannot save this child. This child is going to be a vegetable, so to speak. And the family bought into that, and then they gave us the right to do whatever it takes to get them through the process of letting go.

What I find is how you send information across to people. The perspective that I took was I was envisioned myself, when my child was also premature. And I had to come to that point where if this is what is going to be, then I need to learn to let go. And I brought in my own experience. I shared my own experience with them at the time because my daughter was one pound at birth. And it was at that point where the doctor says it's touch and go. And for me because I was in the health field and I know what death is. And I know how to handle death because, for me, death is a possibility. It's for everybody. Everybody is going to at some point go through that process. But how we deal with it is another issue.

So once I brought my own experience into the mix, the family was more accepting. Because here's somebody speaking to what they are going through and what they will face down the road, therefore, I got that buy in.

Amy recounted three dilemmas involving conflicts with family members. All of the predicaments focused on the families wanting unwarranted aggressive treatment. Amy resolved the issues by providing education, sharing her personal experiences and effectively communicating with the involved persons.

Nurse Mary's Dilemmas

Mary has been a registered nurse for over 20 years, the past 14 years as a hospice case manager. Prior to hospice, Mary worked in long-term care facilities caring for the elderly. Mary visits patients in their home settings including nursing homes and assisted living residences. A licensed practical nurse works alongside Mary, who she oversees. In her current role as a hospice case manager, Mary coordinates the patients' care with different hospice disciplines to actualize a good death.

Mary claimed to have been an "older student" when she went to nursing school. She has an associate degree in nursing (ADN) and was not offered any specific ethics courses. She could

not remember any specific knowledge learned in school to help with current ethical decision making. Mary recalled worrying about the Code of Ethics when she first became a hospice nursing believing that advocating for the use of highly addictive medications may violate some of the codes. Yet, Mary was not able to cite how such an action violated the ANA Code of Ethics.

The first dilemma that Mary recounted focused on how family members requested that the patient not be told that they had a terminal disease requiring hospice services. Mary refused to lie to the patient and used skillful communication to help circumvent the situation. She stated, however, that despite the family's attempts to not discuss death, the patient was generally aware of the situation.

We always have that ethical dilemma of you admit a patient onto hospice, and the family doesn't want you to say hospice in front of the patient. And the family doesn't want you to let the patient know that they're dying; because if mama knows she's dying, she'll give up. We're not going to outright lie to the patient.

And usually, when I go in as a nurse, I just say, "I'm with such and such company--I'm a nurse with such and such company, and I'm here to take care of you." I don't say "I'm your hospice nurse. We're going to keep you comfortable until you die." Generally, you find out later down the road, that the patient knew all along they were dying, and nobody wants to talk about it in front of them. So then you have the opportunity, if you have some long time with the patient, where you can answer the patient's questions truthfully and say, "Yes. You have an illness that you're not going to recover from, but don't be afraid, we're going to help you. We're going to take care of you." And then you answer their questions about symptoms sometimes. If they have questions about that.

We run into that a lot. But we always tell the families we're not going to outright lie to the patient and say, "Oh, you're going to be fine, any day now you're going to get better." Then if the patient has questions, and it's about death and dying, then we're going to answer them truthfully, as truthfully as we can.

Some of them (the families) can be negative about it. And then some of them will say, "Well, she probably won't ever ask you anything."

But it's the elephant in the middle of the room. Nobody wants to talk about it but the patient sees the elephant; and the patient says, "I want to talk about this elephant."

Mary discussed another dilemma centered on the family not being satisfied with the substandard care as she believes effective care was rendered. Mary does not blame herself or the company for delivering because the problem usually centers on deeper problems within the family that hospice services cannot resolve.

We recently had a patient that passed away. And I think she had a very peaceful passing, but the family, the son was never, ever happy with anything that we did. He would take pictures of his mother and say, "See, she's got a frown on her face. See this? You know, she doesn't look good. See."

And then you would make medication changes. And then he still wasn't (happy), it was like there was nothing that was going to make him (happy) so it had to be something on a deeper level. He said at the end he was disappointed in the service that we had provided. And we provided very good service. We had been there and listened to him and taken the time to talk with him. I think sometimes he would act like he heard you and understand, and then he would come back with an issue. You see that a lot in families that have been dysfunctional for years; maybe there's been alcohol in the parent or whatever, or abuse of some sort. You just have to realize sometimes, I can't change (it). I can only do what I can do for the patient. I can't change the family dynamics. It's not like on TV where everybody gathers around at the bedside, and the patient stops breathing.

Another conflict with family focused on the medications used in hospice to control symptoms. In fact, all the participants, with the exception of Amy, discussed how family members were reluctant to give the patient effective pain medications due to their addictive nature or sedative effects. Mary did not offer any specific case when she discussed a family's concerns related to these medications but also discussed her own hesitancy about advocating for Schedule II substances. Conversely, Mary discussed how some families want the nurses to give too much morphine to end the patient's ordeal quickly.

But I used to worry a lot. I'd go, "Oh my gosh. Look at this." Because in nursing school you learn about the Class 2 drugs and getting hooked on things.

And then as you get more education, you learn pain management. You learn that it's just another drug. It's just another drug to take care of a symptom that needs to be taken care of.

And so when you explain that to patients, then they're less afraid. I mean the families they're less afraid when you're using these medications. Sometimes, and it's

very hard, we don't run into it as much as we used to, but you still have families that don't want to medicate the patient, simply because they think it's not good for them to receive that medicine. Or they want to be able to talk to them, and the medication makes them sleepy. So it's very hard sometimes to say, "You idiot."

But you try to gently explain. "I know you want to be able to talk to your mother or father; but at this point, it's more important for them to be comfortable. Don't you want them to be comfortable?" And explain comfort.

And occasionally, it doesn't happen very often either, but occasionally we have families who say, "Okay. Let's just get this over with. Can't you just give them more and more and more morphine?"

And then you explain how the side effects of morphine, as it accumulates faster in the body than the body can get rid of it and the twitching and all of that. And then they're like, "Oh, okay."

I felt kind of uncomfortable with the medication. And I believe in comfort. Because I wouldn't have gone into hospice if I didn't believe in it a lot. Because I worked in the nursing home.

The next dilemma centers on how Mary felt conflicted when caring for a home hospice patient who was also her friend. She admitted to going into the situation voluntarily yet never wants to be placed in that situation again. Usually, Mary can emotionally distance herself from the patient so that feelings and sentiments do not govern her decisions. Due to the friendship, Mary questioned her actions even more. She also believed that the husband was not caring for the patient effectively resulting in inadequate symptom control. Mary wanted her friend to go to a healthcare facility to get the needed nursing care but the friend wanted to die at home. Mary honored the patient's wishes.

I recently helped to take care of a patient. It was very difficult for me because it was a friend of mine, someone I had worked with in the past. And she was dying of cancer. And it was very hard to separate the professionalism.

Usually, I don't have trouble with that. I can distance myself so that I can help. Every time I would go, it would be extremely difficult to distance myself. And there were days when I, really and truthfully, I didn't want to go there because there was an issue in the home. And the spouse was kind of rough and we're supposed to go in and no matter what, we're supposed to take care of the patient. So basically that's what we had to do

was overcome the husband and some of his issues that he had just to take care of a patient.

But I made it through to the end. And I actually was the one that pronounced her, but that was very difficult. Nancy and I were both there that day, and we were both crying as we were filling out paperwork and just crying and passing tissues because it was a friend. I would not want to be in that position again, because I really felt like I was second guessing myself on everything regarding her care. I suppose I could have stepped out, but on the one hand, I did want to help take care of her. But then, on the other hand, you never know what you're going to come into; even when you think you know something. You never know somebody until you're actually going into their home environment they're in.

And it was not good. She really did not need to be at home. She needed to be somewhere where she could be better cared for. And so we tried to get her to go; for her to allow us to place her somewhere where she'd get better care, but she didn't want it. See that was hard to provide the care she needed as much as we could because there wasn't any additional caregiver in the home. And she needed a lot of turning and repositioning and wound care. The wounds were just not good.

He (the husband) would say, "Oh, yes, I can do this. Oh, yes, I can medicate her." But then we found out that he wasn't medicating her and wasn't taking good care of her hygiene-wise; which made it difficult. But we all struggled through it, and we made it through. I think ultimately we had to realize that we were giving her her wish, which was to die at home; no matter what, she wanted to die at home. So it had a good outcome in that respect.

Conflicts with her employer were another ethical concern that Mary relayed during the interview. Similar to Leslie, Mary had to prove to the employer that a medication not on the hospice formulary was an effective and appropriate drug for the patient. As told before by some other participants, the effort expended on obtaining treatment and medications that the patient's condition warranted distracted from the actual nursing care and left Mary frustrated.

You know this drug in this form is the best thing. But the insurance company won't pay for it. So then the doctor has to write a letter and you have to jump through all these hoops to get what you need. And sometimes you get it, sometimes you don't. And it's the same thing in hospice. You have to write down and make the case. Sometimes you just get so tired of fighting City Hall to get what you think would be the best thing for the patient, symptom management. Usually, it's pain medication.

If we can make a case like we've tried this before and this didn't work. We've tried this and this didn't work. It seems like the list gets longer of how many times did

you try something different. And then finally they go, “Oh okay.” Just give it to me the first time. You have to have drug failures. Failed to be controlled on this medication. Failed this one. And then you say, “Okay. Can I have what I want now?” “Yes. You passed the test, now you can have the medicine that you wanted.”

Mary discussed ethical concerns that she had with physicians’ actions. Mary’s apprehension was similar to Leslie’s when she voiced concern how the physicians ordered diagnostic tests without regard to the main focal point of promoting comfort. On occasion, Mary would voice her uneasiness to the doctor but not always.

It’s like the doctor doesn’t want to let go of the patient, and they want one more test. They want all these tests and they want to poke the patient and keep them on the . . . I don’t know.

Hospice just isn’t like it used to be to me. It used to be we just (recommended the treatment)? And the doctor would be like okay. Okay. But now, everybody wants to continue all these tests. And they want to keep poking the patient with needles and doing this and doing that. A lot of times it’s just futile. And you want to say that to them. And sometimes you can say it, and sometimes the doctor doesn’t want to hear it. “Well, how am I supposed to take care of my patient if I don’t have tests?” I guess because they’re trained that way. They’re trained to look at test results. I think sometimes they forget to look at the patient.

In summary, Mary voiced six ethical concerns related to conflicts with the family, her employer, and physicians. Encounters with the families generated three separate scenarios focused on withholding information from the patient, not being satisfied with hospice services, and the use of Schedule II narcotics. The conflict with the hospice company revolved around the struggle to obtain effective medications for the patient. Physicians ordering inappropriate diagnostic tests not congruent with the family and patient wishes was another source of contention for Mary. In addition, Mary discussed the ethical dilemmas that resulted from caring for a friend on hospice. As with all the other participants, Mary focused on the patients’ needs and wishes while resolving these ethical dilemmas.

In reviewing the dilemmas voiced by the participants, a majority focused on conflicts with the family and doing what was best for the patient. Often the patients could not voice their needs resulting in family members taking on the responsibility of speaking for the patients. In so doing, the nurses believed that the patients' needs were usurped by the families' desires. In fact, all of the nurses voiced family interactions as a source of struggles interfering with positive patient outcomes. Conflicts with the employer were the second focus of ethical predicaments whereby the company's goals usurped the patients' and/ or families' well-being. Interference encountered through interactions with other stakeholders including physicians and directors of other agencies were also a source of contention yet paled in significance to family interfaces.

Thematic Analysis

Thematic analysis was used as method for identifying and analyzing patterns within the data (Braun & Clarke, 2006). Incorporating guidelines from Braun and Clarke (2006) three main themes and nine subthemes were extracted from the analysis. Following my theoretical assumptions, the research questions guided the identification of specific themes within the nurses' stories of their ethical practice (Braun & Clarke, 2006). Not wanting to focus solely on semantics, latent themes were identified that reflected underlying ideologies. As Braun and Clarke (2006) explained, "A thematic analysis at the latent level goes beyond the semantic content of the data, and starts to identify or examine the underlying ideas, assumptions, and conceptualizations" (p. 84). To this end I examined the sociopolitical context affecting the nurses' stories. Employing a constructivist paradigm, took me to individual motivations and structural conditions that influenced the nurses' ethical decisions. The analysis culminated in the

identification of three main themes centered on ethics: ethics within practice, ethical knowledge, and ethical solutions (Appendix E).

To best understand the themes, they are framed within discussions of situational context, deliberations on how to solve the conflicts, and actions taken by the nurses to resolve dilemmas. This sequential framework correlates to how nurses faced and solved ethical dilemmas. First, the nurses examined the environment to make moral judgments embedded in nursing roles and practices. Second, the nurses drew on their practical and experiential knowledge as valuable resources to help in analyzing conflicts. Third, the nurses took action based on their judgments, knowledge base, and situational context. It is important to note that although my framework is linear, the judgments, knowledge, and actions are interrelated. This dynamic will be examined further in this section.

Situational Context

Situational context plays a decisive role in ethical decision making due to its interrelationship with interpretation and actions. As we will see, the nurses understood each situation based on how specific patients and families behaved and interacted but also relied on ancillary factors including the patient's medical condition, physical environment, stakeholders' goals and their own value systems. Thus, judgments were formulated based on the demands of the specific context. The nurses interpreted events so that even subtle variations resulted in different judgments. Therefore, the context embedded in time and social conditions was instrumental in how the nurses positioned themselves within ethical conflicts and negotiated the ethical dilemmas they faced.

Theme One: Ethics within Practice

All of the interviewees discussed factors that influenced ethical discourse in nursing practice. Although nursing practice is guided by regulatory agencies, company policies, and professional standards, these are merely guidelines. There is no definitive recipe on how nurses should answer to ethical conflicts as each dilemma is implanted within a certain situational context. Thus, the nurses were faced with making difficult decisions related to ethical concerns within their day-to-day practice. In analyzing the data, three subthemes were generated: nurses' moral insights, nurses cannot do it alone, and the nurses' perceptions of their role. All of these subthemes emphasized the association between making judgments and ethical engagement within the dynamics of a specific situation.

Nurses' moral insights. During their practice, the nurses examined their own belief systems. Most believed that they should not make judgments based on their personal value system. For example, Darlene discussed qualms from encounters with a family member who she considered to be insincere. She discussed how she needed to not allow her personal judgments to cloud nursing interventions:

But it's like almost in the back of my mind, I think, "Oh, yes. But I know better. I know what you've done before." The history of this family . . . You know what I mean? Because I have my feelings, too, in there--my values and the way I've seen things happen--and then, all of a sudden, she acts like she's the caregiver now.

It's hurtful. And I take it--sometimes, and you're not supposed to--sometimes I do take it personally. And I do get a little bit passionate about it; so I will fight about it, and I will push it, and I will push it to all the way--I have to set aside my feelings and do everything, you know, the right way. And that means still updating her on what's going on. I have to be very partial and not judge.

Later in the interview, Darlene explained that her values and beliefs should not interfere in the decision-making process:

It kind of just--and I think it has a lot to do with my values, maybe. What I believe in. Because I think, you know, whatever might be acceptable to me may not be acceptable to someone else. So, you know, our ethics or the decisions we make may be different, you know? We're not all the same people. So you have to kind of adjust, put some type of adjustment to that part.

Chris expressed similar sentiments that personal feelings and values should not interfere with resolving ethical dilemmas:

And I'd learned very quickly that until you walk in those shoes do not judge. So I changed my mind very quickly, but was still true to my beliefs but realized what a difficult decision it is.

I try to not let my own feelings interfere. Because I may have a certain feeling of, "Gee, if that were my mother, I wouldn't let them have that medication, or I would withhold something." And I've learned that that's not my mother. And it may or may not be what I'd do for my mother. I'm not in that situation. That is something I did learn the hard way.

Leslie expressed a parallel attitude to describe how she did not allow her personal beliefs to impede the decision-making process:

So to me, all of the decisions are made . . . I really try as much as possible to look at it through the patient's family's eyes. Because what would be ethical for me and my dad or my mom is not something that's acceptable for the family.

Early in the interview, Leslie stated how she considered the context of each ethical dilemma to be important. Thus, Leslie did not incorporate her own values into ethical decision making nor did she use a prescribed script:

So, I guess, related to actual end of life with a patient . . . a lot of the ethic parts for me is also situational. It all--what is ethically correct for one patient would not be for another patient. So it could--even given very similar circumstances--because of family involvement and because of specific ancillary issues, okay? Does that make sense to you?

Mary explained how she emotionally distanced herself from the situation so that her feelings would not become a barrier to solving the ethical predicament:

I can distance myself so that I can help. But it was--every time I would go it would be extremely difficult to distance myself. And there were--you know, there were days when

I, really and truthfully, I didn't want to go there because--and then there was an issue in the home.

On the other hand, Ellen used her own values when solving ethical predicaments. "You have to say, is this what I would want for me. If it's not, what I would do for me, why would it be what I would do for somebody else?" Ellen also had a deep religious conviction that guided her decision making. For example, Ellen stated: "I mean, I think it (religious conviction) has everything to do with it. And the religion is just something deep down that's kind of added to it." Darlene expressed that not only was religion significant in aiding ethical decision making but a combination of different experiences was beneficial:

It's a combination of things, I think. Your background--spiritual background or religious background, your cultural background, and your environment. Then your education and your experience. I think that has a lot to do with making the right decisions on that. It's not just one thing.

Along with their personal value systems, the nurses expressed a sense of knowing the "right" course of action. Ellen expressed having a keen internal sense of what is right to do that was not learned in nursing education:

I think that's what I'm saying, because I don't have a lot of background, as far as like those two decisions that had to be made. I don't have a lot of background information on them. I just know that it was the right--I just know it was the right thing to do.

When asked to delineate on how she knew the right thing to do, Ellen stated,

Is it innate? Is it learned? I think it's just you--you just have to look at the situation. You have to say, is this what I would want for me. If it's not, what I would do for me, why would it be what I would do for somebody else?

In the same manner, Mary discussed having knowledge of the "right" course of action. "I think a good sense of what's right and what's wrong. . . . And sometimes, I mean, you have to go back to that, you know?" Having similar sentiments, Darlene stated the following: "So you just

have to be very careful and pick the right--make the right choices. I think I know it in my heart, maybe. You know? Because I think nursing is a calling.”

In perusing the nurses’ ethical fortitude, their own goals related to caring for the dying need to be considered. For the nurses, positive outcomes often centered on the patients’ needs. Some of the nurses focused on successful symptom management as a successful conclusion. For example, Leslie stated,

Hospice nurses have to measure things differently than other nurses. Other nurses measure their successes and their gains by the patient lived and went home and lived happily ever after. Our successes are they pooped today. They had a BM today, and they haven’t had one in three days. Or today . . . or I’ll go in and the patient is totally out of control pain-wise. And after spending, you know, four hours with them, I get them out of pain. That is a big success, okay?

Mary shared a similar reaction: “A good outcome should be a peaceful passing of the patient with symptoms managed, and, that should be it. And I would say most of the time that happens; but sometimes, families don’t perceive it that way.”

Darlene believed that patient and family gratification was a measure of a successful outcome. “Patient and family satisfaction. I measure that--most of the time, I guess if they get better. Like, if you’re in a hospital, you know, and patient is getting better.” In addition, Darlene discussed that success was knowing that you did your best in caring for the patient:

And when a patient tells you thank you. When the family tells you thank you after you’ve done all your work; then I guess that’s probably the most--the best reward you get. That’s all you can really do, you know? We don’t take tips so, even if something bad happens or something doesn’t, the outcome is not as what you would like it to be, as good as you would like it to be. At least, you know that you went through the steps. You know? You did the best you could. And you used everybody that you could.

All of the nurses were aware of their own value systems, yet their personal beliefs served as a guide in the decision-making process or as an obstacle. On the other hand, the nurses’ goals

for successful outcomes were a benchmark not always achieved. In either case, the nurses' values and objectives influenced the decision-making process.

Nurses can't do it alone. All of the nurses discussed the importance of collaborating with other healthcare professionals. Nurses, physicians, social workers, chaplains, and nursing assistants were viewed as vital resources for the nurses, offering emotional support and valuable knowledge for improving patient outcomes.

Hospice nurses are part of an interdisciplinary team who care for the patient. The interviewees frequently sought the advice of other team members to enhance patient care. The nurses relied on team members to coach them or to simply present a different perspective. For instance, Darlene explained how different team members were helpful if she was unsure about a course of action:

And if I wasn't confident enough--where I felt like I was doing something wrong--I have a lot of resources. I have a nurse practitioner. I have a doctor. I have other nurses. I have the CNA. I have the social worker. I mean, I have a big team that I can go to.

Another example of collaborating with different disciplines came from Ellen who consulted with respiratory therapy to actually solve an ethical dilemma:

Well, it ended up being that we ended up calling the respiratory therapist and bringing them in. And instead of having to medicate this individual, like we were told to do, instead, we brought the respiratory therapist in, had a consult with them, and tweaked his vent settings, and immediately got rid of his shortness of breath and feeling like he was going to die right there.

In her practice, Mary consulted with other hospice nurses. Regardless of their educational background or authority, Mary viewed the experiences of other nurses as instrumental to her practice:

I work with an LPN, but she has seen and done things that I have not done. And I think RNs and LPNs have to realize that, you know, you might have an RN supervising you,

but you may have more experience in something than she does. So that, you know, kind of elevates you right there.

You know, we're all in nursing, but some of us have--we all have different backgrounds. And we've all seen different things. And I think collaborating with your coworkers. And I've even gone, you know, nurses on another team, you know. Usually it's somebody I've worked with before or somebody I really trust their judgment on something. Or if they've gone through something and I'm going through it, and I go, "Hey, what did you do in this case?"

Several nurses voiced that other healthcare disciplines assisted in enhancing patient care.

Chris was adamant in explaining how the hospice team coordinated their efforts to improve patients' outcomes:

Immediately, it was a team effort. We had the chaplain and the social worker and I were working very closely so that we were all on board with how we would treat this family; in particular, the children, because they were very divisive. They wanted us to be on their side, or at least not be on the wife's side. So if they could catch us saying one thing different--and this, of course, was initially--they wanted that to happen. And by us teaming up together to make sure that we were--not teaming up against the children, but making sure we were all consistent with what our goals were, I think helped us to provide better care.

Other nurses stressed how team members assisted in rendering holistic care. The social worker, chaplain, and nursing assistant were viewed as assets in caring for the patient's physical, spiritual, mental, and social wellbeing. Leslie explained how the hospice team presented different viewpoints to render holistic care to the patient:

Actually, I mean, I use the chaplains and the social workers a lot in my work; and I talk to them, and go this is the situation, you know? And this is what's going on. And this is where the family is. And this is where I am. And this is where the patient is. And we need to come to some kind of consensus on care. Because I believe in--and I know this is new aged crap--but it's the mind-body continuum. All right?

It's not just them over there and him over here. You know, there's a whole linkage there--you know--between the family and the patient, and--you know--kids, sometimes. And everything. And sometimes, I get so stuck in my area that I need a different view, and I count on my social worker and my chaplain and sometimes other nurses to get--to help me with that other view.

Nurses do not practice in isolation. They understand their work as part of a team effort in which professionals collaborate to improve patient outcomes and provide mutual assistance. The nurses recognized that their practice was improved through partnerships with other healthcare workers and appreciated the emotional support they provided.

Nurses' roles. To render effective care for the dying, nurses need to have a clear notion of their roles and responsibilities. The participants were well aware of their obligations during end-of-life care. To this end, they discussed their different roles in symptom management, education, advocacy, ethical decision making, and assessment. Each of these roles will be further discussed.

Nurse as healer. Nurses who work in end-of-life care strive for the patients' physical symptoms to be successfully managed so that the patient can experience a good death. Typically, hospice nurses accomplish symptom control through recommending appropriate medical interventions including medications to the physicians. Complementary therapies such as massage, music therapy, and relaxation techniques may also be employed. All of the interviewees acknowledged that managing symptoms was an important aspect of their responsibilities yet their focal points differed. Symptom control was discussed in terms of knowledge, barriers, and positive outcomes.

Leslie and Mary explained how symptom control was learned either through experience or informal education. In the following excerpt, Leslie discussed how she learned symptom control through exposure to different nursing experiences:

And sometimes the symptoms are so ephemeral, that I don't even know if I can put a word to it, but I just know it; because I've seen it 15,000 times before. And I know--you know, if you move them this way and tilt their head this way, the tongue is going to come

out from the back of their throat, and they're going to be able to breathe easier. That is something you learn through experience.

Furthermore, Leslie indicated that managing symptoms was relatively simple once learned compared to interacting with families:

I think the most--the most--the biggest area that I have experienced and over my time, isn't so much the nuts and bolts of the symptom control. Because really and truly, the nuts and bolts of the symptom control, relatively speaking, are pretty easy. You know? That there are things that we do and things that we try. Where I have really gained and really done well is working with the family.

Mary discussed her concerns about the prevalent use of addictive narcotics in hospice care to control the patients' symptoms. Interestingly her nursing education resulted in a reluctance to recommend narcotics for patients. Yet through informal learning, Mary's apprehensions were alleviated:

So, I used to worry a lot. I'd go, "Oh my gosh. Look at this." Because in nursing school you learn about the Class two drugs, and this is, you know--and getting hooked on things. And then as you get more education, you learn pain management. You learn you know that it's just another drug. It's just another drug to take care of a symptom that needs to be taken care of.

Managing symptoms successfully is considered to be a positive outcome of hospice nursing care. Leslie stated how controlling the patient's pain was a personal success story: "or I'll go in and the patient is totally out of control, pain-wise. And after spending, you know, four hours with them, I get them out of pain. That is a big success, okay?" Mary specifically stated how managing symptoms resulted in a good death: "A good outcome should be a peaceful passing of the patient with symptoms managed, and . . . that should be it."

Although managing symptoms is an integral role for the hospice nurse, there are many barriers that may preclude symptom control. The interviewee discussed these barriers, which included the employer or hospice company, the patient's family, and the patient. Four of the nurses discussed how the company itself was a barrier to effective symptom management. The

non-formulary medications are not financially reimbursed by hospice; therefore, the patient would have to pay for them. In the following excerpt, Leslie refers to medications that are not on the hospice formulary yet are effective in managing pain:

Now, the other issue that I have with end-of-life care, in terms of symptom management, is pain. And there is a point where if you just go with the cheap stuff--which is liquid morphine that sort of thing--then, yes, sometimes you have to go all the way up to the edge of actually causing them to go into respiratory shutdown before you get the pain managed; however, if you can combine some of the other medications with it--and specifically, things like steroids, okay, or some of the more expensive pain management issues--pumps--that sort of thing, we can fine tune the pain management so that the patient is still alert and talking. Now, that kind of stuff makes me crazy because I am for patient care and for symptom relief. And sometimes, I get resistance from the company that I work for because it's not in the formulary.

Darlene discussed how the company requested that continuous care be discontinued yet the patient was still having symptoms that needed to be addressed by the hospice nurse.

Continuous care places skilled nurses into the home on a continuous basis to manage the symptoms. Darlene expressed her frustrations:

After 24 hours, they wanted me to take him off CC (continuous care). Okay, we're talking about somebody that has symptoms, okay? They wanted me to take him off CC after 24 hours being at home--without seeing the patient. It was me. I was the one in charge. And find a caregiver to take care of him, at the last minute. After there was already issues right before we admitted him--about the caregivers.

Another barrier to symptom control discussed by all the participants was the patient's family. In the following passage, Chris discussed how the patient's son did not want the patient medicated for agitation:

And we--me--I'm caught in the middle. Because I have a CNA (certified nursing assistant) that wants me to do something to keep her from getting hit. And I have a staff member at the facility who sees it as my problem because she wants her bed filled. And she wants to be on the side of the son, who she sees as the boss of the person who makes the decisions for the patient. And the patient is very aggressive at times.

Darlene also discussed how the family could be an obstacle in symptom management: “And also, sometimes patients, you know, you see them having symptoms; so you want to treat it, and families go against it--they decline it.”

Leslie discussed how the family interfered with symptom control by not relinquishing treatment modalities:

So there are many times when the family wants to do something that I know in my heart, ethically, really isn't the best thing to do for that patient because--let's say they want to go and have more testing, or they want more MRIs, or they want more CAT scans, or they want more of this or that, or they want more physical therapy, right? For somebody who is in the last month or two of their life. Ethically, I know that that is actually going to cause discomfort for that patient, okay.

Another obstacle for symptom control can be the patient who refused necessary medications to successfully manage their symptoms. Amy discussed the case of a patient who refused to take pain medication and was “writhing in pain”:

And he was in pain. And at this point, he didn't even want to take the pain medication. For him, he just wanted to let go. . . . And I guess, maybe, because I had gone through seeing a lot of patients going through--they just--if the pain could kill them, that's what they want. You know? They just don't want to take anything that will prolong their life. They just wanted to let go. And if the pain will wipe them out, let the pain wipe them out. And that's how he was. And like I said, he was an Army veteran. For them, pain is not a problem. They've seen so many deaths, have gone through so many pains already, that to him, the pain that he's going through right now is tolerable in his mind.

Thus far, I have discussed physical symptom control as a responsibility of the hospice nurse. All the interviewees discussed managing physical symptoms but yet only one alluded to other forms of suffering. In the following excerpt, Leslie discussed the importance of managing distressing spiritual symptoms:

Suffering is not just the pain issue. Suffering is--there could be spiritual suffering, you know? There could be all kinds of suffering; however, she doesn't seem to be suffering at this point. And so I can't justify, in my mind, medicating her.

Managing the patients' symptoms is considered an essential responsibility for the interviewees. They learned about controlling symptoms mainly through experience rather than formal education. The nurses were confronted with obstacles interfering with obtaining optimal patient outcomes. The barriers to symptom control included family interference, company rules, or the patient's goals. Nevertheless, successfully managing the symptoms was considered to be a positive patient outcome and a vital role for the nurse.

Nurse as patient advocate. Being a patient advocate is an important role for the hospice nurse. Oftentimes, patients are too debilitated to speak for themselves and require hospice nurses to be aware of and support their best interests. Five interviewees discussed the role of advocacy in their practice. They addressed the importance of effectively satisfying the patients' needs; nursing interventions inherent in being a patient advocate; and the barriers to performing the advocacy role.

Three participants affirmed the patient was their priority. "While I understand what the staff is saying," Leslie also understood her "duty to this patient to keep her not medically restrained." Ellen stated: "I would always be for the patient." Darlene also proclaimed the importance of the advocacy role: "That's big to me, that's a very, very--probably the biggest part to being a nurse, just being an advocate." Later in the interview, Darlene relayed the following about being a patient advocate:

So when they always ask me a question, I always say, "Well, if it was--if I were in your shoes--if it was me that had this, this is what I would do." And it kind of helps them understand a little better that you're with them. You're really on their side. You're not on anybody else's side.

Different nursing actions are tied to the advocacy role as discussed by Darlene and Ellen.

Darlene relayed the following information about incorporating education and compassion on behalf of the patient:

So even when you're educating, or you're telling them what to do, you got to go down to the patient's level; so that's part of being an advocate, you know? Being the spokesperson for them when they can't talk. You--you feel like you got to empathize, you know? What are you going to do if you were in their shoes?

For Ellen, being an advocate entailed assessing the patients' and families' needs, educating all involved participants, collaborating with other healthcare disciplines, and guiding patients and families toward the preferential course of action:

Oh, investigating and collecting information from the patient about all aspects of whatever it is that you're doing with his care. And then giving--or pointing in the right direction--where that person's care should go. Is that what you mean? That you take that information and you present it to--where you bring other people in--other disciplines in as necessary to benefit him.

Five of the interviewees discussed barriers that interfered with their advocacy role. A significant obstacle that appeared several times during the interviews was the expectations of the hospice company. Ellen discussed how her employer's policies interfered with a course of action that was in the patient's best interest. She stated, "I had to figure out what I could do for him to benefit him to make him feel better to get him off (hospice) without doing something against company policy to get him off." There were many other instances relayed by the nurses in which the hospice company's policies and protocols precluded effective advocacy interventions. For example, Mary stated her frustrations in obtaining what was best for the patient:

I mean, sometimes it just seems like you have to really struggle to put forth what you feel is best for the patient and kind of fight, you know--fight the company on all levels to get what you need.

Leslie discussed conflicting allegiances to the patient versus the employer. She addressed how this predicament had placed her at odds with the company as she fought for providing the patient with the needed care.

So the ethic part comes down to, “Who am I supposed to be taking care of? The patient? Or the bottom line of my company that I work for?” And it’s very difficult. And there have been many times when I’ve been so vocal about it that I’ve actually gotten in trouble from the company, not from my families.

Several participants verbalized how families interfered with what was best for the patient precluding the nurse from being an effective advocate. For example, Darlene stated, “And then the granddaughter is like, ‘She doesn’t need it.’ Now, where does my being an advocate come in there? I can’t fight her.” Mary had similar sentiments:

Sometimes families can be barriers. They--you know, you want to do--like that one I was talking about. You want to do what would ultimately be the best for the patient, but the family doesn’t want, you know, changes.

There are other stakeholders who interfere with being an effective patient advocate such as physicians. Leslie addressed her concerns: “And sometimes I feel with the medical doctors that I really have to do that and fight for the patient. Because they are doing things that, in a hospice context, are totally inappropriate anymore.” Even directors of healthcare facilities in which the patient resides can be a barrier to advocating for the patient. Chris articulated her concern:

And I find, often, that the executive directors promise the families certain things that they feel are appropriate medically, and it’s not necessarily. And they have promised that when I show up I will order certain things--medications, for example, antibiotics--and the sense is, “If you don’t we’ll just call another hospice.” That is a big concern for me because I feel like the patient is caught in the middle. And I am the patient advocate. And if I don’t do what the ED wants, they’ll call another hospice. If I do, then I feel like I’ve betrayed myself and what my judgment is.

Thus, being a patient advocate is an important role for the nurse caring for the dying patient. In being an advocate, the patient becomes the priority centering the nursing care on the

patient's needs. Being an advocate is a multifaceted role incorporating different actions including showing compassion, educating, giving options, being the spokesperson for the patient, assessment, and collaborating with different disciplines. Ultimately the goal of patient advocacy is to act within the patient's best interests. Yet the nurses expressed barriers to their advocacy role. To do what was best for their patients, nurses had to overcome barriers presented by family members, their employer and other stakeholders.

Nurse as family advocate. In addition to being an advocate for the patient, the nurses found that they also had to support the families. All of the nurses discussed the importance of involving the family in caring for the dying patient. The interviewees discussed the importance of being honest with families, offering emotional support, and working within the context of family dynamics.

Leslie addressed the significance of involving the family on a routine basis. She considered the family as much a priority as the patient in caring for their needs. Leslie stated the following:

Because part of my whole decision making is I know I'm going to take care of the patient, one way or the other; but the family is also my patient. I can't look at just one thing. I have to look at it holistically. I have--that's the way I was trained, and that's just the way I am. Everybody is my patient when I take on someone.

Offering emotional support was considered to be an important role for the hospice nurses.

Ellen stated how she supported the family even if she disagreed with their choices:

I just thought, my goodness, you really want to do this for a person who's dying. But that's the family's choice. That's what they wanted to do. So that's what we did. It was their last attempt. A lot of it is what they want to do. It was right for them.

Chris discussed how she rendered emotional support to families although she did not agree with their decision:

And it actually worked out really well once we got to that point. And we did have a family discussion, and it revolved around, mostly, stopping dialysis; which was a major dilemma. It wasn't like, for example, stopping an antibiotic or not starting an antibiotic. It was, "Do you stop something that we know within a week or so will cause death?" And I think, for me that was a very important thing to learn and to understand that the outcomes may not be what I wanted, but as long as it's what the family needs, that's the appropriate outcome.

In fact, Chris was frequently frustrated by family dynamics affecting patient care. In the following excerpt, she discussed the importance of supporting the family to form a consensus on caring for the patient:

I think just by being there, being supportive, listening, but not really actively siding with either party helped them to talk it out--talk it through, become more realistic. And then as the patient progressed, I think all parties involved were able to see the decline and see that he was definitely suffering. Then the stepchildren--I mean the children became more realistic. And they probably still hated the stepmother as much as they always did, but they found themselves on the same side.

Yet later on in the interview, Chris explained how she learned that family dynamics cannot be changed. She emphasized the importance of working within the family structure:

So as far as how I dealt with it, I realized very quickly--it was a good learning experience--that you cannot change family dynamics. You can facilitate communication, and you can facilitate certain things; but that dynamic has been there for 25 years. Nothing I really said or did was going to change that immediately.

Mary expressed similar sentiments:

And, you know, you see that a lot in families that have been dysfunctional for years, like maybe there's been alcohol in the parent or whatever, or abuse of some sort. . . . You just have to realize sometimes, I can't change. I can only do what I can do for the patient. I can't change the family dynamics.

The interviewees spoke to the importance of being honest and sincere in their interactions with family members. Leslie offered the following advice:

Be honest with the family, but also empathetic, and also explain your situation of why that may not be the best idea; but also, sit in their chair, and go, "Yes. I understand why you're doing this and go ahead."

Later in the interview, Leslie stated the following about the nurse's role of being forthright with patients and family members:

Okay. This is what is happening, and this is why. One of the things that I always do--always, always, always--and boy, has this gotten me in trouble in a couple cases--is I'm always dead flat honest with the family. And so I always say in the very beginning, "I will tell everything, and I will speak the truth as I see it. If you don't want to know the answer, please don't ask me because I will tell you. All right?"

Mary spoke to the importance of taking into consideration the families' needs related to losing a loved one.

Because I think a lot of times we forget that, you know, we deal with this every day. And there's a whole lot of families out there that have never dealt with losing a loved one before. Or it's . . . you know, they've only known somebody who's dealt with, you know, losing a loved one.

Through frequent encounters with family members, the nurses realized the importance of including the needs of significant others into their professional practice. The interviewees voiced how family members could either be a source of support or a hindrance to quality patient care. To achieve the best outcomes, the nurses expressed the necessity to be honest with family members while being emotionally supportive.

Nurse as educator. In nursing school, students are taught that educating patients is an important aspect of their nursing role. Patients and their significant others need to be educated on their treatment options, physical care, and disease progression. The interviewees discussed the importance of educating patients and their significant others, how education aids in effective decision making, and how education improved the patient's quality of life.

Darlene expressed the significance of educating not only patients and significant others but the entire healthcare team:

Oh, definitely. Educator. Very big role. I always believe in educating my patient, and--you know--my caregivers, whoever's involved in that care--my social worker, my chaplain, whatever. And then you educate them with all the things--like supportive things. You know, I can say, "Okay. Well, if you can't do this, maybe we could go in and contribute to that part and do this."

Several nurses addressed how improvement in the patient's quality of life resulted through educating the patients and their families about treatment options and disease prognosis.

Leslie explained:

[It's] the same way with patient care. When I'm there looking at the patient and I'm going, "Okay. Why are they doing it this way?" And then I give my opinion, or I do some teaching right at the bedside on how to create a more comfortable environment for this patient.

Amy expressed similar sentiments as she discussed educating patients to alleviate their concerns. Amy explained how she educated through having casual conversations with patients:

That's my first thing going in, educating. And I don't look at what medication you have. I go in and I say: What are your concerns? And that's how I deal with my patients. And once I start to tell them what their concerns are, then I'll say, "Okay. Here's what we can do for this concern." And then when I've done all of that--when I chitchat with you, then I look up to let me see what medications you have. So my approach is a little different. I just don't go in and start doing vital signs and taking blood pressure. I have a conversation with my patients.

The participants discussed how educating patients and their families aided with ethical decision making. The following is an excerpt from Ellen: "Well, depending upon who you were bringing your information to, or even the patient himself, if you are trying to make an ethical decision, you need to educate those individuals that are involved in that decision as well."

Chris summarized the importance of teaching in aiding families to make difficult choices: "I think the most important thing is teaching, and--because the ultimate decision--decisions are the families' and the patient and teaching when the patients step in." Leslie verbalized the same point: "And that's one of those places where I have to sit in their shoes and say, "Okay, where is this coming from? Why are they doing this? And do a lot of teaching. Because they don't want

mama to starve to death.” She continued, “I’ve been able to express over time; I’ve really developed the tools of expressing to the family: ‘Okay. What is this? And what is--you know, what this decision will lead down the road to.’”

Chris discussed in detail how she framed education to help with moral dilemmas:

The patient, all the family members--try to understand what their wishes are, what their concept is of what’s actually happening, and try to make sure that they understand what’s happening. So often, I think they understand--or when I first started doing hospice, I would think they understood. They don’t. So I think validating their knowledge of exactly what’s happening, what--what their role is, what my role is, and understanding what’s going to happen to the patient; hopefully, alleviates any ethical decisions.

Several of the nurses relayed how informing the patient and their family of treatment options better equipped them to make an ethical decision while shifting the responsibility to the patient and significant others. Darlene expressed how educating the family removed the responsibility for ethical decision making from herself to the patient and significant others:

But I think the more I educate my patients, the more comfortable they get with what they’re doing. And it’s kind of placing the responsibility back to your families and your patients. It’s not all about me, you know? What I want you to do. This is--I’m telling you to do this. It’s not that. I’m educating you about what needs to be done. And then, you know, and then you can go and respond to me and tell me, “Well, this is what I can do.” You know?

In summary, the nurses viewed their role as an educator as substantial to their professional ethical practice. The interviewees relayed how they educated patients, significant others, and the hospice team to bring about desirable outcomes. Educating others aided in ethical decision making that improved the quality of the patient’s life, and health.

Nurse as decision maker. All of the nurses discussed ethical decision making as part of their nursing role in end-of-life care. Not all the ethical decisions are the nurses to make, many

fall to the patient or the family. In this section, however, I explore how ethical decisions can and should be made.

In making ethical decisions, the nurses considered time to be a significant factor. Leslie made decisions by looking at future consequences. She expressed how she looked toward the future when faced with moral issues:

I am a three car down the road nurse. I'm not just looking at what's right now, but what's later on. If we do this, okay, is it going to make him better or well? Or is it going to make him, you know, the symptoms more controlled? Or is going to be just so that you know something, but it's going to cause discomfort for them, and then there's no three cars down the road.

On the other hand, Darlene focused on the immediate moment: "Ethical decisions are made, for me, within the context of what is happening at the moment, or--and by moment, I don't mean the actual second--but at the patient's bedside or care."

Leslie described how she made ethical decision during her early years with hospice. Through experience, she learned to empower the family to make wise judgments by offering guidance and imparting knowledge:

And sometimes when I--well, many times, not just sometimes--when we are trying to make decisions about patient care--end-of-life patient care with families, because by then they are usually the ones making the decisions, okay? It's like I said, "It's not about me." And I always promise them, "I will give you all these situations and we will talk it through until you come to a decision. Because I don't ever want you to think that you have to do it because I said so."

So that's a huge leap for me from the beginning of my hospice career. Okay? You know that this is all about you and your decision making.

Later in the interview, Leslie discussed how she made ethical decisions while prioritizing the patient's and the family's needs. She patiently talked with families if their choices would conflict with the patient's best interests:

I'm going to move on to another patient. The family, or the wife, or whoever, is the one that's going to be left after the patient has died asking themselves questions; and so I

make all of my ethical decisions with a mix of, “What’s best for the patient, and what’s best for the family?”

And if the family is really out in left field about things, wanting to do something that really would harm the patient in some way, then I try to talk to the family and try to get them more towards the center. I really try as much as possible to look at it through the patient’s family’s eyes. Because what would be ethical for me and my dad or my mom is not something that’s acceptable for the family.

Mary made judgments after getting advice from other professionals or even family members. The following citation depicts how Mary made an ethical decision:

Usually, if it’s something really, really intense, I’ve been known to sit down and write, you know, pros and cons on each one and then make a decision based on that. Sometimes, I’ll second guess myself, and then I’ll say, “Okay. That doesn’t sound good either.” So then I’ll consult with some--you know, another nurse.

Many of the nurses discussed how their role is to educate or support the family in ethical decision making rather than making the decision themselves. Here is an excerpt from Leslie addressing the families’ responsibility:

So really and truly, at this point in my career, I have really tried as much as possible to get my ego out of the way and listen to what does the family really want. And then I’ll repeat it to them and give consequences good and bad. And then help them make the decision for the patient care.

Chris expanded on assisting families to make difficult choices. She stated how the entire hospice team worked with the family to achieve a consensus among family members on the best course of action for the patient:

I mean, it was obviously the patient’s and the family’s [decision]. We did not participate--other than to give them clinical information that they needed. Once that decision to stop dialysis was made, the entire family was okay with that. And I see that we assisted--or worked very hard on that case. And I do not think they would have ever gotten to that decision without us there. I really see that the entire team worked very hard with that family. And they would have never gotten to that point. They would have probably killed each other, and then more ethical concerns.

The nurses viewed their duty as empowering family members to make the decisions and educating them of available options. A few nurses expressed concerns about balancing the

patients' needs with those of family members. In addition, the nurses frequently utilized the entire team to help with decision making, very rarely were such judgments made in isolation.

The nurses used all of their powers to make an accurate assessment of the dying patient so appropriate interventions could be employed. Ellen who worked remotely from the office explained how she used her senses to make an assessment even when talking with patients and their families on the telephone: "I can see it. I can hear it. I'm imagining it. I imagine it." She gave the following description of when she went to visit a dying patient in their home:

I saw a patient who had a hyperextended neck. He was really pale. His mouth was dry. His lips were dry. He was mouth breathing. His eyes were open. His pupils were pinpoint, and they were fixed. He was stiff and he was rigid. He was in an attempted fetal position, but he had a broken hip. And his feet were starting to mottle, and they were discolored and cool to touch. And he had that smell about him. And he had a dry diaper, and it hadn't been wet for over 24 hours, I think it was. And that smell from his breath was kind of deathly. You know what I'm talking about?

Leslie explained how she drew upon intuition to assess. She stated that her sixth sense became more astute as she gained experience with dying patients.

This is going to sound insane, but I feel it. I feel it in my gut, okay? I think that is only through experience, after you've sat and held the hand. . . . But before I became a hospice nurse, I worked in long-term care for 15 years or more, anyway. And I also worked in a hospital in between time and everything. But I have sat at a lot of bedsides holding somebody's hand when they're dying, and it's such a privilege. So I've got to the point where I can just feel it. And I don't know. . . . You know, how when you first learn something it's all mechanical, and you have to think through everything. Okay. I'm going to put the needle through here. And I'm going to push the air into the thing. And then I'm going to aspirate it out, and blah, blah, blah. And you have to think through everything; and then, all of a sudden, you just do it without thinking. Okay.

Well, in my case, I think that what has happened is I have done this for so many years that I can look at a patient, feel them somehow, and say, "Oh, no. They're going to be here another two days, or another day, or whatever." And so yes, I can say, "Well, they're doing this. They're breathing this way. Their color is this way. You know, their mottling. Or maybe they are not mottling because they're having elevated temperature, and they won't mottle because their temperature is 102."

So I pay a whole lot of attention when I'm with the families, or when I'm with the patient to body language, eye contact, the color--well, in the patient, really, the color. So

when I'm doing that, I'm watching the family for anxiety, and I'm listening to how they phrase things, because how they phrase things gives me really big clues on how I'm going to respond to them.

Chris gave a personal example of how she combined observation with intuition in caring for dying patients. She discussed developing a bond with her dying grandmother, although no words were spoken:

Certainly, I think of my grandmother, for an example, I was very close to her. And at the end of her life, she broke her hip and died within 5 weeks to the day. And they called me and said that she wasn't doing well; and when I got there, they had started an IV (intravenous) because she was dehydrating. And I asked them to remove it. Because I knew it would not do any good, and I did not want to prolong her life in any way because she was dying. And that was difficult.

And I guess I used my senses in that I was able to tell she was dying, even though she had been unresponsive for several days. But I was able to somehow connect with her. And I actually said please don't go. My other sisters were waiting--well, my other sister, because at that point, several of us were up there--and she died 10 minutes after my last sister got there. So I really do feel like there was some communication, even though there wasn't--there wasn't any that you could hear. There was some kind of, like, sixth (sense).

Yes. Definitely. And it made me realize--or I do believe that in the dying process, people do hear. Maybe not like you and I are hearing right now, but in some fashion, there is some form of communication.

Darlene described the physical signs and symptoms when asked how she used her senses in end-of-life care:

First of all, I look at the patient. And you can already tell their color, you know? Once their color starts being like--almost like whitish, grayish, yellowish. You know? That kind of color. It's a change in color. You already pretty much can tell. Then you start looking at the closer ones--breathing, the movements--restless movements. . . . And another thing, they don't eat. You know? So when they start not eating, then you start thinking about that part. Because that's one of the few things that just stresses families the most is the not eating.

Amy drew upon her knowledge of communication during end-of-life care. She used her senses to effectively communicate with patients and their families to actualize a good death:

Okay. If I'm there at the time of death--I'm there and I'm holding their hands and I'm talking to them, telling them it's okay to let go. And that's where my knowledge comes

in. And that's a passion I have for the death and dying; just to make sure that they know it is okay to let go. It is okay. Your family will be fine. So in that sense, I think I'm using my senses there to let the patient know it's okay. It's okay.

There was one patient I had, and I literally held her hand and she died in my hand. You know? And she was worried about two of the girls were up in New York, and one was here. And she usually stayed by her bedside. Her problem was how is she going to manage? She's gone. Remember, she's independent. She's working. She's on her own. I know, but she depends on me for everything. And I soothe her. I say, it's okay to let go. [The Patient] will be fine. And I brought the daughter over, and she held one of the hands, and I held the other hand. And I said: Mom, it's okay to let go. And she spoke with her, and she said: Mama, I'll be fine. You go rest in peace. And she died in both of our hands.

While alert to sights and sounds, Mary also talked about the importance of intuition while working with dying patients:

You know, sometimes you get a sense . . . nothing is really going on with the patient, but you'll look at them and you'll see--I don't know--I don't even know what you'll see or feel or sense, but you sense that something is about to happen, something--you know? And something just doesn't look right or feel right or sound right. But you can't really put your finger on it. And usually, if you trust your gut, you know, that you know, maybe, put them on an increased visit schedule or whatever. You'll find that--oh, I did a good thing.

And then sometimes I will--you know, with time pressures or whatever--I'll say, "They'll be fine." And then you find out that maybe they passed away during the night or somebody had to go out and make an additional visit. They needed to be put on a watch or continuous care or whatever. Then you're like, "Oh, I should have trusted, you know that sense that I had that something was impending." And sometimes--more often than not, if something does happen and you're like, "I'm glad I listened to my intuition." And then--but then, sometimes, nothing happens. But more often than not something is about to happen.

The nurses used their senses to assess patients. Their descriptions vividly described the process of death. Three interviewees, however, referred to a sixth sense, which was more difficult for them to describe. They relied on intuition to guide their professional practice. Experience thus served as a significant aspect of the nurses' knowledge base which will be further explored in the theme, Ethical Knowledge.

Summary of Situational Context

The Dreyfus model assigns a key role to context in the development of knowledge and skills (Dreyfus & Dreyfus, 1986). Going from novice to expert in the Dreyfus learning process, one passes through five levels of proficiency while developing a particular skill: novice, advanced beginner, competent, proficient, and expert. Each level builds on the level before it as learners gain knowledge and skills through experience. At the novice level, practice is governed by objective facts and context-independent rules. As the learner becomes more proficient, context becomes more important. And, as we will see later, rules become less important. Experts act irrationally through exerting behaviors specific to a situation without consciously analyzing actions into parts. Leslie offers us a prime example of such irrational behavior based on her deep understanding of the particular situation and the absence of conscious deliberations:

Talking to the families, you learn through experience and learn through the mistakes, learn through the ways I've screwed up; and hopefully, don't do it again. But I really-- when you ask what I look at, is I look at everything. And the thing is I'm doing it so quickly, that I don't even know that I'm doing it, unless I stop and sit and consciously break it down.

While each ethical predicament is unique, it is contextualized by the nurses' moral insights. Most experienced nurses in this study believed that their personal moral insights should be removed from decision making. A prime example is reflected in Chris's statement: "I try to not let my own feelings interfere. Because I may have a certain feeling of, 'gee, if that were my mother, I wouldn't let them have that medication, or I would withhold something.'" Thus, the nurses examined their own belief systems to resolve ethical dilemmas yet believed that judgments based on their personal value system would be detrimental. Feminist scholars advocate for an embodied knowledge whereby we know our world from our specific locations within it (Harraway, 1988). The nurses in this study believed that they had to place their

emotions and personal values outside the situational context, and draw on objective principles to inform their experiences. Importantly, this appeal to universal moral values of rights and justice does not conflict with the situated nature of ethical judgments. Nurses demonstrated ability in applying such norms in the context of complex, problematic cases.

To what extent does reason and emotion guide moral judgments and actions? Certainly, feminist scholars have argued that human beings are socially, culturally, racially, sexually, and politically situated (Ford, 2007; Haraway, 1988; Harding, 1991; Lang, 2011). In fact, Haraway (1988) argued for a situated objectivity, a posture from within, as opposed to the disengaged stance of a spectator. Yet, these nurses distanced their emotions due to projected negative influences on moral actions. Was emotional distancing taught in nursing school? Emotions are important cues as they are derived from social interactions signaling a need for action. The role of emotions on moral judgment can be positively positioned if moral agency is embodied and socially entrenched (Benner, 2000). Such a task is difficult as the nurses put aside their emotions to act from a disengaged stance. According to Turiel (2002), emotions play an important role in making judgments. For example, moral judgments may be linked to emotions of sympathy and empathy contributing to nursing actions pertaining to cooperation. Thus, a detached posture is not beneficial yet may be due to sources of conflict or oppression. The nurses judged restrictions on their moral activities as unfair as needs of the patients were subordinate to others in power positions. Thus, emotional distancing may be a means of protection emanating from feelings of discouragement.

The experienced nurses in this study believed that they should not make judgments based on their own personal beliefs and values yet used the conventional and moral domains to inform their understanding of the situation. According to Turiel (2002), judgments are socially

contextualized within moral and social domains not just the personal domains. The nurse participants referred to solely the personal domain when they voiced the need to distance their values so as to not interfere with decision making. The moral domain, however, offered the nurses universal values that transcend situations and personal values. Thus, the nurses' actions frequently stemmed from the moral domain as principles of welfare, justice, and rights were incorporated into their ethical decision making. Their moral judgments were justified by appealing to the potential harm to the patients. In addition, the nurses situated their decision within a social framework. As Leslie stated, "I really try as much as possible to look at it through the patient's family's eyes. Because what would be ethical for me and my dad or my mom is not something that's acceptable for the family."

Ethical conflicts are situated by other contextual factors such as stakeholders involved in the discourse. Healthcare team members were considered to be an important asset. The nurses relied on other healthcare workers for emotional support and to validate their decisions. Team members also provided the nurses with expert medical knowledge which was incorporated into their practice.

The nurses' judgments were embedded within their diverse roles but they were not always able to execute them. In the experienced nurses' narratives of their various roles in hospice care, they clearly identified roles in managing symptoms, patient advocacy, family advocacy, educating patients and families, helping with decision making, and assessment. There was no hesitancy in the nurses' voices as they described their roles yet frustration was voiced due to inability of executing their roles.

Interference from stakeholders often prevented the nurses from performing their roles. Opposing objectives of the hospice company, physicians or other involved healthcare personnel

interfered with the nurses' goals of rendering a good death for dying patients. The experienced nurses' sense of powerlessness prevented them from exercising the necessary interventions inherent in their nursing roles. "Punching fog" was the analogy that Leslie used for feelings of frustration resulting from unsuccessful negotiations with authoritative healthcare providers.

Power is key to understanding why these nurses were not consistently able to fulfill their roles. Viewing power through different lenses aids in capturing a more thorough understanding of these nurses' plights. Most especially, as Tureil (2002) suggested, through the dimensions of race, class, or gender. Critical social theory is based on the premise that the controlling group (physicians and company executives) has power over the oppressed group. Those in a subordinated position, such as the nurses in this study, saw power as a repressive force stifling their actions. The nurses in this study recounted many stories of the hospice company preventing them from taking the best course of action for the patients. The nurses saw themselves as subdued, their knowledge not being revered. According to Foucault (1979), power and knowledge are intertwined. Thus, it is those physicians, healthcare corporations' executives, and other healthcare stakeholders in powerful positions who exert their knowledge as "truths." The nurses in this study believed their own knowledge to be the truth yet because they were not in powerful positions, their truths were not honored. This is illustrated by Darlene's statement: "That's what I've been trying to tell everybody, but nobody would listen to the nurse."

The participants discussed their eclectic roles revealing some ambiguity on their responsibilities during end-of-life care. For example, families were seen as an obstacle in patient care yet their needs were considered to be a priority when formulating nursing interventions. Although the nurses' roles merged or barriers presented, the nurses often had a clear sense of their obligations and made specific judgments based on the specific situation confronting them.

In addition, half the nurses explicitly discussed how intuition was a significant factor in performing their roles.

Intuition as a source of knowledge is explored further in the next section on knowledge but here, following Dreyfus, I explore how intuition informs moral judgment and vice versa. Some would see intuition as innate but Dreyfus views intuition as part of the individual, as it is internalized informed by experiences. It cannot be externalized into a set of rules inherent in social conventions. Ellen expressed how intuitive thought was internalized when she repeated several times: “I just know what the right thing to do is.” Her actions did not comply with rules yet with universal principles of welfare, justice, and fairness. Furthermore, intuition informs moral judgments through drawing on intellectual, emotional, and bodily experiences to influence actions (Flyvbjerg, 2001). Judgments once formed structure how events are interpreted and influence future action. In turn, experiences influence the further development of judgments (Turiel, 2002). This dynamic is evident in Leslie’s narrative: “I have done this for so many years that I can look at a patient, feel them somehow, and say, ‘Oh, no. They’re going to be here another two days, or another day, or whatever.’” Then she explains how her intuitive thoughts inform judgments and actions: “So I always say in the very beginning--I will tell everything, and I will speak the truth as I see it. If you don’t want to know the answer, please don’t ask me because I will tell you.” Furthermore, Leslie’s statement reflects how her experiences as a hospice nurse informed her judgments: “And I had to learn, over the years, that it’s never about me. It’s always about the patient and the family and their dynamics.” Thus, the relationship between intuition, moral judgment, and actions is complex, certainly not linear.

Is acting upon universal principles of welfare, fairness, and rights preferred to intuitively doing what is right? It is not either or. Through practical experience, expert nurses have learned

to intuitively apply these principles in their practice. They did not weigh them, except in cases that demanded further reflection. I have previously stated the relationship of how moral judgment informs intuition and similarly intuition informs judgment. Turiel (2002) believed that we all have intuitions about fairness, rights, and welfare learned from our experiences which help form our judgments. Intuition, used by expert practitioners, integrates context with moral intuition. Situated knowledge and moral intuition, not rationality or rules, guide ethical decision making. Knowledge that is “situated” recognizes and incorporates one’s position while taking into account the geographical, social, and political context of the knower (Haraway, 1988). A rational mode of thinking on its own is not adequate for understanding human behavior especially for ethical dilemmas during end-of-life care. Human behavior cannot be explained exclusively through rule-based deliberations. Experienced nurses do not blindly follow rules but their gut feelings. Rules come in with deliberation of complex cases. Thus, the experienced nurses did not rely on ethical principles to guide their practice as would novice nurses. Since each ethical dilemma took place within a specific context, the experienced nurses’ analysis on the right course of action required situated knowledge and moral intuition. In fact, ethical expertise is best seen through situated knowledge, which is informed by moral intuition. Intuitive knowing as “an understanding without a rationale” informed the experienced nurses understanding of the ethical situations they faced (Benner& Tanner, 1987, p. 23). Integrating context, experience, and moral intuition helps us understand how the experienced nurses deliberated on the right course of action.

Deliberations

How are nurses ethical practices informed? Nursing knowledge has been torn between an emphasis on positivism and humanism. Can these two venues peacefully exist to inform ethical discourse? Due to the difficulties of integrating scientific principles with social science, nursing has considered the prospect of nursing knowledge embedded in experiential and intuitive understanding. Yet there is still resistance as to the validity of experience and intuition as valid sources of knowledge. These concerns are addressed in this section as I discuss the second theme of ethical knowledge.

Theme Two: Ethical Knowledge

In this section, the nurses' ethical knowledge is discussed. The interviewees emphasized the importance of education to their current ethical practice. Therefore, I explore the nurses' statements of the significance of formal and informal education. How did the nurses learn about moral reasoning and making the right ethical decisions? Last, I reveal the absence of statements related to specific ethical concepts such as the ANA Code of Ethics.

Importance of education. Some of the nurses discussed the importance of education to their current practice. For example, Amy explained how education helped her to make an ethical decision by acknowledging the existence of different options:

Without education, it's kind of hard to even deal with some issues. And if you're not a well-learned person, then the wall is white and the wall is white. But once you're educated and can see beyond the white wall, then you know you have other sources to harness for you to make that ethical decision. But if you're just fixing the white wall, and the wall is white; then therefore, what are other resources can you use to deal with the issues?

Darlene addressed the significance of education to her nursing practice. She relayed how educating herself aided in gaining the respect of patients and their families but not necessarily the supervisor.

You have got to educate yourself, and then put it out there. You know? Educate. Educate your families. Educate your patients. That would make your life so much easier, seriously. I mean, there are some, of course, that don't listen. But mostly, generally speaking, I'd say at least 95% would defer to you because they know--they think that you know what you're talking about anyway--you've got to act confident. You got to act intelligent or smart. You can't be like wishy-washy.

And . . . it bothers me as a nurse because I think that I have enough, you know, experience and enough--how do you say it, expertise, professionalism. But I think I can make that decision myself. You don't know my patient. And that's the attitude--a case manager would say, "Hey. You're not in the field. I'm in the field. These are my patients."

Knowledge through formal education. The nurses discussed learning ethics in formal settings such as their nursing school programs. There was no consensus as to whether this education was beneficial.

Ellen testified that knowledge from an ethics course in nursing school was not useful to her current practice. "I remember being in that class, *Ethics in Nursing*. And I don't remember a darn thing about it. I don't remember a darn thing about it." Most of the nurses, however, were not as adamant as Ellen. For example, Darlene took a course in ethics but discussed what was learned in general terms even though she could not relate it to her current practice:

We actually had an ethics class. The program I went to was a really good program. And they give us some case scenarios and stuff like that. And then, you know, we had a discussion and we talked about it.

Amy discussed how her undergraduate nursing education incorporated ethics but not to the same extent as her graduate education. Similar to Darlene, she could not recall any specific knowledge that was learned:

Oh, yes. Definitely it (education in nursing school) has. Because I--and even in the master's program we did an entire semester on cultural barriers, cultural education on end of life. We deal with that end of life and the different cultures and how they deal with end-of-life issues, because not everybody deals with end of life the same way.

Mary did not have much education on ethics when she went to nursing school. On the other hand, Leslie believed her nursing ethics education to be extremely valuable to her current practice. She attended a religious university that focused on spirituality and ethics. In the following passage, she related the significance of an ethics course and a course on death and dying to her current nursing practice:

I got my associate's degree but then I went on to the University to get my bachelor's degree. And (the University) is a Lutheran school. And while they did not push Lutheranism, they did push ethics. They did push spiritual stuff and taking into account everything that you do has a spiritual nature to it--not necessarily Christ--but a spiritual nature. So I had to take classes in ethics related to medication--not medications, but related to medical stuff.

Yes. And I also took some death and dying classes when I was in college. Which covered some of these ethical makings. And it was--you know, at the time--I mean, it was good; but over time, I have really depended on that a lot. And one of the biggest things that I always ask families--and that I look at, myself, is--and I use the phrase (I got it from one of my professors who wrote this book that he taught us out of his book because it was his book, you know?) I still have it somewhere. "But are you extending your loved one's life? Or are you extending his death?"

Leslie emphasized the importance of spirituality in her practice several times during the interview. She asserted that her formal education was instrumental in her developing a focus on spirituality:

I try to marry the physical medical facts with their religion, okay? Because I always take into account the family's religion--or their spiritual practice, or lack of spiritual practice. And that is one thing that I really learned at (the university) that I learned at no other place, is that every component of your care, no matter what has a spiritual basis to it.

Knowledge through experience. The nurses discussed the significance of experience to their ethical knowledge base. They talked about the empowerment of both nurses and patients. In

addition, they explained the implications of personal and nursing experiences to their current ethical practice.

Experience empowers. Several nurses discussed how being experienced rendered a sense of empowerment not only for themselves but also the patients and their significant others. For example, Ellen stated that experiences gave her confidence to know and do what was right:

I probably wouldn't have felt empowered enough, experience-wise, to feel like I was doing the right thing, to have enough experience to see how it works. To see people in similar situations, talk to people in situations, do some reading, just have a client base where you've got that background and that experience early on. Probably, no. I think a lot of what I saw was--well, maybe it was learned. Through experience, yes. And through feeling confident in what you're doing. And when I say doing the right thing as you go along it just becomes . . . doing the right thing just becomes second nature.

Leslie discussed how her experiences aided in empowering the families to do what was right for them. "So I'm able, through my experience over the years, to be able to express to the families ways of letting their loved one die, without them having go would've, should've, could've."

Personal and professional experiences. The impact of personal and professional experiences cannot be understated as several nurses explained how experiential knowledge affected their current ethical nursing practice. Chris discussed how she relied on her personal experiences to guide current practice:

A lot of times it's your own experiences, and applying those experiences to your job, you know? Your family life, your parents, your friends, what your expectations are, and then reality. And you realize you can't change the world. I think just experiences from life and your children, your relationships, your dealings with patients for however many years--mine have been quite a few. I hope that I have learned from all the experiences what things work, what things don't work, and, of course, there are things I learn every day that I haven't experienced.

Mary expressed similar sentiments when she stated “I can do this or I can do that. Which is the better thing to do? So I think just going on your life experience and what you learned in nursing school.”

Several nurses discussed the benefits of past nursing experiences to their practice. Leslie relayed how symptom control and interacting with families were learned through experience. She stated that managing the physical symptoms was easier to learn than how to effectively communicate with families:

But where it (experience) has really helped the most is not so much the symptom management with the patients, but the interactions with the family. Talking to the families, you learn through experience and learn through the mistakes, learn through the ways I’ve screwed up; and hopefully, don’t do it again. I’ve been able to express over time; I’ve really developed the tools of expressing to the family, “Okay. What is this?” And what is--you know, what this decision will lead down the road to. What this decision will lead down the road to.

Later in the interview, Leslie argued that substantial learning occurred when theoretical concepts are applied during nursing practice. While learning theory and discussing ethical scenarios are important, the application of knowledge significantly expedited the learning process:

I don’t know if you can teach ethics--no. You can--you can teach ethics in situations and ethical situations, . . . but I don’t think that the practitioner can really get it until they’re there.

You can do all the theory you want, but when you are across the couch talking to somebody about the fact that their 32-year-old wife, mother of three, is going to die in the next month or two--or the next day or two, it’s a lot different than trying to do situational stuff in a class.

Chris stated the following about the usefulness of past nursing experiences in her current nursing practice:

I draw a lot of my resources on my past experience. And I’ve been a nurse for many years. And a lot of my ethical background was in the hospital and seeing how decisions were made there and applying those to the hospice setting.

Darlene repeated Chris' views on the significance of experiences:

I think it has a lot to do with experience and, maybe, my age. You know, as I get older, you know, what might have been more acceptable to me then, might not be now. You know? Because I'm older and wiser.

Not knowing. Surprisingly, when discussing ethical knowledge, the ANA Code of Ethics was rarely referenced. In fact, when two nurses discussed the code, it was referred to in a rather abstract and negative way. Darlene, who participated in an undergraduate ethics course, stated the following about the ANA Code of Ethics:

I can't remember that anymore. Is that the one--can you refresh me? I'm sorry. I can't remember. It's just too long ago. It's just the quality of service or care that you want to put out to your patients. You know? It has a lot to do with that, too. Because I do care a lot about, you know, customer service. I mean, it's a very service-oriented field. I think. And you know, so I follow some of that, too.

Mary was the other nurse that referred to the Code of Ethics but more in terms how the code intimidated her to the extent that she was fearful of doing the wrong thing. Interestingly, Mary stated that experiential knowledge made the ANA Code of Ethics less of a threat to her practice:

You know I used to worry about the code of ethics when I first started doing hospice, you know, when we were medicating patients. And then as I took, you know, more and more in-services and learned about pain management and comfort measures, I worried less about it. I felt kind of uncomfortable, you know, with the medication. And you know, I believe in comfort. Because I wouldn't have gone into hospice if I didn't believe in it a lot. Because I worked in the nursing home. And I thought, "This is crazy making these little old people think they're not eating well because they're not eating 100% of three meals a day."

While two nurses made reference to the ANA Code of Nursing, the others did not refer to the code at all during the interviews. Yet the nurses addressed the importance of being educated through formal and informal means. Mary discussed the repercussions of not knowing information:

Sometimes I even use--you know, if the patient is coming on and they've got something that I've never even heard of before that maybe is a coma--it's usually a coma or something--then I usually go online and research it, so that when you meet the patient and talk to the family you don't sound like an idiot, like you've never encountered this before.

I think so often in nursing, you have to do that. You have to kind of fake your way through it, and say, "Oh, yes. I know how to do this." You know? And then you're like going through a book.

The nurses did not rely on the ANA Code of Ethics to guide their ethical practice. They, however, employed moral principles including beneficence, justice, and autonomy on a daily basis. The nurses' moral intuitions about these principles informed their practice. For the most part, the nurses did not think it important to consciously incorporate the ANA Code of Ethics into their practice although they intuitively abided by the principles.

Summary of Deliberations

Nurses are educated in the sciences and social sciences yet the experienced nurses in this study also relied on alternate sources of knowledge including intuition and experience to make ethical decisions. My concern is that the focus of nursing knowledge continues to rely on what can be measured or observed. Even though nurse scholars are beginning to realize that nursing epistemology can be embodied in experiential and intuitive knowledge, the positivist approach is still the most revered in nursing education. Positivism asserts that the authenticity of knowledge is derived from the natural sciences anchored in the belief that the world can be known in its entirety from an objective stance (MacKenzie, 2011). As addressed by many feminists, positivism impedes the efforts of social scientists to scrutinize social phenomenon (Code, 1996; Haraway, 1988; Harding, 1991). Yet nursing is not solely a scientific endeavor it is also rooted in practice.

Context, experience, and intuition are important in forming knowledge as they are necessary ingredients in understanding the social sciences (Flyvbjerg, 2001). I have already discussed the role of context in understanding ethical discourse. My contention is that practical experience and intuitive thinking deserve an equal place alongside rules and analysis inherent in scientific discourse. The nurses' stories attest to the significance of experience and intuition as important sources of knowledge. In fact, superlative performance relies on nurses' intuition and experience. This conception is evident in the Novice to Expert Theory and Dreyfus Model, which support an abandonment of rational thinking based on rules in the proficient and expertise levels of the learning process (Benner, 1982; Dreyfus & Dreyfus, 1986). Forsaking rules can be seen in the words of interviewees as they used their intuition and past experiences as knowledge sources to inform their present practice. Using intuition to guide her practice is evident in Mary's narrative:

I don't even know what you'll see or feel or sense, but you sense that something is about to happen, something--you know? And something just doesn't look right or feel right or sound right. But you can't really put your finger on it. And usually, if you trust your gut, you know, you'll find that--oh, I did a good thing.

Thus, the experienced nurses replaced rule-based thinking with knowledge situated in context, intuition, and experience.

Several nurses in this study discussed how experiential knowledge from their professional career and personal life positively influenced current ethical nursing practice. Through repeated exposure to different situations, experience guided their actions by adding "nuances or shades of differences to theory" (Benner, 1982, p. 407). Chris succinctly summarized how experience was beneficial to her practice: "I hope that I have learned from all the experiences what things work, what things don't work; and of course, there are things I learn every day that I haven't experienced." Thus, experiences offered the nurses a venue for learning

from specific situations. Consequently, they used what was learned to respond more effectively in similar situations.

As the practitioner draws on past experiences to create expertise, phronesis is developed. Phronesis is an intellectual virtue that can be learned through repeated practice (Aristotle, 1998). To further clarify, phronesis is a “sense of the ethically practical” requiring judgment, choice, and experience (Flyvbjerg, 2001, p. 57). It is context driven while oriented toward action. In fact, the phonetic nurse arrives at the correct conclusion at the right time on the basis of accurate arguments (Saugstad, 2002). The nurses in this study used phronesis to guide their actions as many expressed a sense of knowing the “right” course of action dependent on the situational context. As Ellen stated, “I just know it was the right thing to do. Is it innate? Is it learned? I think it’s just you just have to look at the situation.” Several other nurses discussed how they knew the “right” course of action. All of the experienced nurses in this study practiced phronesis by virtue of relying on their diverse experiences to guide actions.

Nurses who use phronesis incorporate other forms of knowledge including intuition (Flaming 2001). Intuition is the ability to assimilate past and new experiences through relying on bodily, emotional, and intellectual knowledge (Flyvbjerg, 2001). It is seen as a key component of experienced, expert nurses (Benner, 1984; Dreyfus & Dreyfus, 1986). Thus, we see that the experienced nurses in this study relied on intuition to guide their practice. Leslie stated how she relied on intuition although she believed it to not be a conventional source of knowledge: “This is going to sound insane . . . but I feel it. I feel it in my gut, okay? I think that is only through experience, after you’ve sat and held the hands. . . .” Leslie was hesitant to relay how she relied on her intuition yet it is included in two of the five intellectual virtues that can be taught to an individual (Aristotle, 1998). In fact, intuition is inherent in wisdom the highest form of truths

(Aristotle, 1998). Thus, the nurses deliberated as to when intuition should be used to inform their knowledge base.

As previously stated, the nurses did not rely on ethical principles or codes to inform their ethical knowledge. Perhaps not incorporating the Code of Ethics into professional practice was due to the nurses' extensive experiences, which now guided their practice. After all, the participants had been practicing as registered nurses for over 10 years, achieving the role of proficiency or expertise (Benner, 1984). The proficient nurse knows how to modify plans to expected anticipated events. Mary's statement reflects proficiency:

You know I'm the type of person that I always come up with Plan A, Plan B, Plan C. I'm constantly thinking: Okay. If I do this and it doesn't work, then I can do this. And then what do I do?

On the other hand, expert practitioners, having an intense understanding of situations, guide their actions based on intuition informed by experiences not rules. Three interviewees, Leslie, Mary, and Chris, referred to their intuition as significant in informing their practice. So the Code of Ethics may have been relevant in the beginning of their practice but as experiential knowledge and intuition became more prevalent the nurses relied on these sources to guide their practice. In fact, moral intuition was intertwined with practical knowledge to develop intuition necessary for nursing.

In summary, deliberations were informed through theory (formal knowledge), experience and intuition. The experienced nurses deliberated on the right course of action through phronesis not by following ethical principles. Phronesis based on experiences and intuition guided the nurses' thinking. Intuition and experiential knowledge were powerful in informing the nurses' ethical knowledge.

Ethical Actions

Thus far I have examined how the situational context embedded in nursing roles and practices influenced the nurses' judgments. In addition, the nurses' moral insights were important factors in shaping context. Through a discussion on deliberations, I explained how the nurses' ethical practice is informed through formal knowledge, intuition, and experience. This leads us to the discussion on the nurses' actions to solve ethical dilemmas. Thus, the related theme entitled *Ethical Solutions* offers an explanation of actions the experienced nurses used to solve ethical dilemmas.

Theme Three: Ethical Solutions

Nurses used different recourses to solve ethical dilemmas. In the previous section, we saw how ethical decision making was considered to be an essential element of the nurse's role. In this section, I explore how the nurses solved ethical predicaments they faced. Rather than present a philosophical approach to the resolution of moral conflicts, I focus on the nurses' course of action. Did they follow rules or choose acts of resistance?

Following the rules. To resolve the ethical dilemmas, some nurses followed company policies and rules of professional conduct. The nurses expressed how if they did not follow the rules there may be negative consequences. Through their statements, a few nurses indicated the need to take the path of least resistance.

Adhering to company policies was important to several nurses yet often put them in a predicament of making a difficult choice. Ellen clearly stated the dilemma of choosing between the company's expectations and the patients' needs:

The biggest barrier is the company that you work for . . . how do you serve two answers? Do you want to keep your job? Do you want to do the right thing that you feel is the right thing to do versus getting fired and losing your job?

Later in the interview, Ellen described the need to find a solution that appeased the company while obeying their policies: “I had to figure out what I could do for him to benefit him to make him feel better to get him off without . . . without having . . . without doing something against company policy to get him off.”

Mary followed the company’s policies even though it resulted in spending increased time and effort in caring for patients. In the following excerpt, Mary described her frustrations in how following the company’s rules created extra work to get the patients what they needed:

Pretty much, if we can make a case--like we’ve tried this before and this didn’t work. We’ve tried this and this didn’t work. It seems like the list gets longer of how many times did you try something different. And then finally they go, “Oh okay.” Just give it to me the first time, you know?

Yes. You have to have drug failures. You know? Failed to be controlled on this medication. Failed this one. And then you say, “Okay. Can I have what I want now?” Yes. You passed the test, now you can have the medicine that you wanted.

Sometimes Mary would withhold her professional opinion for fear of retributions from the company or physician. She believed that utilizing assertiveness was situational as there were occasions that voicing your expertise was not appropriate or worthwhile:

But now, everybody wants to continue all these tests. And they want to keep poking the patient with needles and doing this and doing that. A lot of times it’s just futile. And you want to say that to them. And sometimes you can say it, and sometimes the doctor doesn’t want to hear it.

Amy described how she followed the rules of professional conduct with patients and families so that they would adhere to the treatment plan:

You have to pull that out of them and subtly. You can’t just blatantly say, “Well, the patient is dying and this is what we need to do.” You have to find a way of getting across to the different cultures. Because not everybody open to discussing death in an open forum. It takes--it may take several visits because I’m seeing them every week. So I just--

a low pace this week. And every week I go, I'm addressing a different piece to get my total answer.

Chris followed the rules of professional conduct when interacting with different stakeholders. In this case, the Executive Director (ED) of an Assisted Living facility wanted to control the hospice team's actions. Chris did not confront her but chose to educate the Executive Director:

And if I don't do what the ED wants, they'll call another hospice. If I do, then I feel like I've betrayed myself and what my judgment is. And I often wonder while we're in there if the ED is allowed to have that much power. And that is a difficult situation that I have not found any answers to. But what I have done too--as each situation comes up--I've tried to work with the ED and just explain to them the nursing medical reason for not doing what she wants, and mostly just stalling, a technique that is let's just wait and see. And those are very difficult, I think, for the hospices to deal with. Because there are certain things you don't have control over. And you can do your very best, and it may or may not be good for them.

Four of the interviewees expressed the need to follow the rules set forth by the company or professional practice. In either case, adhering to the rules was not a simple decision as it frequently resulted in a dilemma revolving around the patient's needs or caused additional work for the nurse. Even though these nurses followed the rules, sometimes they did not, culminating in small acts of resistance.

Acts of resistance. The nurses initiated small acts of resistance to resolve the ethical dilemmas. The interviewees expressed defiant acts including intense verbal exchanges, "white" lies, reporting to higher authorities, or refusing to do a course of action. Oftentimes, the words "fight" or "struggle" surfaced when discussing necessary actions to achieve successful outcomes. The following is an excerpt from Mary on how she had to "struggle" and "fight" with the company to meet the patients' needs:

Sometimes, I think it's the company you work for. Sometimes it's what you--I mean, sometimes it just seems like you have to really struggle to put forth what you feel is best for the patient and kind of fight, you know--fight the company on all levels to get what you need.

Here is an excerpt from Leslie who discussed her "fight" with physicians:

And sometimes I feel with the medical doctors that I really have to do that and fight for the patient. Because they are doing things that, in a hospice context, are totally inappropriate.

Several of the nurses discussed how they refused to do an action that did not concur with their beliefs or was not an appropriate nursing intervention. For example, Ellen stated the following:

And then we have a few nurses that have already made that decision that they're not going to go there, to that patient's house, and who have been reprimanded by the company that's been told, well, you have to go, and those nurses will say, "Well, you know, I don't believe that this is the right thing. I think this is a bad choice that we make to do this." And if I was to be put in that same situation, if it came down to I had to become the runner and go out to see this patient, I wouldn't do it either.

Darlene expressed a similar sentiment when the hospice company asked her to discontinue continuous care: "They wanted (it) their way. So at the end, I said, "You know what? I'm not signing off on it."

Several of the nurses used verbal discourse to achieve best patient outcomes when making ethical decisions. These oral exchanges were either with the hospice company, the physician, or family members. For example, Leslie stated, "And it's very difficult. And there have been many times when I've been so vocal about it that I've actually gotten in trouble--from the company, not from my families." Later in the interview, Leslie added how she had disagreeable discussions with physicians about appropriate interventions for dying patients:

Okay. But they have end-stage cancer, you know? They're going to be dead in 3 months, do we really care? And I say that, but that doesn't mean that I don't care that they're going to be dead in 3 months; but, you know, you have to, at some point, say--you know--talk about the elephant.

Darlene discussed her verbal exchanges with the company to achieve good patient outcomes:

And I do get a little bit passionate about it; so I will fight about it, and I will push it, and I will push it to all the way until I get my way. Because I feel like, “Hey, that’s my decision.” You know? If you have a problem with it, let’s talk about it later; but for now, let’s talk about the patient. That is my first priority.

Some of the nurses reported incidences of interference with their roles and decision-making capabilities to higher authority figures. For example, Darlene stated the following:

It’s like telling me that I’m not good enough to make a decision to do that. You know? And that’s not right. I know when I’m wrong. I will--if I made a wrong decision--you know what I’ll say? Okay. Fine. Okay. You’re right. But if I’m pushing for it and fighting about it--screaming and hollering on the phone--that’s what I had to do. I was so upset. I was so upset about that case. I reported it, actually. I sure reported it to the--not legally but to corporate. Because I decided--I just felt like that’s not right. It’s like micromanaging me. And making the wrong--making me make the wrong decisions that I don’t feel is right.

Leslie’s act of resistance was a little more unconventional when she “stretched the truth” to meet the patient’s needs:

And so what I’ve done, okay, is I have stretched what could be considered the truth and say, “Okay. This person has osteoporosis and gets this medication ordered through the family for osteoporosis, so they’re getting it and we’re not paying for it. Their insurance is paying for it because it’s not hospice related.”

I feel like I’m on the right path, in terms of getting the patient’s symptoms controlled. But I also fight with the fact that I’m not really representing the, you know, the true condition of the patient because I have to lie to get a medication for them that would not--that really and truly we should be paying for.

Sometime the nurses’ efforts to meet the patients’ needs by making the correct ethical decisions go unrewarded. Leslie expressed this sentiment when she stated,

Because a lot of times I feel like, I’m really--I’m really . . . a friend of mine calls it--what is it? Boxing fog. You know, you could keep--you can keep--you can keep hitting at it, but you’re just going to go right through.

Mary expressed a similar attitude: “And I just--sometimes you just get so tired of fighting City Hall to get what you think would be the best thing for the patient, symptom management. Usually, it’s pain medication.”

Summary of Ethical Actions

Resolving ethical dilemmas is a complex endeavor. The nurses sought ethical solutions either by following the rules of professional conduct and company policies or committing small acts of resistance. Interestingly, nurses utilized both adherence to rules and defiance in their nursing practice. The nurses’ defiant acts included verbal quarrels, “white” lies, reporting to higher authorities, and refusing to do a course of action. Through challenging those in more powerful positions, the nurses tried to create changes to improve patients’ outcomes. Yet it should be noted four of the experienced nurses used acts of resistance while others followed the rules dictated by the company. The two nurses that followed the company rules exclusively did not have less nursing experience or less education than the other four. But that is not to say that nurses that used acts of resistance to bring about change never followed company policies; so that one action was not exclusive of the other. There are many reasons for these inconsistencies as the nurses’ actions were implemented to a particular situation (Turiel, 2002). Thus, the issue of context becomes important in explaining the how nurses’ solve ethical dilemmas.

Looking at following the rules versus acts of deception leads us to a discussion of social and moral conventions. As previously mentioned, Turiel (2002) distinguished between concepts of morality, and other domains of social knowledge, such as social convention and personal choice. Each of the three domains applies different principles based on a cognitive sphere of influence with inherent normative values. For instance, actions within the moral domain are

guided by principles of how individuals ought to treat one another. The moral domain is structured by concepts of harm, welfare, and fairness regardless of the nature of existing social rules. Comparatively, actions related to social convention includes rules and regulations particular to the institutional context. Thus, conventional rules are somewhat arbitrary as they are contextualized within cultural norms and power structures. Judgments are formed within these domains to inform actions and vice versa. Yet the relationship between actions and judgments is complicated by competing interfaces of the personal, social, and moral domains (Turiel, 2002).

Seemingly a source of contention for the nurses was the contradiction of judgments presented in the moral, social, and personal domains. We have already seen how the nurses viewed judgments within the personal domain as detrimental to informing their actions. The nurses were also faced with two conflicting claims: the moral claim to improve the patients' welfare and the conventional claim to follow the hospice company's rules. For example, Ellen's statement best summarizes this dilemma: "How do you serve two masters? Do you want to keep your job? Do you want to do the right thing that you feel is the right thing to do versus getting fired and losing your job?" The nurses were confused as to which competing moral or social consideration is given priority. Sometimes they chose the social conventions as a priority as did Chris:

But what I have done too--as each situation comes up, I've tried to work with the ED and just explain to them the nursing medical reason for not doing what she wants, and mostly just stalling, a technique that--let's just wait and see.

Chris followed the rules through "stalling" but yet the patient's welfare was protected. When the patients' rights were jeopardized the nurses' actions stemmed from moral judgments. Mary's statement depicts how moral judgments were employed: "sometimes it just seems like you have to really struggle to put forth what you feel is best for the patient and kind of fight, you know--

fight the company on all levels to get what you need.” Thus, judgments were used specific to the situational context to inform the nurses’ actions. They followed conventional rules when there was minimal or no threat to patient’s wellbeing. If the patient’s welfare, justice, or rights were in jeopardy the nurses’ actions of resistance reflected judgments based on the moral domain.

Leslie’s moral judgments resulted in acts of resistance to sustain the patients’ wellbeing. She was the only nurse that used acts of deception. Although, Leslie’s story of deception is only one case, I think that we can learn from Leslie’s statements as my purpose is not to generalize this knowledge. Generalizing on the basis of one case study is more in tune with scientific methods (Flyvbjerg, 2001). After all, generalizations are only one way to create knowledge. In fact, Harding believes that it should be our goal as feminist researchers, not to justify truth claims, but to enable different forms of knowledge to emerge. Leslie’s descriptive narrative is certainly valuable to the nursing profession as a source of “embodied knowledge” from an expert nurse. Leslie contributes context dependent knowledge from her experiences with dying patients which is the focus of expert activity (Flyvbjerg, 2001). Furthermore, it is through experiences with exemplar cases such as Leslie’s story that the practitioner moves from level three to level four in the learning process. Leslie abandoned rule-based thinking and replaced it with context, experience, and intuition. Logically based action is substituted by experientially-based action. Thus, Leslie’s story walks us through an expert’s rendition of how she connected moral judgments with actions to improve the patient’s welfare.

Leslie’s engagement in deceptive acts to obtain symptom control was not for personal gain but to promote the health of the patient. She believed that lying was justified: “So ethically, I feel like I’m on the right path, in terms of getting the patient’s symptoms controlled.” It is not that Leslie did not respect honesty but obtaining symptom relief outweighed the need to tell the

truth. For Leslie, the most compelling reason for lying was the welfare of the patient. Depending on the social context and circumstances, lying may be justified in being the better course of action (Turiel, 2002). Lying as a moral issue is complex and not always judged as wrong (Turiel, 2002). Thus, I would not attribute Leslie's acts of deception as a flaw in her moral character but as an action based on moral judgment relevant to a specific situational context. After all, lying can be legitimate in certain situations especially where power structures prevent moral actions. Certainly, nurses such as Leslie do not engage in lying most or all of the time but use it to overcome unjust barriers inherent in social conventions. Leslie judged the deception undesirable but necessary to promote the health of patients. She was reluctant but felt it necessary to undermine those in power (the hospice company) who were unresponsive to the needs of its clients.

Resolving ethical issues can be complicated due to the interplay of power structures. I already discussed how controlling institutions such as the hospice company prevented the nurses from actualizing their roles. It is important to examine the influence of power on moral actions. In facing those in power, the nurses coordinated their conflicting personal, social, and moral judgments. As we have seen, social judgments dominated if the patients' immediate welfare was not at stake. Power is rule-based whereby rules determine what is permitted and forbidden. As hospice companies and physicians exercised authority, the nurses did not simply accept rules and policies. They tried to alter rules from within as seen with Leslie: "I've gone out on this campaign with my company. Bringing in info . . . and showing how it's really better to show that it's money well spent. I think we're on the verge of being able to use it." The alternative to following the rules was for the nurses to use acts of resistance. In an attempt to make the system more just, the nurses, who were in subordinate positions, engaged in acts of resistance to make

their world more righteous (Turiel & Perkins, 2004). I see the nurses' acts of resistance as justified in the context of unequal power structures.

The nurses' acts of resistance should be viewed as a moral act to halt power imbalances. In fact, Foucault (1980) contended that resistance is a part of power. Recalling Foucault's concept of power in terms of relationships, I have examined the nurses' resistive acts as means of confronting those in power. The nurses implemented various yet individualistic resistant acts that were not centralized or organized. Nevertheless, these acts of resistance had the potential to produce change within the hospice company and how the nurses viewed themselves. Resistance can be viewed as a moral act, even heroic, entailing an analysis of power structures to generate new knowledge to halt power imbalances (Foucault, 1980).

To summarize, discussions of situational context, deliberations, and actions outlined the analysis of findings from the thematic analysis. First, the nurses made judgments informed by social context inherent in their roles, practices, and moral insights. The theme of *Ethics within Practice* guided the discussion given stability through theory. Three subthemes were generated: *Nurses' Moral Insights*, *Nurses Can't do it Alone*, and *Nurses' Perceptions of their Roles*. Second, the nurses deliberated through relying on their practical and experiential knowledge as valuable resources. *Ethical Knowledge* was the theme that guided the discussion on deliberations focusing on the significance of formal and informal education to the nurses' practice. Subthemes that aided in organizing the findings included the following: *Importance of Education*, *Knowledge through Experience*, and *Not Knowing*. Theory was applied to the findings to situate them in a philosophical foundation. Third, the nurses took action based on their judgments, knowledge base, and situational context. Thus, the themes entitled Ethical Solutions framed the discussion of the findings relevant to the subthemes of *Following the Rules* and *Acts of*

Resistance. To ground my findings, theoretical discourse was used. I conclude by answering the five research questions that guided this study.

Findings Related to Research Questions

In order to summarize the findings of this study, I answered the research questions that guided my inquiry.

Research Question 1

The first question was, “What are experienced nurses’ insights to the nurse’s role in ethical dilemmas during end-of-life care?”

The nurses had a clear understanding of their role in ethical conflicts. They understood their obligations in managing symptoms, patient advocacy, family advocacy, educating patients and families, helping with decision making and assessment. The nurses realized that carrying out these responsibilities was in the best interest of the patient’s and family’s welfare. Thus, they frequently engaged the moral domain when confronted with conflicts focusing on justice and wellbeing. Actualizing their roles, however, was a source of contention due to power struggles and conflicting judgments.

The nurses became frustrated when they were not able to perform their roles due to barriers focused on family dynamics and the hospice company. Thus, even though the nurses understood duties inherent in their roles, they were not always able to perform their obligations. Interference from the hospice company often created a dilemma as the nurses were torn between allegiance to the patient or employer. They incorporated moral judgments if the patient’s welfare was at stake otherwise social judgment was employed. Moral judgments were apparent in

individual acts of resistance, such as deception, whistleblowing, or refusal to follow rules. The experienced nurses struggled to enact their roles due to the company's interference but families proved to be the main barrier to role performance.

The nurses' dilemmas focused on conflicts between families' demands and doing what was best for patients. Often patients could not voice their needs and family members took the responsibility of speaking for them. In so doing, the nurses believed patients' needs were often usurped. In fact, all of the nurses voiced family interference as a barrier to enacting their roles. Coordinating their moral judgments was difficult for the nurses because the welfare of the patient and family were both in question. Mary recounted, "You want to do what would ultimately be the best for the patient, but the family doesn't want changes . . . it gets very frustrating."

The experienced nurses understood their role in ethical decision making was to empower families to make informed choices. Therefore, the nurses rarely made decisions concerning treatment options yet educated families to make their own decisions. They educated families on various treatment modalities hoping they would choose the best alternative for their loved one. However, sometimes families' goals were not in line with what was best for patients. For example, pain medication may be effective yet render the patient lethargic. Some family members would voice concern as they wanted to communicate with the dying patient. Although the nurses educated families to endorse appropriate interventions to enhance patients' wellbeing, outcomes were not in the nurses' control. Sometimes, families made decisions that supported their own needs, not the patients'. Thus, the nurses expressed frustration as they had to choose between the welfare of the patient or the family. They believed meeting patients' needs was their primary responsibility, yet families' requests interfered with the nurse-patient advocacy role. Should the nurses' allegiance be to the patient or to the family? After all, as Leslie stated, "The

family, or the wife or whoever, is the one that's going to be left after the patient has died asking themselves questions." Moral judgments conflicted as to whose welfare was priority. Frequently, the nurses' moral judgments were exercised in favor of the patients' wellbeing but not always. As Leslie stated, "So there's a lot of times where personal ethics--in terms of not putting the patient through anymore stuff--is sublimated by the needs of the family at stake."

What are expert nurses' insights about their roles in ethical decision making during end-of-life care? Leslie presents as an exemplar case of an expert nurse fulfilling the criteria set forth in Benner's Novice to Expert Model (Benner, 1982). This is not to say that other participants were not experts but Leslie's narrative offered the best rendition of expertise. Leslie's role performance seems effortless informed through experience and intuition. Her actions were not based on calculated deliberations but intuitive decision making informed through years of experience. As an expert, Leslie exercised situated knowledge in which the problem and solutions become embodied. Her skill set became so much a part of herself that she was not even aware of them. As an expert practitioner, Leslie, confided insights related to her various roles:

And sometimes the symptoms are so ephemeral, that I don't even know if I can put a word to it, but I just know it; because I've seen it 15,000 times before. . . . That is something you learn through experience.

Talking to the families, you learn through experience and learn through the mistakes, learn through the ways I've screwed up, and hopefully, don't do it again. But I really--when you ask what I look at, is I look at everything. And the thing is I'm doing it so quickly, that I don't even know that I'm doing it, unless I stop and sit and consciously break it down.

Informed through experiences and intuition, Leslie excelled in all the various nursing roles including interactions with families.

Research Question 2

The following was my second research question: What are the available recourses to the experienced nurse in end-of-life care to assist with ethical decision making?

The nurses' recourses in ethical decision making included their own knowledge base informed through intuition and experience. They were experienced nurses functioning within levels four and five in Benner's Novice to Expert Model. Proficient and expert nurses base their actions on prior experience and intuition. The nurses' memory of prior experiences generated intuitive thinking. The proficient nurse such as Mary used intuition to inform practice but also reflected analytically over what will happen. Mary stated "And usually, if you trust your gut, you know . . . you'll find that--oh, I did a good thing." Yet Mary also commented on how she methodically deliberated over what action to take: "If it's something really, really intense, I've been known to sit down and write, you know, pros and cons on each one and then make a decision based on that." Contrast to the statements of an expert, Leslie: "You know, how when you first learn something it's all mechanical, and you have to think through everything . . . I have done this (nursing) for so many years that I can look at a patient and feel them somehow." Leslie's deliberation is not based on calculated problem solving but on her intuition. Thus the rule-based, context independent thinking of the novice, advanced beginner, and competent nurses was replaced with experience-based, situational behavior seen in the expert nurse (Flyvbjerg, 2001).

Was formal education instrumental to the nurses in assisting with ethical decisions at the end-of-life? Most of the nurses did not rely on ethical theory or were never taught ethics or concepts related to death and dying. In fact, Leslie was the only nurse who incorporated formal knowledge into her practice. Thus, as an expert in her field, Leslie was able to integrate formal

knowledge with intuition and experience. Was she able to incorporate formal knowledge with other forms of knowing because she was an expert or did integrating formal education with intuition and experiential knowledge make her an expert?

It is my contention that formal education, intuitive thinking and experiential ways of knowing created situated knowledge to make Leslie an expert nurse caring for the dying. Certainly all three diverse ways of understanding added to Leslie's formation of endowed situated knowledge embodied in time, place, and person. Leslie's statement depicts how her knowledge is situated:

All of the ethic part isn't just about the patient, himself, dying, it also includes family stuff, and also includes office stuff, you know? Is it ethical to not provide something that they might need to make them more comfortable because of money? You know, because of budget; that sort of thing.

Furthermore, Leslie's situated knowledge permitted her to engage in "webs of connection" while requiring her to take an ethical stance (Harding 1991). Leslie's intense concentration on families and patients revealed how she stayed connected:

What would your family members say could they talk right now? Because part of my whole decision making is, I know I'm going to take care of the patient, one way or the other; but the family is also my patient. The whole--I can't look at just one thing. I have to look at it holistically. I have--that's the way I was trained, and that's just the way I am. Everybody is my patient when I take on someone.

Notice that Leslie used the term "trained" reflecting on how formal education was important to current practice. In addition, Leslie's situated knowledge required a strong objectivity that was practiced by Leslie not removing herself from the situation but locating her situated space. "Be honest with the family, but also empathetic; and also explain your situation of why that may not be the best idea; but also, sit in their chair, and go, 'Yes. I understand why you're doing this.'" Thinking from the position of the other person permits biases to be uncovered by relocating ourselves into another's standpoint, which is the crux of Standpoint Theory (Harding, 1992).

The nurses used collaboration as a valuable recourse through relying on other healthcare team members' discipline specific knowledge to help solve ethical dilemmas. They cooperated with team members to help them with ethical decision making as they realized they could not do it alone. Leslie emphasized the significance of collaboration with different disciplines when she stated,

Actually, I mean, I use the chaplains and the social workers a lot in my work; and I talk to them, and go, "this is the situation, you know?" And this is what's going on. And this is where the family is. And this is where I am. And this is where the patient is. And we need to come to some kind of consensus on care.

Teamwork was learned through experience as the hospice nurses learned their role included collaboration with other professionals.

Research Question 3

My third research question was as follows: What are the challenges faced by the experienced nurse in ethical decision making during end-of-life care?

The experienced nurses in this study found that shared decision making was often impeded due to conflicts with stakeholders, mainly the hospice company and family members. They viewed the conflicts with families and the hospice company as significant impediments preventing sound decision making intensifying ethical dilemmas. I already discussed these barriers in Research Question 1. The nurses were frequently placed in a precarious position between two adversaries, resulting in challenging situations.

The hospice nurses encountered other challenges including navigating around physicians' behavior. Some doctors thought and acted in terms of treatment not focusing on palliative care. As Mary stated, "It's like the doctor doesn't want to let go of the patient, and they want one more

test. They want all these tests and they want to poke the patient.” Or perhaps the physician was not honest with the patient. Leslie voiced her frustration:

To get a patient . . . who the doctor has not told the patient that they’re dying. And then we go in there and the patient--if they’re alert and oriented--or even the families, sometimes. The families don’t know that they’re terminal. And then I’m going in there saying, “Well, I’m a hospice nurse.”

Amy reminds patients of limitations of physicians’ capabilities: “Like I told them (patient), even though the doctors gave him a few months to live, we’re not God. It’s only God who determines life.” Then there are physicians who did not refer the patient in a timely manner to hospice for symptom management and education to be effective. Leslie stated the following about referrals from physicians that came too late in the disease process: “When we have a finite amount of time to do this--like two or three days--it can be a real disaster.” Thus, interactions with physicians presented challenging situations.

Research Question 4

The fourth research question explored the nurses’ insights: What are the insights of experienced nurses on the effect of ethical decisions during end-of-life care on patient outcomes?

The nurses believed that sound ethical decisions lead to good patient outcomes resulting in peaceful deaths with symptoms controlled. Mary expressed this objective: “A good outcome should be a peaceful passing of the patient with symptoms managed, and that should be it.” Yet good outcomes may not always comply with the nurses’ parameters. Families and patients may have different notions of a good outcome. Through her experiences, Chris learned that criteria for good outcomes are not always uniform as reflected in her statement: “I think, for me that was a very important thing to learn and to understand that the outcomes may not be what I wanted, but as long as it’s what the family needs, that’s the appropriate outcome.” Thus the nurses were

aware good outcomes resulted from effective ethical decision making. The benchmarks for defining a good death, however, vary according to patients' and families' priorities.

Patients referred by physicians in a timely manner presented best case scenarios for effective education and building trusting relationships. Achieving a good death required time to educate families, patients, and caregivers about symptom management and the disease process. All of the nurses discussed the importance of education in the decision-making process. In fact, Amy expressed how she developed a rapport with patients through education:

That's my first thing going in, educating. And I don't look at what medication you have. I go in and I say, "What are your concerns?" And that's how I deal with my patients. And once they start to tell me what their concerns are, then I'll say, "Okay. Here's what we can do for this concern." And then when I've done all of that--when I chitchat with you, then I look up to let me see what medications you have. So my approach is a little different. I just don't go in and start doing vital signs and taking blood pressure. I have a conversation with my patients.

Education was key in positioning the patient for a good death but so was the relationship between the nurse, patient, and family, as described by Leslie:

The good outcomes usually happen . . . if we've had time with the family and with the patient. So let's say we have met somebody, and we've had them for 4 or 5, maybe 6 months before they actually die. And so we--I've had time to work with the family to gain trust and time to work with the patient to gain trust.

Building cohesive relationships permitted the patients and families the milieu to trust nurses and their knowledge.

Once a trusting relationship was formed and knowledge disseminated, the nurses empowered patients and families to make their own decisions about treatment and palliative care options. Leslie spoke with clarity as she retold how she no longer makes ethical decisions by herself.

I don't make the quote/unquote ethical decision anymore. Because it really isn't my place to make an ethical decision, regarding patient care. But what I do is I really and truly try to get the family and the caregivers and the doctor and the people at work to see, you

know--and I might be fooling myself. But I have actually gone and said, "Okay. This is what I think. This is another way of thinking. This is another way of thinking. What is your way of thinking?" Or I will ask them what their way of thinking is first, so it's not influenced by what I think.

Through education, the nurse helped families and patients analyze their options yet left decisions up to them. Thus, the nurses did not see their knowledge as an instrument of power to control the patients' bodies (Foucault, 1980). Instead their knowledge spoke to empowerment of patients and families so that they could make informed decisions.

Expert nurses such as Leslie were not looking for patient compliance to achieve good outcomes. She was not requesting patients to relinquish control over their bodies to power relationships found in the nurse-patient liaison. Nor was Leslie seeking compliance to a socially accepted norm reinforced through punishments and rewards (Foucault, 1980). Patient compliance was revered in her earlier practice yet through experience she learned to respect patients' and families' objectives even if they did not conform to the nursing standards:

So really and truly, at this point in my career, I have really tried as much as possible to get my ego out of the way and listen to, "What does the family really want?" And then I'll repeat it to them and give consequences good and bad. And then help them make the decision for the patient care.

The nurses were aware that although they had the capability of making sound ethical decisions their efforts could be thwarted. I already discussed how families and hospice employers could adversely affect outcomes. Darlene best summarized this experience: "Because whoever was on top, kept wanting to make the decisions and pushing me for it." Yet even though good outcomes may not be the immediate reward, the nurses expressed comfort in knowing they did their best. This was expressed by Darlene:

So even if something bad happens or something doesn't--the outcome is not as what you would like it to be--as good as you would like it to be. At least, you know that you went through the steps. You did the best you could. And you used everybody that you could.

In summary, the experienced nurses in this study believed that effective ethical decisions resulted in good patient outcomes. Definitions of a good outcome, however, are not uniform as patients and families have diverse criteria that may differ from those of healthcare professionals. Through building a trusting relationship, nurses are able to successfully educate patients and families to make informed ethical decisions. Many of the nurses believed in empowering patients and families through disseminating knowledge and not demanding compliance to medical norms. Thus, good outcomes relied on sound ethical decisions empowered by knowledge and enveloped in trusting relationships.

Research Question 5

The fifth research question had to do with situational context: How do the contextual (institutional, personal, professional, social, legal) issues influence ethical decision making during end-of-life care?

There is no doubt that ethical discourse during end-of-life care is influenced by contextual factors. Patients do not die in a vacuum nor do nurses care for the dying in isolation. Social, institutional, personal, legal, and professional issues affect ethical decisions made during end-of-life care. Certainly, patients have unique circumstances surrounding their dying experiences. So what may be the correct ethical decision for one patient may not be for another dying patient. Patients and families present with unique situations nestled in a contextualized environment within a specific time period. Leslie stated how decisions were contextualized by time and circumstances. “Ethical decisions are made, for me, within the context of what is happening at the moment, or--and by moment, I don’t mean the actual second--but at the

patient's bedside or care." Thus, the nurses could not guide their actions by using a scripted Code of Ethics that ignores contextualized factors.

The experienced nurses' stories were situated within a specific time and place influenced by institutional, social, and professional factors. For example, the nurses expressed how institutional policies adversely effected ethical decisions. Throughout her narrative, Darlene voiced concerns about the hospice company's intrusion with ethical decision making. "Your supervisors or people who have control over your decisions . . . and making the wrong--making me make the wrong decisions that I don't feel is right." Social context was another obstacle to sound ethical decisions as the nurses told endless stories of families undermining ethical decisions. Some nurses such as Darlene explained how political factors influenced ethical decisions. She discussed how hospice criteria stipulated by a governmental agency, Medicare, was confusing by giving a lack of specific guidelines.

You should be transitioning out of that full code into a DNR (Do Not Resuscitate) and DNH (Do Not Hospitalize) when you get to hospice. Because that's end state. So that's where we have a lot of problems with Medicare.

The professional context was also an impediment to end-of-life ethical decisions. Several nurses recounted how hospice physicians were fixated on the medical model of cure by focusing on patient's physiological activities. Therefore, the medical doctors attempted to prolong life utilizing scientific and technological advances. Thus, institutional policies, family interactions, and physicians' professional practice effected the decisions made during end-of-life care.

Through their voices, the nurses used situated knowledge to share personal interpretations of their nursing practice while taking into account influential institutional, social, and political issues. Instead of using Codes of Ethics to guide ethical decision making, the nurses employed situated knowledge. They incorporated intuitive thinking and experiential knowledge to inform

their understanding. In addition to using knowledge from intuition and experience, the expert nurse, Leslie, incorporated formal knowledge into her professional practice.

Most experienced nurses in this study believed that their personal moral insights should be removed from ethical decision making. According to Turiel (2002), judgments are formed within moral, social, and personal domains. Through their experiences, the nurses learned to use moral intuition in applying moral principles. They believed, however, that their personal values should not interfere with patients' end-of-life ethical decisions. Instead the experienced nurses used judgments from social and moral domains to inform their practice. Yet, the nurses needed an awareness of their personal values to exclude their impact on caring for the dying. In a sense, they possessed a "strong objectivity" through not eliminating themselves from end-of-life scenarios. The nurses recognized their situated whereabouts while being reflexive of their personal position (Harding, 1993).

Summary of Chapter IV

This chapter focused on the findings from the interviews of six hospice nurses on ethical decision making during end-of-life care. The nurses' narratives were analyzed using core story creation and thematic analysis. Through these strategies, ethical dilemmas and themes surfaced depicting the nurses' predicaments and recourses in caring for the dying.

The interviews were analyzed to obtain a description of different ethical dilemmas faced by the nurses. For the most part, conflicts resulted from barriers that interfered with nurses' efforts to successfully fulfill the dying patients' needs. The barriers were typically other parties interested in the patients' care. For example, patients' families, hospice companies, physicians, and directors of healthcare facilities were often cited as obstacles in effectively caring for

patients creating ethical dilemmas. By far, most encounters focused on conflicts with employers and patients' families.

The thematic analysis resulted in identification of three main themes centered on ethics, *Ethics within Practice*, *Ethical Knowledge*, and *Ethical Solutions*, and nine subthemes.

To best understand these themes, they were framed within discussions of situational context, deliberations on how to solve the conflicts, and actions taken by nurses to resolve the dilemmas.

The nurses examined the environment to make moral judgments embedded in nursing roles and practices. The theme of *Ethics within Practice* revealed how nurses viewed each ethical predicament as uniquely contextualized by environment and professional responsibilities as well as their own moral insights. Judgments from personal, conventional, and moral domains informed their understanding of ethical conflicts. The nurses deliberated by drawing on their practical and experiential knowledge as valuable resources to help in analyzing conflicts. The theme of *Ethical Knowledge* revealed how experienced nurses integrate context, experience, and intuition to deliberate on the right course of action. Based on their judgments, knowledge base, and situational context, the nurses sought ethical solutions either by following the rules of professional conduct and company policies or committing small acts of resistance. The third theme, *Ethical Solutions*, focused on how the nurses solved ethical dilemmas using conventional methods and/or acts of defiance. Chapter V presents the implications of these findings for the design of nursing education programs.

CHAPTER V

SUMMARY, FINDINGS, AND RECOMMENDATIONS

This chapter examines the implications of this study on how experienced nurses' successful resolutions of day-to-day ethical dilemmas during end-of-life care can inform nursing ethics education. I begin with a summary of my findings and proceed by investigating their inferences for current and future research. I also discuss their relevance for policy issues related to caring for the dying. Recommendations for future research are also explored.

Overview of the Study

My purpose for conducting this qualitative inquiry was to explore how experienced hospice nurses resolve day-to-day ethical dilemmas. It is my contention that the narratives of expert nurses are an effective pedagogic resource in teaching end-of-life care. Their stories can aid in promoting understanding of a good death for dying patients through adding important knowledge to nursing ethics education. There is wide agreement that nursing ethics education fails to prepare students to adequately make sound ethical decisions during end-of-life care. In order to answer the guiding research question, "How can experienced nurses' narratives depicting successful resolution of day-to-day ethical dilemmas during end-of-life care inform nursing ethics education?," I conducted interviews with six hospice nurses with 2 or more years of working exclusively with dying patients. Participants were recruited using purposeful sampling because their specific knowledge on ethical decision making directly informed the

research problem: Using a semi-structured approach, the face-to-face interview questions were designed to encourage participants to recount experiences of ethical discourse in their practice. The two-part narrative interviews were audio-recorded by an independent transcriber. I reread the transcripts numerous times to obtain core stories and themes.

The data were examined through two different narrative analytical approaches. To identify specific narratives of ethical dilemmas faced by the nurses, the methodology of core story creation was utilized (Emden, 1998). To create the core stories, I read interviews several times while deleting detracting words from key ideas in sentences. By moving fragments of integral themes together, comprehensible core stories were created using participants' own words. Several different ethical dilemmas were identified divulging struggles with key stakeholders. A majority of predicaments focused on conflicts with family members whose demands jeopardized the best interests of patients. Thematic analysis was then used to analyze the nurses' non-narrative responses. Interesting aspects of the data were coded and then collated into potential themes consistent with situational context, deliberations, and ethical actions. Using a theoretical approach (Braun & Clarke, 2006), three main themes were identified: *Ethics within Practice*, *Ethical Knowledge*, and *Ethical Solutions*, together with nine subthemes.

To establish rigor, I used reflexivity to scrutinize my own motivations, assumptions, and interests in caring for the dying and nursing ethics. Being a hospice nurse, I cannot claim to be an objective observer. Therefore, I looked inward into my own story to retrieve a vantage point for interpreting narratives. To member check, the core stories were provided to research participants for validation.

Implications

Answers to my research questions comprise findings related to ethical situations, deliberations, and actions. The alignment of these three components with the adopted theoretical framework has important implications for the literature on end-of-life care and nursing ethics education. Implications will be addressed by addressing themes relevant to each category.

Situational Context

The experienced nurses in this study incorporated situational context when making ethical decisions, as judgments were not formed in isolation. They were aware that ethical conflicts are situated by contextual factors including social, political, and personal issues. Thus, integrating context included attentiveness to the nurses' roles and moral insights.

Consistent with findings from research literature, the nurses believed that their personal values should be removed from decision making to assist patients and families in maintaining their values and beliefs (Mick, 2005). The experienced nurses examined their personal beliefs and values to better inform nursing practice (Barrere et al., 2008) yet placed personal values aside so patient autonomy could be exercised. Autonomy is viewed as the most influential ethical principle and main focal point in healthcare (Beauchamp & Childress, 2001; Fry & Johnstone, 2002). Dedicated to their moral commitments, the experienced nurses strived for promoting patient autonomy through encouraging patients to make autonomous decisions reflecting their own personal values not influenced by the nurses' beliefs (Breier-Mackie, 2001). Most importantly, they drew upon moral intuitions in applying ethical principles such as autonomy.

The experienced nurses in this study had a profound awareness of the situational context inherent in their professional roles. Although several research studies focused on nurses'

confusion as to roles during end-of-life care (Van Bruchem-van de Scheur et al., 2008; Reinke et al., 2010), the nurses expressed clarity in knowing their roles. In their narratives of various roles in hospice care, they clearly identified their part in managing symptoms, patient advocacy, family advocacy, educating patients and families, helping with decision making, and assessment of patients' and families' needs. All these roles are consistent with end-of-life research studies (de Veer et al., 2008; Efstathiou & Clifford, 2011; Hildén & Honkasalo, 2006; McMillen, 2008; Reinke et al., 2010; Smith, 2000; White & Coyne, 2011; White et al., 2012). In addition, giving emotional support to patients and families was inherent in many of the experienced nurses' roles including decision making and advocacy. Communication with patients and families was also viewed as an extremely important role by the nurses in this study. These findings are consistent with research literature, as rendering emotional support and facilitating effective communication were often cited as nurses' primary roles involving family members (Jackson & Dixon, 2011; Haraldsdottir, 2011; McMillen, 2008; Royak-Schaler et al., 2006; Steinhäuser et al., 2000).

For the experienced nurses, nursing roles inherent in advocacy, emotional support, and education were a priority rather than symptom management. Research studies, however, have shown that attention to physical signs and symptoms are frequently the focus for nurses who care for the dying (Clark, 2002; White & Coyne, 2011; White et al., 2012). Through their repeated experiences with dying patients, symptom management became an automatic behavior for the study's participants. Yet as evidenced in this study, physicians and company administrators often interfered with symptom management causing the nurses to "jump through hoops" to actualize a good death for patients. Moral principles of justice, fairness, and wellness fused with the nurses' experiences to oppose blind power structures in the name of the patient's good.

There was no hesitancy in the nurses' voices as they described their roles; yet frustration was voiced due to their inability to fulfill their responsibilities to render quality care to the dying. Interference from stakeholders often prevented the nurses from performing their roles. Opposing objectives of the hospice company, physicians, or other involved healthcare personnel meddled with the nurses' goals of rendering a good death for dying patients. These barriers to effective end-of-life care have been reported in the research literature (Hewitt, 2002; Hildén & Honkasalo, 2006; Jennings & Morrissey, 2011; Mahon, 2010; Thacker, 2008). By far, a primary obstacle was the hospice company, as nurses in this study recounted many stories of their employer preventing them from implementing preferred interventions for patients. Hospices, governed by state licensure requirements and federal Medicare conditions of participation, strive to deliver cost effective end-of-life care. Thus, the employers' efforts to control healthcare costs by allocating limited financial resources created a significant ethical challenge interfering with nurses' roles to promote a good death. There is limited nursing research on healthcare costs and federal and state regulations as a significant barrier in delivering high quality end-of-life care; more work needs to be done on this question. In addition, an expanded understanding of power that enables us to see the dynamics of institutional and corporate authority in the work of the nurse is needed.

The patients' families presented as a barrier to quality end-of-life care. The hospice nurses in this study often experienced difficulty in advocating for the patient and family if both had conflicting goals. Families sometimes acted in their own best interests rather than those of the patients. This finding is consistent with research literature revealing how nurses are placed in conflicting roles between two adversaries (Pavlish et al., 2011; Schou, Alvsvag, Blaka, & Gjengedal, 2008; Thacker, 2008). The perspective of situational context, however, puts this

conflict in a new light. The interplay of values inherent in the personal, social, and moral domains as depicted by Turiel is a guide to understanding choices and actions of experienced nurses.

Deliberations

This section correlates findings from the research literature with my conclusions of how experienced nurses deliberated ethical conflicts. As discussed, deliberations were informed through formal, experiential, and intuitive knowledge. All three sources of information created a sense of phronesis as the experienced nurses deliberated on right course of actions. Phronesis therefore guided the nurses' ethical thinking, resulting in worthy actions, praxis.

The experienced nurses did not rely on the ANA Code of Ethics or ethical principles as guides to resolve ethical dilemmas yet their tenants were employed. Primarily, a professional code of ethics is a set of rules to enhance decision making by providing a framework of practices, attitudes, and behaviors that are to be assumed by practitioners (Hussey, 1996; Pattison, 2001). Even though the ANA Code of Ethics was taught as a tool to guide nursing actions in their formal nursing education, the experienced nurses did not reference them. These findings are consistent with research revealing that teaching codes of ethics had minimal value in ethical discourse within the realities of modern nursing practice (Numminen, Leino-Kilpi, Arie, & Katajisto, 2011; Tadd et al., 2006; Woods, 2005). The nurses' source of guidance was their moral intuitions as described by Turiel. Grounded in practical experiences, the nurses relied on their intuition in applying principles of rights, fairness, and welfare that are captured in the ANA Code of Ethics.

Another finding from this study is that the nurses did not reach a consensus as to the merits of nursing ethics education. There is broad agreement that ethics education should assist nurses in their decision making through achieving objectives including supporting ethical aspiration, facilitating recognition of ethical dilemmas, and enhancing understanding of ethical issues (Begley, 2006; Lin et al., 2010; Vanlaere & Gastmans, 2007). With the exception of Leslie, formal nursing education was not considered to be relevant to the nurses' current ethical practice. Ethics education is valuable but not as delivered in its current "objectivist" format. It needs to be restructured through the concept of phronesis. This finding coincides with the research literature calling for improvement in teaching methodologies of ethics in nursing education (Brien et al., 2008; Garity, 2009; Mooney, 2005; Sellman, 2009, Woods, 2005). My research adds to the body of current knowledge for the need to revamp nursing ethics education to coincide with complexity of nursing practice.

Religion was an important component in nursing practice for three of the participants. For example, ethics and spirituality learned in nursing education guided Leslie in her current professional practice. Interestingly, none of the other nurses' education was religious based. Thus, little can be concluded at this juncture about the significance of religious values or spirituality in guiding nursing ethics practice yet it is a worthwhile observation. There is little in nursing research literature on how to incorporate religious views of students into ethics education; yet research in medical education addresses the complexity of the sensitivity of this issue (McLachlan, 2008). Psychological research shows that moral concepts are context independent and universal (Nucci & Turiel, 1993). Nurses may see religious beliefs as binding upon themselves, but in large part they do not seek to impose them on others. Nor do they see

moral principles as coming from their own faith. Moral principles of justice, fairness, and welfare apply to all irrespective of their belief system.

Another finding from this study is focused on how the experienced nurses used alternate sources of knowledge such as intuition and experience to inform their ethical practice. This conclusion is consistent with research literature as nursing knowledge has wandered to some extent from a scientific standpoint to include alternative ways of knowing (Benner, 1991; Benner & Tanner, 1987, Green, 2012; Traynor, Boland, & Buus, 2010). The nurses in this study described how their ideas and thoughts were refined through experiences that are consistent with research literature (Benner, 1982; Benner & Wrubel, 1982). Experiences are key to developing intuition, which has been reported in qualitative and quantitative studies (Pretz & Folse, 2011; Traynor et al., 2010). Consistent with research literature, the experienced nurses in this study relied on intuition and experience to guide their practice.

Recently, *phronesis* has appeared in the nursing literature to convey the significance of moral reasoning in nursing practice (Flaming 2002, Sellman, 2009). *Phronesis*, concerned with situated particularities, was displayed by the experienced nurses through their careful consideration of context in ethical decision making (Kristjánsson, 2005). In fact, the expert nurse, Leslie, incorporated situational context when making ethical decisions but also relied on intuitive, formal, and experiential knowledge to create embodied moral expertise as seen in *phronesis*. There is, however, limited information in nursing literature on how to teach and practice as a *phronetic*-based social science. My research adds to the benefits of incorporating a *phronetic* approach in nursing ethics discourse as a means of value relational deliberation and action. After all, nursing focuses on particularities not generalizations inherent in social context.

The findings of this study highlight the crucial elements of phronesis as context, experience, and intuition in nursing ethics.

Ethical Actions

The experienced nurses solved ethical predicaments using different actions. They either followed rules or chose acts of resistance. Different recourses were used to solve ethical conflicts, some more effective than others. In this section, I relate the study's findings on ethical solutions to findings in research literature.

Some of the experienced nurses in this study resolved ethical dilemmas through acts of resistance. The nurses' defiant acts included verbal quarrels, "white" lies, reporting to higher authorities, and refusing to do a course of action. Through challenging those in more powerful positions, the nurses tried to create changes to improve patients' outcomes. The findings of nurses exercising their power through acts of resistance are consistent with research literature (Kagan et al., 2010; Peter et al., 2004).

Another significant conclusion is that the nurses in this study collaborated with other healthcare disciplines to help them with ethical decision making as they realized they could not do it alone. This is an important finding although not addressed in my initial search of the research literature. The ANA (2002) supports collaboration among healthcare professionals to improve nurses' job satisfaction and autonomy. The IOM (2003) recommended interdisciplinary collaboration as a core competency for all healthcare professionals in the 21st century. The necessity for nurses to collaborate has been emphasized between nurse and physician but not across disciplines, until recently (Orchard, 2010). Furthermore, there is evidence that interdisciplinary cooperation and collaboration improves patient outcomes (Keene, Byington, &

Samples, 2009; Nelson, King, & Brodine, 2008; Sterchi, 2007). Thus, collaboration is a forthcoming initiative in healthcare backed by current research in addition to governmental and professional organizations.

Another finding is that the nurses in this study did not make key ethical decisions alone but empowered patients and families to make their own decisions. This conclusion is consistent with research literature that reveals nurses prefer to be involved in decision-making procedures by initiating the process and involving families (de Veer et al., 2008). Thus, nurses often empowered patients and families to participate in end-of-life care decision making (Hildén & Honkasalo, 2006; Smith, 2000). Yet, the experienced nurses in this study found that shared decision making was often impeded due to conflicts with stakeholders, mainly hospice companies and family members. This finding is contrary to the research literature, which revealed primary obstructions due to the nurses' preparedness, confusion related to patient advocacy role, and conflicts between physicians and nurses (Hildén & Honkasalo, 2006; Mahon, 2010).

Implications for Nursing Education

There are ways to improve nursing ethics education to move beyond current practice of emphasizing theory, skills to resolve ethical dilemmas, codes of ethics, ethical principles, and professional obligations (Fry, 2004). If nurses are exclusively educated in context independent knowledge found typically in textbooks, they will remain at the first two levels of the learning process in Benner's Novice to Expert Theory. While basic knowledge and rules are important, they should not be the highest goal of learning. Abstract principles are necessary but will not guarantee that one will recognize when these norms may be relevant. Findings from this study

reveal that nursing ethics education can benefit from nurses' narratives of contextualized ethical deliberations and solutions guided by their moral intuitions. I would recommend and encourage, however, that further research be conducted on how expert narratives can enhance nursing ethical practice.

Understanding ethical discourse in nursing needs to start with practice-based knowledge of what is it to be a patient, a family member, and a member of the community. Where do nursing students get this information? They are afforded clinical experiences to apply theories from didactic instruction to interactions with patients and families. Nevertheless, practicum experiences are limited leaving nursing students to function as novices. Although beginner's knowledge is important, can we achieve higher levels of learning toward competence? I believe that the gap between theoretical and practical moral reasoning can be addressed through narratives of ethical situations contextualized within sound, sight, and feelings (Benner, 1991).

The experienced nurses were able to use their senses to vividly describe ethical dilemmas. We teach nursing students to use their senses in making assessments to produce formulaic accounts of physiological processes. However, we do not teach nursing students to use their senses in a free flowing manner to describe what they see, hear, and feel. Thus, along with pragmatic assessments, we need to convey an appreciation for using our senses in a variety of ways to inform ethical decision making.

The nurses' narratives revealed how they used their senses to understand the interrelationship of body, mind, and environment. They used their vision, smell, and touch as sensory modalities contributing to their understanding of the dying process. The nurses' vivid descriptions of families and patients depicted not only the dying process but the environment. Through Ellen's portrayal of a dying patient, we are able to visualize the dying patient:

I saw a patient who had a hyperextended neck. He was really pale. His mouth was dry. His lips were dry. He was mouth breathing. His eyes were open. His pupils were pinpoint, and they were fixed. He was stiff and he was rigid. He was in an attempted fetal position, but he had a broken hip. And his feet were starting to mottle, and they were discolored and cool to touch. And he had that smell about him. And he had a dry diaper, and it hadn't been wet for over 24 hours, I think it was. And that smell from his breath was kind of deathly.

Sharing sensory creations of the patient, family, and environment offers a learning modality for nursing students to understand the dying process.

The experienced nurses' attention to their own senses informed their actions. Using their senses, they retrieved vital information about the patient, family, and environment to make sound ethical decisions during end-of-life care. Leslie's narrative relays how she used her senses to inform actions: "So when I'm doing that, I'm watching the family for anxiety, and I'm listening to how they phrase things; because how they phrase things gives me really big clues on how I'm going to respond to them." Narratives obtained from sensory ethnography interviews can educate others on how experienced nurses attend to their senses.

Benner's Novice to Expert Theory (1982) proposed that nurses pass through five levels of proficiency while developing a particular skill: novice, advanced beginner, competent, proficient, and expert. Each level builds on the one before it as the novice gains knowledge, skills and experience. It takes approximately 5 years to move through the five stages from novice to expert. Throughout, the practitioner is learning through experience yet it does not factor into decisive actions until more advanced stages. Nursing students are novices following conventional rules and formal knowledge to guide their practice. Thus, students' nursing interventions lack the knowledge informed by years of professional experiences.

The Novice to Expert Model reveals a profound difference from the first three levels to the level of the proficient and expert nurse. The gap discloses experiential and intuitive thinking

as the most important factors informing actions of the proficient and expert nurse. Experienced nurses abandon rule-based, rational thinking as a significant basis for action. In contrast to rational thinking which is calculated, analytical and devoid of context, proficient and expert nurses use experiential knowledge situated in context. They use rational thinking but its significance is not elevated as it complements experiential, context-based thinking. Thus, as experienced nurses enter into the last two levels of Benner's Model, they draw on their diverse experiences to create a phronetic way of knowing using their moral intuition.

Learning to become a phronetic nurse who uses intuition as a source of knowledge requires students to engage with and emulate others who have achieved professional phronesis. Narratives can move us beyond context to reveal how nurses draw on their experiences to create intuitive knowing. Nursing students, having not yet developed intuitive knowledge, can learn from stories of nurses who use moral intuition to make judgments. This is not to say that phronetic nurses discard reason and intellect but are able to marry them with intuition instead of applying formulaic responses. An intuitive way of knowing requires not only experience but multiple ways of knowing what students are lacking.

How do we teach intuitive thinking if it is learned through diverse experiences taking several years to formulate? One way is through case studies told by proficient and expert nurses. Their narratives depict the complexities and intricacies of actual end-of-life situations and how they used their moral intuition to apply ethical principles. Furthermore, the nurses' stories depict intuitive and experiential thinking based on intimate interactions with many dying patients. Through their narratives, nurses disclose situated knowledge based on experiences, intuition, and formal education that can be translated into ethical reasoning. Indeed, Benner (1991) claimed that clarity in ethical discourse is dependent on the situated knowledge of the nurse. Proficient

and expert nurses tell their stories to shape others' ethical comportment by sharing learned ways to resolve ethical dilemmas. It is my contention that the narratives of experienced nurses can be used to inform practice to enhance ethical reasoning. Benner (1991) espoused to the significance of stories contextually situated to inform ethical comportment. Nursing students can learn through the narratives of experienced nurses transmitting their stories on how they used intuition informed through experience to solve contextualized ethical dilemmas.

The nurses' narratives produce context dependent knowledge that surpasses theory to reveal a phronetic way of knowing. Aristotle (1988) referred to phronesis as the practical knowledge of ethics with an understanding of what is the best course of action for a particular occurrence. The nurses told many stories of how they encountered and solved ethical conflicts. Their narratives revealed how they applied phronesis to make wise clinical judgments using moral intuition based on years of practical experience. Employing narratives of proficient and expert nurses offers a venue for nursing education to move beyond educating future nurses to be competent and safe with an emphasis on evidence-based practices to developing phronesis.

Nursing students need to be taught how to draw on *theoria*, *techne*, and *phronesis* and integrate them into practice. We already excel at teaching *theoria* and *techne* but now need to include *phronesis* into nursing curriculum. Yet, *phronesis* is about value judgment requiring years of experience to develop. Although nursing education provides opportunities for acquiring *phronesis* through experiential learning, time constraints minimize opportunities for practical experiences. Nursing curriculum should include narratives of phronetic nurses' insights on how they arrived at the correct conclusion at the right time, on the basis of accurate arguments. The nurses' stories revealed phronetic deliberations about ethically correct nursing actions in specific situations. In light of limited practical experience in nursing curriculum, the narratives are an

asset to students' understanding of ethical reasoning. Reasoning through a specific patient's situation is a key component of the way nurses' use knowledge. By using nursing narratives as a teaching strategy, students can emulate experienced nurses' phronetic ways as they share their knowledge. They can benefit from experienced nurses' stories in light of their limited real-world experience in caring for the dying.

To teach toward phronesis, we need to understand how ethical problems occur in an environment structured by power relationships. The nurses' stories of following the rules and active resistance revealed how they exercised their power. Acts of resistance were seen in the nurses challenging power inequalities through speaking up, confrontation, reporting to higher authorities, and defiance. To ensure the best ethical course of action was upheld, the nurses resisted by not submitting to aversive power entities. Through challenging the status quo, the nurses attempted to create changes in policies and practices. Their acts of resistance did not lead to punishment and loss of employment as the nurses knew how to negotiate through power systems for conflict resolution. They experientially learned how to employ recourses including small acts of defiance to effectively navigate ethical spaces to bring about changes resulting in improved patient care. This knowledge, transmitted to novice nurses through narratives, can empower students to analyze and negotiate power structures to achieve good patient outcomes. Thus, nursing education should not only teach nursing roles but how to execute them in light of barriers presented by power structures. Nursing students need to be taught how to analyze power to assure that their voice are heard while their expertise is acknowledged.

Teaching for phronesis involves making ethical decisions based on judgments informed through mutual trust relationships between nurses, and patients, and families. Thus, it is my contention there needs to be a greater emphasis on family dynamics in nursing ethics education.

The experienced nurses in this study viewed families as potential barriers to a good death. Interactions with families need to be incorporated into ethics education so that nursing students learn how to communicate with different family members to build trusting relationships. In fact, ethical discourse with families should be incorporated across the nursing curriculum.

Incorporating Turiel's Domain Theory into nursing ethics education is advantageous for understanding how people make judgments. Teaching strategies could be designed to be concordant with the appropriate domain. Thus, issues related to the moral domain would focus on underlying justice or human welfare considerations. With respect to social conventions, the attention would shift to the role of societal expectations and social norms. The nursing curriculum can present complex issues containing elements from several domains to assist students' understanding of moral and social meanings of specific courses of action. Including Turiel's Domain Theory would also offer students an appreciation for how expert nurses use their moral intuition in applying moral principles

Nursing ethics education needs to include the importance of collaboration among different professionals. The experienced nurses relied on other professionals to help ensure good patient outcomes. They not only depended on others for their discipline expertise but joined forces to deliver cohesive, holistic care to patients. The nurses realized that they were not capable of fulfilling all of the patients' needs by themselves. Other professionals, including social workers and chaplains, were needed to deliver comprehensive care. Nursing education needs to convey the importance of cooperation among disciplines, which can be best shown through interdisciplinary teaching. We cannot afford to teach in silos anymore. Interprofessional teaching with other disciplines is advantageous to enlighten nursing students to different professional roles. Ethics education with student in social work, business, theology, and

medicine enables nursing students to view ethical discourse from different angles gaining an awareness of the benefits of collaboration.

It is my contention that nursing education needs to do a better job in enabling different forms of knowledge to emerge. In addition to embracing scientific knowledge inherent in evidenced-based practice, we must advocate for an embodied knowledge that is situated in time, place, and person. As nurses, we know our world from our specific locations within it as we engage in relationships with other professionals, and patients and their significant others. Understanding people demands knowledge of the socially situated relationships of the patient, the family, and the nurse. It is in this context that moral intuitions and practical knowledge inform ethical decision making during end-of-life care.

Policy Considerations

This study offers insights into the need for policy modifications, yet further research is needed to verify my findings. I have shown that experienced nurses view hospice companies as major barriers to providing quality care in end-of-life situations. Nurses recounted how imposing policies and decisions from the top fostered resentment and subtle forms of noncompliance. What are possible solutions to eliminating these barriers? Hospice companies can initiate actions to improve patient outcomes through removing obstacles. Decision making and policymaking at the corporate level needs to become more transparent through opening channels of communication. Hospice companies should provide an appropriate forum for discussion of resource allocation and policies with their employees. Open communication will provide constructive ways for employees to express concerns and to share experiences and expertise to effectively negotiate corporate policies.

Teachers and administrators need to portray open mindedness in educational policy as following the rules can conflict with moral reasoning. Ethical codes of conduct within learning institutions should be viewed through a lens discerning how people make judgments. This is best accomplished through separating actions within ethical codes by moral, social, and personal domains. Therefore, breaches of social convention may not have the same consequences as violations of moral conduct. Thus, corrective actions of misconduct need to be individualized through addressing the formation of specific judgments taking into consideration the domain and contextual nature of how students behave.

Just as experienced nurses use intuition to inform their practice, nurse educators need to rely on their intuition as sources of knowledge. Considering intuition as a venue for enlightening our practice renders another rationale why educational policies need to have a degree of flexibility. We should be able to clearly articulate how intuitive knowledge informs our ethical decisions related to students' behaviors. As educators, combining our intuition with empirical evidence when evaluating students' behavior ensures an open-minded approach to ethical discourse.

Suggestions for Future Research

This research study focused on how experienced nurses resolved ethical dilemmas during end-of-life care. The results indicated that nurses considered the contextual nature inherent in their roles and moral insights when making ethical decisions. They deliberated by employing different forms of knowledge including intuitive and experiential ways of knowing. The nurses' actions indicated compliance with rules or small acts of resistance.

There were several limitations in my study. Hospice nurses with two or more years of experience participated in telling their stories of how they solved ethical dilemmas in end-of-life care. One limitation is that I did not include nurses from different nursing specialties nor concentrate on different levels of the learning process as specified by Benner. In addition, all of the participants were females. Keeping in mind that I limited my study to six participants, I could have also concentrated my inquiry on solely expert hospice nurses. In addition, my study was conducted in one central location, which may have also affected the study's findings.

Considering the limitations, it would be desirable to conduct more studies of this type to identify commonalities as well as differences in how experienced hospice nurses solve ethical predicaments when caring for the dying. Thus, I would expand this study to include more participants in future studies. In addition, further research is recommended in other locations throughout the United States. Further qualitative studies should include narratives of those nurses who work in emergency departments, intensive care, and medical-surgical floors. More studies would help to uncover other personal truths pertaining to solving ethical dilemmas during end-of-life care.

In addition to using narrative inquiry, I recommend using other qualitative research designs. Case studies would be beneficial in gaining further knowledge on how hospices nurses negotiate ethical solutions during end-of-life care. The carefully designed case study is well suited to provide context dependent knowledge crucial to informing nursing practice. Case studies of nurses at different levels of Benner's Novice to Expert learning process can identify the unusual due to its in-depth approach. Examining real life situations of nurses at various levels of learning and correlating their views directly to the phenomenon will add to our body of

knowledge on how we care for the dying. The good example can be a powerful source of information.

More research needs to be conducted to compare the differences between females' and males' deliberations and solutions pertaining to ethical discourse during end-of-life care. Initially, I had anticipated that gender inequalities would take on a more central role yet my findings brought me down another path. Although gender disparities were not the focus of this inquiry, results indicated that female nurses embodied their knowledge while accounting for the geographical, social, and political context of all the stakeholders. They understood the interplay of ethical reflections and the dying process as an historical event and a current phenomenon within social and political contexts. The nurses recognized their situated stance and reflected on their position. Using their situated knowledge, they used acts of defiance to obtain best patient outcomes. Are male nurses' deliberations and behaviors similar to females when faced with ethical dilemmas? More research studies are recommended to study the differences and similarities between male and female nurses' ethical solutions during end-of-life care.

The issue of end-of-life care and racial minorities means learning to understand people who may express themselves differently. It is not solely an appreciation for the perspectives of racially diverse patients and families that is needed but also an understanding of how healthcare professionals' ethnicity and race interplays with caring for the dying. We need qualitative studies to explore how racially and ethnically diverse healthcare professionals, including nurses, perceive their role in ethical decision making during end-of-life care. Thus, insight is needed through further research on racial disparities as a permeating dynamic in terms of staff, patients, and families.

Following implications of the phronetic model, managing emotions and how they fit into phronesis is a topic worthy of future research. After all, inherent in the definition of intuition is a reliance on emotional knowledge. Certainly, the nurses in this study had a keen sense of their own emotional state. Ever since Aristotle, philosophers have recognized that actions are motivated by emotions. This is certainly true of nurses.

Summary

In Chapter I, I demonstrated the need for a research study on how experienced nurses' narratives' depicting successful resolution of day-to-day ethical dilemmas during end-of-life care can inform nursing ethics education. An introduction to the study with attention to focus of inquiry, research questions, background, and significance to nursing were discussed. In the second Chapter, I explored scholarship and theoretical frameworks supporting this study on the efficacy of nursing ethics education to prepare future nurses to make sound ethical decisions during the dying process. The third chapter described the research plan including research methodology, participants, data generation and analysis strategies, and methodological rigor. The interpretation and analysis of the data was disclosed in Chapter IV. The dilemmas were presented first to foster an appreciation of each nurse's moral struggles followed by the thematic analysis of the narratives. The resulting data were then used to answer the research questions. In the final section, an overview of the study, conclusions, and implications for nursing education, policy, and research were explored.

The results gained from this research study provided information on how to improve nursing ethics education through the use of narratives of experienced nurses. The nurses used in this research were dedicated and skilled nurses caring for the dying. They told their stories

depicting a keen awareness of ethical conflicts situated by contextual factors including social, political, and personal issues. The nurses' deliberations were informed through formal, experiential, and intuitive knowledge creating a sense of phronesis as they negotiated right course of actions. They solved ethical predicaments by either following rules or choosing acts of resistance. We can utilize the experienced nurses' wisdom to improve nursing ethics education, which ultimately translates to providing better deaths for patients. It is my contention that the results of this study will empower practicing nurses and nurse educators to appreciate and incorporate context and different forms of knowledge to inform their ethical discourse. In addition, I hope for a greater understanding of how ethical actions are informed through judgments influenced by different domains. Most importantly, through disseminating the findings of this study, additional research studies, and educational opportunities, the care of the dying can be improved to enhance the likelihood of a good death.

REFERENCES

- Agger, B. (2006). *Critical social theory: An introduction* (2nd ed.). Boulder, CO: Paradigm.
- Aggleton, P., & Chalmers H. (2002). *Nursing models and nursing practice* (2nd ed.). Basingstoke, UK: Palgrave.
- Aita, V. A. (2000). Science and compassion: Vacillation in nursing ideas 1940s-1960. *Research and Theory for Nursing Practice*, 14(2), 115-138.
- American Association of Colleges of Nursing. (2001). *Peaceful death: Recommended competencies and curricular guidelines for end-of-life nursing care*. Retrieved from <http://www.aacn.nche.edu/education/deathfin.htm>
- American Association of Colleges of Nursing. (2008). The essentials of baccalaureate education for professional nursing practice. Retrieved from www.aacn.nche.edu/educationresource/baccessentials08.pdf
- American Nurses' Association. (1992). *Compendium of position statements on the nurse's role in end-of-life decisions* Retrieved from <http://www.nursingworld.org/EthicsHumanRights>
- American Nurses Association (ANA). (2001). *Code of ethics for nurses with interpretive statements*. Silver Spring, MD: American Nurses Publishing.
- American Nurses Association. (2002). *Nursing's agenda for the future*. Retrieved June 10, 2013 from <http://www.nursingworld.org>.
- Aries, P. (1974). *Western attitudes toward death: From the middle ages to the present*. Baltimore, MD and London: John Hopkins University Press.
- Aristotle, (1998). *The Nicomachean ethics* (D. Ross Trans.). Oxford: Oxford University Press. (Original work published 1925).
- Atkinson, C. B., & Atkinson, J. B. (1993). Changing attitudes to death: Nineteenth-century parlour songs as consolation literature. *Canadian Review of American Studies*, 23(2), 79-96.
- Ayer, A. J. (Ed.). (1959). *Logical positivism*. Glencoe, IL: The Free Press.
- Bailey, M. A. (2011). Futility, autonomy, and cost in end-of-life care. *Journal of Law, Medicine & Ethics*, 39(2), 172-182. doi: 10.1111/j.1748-720X.2011.00586.x

- Barnato, A. E., McClellan, M. B., Kagay, C. R., & Garber, A. M. (2004). Trends in inpatient treatment intensity among Medicare beneficiaries at the end of life. *Health Service Research, 39*(2), 363-375. doi: 10.1111/j.1475-6773.2004.00234.x
- Barrere, C. C., Durkin, A., & LaCoursiere, S. (2008). The influence of end-of-life education on attitudes of nursing students. *International Journal of Nursing Education Scholarship, 5*(1), 1-17.
- Bassford, H. A. (1982). The justification of medical paternalism. *Social Science & Medicine, 16*(6), 731-739. Retrieved from [ww.journals.elsevier.com/social-science-and-medicine/](http://www.journals.elsevier.com/social-science-and-medicine/)
- Beauchamp T. L., & Childress J. F. (2001). *Principles of biomedical ethics*. Oxford, UK: Oxford University Press.
- Beckstrand, R. L., Callister, L. C., & Kirchoff, K. T. (2006). Providing a “good death”: Critical care nurses’ suggestions for improving end-of-life care. *American Journal of Critical Care, 15*(1), 38-45. Retrieved from jcc.aacnjournals.org/content/15/1/38.abstract?ijkey=d566f160b2cf6eab29a550eba696d7314f97d744&keytype2=tf_ipsecsha
- Begley, A. M. (2006). Facilitating the development of moral insight in practice: Teaching ethics and teaching virtue. *Nursing Philosophy, 7*(4), 257-265. doi: 10.1111/j.1466-769X.2006.00284.x
- Bendle, M. F., & Cook, J. (2001). The contemporary episteme of death. *Cultural Values, 5*(3), 349-366. Retrieved from <http://www.tandf.co.uk/journals/titles/13625179.html>
- Benner, P. (1982). From novice to expert. *The American Journal of Nursing, 82* (3), 402-407.
- Benner, P. (1984). *From novice to expert: Excellence and power in clinical nursing practice*. New York: Addison Wesley Publishing.
- Benner, P. (1991). The role of experience, narrative and community in skilled ethical comportment. *Advances in Nursing Science, 14*(2), 1-21.
- Benner, P. (2000). The roles of embodiment, emotion and lifeworld for rationality and agency in nursing practice. *Nursing Philosophy, 1*(1), 5-19.
- Benner, P., Sutphen, M., Leonard, V., & Day, L. (2010). *Educating nurse: A call for radical transformation*. San Francisco, CA: Jossey-Bass.
- Benner, P., & Tanner, V., (1987). Clinical judgment: how expert nurses use intuition. *American Journal of Nursing, 87*, 23-31.
- Benner, P., & Wrubel, J. (1982). Skilled clinical knowledge. The value of perceptual awareness . . . part 1. *Journal of Nursing Administration, 12*, 11-14.
- Bertaux, D., & Kohli, M. (1984). The life story approach: A continental view. *Annual Review of Sociology, p.* 215-237. Retrieved from: <http://www.annualreviews.org/journal/soc>

- Borsay, A. (2009). Nursing history: An irrelevance for nursing practice? *Nursing History Review*, 17, 14-27.
- Braun, V., & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. doi.org/10.1191/1478088706qp063oa
- Breier-Mackie, S. (2001). Patient autonomy and medical paternity: Can nurses help doctors to listen to patients? *Nursing Ethics*, 8(6), 510-521.
doi:10.1191/09697330168255380510.1177/096973300100800605
- Brien, L., Legault, A., & Temblay, N. (2008). Affective learning in end-of-life care education: The experience of nurse educators and students. *International Journal of Palliative Nursing*, 14(12), 610-614.
- Burnard, P. (1992). Learning from experience: nurse tutors' and student nurses' perceptions of experiential learning in nurse education: some initial findings. *International Journal of Nursing Studies*, 29(2), 151-161.
- Byock, I. (1997). *Dying well: The prospect for growth at the end of life*. New York, NY: Riverhead Books.
- Calvin, A. O., Lindy, C. M., & Clingon, S. L. (2009). The cardiovascular intensive care unit nurse's experience with end-of-life care: A qualitative descriptive study. *Intensive and Critical Care Nursing*, 25(4), 214-220. doi: 10.1016/j.iccn.2009.05.001
- Carper, B. A. (1978). Fundamental patterns of knowing in nursing. *Advances in Nursing Science*, 1(1), 13-23.
- Castledine, G. (2010). What constitutes a "good death"? *British Journal of Nursing (BJN)*, 19(22), 1445-1445.
- Chinn, P. L., & Kramer, M. K. (2004). *Integrated knowledge development in nursing* (6th ed.). St. Louis, MO: Mosby.
- Clark, D. (2002). Education and debate. between hope and acceptance: The medicalisation of dying. *BMJ: British Medical Journal (International Edition)*, 324(7342), 905-907. doi: 10.1136/bmj.324.7342.905
- Code, L. (1991). *What can she know? Feminist theory and the construction of knowledge*. Ithaca, NY: Cornell University Press.
- Cody, W. K. (2000). Paradigm shift or paradigm drift? A meditation on commitment and transcendence. *Nursing Science Quarterly*, 13(2), 93-102.
- Comte, A. (1853). *The positive philosophy of Auguste Comte*. (H. Martineau Trans.). London: John Chapman.

- Connelly, F. M., & Clandinin, D. J., (1990). Stories of experience and narrative inquiry. *Educational Researcher*, 19(5), 2-14.
- Connors, D. D. (1980). Sickness unto death: Medicine as mythic, necrophilic and iatrogenic. *Advances in Nursing Science*, 2(3), 39-51.
- Conway, S. (2007). The changing face of death: implications for public health. *Critical Public Health*, 17(3), 195-202. doi: 10.1080/09581590701557975.
- Costello, J. (2001). Nursing older dying patients: Findings from an ethnographic study of death and dying in elderly care wards. *Journal of Advanced Nursing*, 35(1), 59-68. doi: 10.1046/j.1365-2648.2001.01822.x
- Cowling, W. R., Shattell, M. M., & Todd, M. (2006). Hall's authentic meaning of medicalization: An extended discourse. *Advances in Nursing Science*, 29(4), 291-304.
- Coyle, N. (2005). Introduction to palliative nursing care. In B. R. Ferrell & N. Coyle (Eds.), *Textbook of palliative nursing* (2nd ed., pp. 5-12). New York, NY: Oxford University Press.
- Creswall, J. D. (2007). *Qualitative inquiry & research design: Choosing among five approaches* (2nd ed.). Thousand Oaks, CA: Sage.
- Daly M. (1978). *Gyn/Ecology: The metaethics of radical feminism*. Boston, MA: Beacon Press.
- Department of Health (2008) *End-of-life care Strategy: Promoting high quality care for all adults at the end of life*. Retrieved from http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277.
- de Veer, A., Francke, A. L., & Poortvliet, E. (2008). Nurses' involvement in end-of-life decisions. *Cancer Nursing*, 31(3), 222-228. doi: 10.1097/01.NCC.0000305724.83271.f9.
- Dickinson, G. E. (2006). End-of-life issues in US nursing school curricula: 1984-2006. *Progress in Palliative Care*, 14(4), 165-167. doi: <http://dx.doi.org/10.1179/096992606X112360>
- Dickinson, G. E. (2007). End-of-life and palliative care issues in medical and nursing schools in the United States. *Death Studies*, 31(8), 713-726. doi: 10.1080/07481180701490602.
- Dickinson, G. E. (2012). Twenty-first century end-of-life issues in selected U.S. professional schools. *Illness, Crisis & Loss*, 20(1), 19-32. doi: 10.2190/IL.20.1.c
- Doering, L. (1992). Power and knowledge in nursing: A feminist poststructuralist view. *Advances in Nursing Science*, 14(4), 24-33.
- Dreyfus, H. L., & Dreyfus, S. (1986). *Mind over machine: The power of human intuition and expertise in the era of the computer*. Oxford: Blackwell Science.

- Duke, G. J., & Northam, S. (2009). Discrepancies among physicians regarding knowledge, attitudes, and practices in end-of-life care. *Journal of Hospice & Palliative Nursing*, 11(1), 52-59. doi: 10.1177/0969733009342636
- Efstathiou, N., & Clifford, C. (2011). The critical care nurse's role in end-of-life care: Issues and challenges. *Nursing in Critical Care*, 16(3), 116-123. doi:10.1111/j.1478-5153.2010.00438.x
- Elliott, B. A., Gessert, C. E., & Peden-McAlpine, C. (2009). Family decision-making in advanced dementia: Narrative and ethics. *Scandinavian Journal of Caring Sciences*, 23(2), 251-258. doi:10.1111/j.1471-6712.2008.00613.x
- Emden, C. (1998). Conducting a narrative analysis. *Collegian*, 5, 34-39.
- Emden, C., & Sandelowski, M. (1998). The good, the bad and the relative, part one: Conceptions of goodness in qualitative research. *International Journal of Nursing Practice*, 4(4), 206-212.
- Emmanuel, E., & Emmanuel, L. (1998). The promise of a good death. *Lancet*, 14(6), 21-29.
- Ferrell, B., Virani, R., Grant, M., & Juarez, G. (2000). Analysis of palliative care content in nursing textbooks. *Journal of Palliative Care*, 16(1), 39-47.
- Ferrell, B., Virani, R., Jacobs, H. H., Malloy, P., & Kelly, K. (2010). Arts and humanities in palliative nursing education. *Journal of Pain & Symptom Management*, 39(5), 941-945. doi: 10.1016/j.jpainsymman.2009.11.314
- Finlay, L. (2002). "Outing" the researcher: The provenance, process, and practice of reflexivity. *Qualitative Health Research*, 12(4), 531-545. doi: 10.1177/104973202129120052
- Flaming, D. (2001). Using phronesis instead of 'research-based practice' as the guiding light for nursing practice. *Nursing Philosophy*, 2(3), 251-258. Retrieved from [http://onlinelibrary.wiley.com/journal/10.1111/\(ISSN\)1466-769X](http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1466-769X)
- Flexner, A. (1910). *Medical education in the United States and Canada*. New York, NY: Carnegie Foundation for the Advancement of Teaching.
- Ford, M. (2007). Situated knowledge: a coalition work. *Educational Theory*, 57(3), 307-324. doi: 10.1111/j.1741-5446.2007.00259.x
- Foucault, M. (1965). *The order of things: An archeology of the human sciences*. New York, NY: Routledge.
- Foucault, M. (1979). Governmentality. *Ideology and Consciousness* 6, 5-21.
- Foucault, M. (1980). *Power/knowledge*. New York, NY: Pantheon Books.
- Foucault, M. (2002a). *Surveiller et punir*. Gallimard, Paris.

- Foucault, M. (2002b). *Histoire de la sexualité. La volonté de savoir*. Gallimard, Paris.
- Frank, R. K. (2009). Shared decision making and its role in end-of-life care. *British Journal of Nursing (BJN)*, 18(10), 612-618.
- Fry, S. T., & Johnstone, M. J. (2002). *Ethics in nursing practice: A guide to ethical decision making* (2nd ed.). Geneva: Blackwell Science.
- Fry, S.T. (2004) Nursing ethics. In I. Ebrary and G. Khushf (Eds.), *Handbook of bioethics: Taking stock of the field from a philosophical perspective* (pp. 489-506). Dordrecht and Boston, MA: Kluwer Academic Publishers
- Galbraith, M. E., Hays, L., & Tanner, T. (2012). What men say about surviving prostate cancer: Complexities represented in a decade of comments. *Clinical Journal of Oncology Nursing*, 16(1), 65-72. doi:10.1188/12.CJON.65-72
- Garity, J., (2009). Fostering nursing students' use of ethical theory and decision making models: Teaching strategies. *Learning in Health and Social Care*, 8(2), 11-122. doi: 10.1111/j.1473-6861.2009.00223.x
- Garry, A. (2001). Medicine and medicalization: A response to Purdy. *Bioethics*, 15(3), 262-269. doi: 10.1111/1467-8519.00236
- Georgia Department of Community Health. (2009). *Rules and regulations for hospices, Chapter 111-8-62*. Retrieved July 2, 2012 from [http://dch.georgia.gov/vgn/images/portal/cit_1210/8/35/158464497Hospice%20Rules%20v4%20\(2\).pdf](http://dch.georgia.gov/vgn/images/portal/cit_1210/8/35/158464497Hospice%20Rules%20v4%20(2).pdf)
- Gibbins, J., McCoubrie, R., & Forbes, K. (2011). Why are newly qualified doctors unprepared to care for patients at the end of life? *Medical Education*, 45(4), 389-399. doi: 10.1111/j.1365-2923.2010.03873.x
- Gilligan, C. (1977). In a different voice: Women's conceptions of themselves and of morality. *Harvard Educational Review*, 47(4), 481-517.
- Gjerberg, E., Førde, R., Pedersen, R., & Bollig, G. (2010). Ethical challenges in the provision of end-of-life care in Norwegian nursing homes. *Social Science & Medicine*, 71(4), 677-684. doi:10.1016/j.socscimed.2010.03.059
- Glasberg, A., Eriksson, S., & Norberg, A. (2008). Factors associated with 'stress of conscience' in healthcare. *Scandinavian Journal of Caring Sciences*, 22(2), 249-258. doi: 10.1111/j.1471-6712.2007.00522.x
- Goldenberg, M. J. (2006). On evidence and evidence-based medicine: Lessons from the philosophy of science. *Social Science & Medicine*, 62(11), 2621-2632. doi:10.1016/j.socscimed.2005.11.031.

- Good, M. D., Gadmer, N. M., Ruopp, P., Lakoma, M., Sullivan, A. M., Redinbaugh, E., . . . Block, S. D. (2004). Narrative nuances on good and bad deaths: Internists' tales from high-technology work places. *Social Science & Medicine*, 58(5), 939-953.
- Green, C. (2012). Nursing intuition: A valid form of knowledge. *Nursing Philosophy*, 13(2), 98-111. doi:10.1111/j.1466-769X.2011.00507.x
- Griggs, C. (2010). Community nurses' perceptions of a good death: A qualitative exploratory study. *International Journal of Palliative Nursing*, 16(3), 139-148.
- Guroian, V. (2004). Salvation: Divine therapy. *Theology Today*, 61(3), 309-321.
- Hall, B. A. (2003). An essay on an authentic meaning of medicalization: The patient's perspective. *Advances in Nursing Science*, 26(1), 53-62.
- Hansen, H. (2006). The ethnonarrative approach. *Human Relations*, 59(8), 1049-1075. doi: 10.1177/0018726706068770
- Haraldsdottir, E. (2011). The constraints of the ordinary: 'being with' in the context of end-of-life nursing care. *International Journal of Palliative Nursing*, 17(5), 245-250. Retrieved from www.ijpn.co.uk/
- Haraway, D. (1988). Situated knowledge: The science question in feminism and the privilege of partial perspective. *Feminist Studies*, 14(3), 575-599.
- Haraway, D. (1991). *Simians, cyborgs, and women: The reinvention of nature*. New York, NY: Routledge.
- Harding, S. (1991). *Whose science? Whose knowledge?: Thinking from women's lives*. Ithaca, NY: Cornell University.
- Harding, S. (1993). Rethinking standpoint epistemology: What is 'strong objectivity'? In L. Alcoff and S. Potter (Eds.), *Feminist epistemologies*. New York, NY: Routledge.
- Harding, S. (2009). Standpoint theories: Productively controversial. *Hypatia*, 24(4), 192-200. doi: 10.1111/j.1527-2001.2009.01067.x
- Hardwig, J. (2009). Going to meet death: the art of dying in the early part of the twenty-first century. *Hastings Center Report*, 39(4), 37-45. Retrieved from
- Henderson, V. (1961). *Basic principles of nursing care*. London: International Council of Nurses.
- Hernandez, J., & Anderson, S. (2012). Storied experiences of nurse practitioners managing prehypertension in primary care. *Journal of the American Academy of Nurse Practitioners*, 24(2), 89-96. doi:10.1111/j.1745-7599.2011.00663.x

- Hewitt, J. (2002). A critical review of the arguments debating the role of the nurse advocate. *Journal of Advanced Nursing*, 37(5), 439-445. doi: 10.1046/j.1365-2648.2002.02110.x
- Hildén, H., & Honkasalo, M. (2006). Finnish nurses' interpretations of patient autonomy in the context of end-of-life decision making. *Nursing Ethics*, 13(1), 41-51. doi:10.1191/0969733006ne856oa
- Hildén, H., Louhiala, P., Honkasalo, M., & Palo, J. (2004). Finnish nurses' views on end-of-life discussions and a comparison with physicians' views. *Nursing Ethics*, 11(2), 165-178. doi:10.1191/0969733004ne681oa
- hooks, b. (1984) *Feminist theory: From margin to center*. Boston, MA: South End Press.
- Hopkinson, J., & Hallett, C. (2002). Good death? An exploration of newly qualified nurses' understanding of a good death. *International Journal of Palliative Nursing*, 8(11), 532-539.
- Hume, D. (1907). *An enquiry concerning human understanding*. New York, NY: The Open Court Publishing Company. (Original work published 1748)
- Hsu, M., Yi, & McCormack, B. (2012). Using narrative inquiry with older people to inform practice and service developments. *Journal of Clinical Nursing*, 21(5), 841-849. doi:10.1111/j.1365-2702.2011.03851.x
- Hussey, T. (1996). Nursing ethics and codes of professional practice. *Nursing Ethics*, 3(3), 250-258.
- Institute of Medicine (1997). *Approaching death: Improving care at the end of life*. Washington, DC: National Academy Press.
- Institute of Medicine. (2003). *Describing death in America*. Washington, DC: The National Academies Press.
- Institute of Medicine. (2003). In A. C. Greiner & E. Knebel (Eds.), *Health professions\education: A bridge to quality*. Washington, DC: The National Academies Press.
- Izumi, S (2010). Ethical practice in end-of-life care in Japan. *Nursing Ethics*, 17(4), 457-468. Retrieved from nej.sagepub.com/
- Jackson, A., & Dixon, R. (2012). Developing an end-of-life care support pathway. *Primary Healthcare*, 22(1), 22-24. .doi.org/10.7748/phc2012.02.22.1.22.c8914
- James, I., Andershed, B., Gustavsson, B., & Ternestedt, B. (2010). Knowledge constructions in nursing practice: Understanding and integrating different forms of knowledge. *Qualitative Health Research*, 20(11), 1500-1518. doi: 10.1177/1049732310374042

- Jennings, B., & Morrissey, M. B. (2011). Healthcare costs in end-of-life and palliative care: The quest for ethical reform. *Journal of Social Work in End-Of-Life & Palliative Care*, 7(4), 300-317. doi: 10.1080/15524256.2011.623458
- Jootun, D., McGhee, G., & Marland, G. R. (2009). Reflexivity: Promoting rigor in qualitative research. *Nursing Standard*, 23(23), 42-46.
- Kagan, P., & Chinn, P. (2010). We're all here for the good of the patient: a dialogue on power. *Nursing Science Quarterly*, 23(1), 41-46. doi:10.1177/0894318409353808
- Kagan, P. N., Smith, M. C., Cowling, W. R., III, & Chinn, P. L. (2010). A nursing manifesto: An emancipatory call for knowledge development, conscience, and praxis. *Nursing Philosophy*, 11(1), 67-84. doi: 10.1111/j.1466-769X.2009.00422.x
- Kear, T. M. (2012). The use of narrative analysis to study transformative learning in associate degree nursing students: A focus on the methodology. *Teaching & Learning in Nursing*, 7(1), 32-35. doi:10.1016/j.teln.2011.07.003
- Keene, S., Byington, R., & Samples, D. (2009). A study in the development of a multidisciplinary [sic] clinical and rehabilitative outpatient clinic at a regional university: the implications for the university and the community. *Internet Journal Of Healthcare Administration*, 6(1), 2.
- Kelly, T., & Howie, L. (2007). Working with stories in nursing research: Procedures used in narrative analysis. *International Journal of Mental Health Nursing*, 16, 136-144.
- Kirchhoff, K. T., Beckstrand, R. L., & Anumandla, P. R. (2003). Analysis of end-of-life content in critical care nursing textbooks. *Journal of Professional Nursing*, 19(6), 372-381.
- Kirsch, N. R. (2009). The multidisciplinary team: End-of-life ethical decisions. *Topics in Geriatric Rehabilitation*, 25(4), 292-306.
- Koch, T., & Harrington, A. (1998). Reconceptualizing rigor: The case for reflexivity. *Journal of Advanced Nursing*, 28(4), 882-890. doi: 10.1046/j.1365-2648.1998.00725.x
- Kohnke M. (1982). *Advocacy, risk, and reality*. St. Louis, MO: Mosby.
- Krisman-Scott, M. (2000). An historical analysis of disclosure of terminal status. *Journal of Nursing Scholarship*, 32(1), 47-52. doi: 10.1111/j.1547-5069.2000.00047.x
- Kristjánsson, K. (2005). Smoothing it: Some Aristotelian misgivings about the phronesis-praxis perspective on education. *Educational Philosophy & Theory*, 37(4), 455-473. doi: 10.1111/j.1469-5812.2005.00135.x
- Laderman, G. (1996). *The sacred remains: American attitudes toward death 1799-1883*. New Haven and London: Yale University Press.

- Lang, J. C. (2011). Epistemologies of situated knowledge: Troubling” knowledge in philosophy of education. *Educational Theory*, 61(1), 75-96.
- Larochelle, M. R., Rodriguez, K. L., Arnold, R. M., & Barnato, A. E. (2009). Hospital staff attributions of the causes of physician variation in end-of-life treatment intensity. *Palliative Medicine*, 23(5), 460-470. doi: 10.1177/0269216309103664
- Law, R. (2009). Bridging worlds: Meeting the emotional needs of dying patients. *Journal of Advanced Nursing*, 65(12), 2630-2641. doi:10.1111/j.1365-2648.2009.05126.x
- Liaschenko, J., & Fisher, A. (1999). Theorizing the knowledge that nurses use in the conduct of their work. *Research and Theory for Nursing Practice*, 13(1), 29-41.
- Lin, C., Lu, M., Chung, C., & Yang, C. (2010). A comparison of problem-based learning and conventional teaching in nursing ethics education. *Nursing Ethics*, 17(3), 373-382.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.
- Mackay, F., (2004). Gender and political representation in the UK: The state of the discipline. *The British Journal of Politics & International Relations*, 6(1), 99-120. doi: 10.1111/j.1467-856X.2004.00129.x
- Mackintosh, N., & Sandall, J. (2010). Overcoming gendered and professional hierarchies in order to facilitate escalation of care in emergency situations: The role of standardised communication protocols. *Social Science & Medicine*, 71(9), 1683-1686. doi: 10.1016/j.socscimed.2010.07.037.
- MacKenzie, J. (2011). Positivism and constructivism, truth and ‘truth’. *Educational Philosophy & Theory*, 43(5), 534-546. doi: 10.1111/j.1469-5812.2010.00676.x
- MacIntyre, A. (1985). *After virtue: A study in moral theory* (2nd ed.) London: Duckworth.
- Mahon, M. M. (2010). Clinical decision making in palliative care and end-of-life care. *Nursing Clinics of North America*, 45(3), 345-362. doi:10.1016/j.cnur.2010.03.002
- Malloy, D. C., Hadjistavropoulos, T., McCarthy, E. F., Evans, R. J., Zakus, D. H., Park, I., . . . Williams, J. (2009). Culture and organizational climate: Nurses’ insights into their relationship with physicians. *Nursing Ethics*, 16(6), 719-733. doi: 10.1177/0969733009342636
- Mason, J. D. (2002). Non-professional perceptions of a good death: A study of the views of hospice care patients and relatives of deceased hospice care patients. *Mortality*, 7(2), 192-209.
- McCabe, J. L., & Holmes, D. (2009). Reflexivity, critical qualitative research and emancipation: A Foucauldian perspective. *Journal of Advanced Nursing*, 65(7), 1518-1526. doi: 10.1111/j.1365-2648.2009.04978.x

- McKnight, D. (2004). An inquiry of NCATE's move into virtue ethics by way of dispositions (is this what Aristotle meant?). *Educational Studies*, 35(3), 212-230.
- McLachlan, H. (2008). The religious beliefs of students and the teaching of medical ethics: A comment on Brassington. *Journal of Medical Ethics*, 34(5), 396-398.
doi:10.1136/jme.2007.021121
- McMillen, R. E. (2008). End of life decisions: Nurses perceptions, feelings and experiences. *Intensive and Critical Care Nursing*, 24(4), 251-259. doi:10.1016/j.iccn.2007.11.002
- McSteen, K., & Peden-McAlpine, C. (2006). The role of the nurse as advocate in ethically difficult care situations with dying patients. *Journal of Hospice & Palliative Nursing*, 8(5), 259-269.
- Meghani, S. H. (2004). A concept analysis of palliative care in the united states. *Journal of Advanced Nursing*, 46(2), 152-161. doi:10.1111/j.1365-2648.2003.02975.x
- Melnyk, B. M., & Fineout-Overholt, E. (2011). *Evidence-based practice in nursing and healthcare: A guide to best practices* (2nd ed.). Philadelphia, PA: Lippincott Williams & Wilkins.
- Mick, J. (2005). The ethical dilemma of medical futility: The case of Mr. X. *Clinical Journal of Oncology Nursing*, 9(5), 611-616.
- Moen, T. (2006). Reflections on the narrative research approach. *International Journal of Qualitative Methods*, 5(4), 1-11.
- Mooney, D. (2005). Tactical reframing to reduce death anxiety in undergraduate nursing students. *American Journal of Hospice & Palliative Medicine*, 22(6), 427-432.
- Morse, J. M. (1999). Myth #93: Reliability and validity are not relevant to qualitative inquiry. *Qualitative Health Research*, 9(6), 717.
- Mylott, L., (2005). The ethical dimension of the nurse's role in practice. *Journal of Hospice and Palliative Nursing*, 7(2), 113-118.
- Mystakidou, K., Parpa, E., Tsilika, E., Katsouda, E., & Vlahos, L. (2005). The evolution of euthanasia and its perceptions in Greek culture and civilization. *Perspectives in Biology and Medicine*, 48(1), 95-104.
- National Council for Palliative Care. (2006). *End-of-life care strategy*. London: NCPC.
- National Institute of Health. (2004, December 6-8). *NIH state-of-the-science conference statement on improving end-of-life care* (Conference Report Vol. 21, No. 4). Retrieved from <http://consensus.nih.gov/2004/2004EndOfLifeCareSOS024html.htm>
- Nelson, G., King, M., & Brodine, S. (2008). Nurse-physician collaboration on medical-surgical units. *MEDSURG Nursing*, 17(1), 35-40.

- Noddings, N. (1984). *Caring: A feminist approach to ethics and moral education*. Berkeley, CA: University of California Press.
- Nucci, L., & Turiel, E. (1993). God's word, religious rules, and their relation to Christian and Jewish children's concepts of morality. *Child Development, 64*(5), 1475-1491.
- Numminen, O., Leino-Kilpi, H., Arie, & Katajisto, J. (2011). Comparison of nurse educators' and nursing students' descriptions of teaching codes of ethics. *Nursing Ethics, 18*(5), 710-724. doi:10.1177/0969733011408054
- Orchard, C. (2010). Persistent isolationist or collaborator? The nurse's role in interprofessional collaborative practice. *Journal of Nursing Management, 18*(3), 248-257. doi:10.1111/j.1365-2834.2010.01072.x
- Pace, J., C., & Lunsford, B. (2011). The evolution of palliative care nursing education. *Journal of Hospice & Palliative Nursing, 13*(6), S8-19. doi: 10.1097/NJH.0b013e31822ff0da
- Park, M. (2009). The legal basis of nursing ethics education. *Journal of Nursing Law, 13*(4), 106-113.
- Pattison, S. (2001). Are nursing codes of practice ethical? *Nursing Ethics, 8*(1), 5-18.
- Pavlish, C., Brown-Saltzman, K., Hersh, M., Shirk, M., & Rounkle, A. (2011). Nursing priorities, actions, and regrets for ethical situations in clinical practice. *Journal of Nursing Scholarship, 43*(4), 385-95. doi: 10.1111/j.1547-5069.2011.01422.x.
- Peter, E., Lunardi, V. L., & Macfarlane, A. (2004). Nursing resistance as ethical action: Literature review. *Journal of Advanced Nursing, 46*(4), 403-416. doi: 10.1111/j.1365-2648.2004.03008.x
- Pink, S. (2010). *Doing sensory ethnography*. Thousand Oaks, CA: Sage.
- Polkinghorne, D. E. (1995). Narrative configuration in qualitative analysis. In J. A. Hatch & R. Wisniewski (Eds). *Life history and narrative* (pp. 5-23). London: The Falmer Press.
- Pretz, J., & Folse, V. (2011). Nursing experience and preference for intuition in decision making. *Journal of Clinical Nursing, 20*(19/20), 2878-2889. doi:10.1111/j.1365-2702.2011.03705.x
- Random House. (1991). In *Webster's college dictionary*. New York, NY: McGraw-Hill Publishing Company.
- Reinke, L. F., Shannon, S. E., Engelberg, R., Dotolo, D., Silvestri, G. A., & Curtis, J. R. (2010). Nurses' identification of important yet under-utilized end-of-life care skills for patients with life-limiting or terminal illnesses. *Journal of Palliative Medicine, 13*(6), 753-759. doi:10.1089/jpm.2009.0423
- Riessman, C. K. (1993). *Narrative analysis*. Newbury Park, CA: Sage.

- Rinpoche, S. (1992). *The Tibetan book of living and dying*. San Francisco, CA: Harper.
- Robichaux, C., & Clark, A. (2006). Practice of expert critical care nurses in situations of prognostic conflict at the end of life. *American Journal of Critical Care, 15*(5), 480-491.
- Royak-Schaler, R., Gadalla, S. M., Lemkau, J. P., Ross, D. D., Alexander, C., & Scott, D. (2006). Journal club. Family perspectives on communication with healthcare providers during end-of-life cancer care. *Oncology Nursing Forum, 33*(4), 753-760. doi:10.1188/06.ONF.753-760
- Rush, S. (1992). Nursing education in the United States, 1898-1910: a time of auspicious beginnings. *Journal of Nursing Education, 31*(9), 409-414.
- Sadler, J. Z., Jotterand, F., Lee, S. C., & Inrig, S. (2009). Can medicalization be good? Situating medicalization within bioethics. *Theoretical Medicine & Bioethics, 30*(6), 411-425. doi: 10.1007/s11017-009-9122-4
- Saugstad, T. (2002). Educational Theory and Practice in an Aristotelian Perspective. *Scandinavian Journal of Educational Research, 46*(4), 373-390. doi:10.1080/0031383022000024561
- Schou, K., Alvsvåg, H., Blåka, G., & Gjengedal, E. (2008). The (dis)appearance of the dying patient in generalist hospital and care home nurses' talk about the patient. *Nursing Philosophy, 9*(4), 233-247.
- Schulman-Green, D., McCorkle, R., Cherlin, E., Johnson-Hurzeler, R., & Bradley, E. H. (2005). Nurses' communication of prognosis and implications for hospice referral: A study of nurses caring for terminally ill hospitalized patients. *American Journal of Critical Care, 14*(1), 64-70.
- Sellman, D. (2009). Practical wisdom in health and social care: Teaching for professional pronesis. *Learning in Health & Social Care, 8*(2), 84-91.
- Seymour, J. E., Bellamy, G., Gott, M., Ahmedzai, S. H., & Clark, D. (2002). Good deaths, bad deaths: Older people's assessments of the risks and benefits of morphine and terminal sedation in end-of-life care. *Health, Risk & Society, 4*(3), 287-303.
- Sheehan, M. (2000). On dying well. *America, 183*(3), 12-15.
- Sirota, T. (2007). Nurse/physician relationships: Improving or not? *Nursing, 37*(1), 52-56. doi: 10.3912/OJIN.Vol14No03Man04
- Smith, R. (2000). A good death. *British Medical Journal, 320*(1), 129-130.
- Soderberg, A., & Norberg, A. (1993). Intensive care: Situations of ethical difficulty. *Journal of Advance Nursing, 18*(12), 2008-2014.

- Stanley, L. (2008). Madness to the method? Using a narrative methodology to analyze large-scale complex social phenomena. *Qualitative Research*, 8(3), 435-447. doi: 10.1177/1468794106093639
- Stein, A. M. (1998). History of continuing nursing education in the United States. *The Journal of Continuing Education in Nursing*, 29(6), 245-252.
- Steinhauser, K. E., Clipp, E. C., McNeilly, M., Christakis, N. A., McIntyre, L. M., & Tulsky, J. A. (2000). In search of a good death: Observations of patients, families, and providers. *Annals of Internal Medicine*, 132(10), 825-832.
- Sterchi, L. (2007). Perceptions that affect physician-nurse collaboration in the perioperative setting. *AORN Journal*, 86(1), 45. doi:10.1016/j.aorn.2007.06.009
- Streubert, H. J., & Carpenter, D. R. (1995). *Qualitative research in nursing*. Philadelphia, PA: J.B. Lippincott.
- Syme, A., & Bruce, A. (2009). Hospice and palliative care: What unites us, what divides us? *Journal of Hospice & Palliative Nursing*, 11(1), 19-26. doi: 10.1097/NJH.0b013e3181917ee3
- Tadd, W., Clarke, A., Lloyd, L., Leino-Kilpi, H., Strandell, C., Lemonidou, C., . . . Heymans, R. (2006). The value of nurses' codes: European nurses' views. *Nursing Ethics*, 13(4), 376-393.
- Thacker, K. S. (2008). Nurses' advocacy behaviors in end-of-life nursing care. *Nursing Ethics*, 15(2), 174-185. doi: 10.1177/0969733007086015
- Todaro-Franceschi, V. (2011). Changing the face of death: A pedagogic intervention. *Journal of Professional Nursing*, 27(5), 315-319. doi: 10.1016/j.profnurs.2011.04.002
- Tong, E., McGraw, S. A., Dobihal, E., Baggish, R., Cherlin, E., & Bradley, E. H. (2003). What is a good death? Minority and non-minority perspectives. *Journal of Palliative Care*, 19(3), 168-175.
- Todaro-Franceschi, V. (2011). Changing the face of death: A pedagogic intervention. *Journal of Professional Nursing*, 27(5), 315-319. doi: 10.1016/j.profnurs.2011.04.002
- Traynor, M., Boland, M., & Buus, N. (2010). Autonomy, evidence and intuition: nurses and decision-making. *Journal of Advanced Nursing*, 66(7), 1584-1591. doi:10.1111/j.1365-2648.2010.05317.x
- Turiel, E. (2002). *The culture of morality: Social development, context, and conflict*. New York. NY: Cambridge Press.
- Turiel, E., & Perkins, S. A. (2004). Flexibilities of mind: conflict and culture. *Human Development*, 47(3), 158-178. doi:10.1159/000077988

- Ulrich, C. M., O'Donnell, P., Taylor, C., Farrar, A., Danis, M., & Grady, C. (2007). Ethical climate, ethics stress, and the job satisfaction of nurses and social workers in the United States. *Social Science & Medicine*, 65(8), 1708-1719. Retrieved from <http://www.journals.elsevier.com/social-science-and-medicine/>
- Ulrich, C. M., Taylor, C., Soeken, K., O'Donnell, P., Farrar, A., Danis, M., & Grady, C. (2010). Everyday ethics: ethical issues and stress in nursing practice. *Journal of Advanced Nursing*, 66(11), 2510-2519. doi:10.1111/j.1365-2648.2010.05425.x
- Van Bruchem-van de Scheur, G., van der Arend, A. J., Abu-Saad, H. H., van Wijmen, F.C., Spreeuwenber, C., & ter Meule, R. H., (2008). Alleviation of pain and symptoms with a life shortening intention. *Nursing Ethics*, 15(5), 682-696. doi:10.1177/0969733008092876
- Vanderspank-Wright, B., Fothergill-Bourbonnais, F., Brajtman, S., & Gagnon, P. (2011). Caring for patients and families at end of life: The experiences of nurses during withdrawal of life-sustaining treatment. *Dynamics*, 22(4), 31-35. Retrieved from <http://www.caccn.ca/en/publications/dynamics/>
- Van Laan, T. (1963). Everyman: A structural analysis. *PMLA*, 78(1), 465-475.
- Vanlaere, L., & Gastmans, C. (2007). Ethics in nursing education: Learning to reflect on care practices. *Nursing Ethics*, 14(6), 758-766.
- Vig, E. K., Davenport, N. A., & Pearlman, R. A. (2002). Good deaths, bad deaths, and preferences for the end of life: A qualitative study of geriatric patients. *JAGS*, 50(9), 1542-1548.
- Walter, T. (2003). Historical and cultural variants on the good death. *British Medical Journal*, 327, 218-220.
- Walters, G. (2004). Is there such a thing as a good death? *Palliative Medicine*, 18, 404-408.
- White, K. R., & Coyne, P. J. (2011). Nurses' perceptions of educational gaps in delivering end-of-life care. *Oncology Nursing Forum*, 38(6), 711-717. doi:10.1188/11.ONF.711-717
- White, K., Coyne, P., & White, S. (2012). Are hospice and palliative nurses adequately prepared for end-of-life care? *Journal of Hospice & Palliative Nursing*, 14(2), 133-140. doi:10.1097/njh.0b013e318239b943
- Whitehead, P. B., Anderson, E. S., Redican, K. J., & Stratton, R. (2010). Studying the effects of the end-of-life nursing education consortium at the institutional level. *Journal of Hospice & Palliative Nursing*, 12(3), 184-193.
- Willard, C., & Luker, K. (2006). Challenges to end-of-life care in the acute hospital setting. *Palliative Medicine*, 20(6), 611-615.

Woods, M. (2005). Nursing ethics education: are we really delivering the good (s)? *Nursing Ethics*, 12(1), 5-18.

Wright, D., & Brajtman, S. (2011). Relational and embodied knowing: nursing ethics within the interprofessional team. *Nursing Ethics*, 18(1), 20-30. doi:10.1177/0969733010386165

Zomorodi, M., & Foley, B. J. (2009). The nature of advocacy vs. paternalism in nursing: Clarifying the thin line. *Journal of Advanced Nursing*, 65(8), 1746-1752. doi:10.1111/j.1365-2648.2009.05023.x

APPENDIX A
PRE-DETERMINED LIST OF INTERVIEW QUESTIONS

1. Discuss some ethical dilemmas you experienced in end-of-life care.
2. Discuss barriers affecting your ability to make ethical decisions during end-of-life care.
3. Discuss factors that assisted you to make ethical decision during end-of-life care.
4. How do you make ethical decisions during end-of-life care?
5. What are your beliefs about your role in ethical dilemmas during end-of-life care?
6. What are your views on the patient outcomes of your ethical decisions during end-of-life care?

APPENDIX B
IRB APPROVAL LETTER

Office for Research
Institutional Review Board for the
Protection of Human Subjects

THE UNIVERSITY OF
ALABAMA
R E S E A R C H

January 4, 2013

Judith L. Hold
ELPTS
College of Education
Box 870302

Re: IRB # 13-OR-003-ME, "A Good Death: The Experiential Ethics of Nursing"

Dear Ms. Hold:

The University of Alabama Institutional Review Board has granted approval for your proposed research.

Your application has been given expedited approval according to 45 CFR part 46. Approval has been given under expedited review category 7 as outlined below:

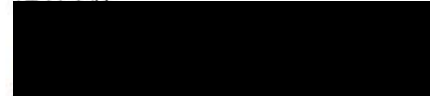
(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Your application will expire on January 3, 2014. If the study continues beyond that date, you must complete the IRB Renewal Application. If you modify the application, please complete the Modification of an Approved Protocol form. Changes in this study cannot be initiated without IRB approval, except when necessary to eliminate apparent immediate hazards to participants. When the study closes, please complete the Request for Study Closure form.

Should you need to submit any further correspondence regarding this application, please include the assigned IRB application number.

Good luck with your research.

Sincerely,


Carpentato T. Myles, MSJ, CIM
Director & Research Compliance Officer
Office for Research Compliance
The University of Alabama



358 Rose Administration Building
Box 870127
Tuscaloosa, Alabama 35487-0127
Fax: 205 348 2441
Tel: (205) 348-7189
Toll free 1-877-820-2056

APPENDIX C

INFORMED CONSENT FORM/AGENCY PARTICIPATION

Project: Qualitative Research Study

Researcher: Judith L. Hold RN, BSN, MS

Phone Number: 770-722-1247

Location of the Study: Mutually agreeable place.

Supervising Professor: Stephen Tomlinson, PhD

Purpose of the Study: The purpose of this qualitative study is to describe ethical dilemmas faced by registered nurses in end-of-life situations and the available recourses to address end-of-life decisions.

Procedures to be Followed: One-on-one interviews with hospice nurse

Benefits of the Study: Improve end-of-life care and nursing education

Confidentiality Statement: Participation in this project is confidential. Only the researcher and The University of Alabama's supervising professor will have access to the participant's identities and to information that can be associated with their identities.

This study has been explained to me and I have read and understand this consent form, all of my questions have been answered, and I agree to permit the participation of this agency's hospice nurses.

Signature of Executive Director

Date

APPENDIX D
INFORMED CONSENT FORM/AUTHORIZATION TO PARTICIPATE

Dear ,

I understand that I am being asked to participate in a research study to explore my experiences and perceptions related to ethical decision making during end-of-life care. The interview, lasting about one to two hours, will be conducted at a mutually agreeable place. The investigator will return for a second visit to seek clarification of topics introduced in the first interview and ask questions related to the educational preparation for ethical decision making. In addition, I will be given the opportunity to read the interview transcription for accuracy. My participation in this study is strictly voluntary. I may withdraw from this study at any time by notifying the researcher. The researcher is Judy Hold at 770-722-1247, a doctoral student at The State University of Alabama.³

My participation in this project is strictly confidential. Only the researcher and supervising professor will have access to my identity and to information that can be associated to my identity. The interview will be audiotaped, transcribed and kept in a locked cabinet for a period of ten years. After the period of ten years, the research data will be destroyed. I understand that no identifying information will be included in the transcription or the data. I can review the taped interview and transcription at any time. Furthermore, I understand that this information may be used in nursing publications or presentations.

I understand that there is no physical risk to participating in this study. Benefits of participating in this study include increased self-awareness and the satisfaction that my participation will provide information related to improving nursing care at the end-of-life. The discomforts include the possibility that I may become sad during the interview process. If this happens, the interview will be temporarily stopped until I feel that I can continue. The hospice chaplain or social worker will be available to render emotional support, if needed.

This study has been explained to me. I have read and understand the consent form. All of my questions have been answered, and I agree to participate. I understand that I will be given a copy of this signed consent form.

Signature of Participant

Date

Signature of Investigator

Date

APPENDIX E

THEMES AND SUB-THEMES CONCEPT MAP

Themes and Subthemes Map

Theme 1: Ethics within practice

Sub-theme: Moral Insights

Sub-theme: Nurses Can't do it Alone

Sub-theme: Nurses' Roles

Theme 2: Ethical Knowledge

Sub-theme 1: Importance of Education

Sub-theme 2: Knowledge through Formal Education

Sub-theme 3: Knowledge through Experience

Sub-theme 4: Not Knowing

Theme 3: Ethical Solutions

Subtheme 1: Following the Rules

Subtheme 2: Active Resistance