

ABSTRACT

EXPERIENCES OF ONCOLOGY NURSES IN END-OF-LIFE CARE: A PHENOMENOLOGICAL STUDY

By Patricia J. Martins

The purpose of this qualitative study was to explore the experiences of oncology nurses (ONs) in end-of-life (EOL) care. Oncology nurses often have an intimate role in assisting patients psychologically, physically and emotionally at the EOL. As a result, caring for dying patients affects ONs professionally as well as personally, and ultimately becomes a fundamental part of who they are as human beings. There is a lack of nursing research regarding the experiences of ONs in EOL care.

Understanding the experiences and perspectives of ONs who care for patients at the EOL is important for developing strategies to support them in delivering quality care, as well as preserving their individual health and well being.

Parse's (1998) theory of human becoming was the theoretical framework guiding the study. The sample was a purposive convenience sample of nurses currently practicing in either an inpatient or outpatient oncology setting. A demographic questionnaire was utilized to aid in data collection, and semi-structured face-to-face interviews were conducted using a researcher-developed interview guide. Data were analyzed utilizing Giorgi's (1985) approach to phenomenological data analysis.

The three themes that emerged during data analysis include: (a) *emotional work*, (b) *knowing and unknowing*, and (c) *care for the caregiver*, which supported Parse's (1998) practice methodology of illuminating meaning, synchronizing rhythm, and mobilizing transcendence. The data discussed reveal what caring for patients at the EOL means to ONs and how it impacts them personally. Further research is recommended with larger samples and a larger geographical area to understand this subject in greater depth.

EXPERIENCES OF ONCOLOGY NURSES
IN END-OF-LIFE CARE: A PHENOMENOLOGICAL STUDY

by

Patricia J. Martins

A Clinical Paper Submitted
In Partial Fulfillment of the Requirements
For the Degree of

Master of Science in Nursing

Family Nurse Practitioner

at

University of Wisconsin Oshkosh
Oshkosh, Wisconsin 54901-8621

April 2008

APPROVAL

Mary E. Wuybach Advisor
4/27/08 Date Approved

PROVOST
AND VICE CHANCELLOR

J. R. G.
4/27/2008
Date Approved

FORMAT APPROVAL

Gloria Spittgerber
4/11/2008 Date Approved

This project is dedicated to the heroes in my life: my family. To my husband, and the love of my life, John, I so admire your zest for life and thank you for your constant love and generosity of your time. To my son, Joe, who is embarking on his own future. Never lose your kind and gentle nature. You will go far in life. To my son, Will. I treasure your giving and caring heart. Always have faith in yourself and your abilities. You will also go far in life. Finally, to my parents, who have been there from the very beginning. I could never thank you enough. You have been true role models. I love you all!.

ACKNOWLEDGEMENTS

I wish to acknowledge and graciously thank my clinical chair, Dr. Mary Ellen Wurzbach, for her genuine interest in this study as well as her gentle encouragement along the way. I always felt inspired and enlightened after our conversations to continue on in this sometimes daunting, but worthwhile task. I offer my deepest gratitude.

266
M36
008
c.2

TABLE OF CONTENTS

	Page
LIST OF FIGURES.....	vi
CHAPTER I – INTRODUCTION.....	1
Significance to Nursing.....	3
Problem Statement.....	4
Purpose of the Study.....	4
Research Question.....	4
Definitions of Terms.....	5
Conceptual Definitions.....	5
Operational Definitions.....	5
Assumptions.....	6
Summary.....	6
CHAPTER II – THEORETICAL FRAMEWORK AND LITERATURE REVIEW.....	7
Introduction.....	7
Theoretical Framework.....	7
Illuminating Meaning.....	9
Synchronizing Rhythm.....	9
Mobilizing Transcendence.....	10
Review of Literature.....	10
Summary.....	16
CHAPTER III – METHODOLOGY.....	18
Introduction.....	18
Research Design.....	18
Population, Sample and Setting.....	18
Data Collection Instrument.....	19
Data Collection Procedures.....	20
Data Analysis Procedures.....	21
Limitations.....	22
Summary.....	22
CHAPTER IV – RESULTS AND DISCUSSION.....	23
Introduction.....	23
Demographic Data.....	23
The Interview Process.....	23
Results.....	24
Emotional Work.....	25
Knowing and Unknowing.....	27
Care for the Caregiver.....	29
Discussion.....	31
Summary.....	34

TABLE OF CONTENTS (Continued)

	Page
CHAPTER V – SUMMARY, CONCLUSIONS AND RECOMMENDATIONS.....	36
Introduction.....	36
Summary of Study Findings.....	36
Conclusions	38
Implications for Nursing Practice	40
Implications for Nursing Education	41
Implications for Nursing Administration.....	41
Recommendations for Future Research	41
Summary	42
APPENDIXES	
Appendix A: Demographic Questionnaire	43
Appendix B: Interview Guide.....	45
Appendix C: UW Oshkosh IRB Approval Letter	47
Appendix D: Informed Consent Document.....	49
REFERENCES.....	52

LIST OF FIGURES

	Page
Figure 1. Parse's Theoretical Structures of Human Becoming	8
Figure 2. Parse's Practice Methodology	39

CHAPTER I

INTRODUCTION

Cancer is the second leading cause of death in the U.S., exceeded only by heart diseases. In 2003, there were 556,902 cancer deaths in the U.S. (American Cancer Society, 2007). Cancer-related deaths have a significant impact on not only the patients and their families, but also the oncology nurses (ONs) who care for them. Oncology nurses are in a unique position to address the needs of patients facing the EOL. Oncology nursing can pose many challenges, such as the stress of practicing in a cure-focused profession and witnessing the anguish of patients at the EOL, when cure is no longer possible. End-of-life care has emerged as an important focus of nursing research over the past several decades. "All people will die. Most deaths are not sudden. Most persons will experience death also as caregivers or family" (National Institutes of Health [NIH], 2006).

Providing care for patients at the EOL is a challenging endeavor. "Dying patients and their families often have unique physical, psychosocial, social, and spiritual needs that require specialized end-of-life (EOL) skills" (Caton & Klemm, 2006, p. 604). Oncology nurses have a long and rich tradition of caring for patients at the EOL. Therefore, ONs must not only be skilled at the assessment and management of symptoms common during the final days of life, but must also possess an acute self-awareness about how caring for people who are dying affects them personally and professionally.

Nursing literature is rich with studies exploring factors related to patient issues in EOL care, but few research studies address the lived experiences of ONs in EOL care.

Several phenomenological research studies have explored specific aspects of nurses' experiences with EOL care. Belcher and Griffiths (2005) and Hegerty, Hammond, Parish, Glaetzer, McHugh and Grbich (2005) both have explored the spiritual role of nurses in EOL care. Mitchell, Sakraida, Dysart-Gale and Gadmer (2006) also investigated the experience of nurses in EOL, but focused primarily on Intensive Care (ICU) and medical surgical nurses' emotional and cognitive responses to death.

Several qualitative research studies on EOL care focused on nurses' perspectives on improving patient care at the EOL. Volker, Kahn and Penticuff's (2004) qualitative study findings revealed that advanced practice nurses (APNs) can play an integral role in assisting patients in achieving control and comfort at EOL. Hopkinson, Hallett, and Luker (2002) conducted a phenomenological research study to explore novice nurses' experiences in EOL as a means to further develop a theory to assist new nurses in improving care for dying patients in a hospital.

Finally, several empirical studies related to EOL care were reviewed, such as Dunn, Otten and Stephens (2005), who conducted a descriptive correlational study to explore nurses' attitudes toward death and caring for dying patients. The findings of the study revealed that nurses generally had a positive attitude toward caring for dying patients, a positive relationship exists between professional experience and attitudes towards death, and there was no correlation between nurses' personal attitudes about death and their attitude toward caring for dying patients. A correlational study by Tan, Low, Yap, Lee, Pang and Wu (2006) solicited multicultural nurses' views, opinions, and experiences in caring for dying patients through self-administered surveys. Finally, a correlational study by Pierce, Dougherty, Panzarella, Le, Rodin and Zimmermann (2007) compared staff stress, work satisfaction and death attitudes between an inpatient

palliative care unit (PCU) and a medical and radiation oncology inpatient unit. The findings showed that palliative care nurses reported less stress and higher job satisfaction than the medical or radiation oncology inpatient nurses.

In the above studies, a gap in research exists in the research, particularly in the qualitative studies, because ONs' experiences were not examined exclusively, nor did any qualitative studies address the overall lived experiences of nurses caring for dying patients. Several quantitative studies addressed various aspects of EOL care, but like the other studies cited, these investigated only certain issues in EOL care, such as improving patient care, and exploring different nursing approaches.

From the available studies, it is clear that EOL care has a significant impact on all persons involved. By exploring the impact of EOL care from the ON perspective, the researcher, as well as the profession of nursing as a whole, can gain greater insight into the issue, and act to effect changes if necessary.

Significance to Nursing

Nurses and specifically, ONs often have an intimate role in assisting patients psychologically, physically and emotionally at the EOL. As a result, care for dying patients also affects ONs professionally and personally, and ultimately becomes a fundamental part of who they are as human beings.

"Through the exploration of their own feelings, clinicians can learn to be fully present and to put aside personal fears to attend to the needs of others" (Wessel & Rutledge, 2005, p. 213). The process of exploring nurses' experiences in EOL care allows nurses to assess their own biases about death, and work toward finding a balance between professional and personal lives. Understanding the perspective of

nurses caring for patients at the EOL is important knowledge for the profession of nursing about how to support them both professionally and personally. Advance practice nurses are leaders in the profession of nursing and possess both theoretical and research-based knowledge to provide valuable insight into EOL issues. Additionally, APNs are increasingly becoming involved in EOL care, either in the primary care setting or in more specialized areas. Gaining increased knowledge on experiences of ONs in EOL care, can assist APNs in developing strategies to facilitate their own practices.

Problem Statement

Caring for dying patients affects ONs professionally, as well as personally and ultimately becomes a fundamental part of who they are as human beings. Understanding the experiences and perspectives of ONs who care for patients at the EOL is important for developing strategies to support them in delivering quality care, as well as preserving a positive personal health and well being.

Purpose of the Study

The purpose of this study was to explore ONs' experiences in EOL care.

Research Question

The research question for this study was: What are ONs' experiences in EOL care?

Definitions of Terms

Conceptual Definitions

Oncology nurse: A registered nurse who specializes in the care of cancer patients.

Experience: The accumulation of knowledge or skill that results from direct participation in events or activities.

End-of-life care: A subjective term that has many variables and is difficult to define. The lack of definition for the term *EOL* creates a barrier to research in improving EOL care, for not only the patient, but also for the healthcare provider, and in particular the ON. Most definitions of EOL in literature are incomplete and are constructed out of regulatory necessity. Such regulatory bodies as Medicare (2005) consider EOL care in the terms of when hospice services are coverable, and is defined as when the "doctor and the hospice medical director certify that you are terminally ill and have 6 months or less to live if your illness runs its normal course" (p. 3). The NIH State of the Science Conference (2004) defines EOL as:

(1) the presence of a chronic disease(s) or symptoms or functional impairments that persist but may also fluctuate; and (2) the symptoms or impairments resulting from the underlying irreversible disease require formal (paid, professional) or informal (unpaid) care and can lead to death" (para. 14).

Additionally, the NIH defines EOL care as, "the care provided to a person in their final stages of life" (para. 14).

Operational Definitions

Oncology nurse: A registered nurse who specializes in the care of cancer patients, with at least 6 months' experience in an inpatient or outpatient oncology setting.

Experience: The accumulation of knowledge or skill that results from direct participation in EOL care, as reported by ONs.

End of life care: Care provided by a registered nurse for a "person in the final stages of life" (NIH State of the Science Conference, 2004, para. 14).

Assumptions

Several key assumptions were made in the research process and were based on Parse's (1998) assumptions in the theory of human becoming.

1. Oncology nurses are open beings capable of freely choosing and expressing meaning in situations.
2. Oncology nurses possess a unique perspective in EOL care.
3. The participants in the study will be honest in their discussion on their experiences in EOL care.

Summary

Cancer is the second leading cause of death among adults in the U.S., and cancer-related deaths have a significant impact on not only patients and their families, but also the nurses who care for them. Nursing literature contains many studies related to patient issues in EOL care, but few research studies address ONs' lived experiences in EOL care. The purpose of this study was to explore the experiences of ONs in EOL care. This issue is significant to the profession of nursing, as well as the APN role. Key concepts are both conceptually and operationally defined, and assumptions related to the theoretical framework are presented.

CHAPTER II

THEORETICAL FRAMEWORK AND LITERATURE REVIEW

Introduction

The purpose of this study was to explore ONs' experiences in EOL care. Oncology nurses often have an intimate role in assisting patients psychologically, physically and emotionally at the EOL. Understanding the experiences and perspectives of ONs who care for patients at the EOL is important for developing strategies to support them in delivering quality care, as well as preserving individual health and well being. This chapter provides the theoretical basis upon which the study was based. Then a literature review is presented, and gaps in the current literature are discussed.

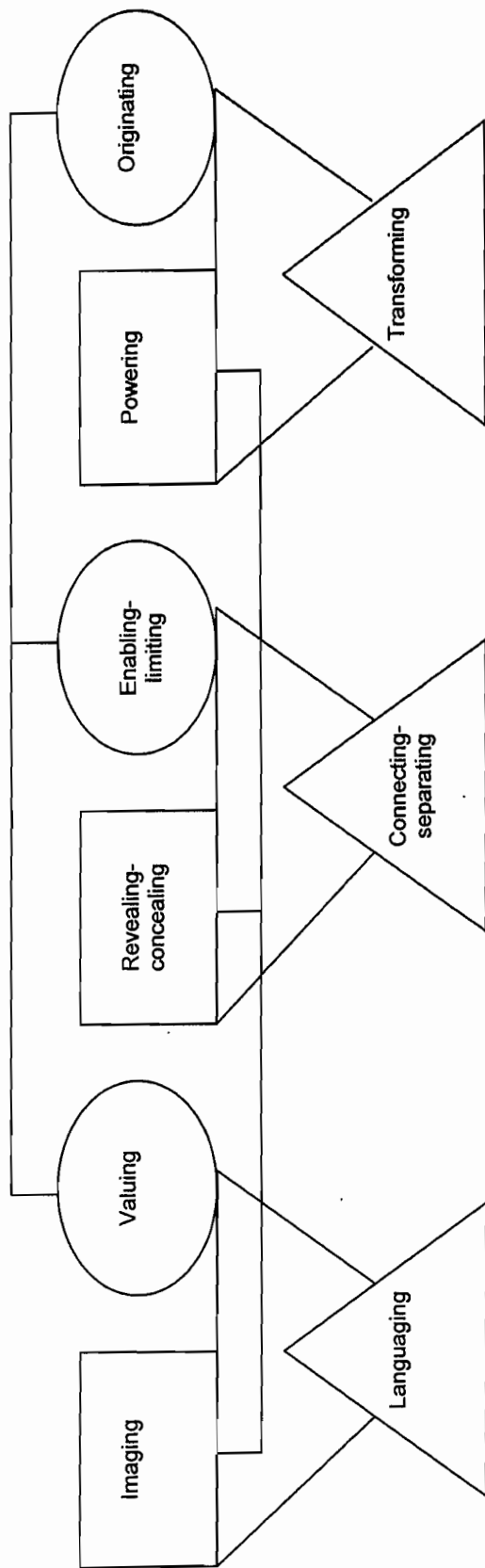
Theoretical Framework

The human becoming school of thought (Parse, 1998) was the theoretical perspective guiding this study (Figure 1). Parse's theory of human becoming proposes a belief in the openness of human beings in mutuality with the universe. "The human, in open process with the universe, chooses ways of becoming in situation and is accountable for these choices" (Parse, 1998, p. 21). Parse (1998) further developed a practice methodology from the theoretical model that consists of three processes of illuminating meaning, synchronizing rhythm, and mobilizing transcendence, in which the nurse co-participates with the patient or family. Application of Parse's theory is

*Principle 1: Structuring meaning:
Meaning multidimensionally is
Co-creating reality through the
language of valuing and
Imaging.*

*Principle 2: Co-creating rhythmical
patterns of relating is living the
paradoxical unity of revealing-
concealing and enabling-limiting
while connecting-separating.*

*Principle 3: Co-transcending
with the possibles is powering
unique ways of originating in the
process of transforming.*



Concepts in the squares:
Concepts in the ovals:
Concepts in the triangles:

*Powering emerges with the revealing-concealing of imaging.
Originating emerges with the enabling-limiting of valuing.
Transforming emerges with the language of connecting-separating.*

Figure 1. Parse's theoretical structures of human becoming.

appropriate in guiding research into ONs' experiences in EOL care. By applying the three processes of meaning, rhythmicity and transcendence, the researcher can illuminate the unique meanings of the lived experiences of ONs in EOL care.

Illuminating Meaning

The process of "illuminating meaning is explicating what was, is, and will be. Explicating is making clear what is appearing now through languaging" (Parse, 1998, p. 69). The researcher, with the participants of the study, promotes a discussion of the meaning of nurses' experiences with EOL care. In genuine presence with the participants, the researcher encourages the nurses to share their experiences, and in doing so, reveals hidden meanings of the experience. Additionally, ONs practice illuminating meaning in their interactions with dying patients. Through Parse's theory of human becoming, nurses who live true presence with patients at the EOL, do so through the patient perspective, rather than the health care perspective.

Synchronizing Rhythm

Parse's second underlying theme is synchronizing rhythm, which is "immersing with the flow of connecting-separating" (Parse, 1998, p. 70). The researcher practicing the human becoming theory does not try to intervene when interviewing participants, but rather "moves with the flow of the rhythms as persons discuss and recognize ups and down, joys and sorrows within the struggles of the situation" (Parse, 1998, p. 70), until underlying themes emerge giving a greater understanding of the phenomenon. Oncology nurses also encounter synchronizing rhythms in caring for dying patients. End-of-life care is filled with many ups and downs. Nurses who practice the human becoming theory do not attempt to alter the rhythms of EOL issues, but rather guide

patients and families in finding solace, and assist them in finding their own meaning in the experience.

Mobilizing Transcendence

The dimension of "mobilizing transcendence is moving beyond the meaning moment with what is not—yet " (Parse, 1998, p. 70). Throughout the study, the researcher participates in true presence with the participants as they explore their lived experience with EOL issues. Through the interaction, the participant can rise above, achieving a greater understanding as a result of the process. Subsequently, the ON who practices human becoming can assist the dying patient in realizing new possibilities, and finding peace in the EOL process.

The purpose of this study was to explore ONs' experiences in EOL care. Parse's theory of human becoming is applicable in both the research process, as well as the practice of EOL care. Oncology nurses possess a unique perspective in EOL care and are open beings capable of freely choosing and expressing meaning in situations.

Review of Literature

The literature review for this study included information about the lived experiences of ONs in relation to EOL care. Very few of the research articles that were reviewed, dealt specifically with the experiences of ONs in EOL care. Most qualitative studies regarding nurses and EOL care focused more intently on how nursing care can impact EOL care for patients and their families, and often investigated nurses in settings other than oncology. Suitable qualitative studies that did specifically address ONs' experiences with EOL issues, focused on limited areas in EOL care, such as spiritual

aspects or nursing stress. Several others researched ONs' experiences with EOL, but were more quantitatively focused, rather than qualitatively.

Studies that focused on EOL care in acute care settings, such as in an ICU or on a medical-surgical unit, included a phenomenologically based study by Hopkinson et al. (2002), who "conducted in-depth interviews with 28 newly qualified nurses, focusing on their experiences of caring for dying people on medical wards in two acute hospitals in England in 1999" (p. 525). The focus of the study was to develop a theory for improving care for dying patients in a hospital. The authors came up with six essences: (a) the personal ideal, (b) the actual, (c) the unknown, (d) the alone, (e) tension and (f) anti-tension, which they used as a central focus to develop a tool to assist hospital nurses to be more prepared in caring for dying patients. Hopkinson et al. (2002) believed that "knowledge of the six essences identified could be helpful in shaping students' expectations and preparing them for encounters with death and dying on acute medical wards" (p. 531). Knowledge is an important component in ensuring that nurses are prepared to assist patients at the EOL, but is not all-inclusive in addressing the full impact of EOL care.

Mitchell et al. (2006) utilized an exploratory, descriptive design to study ICU and medical-surgical nurses' emotional and cognitive responses to the death. Mitchell et al. examined nurses' cognitive reactions to EOL care by utilizing 19th century social scientist Droysen's differentiation of three cognitive approaches of knowing, explaining and understanding. Although, the authors did explore the experiences of nurses in EOL care, the population studied was that of ICU and medical-surgical nurses, and focused solely on the cognitive aspects, and not the entire lived experience as perceived by ONs.

Hamric and Blackhall (2007) used a descriptive pilot study to survey nurses and physicians' perspectives on caring for dying patients in the ICU. The results revealed that both physicians and nurses experienced moral distress in caring for dying patients, and that nurses also experienced a more negative ethical environment in the ICU setting than did the physicians. The researchers suggest that a greater focus on collaboration between the two groups is necessary to improve EOL care. As in the previous examples, this research is important to improving nursing care in EOL, but does not explore nurses' and more specifically, ONs' experiences in EOL.

In a subset of a larger quantitative study on the differences between hospital and community nurses practices in caring for end stage heart failure (ESHF) patients, Borbasi, Wotton, Redden, and Chapman (2005) "present one aspect of an interpretive study exploring nurses' perceptions of care provided to end stage heart failure patients (ESHF) in community and hospital settings" (p.104). Findings showed that nurses viewed EOL in terms of good death or bad death, and identified several key themes in each category. For instance, a good death was associated with open communication between all key participants, whereas a bad death was related to lack of preparedness of both nurse and patient. The authors ascertained that nurses, and primarily nurses in an acute setting, often lack the training and knowledge related to caring for dying patients. As a result, both patients and nurses are affected adversely when faced with EOL issues. The Borbasi study focused on what nurses felt to be important factors for dying end stage heart failure patients in terms of achieving a good death, but only vaguely alluded to the effects on nurses in caring for patients at EOL.

Volker et al. (2004) explored the APN's role in ensuring cancer patients' sense of control at the EOL in a descriptive, naturalistic study based on interviews with nine

oncology APNs. Two overriding themes were revealed, with the first being issues related to "patient preferences regarding control and comfort at the EOL" and the second being "APNs role in assisting patients in achieving control and comfort at the EOL" (p. 949). This study fills a vital gap in outlining the crucial role that oncology APNs play in assisting patients in achieving their preferences for end-of-life care. As in the previous studies, the findings also show a need for increased education in the area of EOL care. Although these issues are significant in assisting APNs in providing competent, evidenced-based care for patients, it too fails to identify how caring for patients at EOL, affects nurses both professionally and personally.

In a phenomenological study focusing more intently on the nurse–patient relationship in palliative care, Mok and Chiu (2004) explore how trust, achievement of goals, caring and reciprocity are several key factors in promoting a positive relationship in EOL care. However, Mok and Chiu point out that reciprocity is not equal in the nurse–patient relationship, because nurses often know more about the patients than vice versa. The authors interviewed 10 hospice nurses and 10 terminally ill hospice patients in China, and asked them to reflect on their experiences in EOL care and how their relationships with each other affected that experience.

Four major categories emerged from the perspectives of patients and nurses:

(a) Forming a relationship of trust; (b) being part of the family; (c) refilling with fuel along the journey of living and dying; and (d) enriched experiences.

Responses revealed that a relationship of trust is formed, and that nurses are not only regarded as health professionals, but also become part of the family or a good friend. Nurses who develop trusting relationships demonstrate a holistic approach to caring, show their understanding of patients' suffering, are aware of

their unvoiced needs, provide comfort without actually being asked, and are reliable, proficient, competent and dedicated in their care (Mok & Chiu, 2004, p. 475).

The findings revealed that both nurse and client found meaning and satisfaction in the patient-nurse relationship in a hospice setting. However, ONs also care for patients at the end of their lives and may have different outcomes than revealed in this particular setting due to both the nature of their job and type of training received in EOL care.

Several studies regarding nurses' experiences in EOL care explicitly explored the spiritual aspect, such as by Belcher and Griffiths (2005), who contrasted the difference between how hospice nurses and other specialty nurses expressed and integrated spiritual care into their role. In a retrospective study, Hegarty et al. (2005) explored nurses' knowledge and practices regarding psychosocial, spiritual and cultural aspects of palliative care in an inpatient acute care setting. Additionally, in a phenomenological study, Touhy, Brown and Smith (2005), researched how health care providers in a nursing home setting responded to the spiritual needs of dying residents. The findings of all three studies revealed that spiritual care was believed by providers to be an important aspect in EOL care, and more education was needed in this area. Spiritual care is important in EOL issues, from both a patient and nursing perspective, however, spiritual care is merely one aspect in EOL care related to nurses' experiences, and more research is needed on the other aspects involved, such as emotional, psychological and professional aspects.

A similar phenomenological study by McGrath and Holewa (2006) investigated hematologic ONs' experiences with terminal care in Australia. McGrath and Holewa focus explicitly on nursing stress related to lack of or late referral of terminal patients to

palliative care. The findings revealed that "nurses indicated it is stressful to be caught in a cure-oriented medico-centric system having to be witness to the distress of dying patients coping with high-tech and invasive treatment" (McGrath & Holewa, 2006, p. 300). Although this study is similar in that it explores ONs' experience with terminal care, it focuses specifically on one area of referral to palliative care, and does not explore what other issues ONs may experience in caring for patients at the EOL.

Several research studies have explored ONs' experiences in EOL care. Most studies, however, are quantitative in nature, and often contrast ONs' experiences with nurses in other healthcare settings. In a descriptive correlational research study, Dunn et al. (2005) explored nurses' attitudes toward death and caring for dying patients. The researchers used three tools of measurement, a demographic survey, Frommelt Attitudes Toward Care of the Dying (FATCOD) Scale, and Death Attitude Profile–Revised (DAP-R) Scale, to determine what variables affected medical/surgical and ONs' attitudes toward caring for dying patients, postulating that nurses with more personal and professional experience with death, and those with more education would have a more positive attitude than those who did not possess those traits. Dunn et al. (2005) concluded several results from the findings. First, that nurses in the study, generally had a positive attitude toward caring for dying patients. Second, that a positive relationship exists between professional experience and attitudes towards death, and finally, that there was no correlation between nurses' personal attitudes about death and their attitude toward caring for dying patients. Although, this study focused on the nurses, it was limited to attitudes toward death and dying, and how these attitudes affected patient outcomes.

Pierce et al. (2007) compared staff stress, work satisfaction and death attitudes between an inpatient palliative care unit (PCU) and a medical and radiation oncology inpatient unit. In the correlational study, researchers surveyed 84 staff members between the two aforementioned units. Results showed that overall, the PCU staff reported less stress and higher support and job satisfaction than members on the medical and radiation oncology unit. However, the external validity of the study is questionable due to the relatively small sample size. In a correlational study by Tan et al. (2006), nurses' views, opinions, and experiences in caring for dying patients were investigated. This study was unique from most others, in that it explored nurses' experiences from a cultural aspect through a self-administered survey.

Summary

The purpose of this study was to explore ONs' experiences in EOL care. Parse's theory of human becoming, and in particular, the practice methodology derived from the theory was utilized as the framework for the study. Parse (1998) outlined three principles in practice that are in correspondence with the human becoming theory. Illuminating meaning, synchronizing rhythm and mobilizing transcendence are the principles that guide both researcher and ON to be truly present in the process of becoming. By applying the three dimensions of meaning, rhythmicity and transcendence, the researcher could illuminate the unique meanings of the lived experiences of ONs in EOL care.

Several qualitative studies focused on EOL issues from various nursing specialties, as well as specific issues related to EOL, such as spirituality, nursing education and nursing stress. Qualitative research studies also addressed EOL issues

and contrasted ONs' experiences with nurses in other healthcare settings. However, no studies exist that specifically research ONs' experiences in EOL care. In this study, the experience of ONs in EOL care will be researched and the author will provide further suggestions for future practice.

CHAPTER III

METHODOLOGY

Introduction

The purpose of this qualitative study was to explore ONs' experiences in EOL care. In this chapter, the research design, population, sample and setting, the instrument for data collection, data collection procedures, and data analysis are described.

Research Design

A phenomenological design was utilized in this study to investigate ONs' experiences in EOL care. Phenomenology is the study of real meaning, and "phenomenological inquiry brings to language perceptions of human experience with all types of phenomena" (Speziale & Carpenter, 2007, p. 75). The field of nursing is entrenched in personal life experiences, whether from a patient or nursing perspective. As a result, phenomenology is an appropriate research design in exploring the experiences of ONs related to EOL care. Participants were able to freely express ideas through semi-structured interviews using open-ended questions.

Population, Sample and Setting

The target population for this study was registered nurses currently practicing in either an inpatient or outpatient oncology setting in the Midwest. The accessible population was registered nurses in Northeast Wisconsin, currently practicing in either an inpatient or outpatient oncology setting. The sample was a purposive sample of ONs.

Purposive sampling is the process of selecting ONs who will provide information rich-cases for in-depth analysis related to EOL care. Snowball sampling or asking earlier participants for referrals, was incorporated to add to the richness of the data. The sample size was based on when data saturation was reached. Polit and Beck (2004) describe data saturation as, "sampling to the point at which no new information is obtained and redundancy is achieved" (p. 308). The criteria for selection includes registered nurses with at least six months experience in oncology, male or female, currently care for patients in EOL as a part of their practices, willingness to participate, and are able to speak and understand English. Participants were solicited through the researcher's professional association with a local Midwestern U.S. chapter of the Oncology Nursing Society (ONS).

Data Collection Instrument

A demographic questionnaire was developed to aid in data collection (Appendix A). The demographic questionnaire included information on gender, age, years in nursing, years in oncology nursing, type of oncology setting, marital status, educational level, and ethnicity. The researcher conducted semi-structured face-to-face interviews using open-ended questions. An interview guide of several broad questions related to the topic was developed by the researcher, based on the review of literature, and utilized to direct the interview process (Appendix B).

Establishing trustworthiness of data in a qualitative study involves the four criteria of credibility, dependability, confirmability and transferability. Credibility of the findings was assured through prolonged engagement, by spending sufficient time collecting the data, and through persistent observation by keeping detailed field notes throughout the

process. Investigator triangulation was performed through the use of at least two or more persons analyzing the data. Researcher qualifications, experience and reflexivity was also included to ensure credibility. The dependability and confirmability of the data was assured through the use of member checking, or soliciting participants' views of the credibility of the interpretation of the interview. The transferability of the data was demonstrated by providing sufficient descriptive data that could be critically analyzed for relevance to other similar studies. Prior to conducting interviews, the researcher engaged in a critical self-reflection of potential biases and presuppositions. The researcher then bracketed so as to confront the data in pure form.

Data Collection Procedure

Prior to data collection, approval to conduct the study was obtained by the University of Wisconsin Oshkosh (UWO) Institutional Review Board (IRB), for the protection of human participants (Appendix C). Ethical considerations specific to the research project, include protecting confidentiality, because of the researcher's professional association with some of the participants, and ensuring anonymity when presenting results of the study.

Participants who met eligibility requirements were asked to participate by the researcher either in person or by phone. Participants were informed about the purpose of the study, the expected time commitment, the data collection procedures, confidentiality procedures, contact information, and any potential risks or benefits. Participants were notified that their participation was voluntary, and they could choose to withdraw from the study at any time without consequence. Approval from the individual participants was obtained through written informed consent (Appendix D).

Participants were asked to complete a demographic questionnaire. Semi-structured interviews were conducted at the participants' place and time of convenience. A pilot study (N = 1) was conducted to facilitate a systematic approach to data collection and analysis. The interviews lasted approximately 30 to 90 minutes, were audiotaped, did not contain any identifying information, and were transcribed verbatim by a third party and returned to the researcher. Interviews were coded by the researcher and guided by the overseeing UWO graduate nursing chair. A debriefing session followed each interview to permit the participant to ask questions or air concerns.

Participant confidentiality was protected by assigning of code names to each of the participants. There was no identifying data on the questionnaires. The principal investigator was the only person privy to participants' names and other identifying information. All forms related to the research study were kept in a locked and secure place throughout, and after the study, until they are physically destroyed.

Data Analysis Procedures

Data was analyzed using the phenomenological method of Giorgi (1985), who outlines seven steps for accurate data analysis:

Read the entire description of the experience to get a sense of the whole; reread the description; identify the transition units of the experience; clarify and elaborate the meaning by relating constituents to each other and to the whole; reflect on the constituents in the concrete language of the participant; transform concrete language in the language or concepts of science; and integrate and synthesize the insight into a descriptive structure of the meaning of the experience (Speziale & Carpenter, 2004, p.83).

The interview transcripts were verified for accuracy and then coded for themes and categories.

Limitations

1. Generalizability of the study was limited due to the small sample size, and the small geographical area in Midwestern U.S.
2. Credibility of the study was limited due to self-selection by the participants, resulting in potential alternative outcomes or themes, if the study were replicated.

Summary

The purpose of this qualitative study was to explore ONs' experiences in EOL care. The researcher conducted semi-structured face-to-face interviews with ONs using an interview guide. Data were analyzed using Giorgi's (1985) phenomenological data analysis procedure, and common themes were extrapolated. Limitations of the study are recognized and include self-selection, potential lack of generalizability and response bias.

CHAPTER IV

RESULTS AND DISCUSSION

Introduction

The purpose of this qualitative study was to explore ONs' experiences in EOL care. Six ONs were interviewed and demographic data was obtained. This chapter presents a description of the participants and the themes that emerged.

Demographic Data

A questionnaire was used to collect demographic data. All six participants were female. The participants' ages ranged from 28 to 55 years with a mean age of 40 years. Two participants were single and four were married. All participants were White. Three of the registered nurses had associate degrees, and three were baccalaureate prepared. The mean number of years of nursing experience was 16.8 years. The mean number of years of oncology nursing was 12 years. Five of the nurses worked in an outpatient oncology setting and one worked in both an inpatient and outpatient setting. However, the narratives they shared reflected a broader range of settings, beyond their current areas of employment.

The Interview Process

Interviews took place over a 2-month time period. Each interview lasted from 30 to 90 minutes. Much of the interview process took place in an office with the door closed to ensure both a quiet and private environment. One interview took place at a coffee shop, in a private area, and voices were kept low to ensure confidentiality. Meticulous

field notes were taken during and after each interview to add to the depth of the information. Tapes were transcribed verbatim and were read and revisited to ensure the researcher had comprehensive knowledge of the material. Qualitative data were analyzed using Giorgi's (1985) phenomenological data analysis procedure.

Results

End-of-life care was defined as care provided by a registered nurse for a "person in their final stages of life" (NIH State of the Science Conference, 2004, para. 14). However, the participants viewed EOL care as process in which the nurse is present to assist both the dying patient and his or her family in meeting both their physical and emotional needs. The process could include assisting in helping the patient and family to come to terms with the finality of death, ensuring the patient is comfortable by turning or giving pain medications to holding their hands. Data emerged quickly during the interview process, and it became acutely apparent that the participants believed that caring for patients at the EOL was more than a job. The participants viewed caring for patients at the EOL as a way to honor the unique personhood of each dying patient, as well as their family members. Caring for dying patients was viewed as rewarding, but also emotional work that took a toll on the caregiver too.

Transcripts were scrutinized many times by the researcher to discover the full meanings of the data. Following a comprehensive analysis of the data, three major themes emerged describing the experiences of ONs in caring for patients at the EOL. The themes include: *emotional work*, *knowing and unknowing*, and *care for the caregiver*. Several subcategories were also identified. The data discussed reveal what

caring for patients at the EOL means to ONs and how it impacts them personally.

Quotes from the interviews are included to support the themes.

Emotional Work

Caring for patients at the EOL is often an emotional and uncomfortable situation for even the most seasoned ON. When open-ended questions were asked how caring for patients at the EOL affected the participants both personally and professionally, emotions played an enormous role in the process. The participants verbalized developing an emotional attachment to their clients, and felt at times the lines between personal and professional relationships can become blurred at times. However, all the participants interviewed understood their role in the dying process as that of caregiver, which required them to emotionally detach themselves, in order to fully meet the needs of the patient, as well as survive in the profession of oncology nursing. As a result, several subcategories arose from the theme of *emotional work*. The subcategories are: large emotional investment, blurred lines of care, and emotional detachment.

Caring for patients at the EOL was viewed as an enormous emotional investment that can be both rewarding and frustrating. One participant's narrative reflected this:

It was somebody that we had treated in the office for years and years for her disease and watched her go downhill treatment after treatment and watched her family follow behind her and come to all the appointments and she would sit there crocheting in the chair for hours and hours and hours with the emesis basin right next to her...and a lot of us would wonder why they would do something else to her?

Emotional work was also described as being fulfilling and impacting the participants in a lifelong manner. As one participant recalled an experience in caring for a patient at the

EOL, she teared up stating: "I still walk by her house and think of her. In caring for people, you do get yourself so involved in their life, you know; it's such as intimate time."

Many participants felt it to be a challenge to ensure they did not cross the line between a professional and personal relationship. Others believed it was acceptable and necessary to blur those professional boundaries to provide the care the patient needed at the EOL.

It really impacted me personally, because I became such good friends with him and his family that I really took it harder than any other patient that I had cared for before. For a long time after his death, I went through a sort of depression. Another participant recounted the positive impact developing a personal relationship had on her.

We have a few patients that we've become friends with and their family and go out to dinner with them sometimes, you know, or just call and see how are they doing. So you just have to remember all the good things you get out of it.

Most participants stated that it was important to keep a professional distance for two reasons. First, to ensure that one was staying objective, and secondly, to survive in the field of oncology and prevent professional burnout. Several participants stated they used to go to funerals, but found it too difficult.

But for me, if I made funerals part of my nursing experience, I would get negative out of it because I would feel a lot of bad thoughts and, you know, when you're here and when you're working with working with them and your conversation, that's the me that I can share.

The majority of participants echoed the sentiment that it was mutually beneficial to stay at least somewhat emotionally detached. As one person stated, "I try to keep in

my mind that my job is to be there to support the patient and his or her family and it is not about me."

Knowing and Unknowing

The second theme that emerged from the data described the art of knowing in terms of intimacy with the patient, knowing oneself and the dilemma or distress of unknowing. Knowing involves a deliberate awareness or understanding of the reality of one's own needs, as well as the needs of the patients. Unknowing, however, is the lack of knowledge and uncertainty that comes with the reality of death. The three subcategories that emerged under this theme involve, intimate knowing, or being aware of what the patients needs are; personal knowing, or knowing oneself, and unknowing or uncertainty.

Caring for patients at the EOL is an intimate task, and all participants discussed experiencing intimate knowledge of patients and families in the EOL, as well as respect for that relationship. One participant recalled caring for a patient whose husband and sister were at odds with each other. The night that the patient was dying, the nurse spoke of how she facilitated the husband and sister coming together,

[Chaplaincy] spent a lot of time with her (and the husband) and the patient did die during the night, kind of only after they had kind of brought the sister and husband together and around the patient's bed kind of cleared the air a little bit and that's when the patient died.

Another participant recalls how her experience in nursing, and in particular, EOL care, has helped her in meeting the needs of not only the patients, but also the families.

Just dealing mainly with the survivors, the families, um, you kind of learn how to comfort somebody better...you have to try to meet them where they're at because what you think they're thinking is not what they're thinking.

Several participants relayed how caring for patients at the EOL has enriched their lives, and helped them to become more aware of what is important in their own lives. One nurse reflected on how caring for dying patients has changed throughout her years of experience as both an ON and a person, in general: "I think a lot of it has to do with for nurses of all ages, and the nurse I would have been at 19 is different than the nurse that I am at 54 and I look at life different." Another participant reflected on the experience of caring for dying patients and how it has impacted her own life. "I totally appreciate life so much more and I don't take things for granted and, you know, little things don't matter as much."

The uncertainty and unpredictability of death can unnerve even the most seasoned ON. Several participants discussed situations when they felt uncomfortable and unsure when caring for patients at the EOL. Some participants recalled not knowing what to do, particularly when they felt the patient was suffering. One participant shared how, "at times, I felt unprepared and inadequate to help them [the patients] through what they were going through." Others recalled their first experience with death and the anxiety they felt. One nurse described EOL as a "kind of a drawn out thing." Another participant shared her first experience with a dying patient who was experiencing a significant amount of respiratory difficulty as "the most traumatic death I have ever seen."

Care for the Caregiver

The final theme that emerged from the data, *care for the caregiver*, consisted of the following subcategories: professional networking, professional support, and "me time." All participants acknowledged the importance of caring for oneself in order to be able to continue in such an emotionally challenging career as EOL care. Several recognized the dangers of not taking care of oneself. One participant verbalized this, "I can see how nurses can get burned out or cope in not so healthy ways, like drinking or getting cold in their jobs."

Professional networking was identified as being important in maintaining a balance between meeting the emotional needs of patients and the EOL, and sustaining one's own emotional health. One participant discussed tapping into other professionals, such as a palliative physician she works with, "[Dr. S] is always willing to give a suggestion, so that's helpful." Another participant discussed the satisfaction she received when she was able to utilize her expertise in assisting other professionals in EOL care issues:

And I think it feels good at work when somebody asks me a question about "What do you think?" or "What would you do?" After so many years there's a lot of stuff stashed up there that I'm able to say, "You know for this person this worked really good."

Each participant was asked if she felt she was being supported both professionally and personally. Most participants identified professional support coming more from their peers than the institutions they worked for. All participants indicated having a positive and mutual relationship with their peers, which they felt was beneficial

in being able to care for patients at the EOL. On the other hand, several participants indicated a need for more formal support:

I don't know that I would say the institution supports us real well in that area. We talked over the years a few times of how they could better support us, like have a chaplain come in once in awhile.

Several participants indicated the importance of continuing education on EOL care through national conferences or local programs, as a means of continued professional growth.

The final subcategory under the theme of care for the caregiver, is that of "me time," which incorporates all the ways in which the participants identified caring for their own needs outside of work. The task of caring for oneself was very individualized according to each person's values and preferences. Several participants identified the importance of some sort of spirituality in filling one's own emotional cup. One participant shared how: "Initially, I take time for myself, just quiet time. I might go for a long walk. Sometimes go to church; I pray a lot." The importance of spirituality was reverberated throughout many participants' definitions of ways of regenerating oneself. Several participants participate in yoga and meditation, where others spend time with their family and friends. One participant found refuge in music:

I like to listen to music and if I've had a really particularly bad day, you know, I'll listen to something more quiet and actually when I'm sad I like to listen to sad music and I don't know why that is, but it kind of helps me project what my emotions are.

Discussion

Parse's theory of human becoming was the theoretical framework for this study. The researcher focused on the three processes of Parse's clinical practice model: (a) illuminating meaning, (b) synchronizing rhythm, and (c) mobilizing transcendence. The participants in the study reverberated the process of illuminating meaning with their patients, through countless statements on keeping the focus on the patient and the family, and just being there in genuine presence. Several participants discussed viewing EOL care as creating the most favorable environment for patients with limited life expectancy. As one participant stated, "It's getting them to be able to talk about their fears." Participants focused on finding the hidden meanings in patients' fears, whether it was the fear of being a burden or a fear of dying itself. Through Parse's theory of human becoming, the participants in this study lived true presence with patients at the EOL, through the patient perspective, rather than the health care perspective. The process of synchronizing rhythms was also elucidated in the participants stories of allowing their patients and families live through the experiences in their own way, and not trying to interfere or put patients into a preconceived mold. As one participant shared, "[I] don't try to make them think what I'm thinking. Just meet them where they are and try to support them through that." Most of the participants in this study did not attempt to alter the rhythms of EOL issues, but rather guide patients and families in finding solace, and assist them in finding their own meaning in the experience. However, one participant did discuss how she had called a family member against the wishes of the patient's husband because she felt it was what the patient would have wanted. The final process of Parse's theory that was utilized was mobilizing transcendence or rising above, and achieving a greater understanding as a result of the

process of dying. The majority of the nurse participants in the study had more than five years in EOL care, and through that experience all were able to verbalize how they had gone through a process of learning how to care for patients at the EOL. The participants discussed how they could make a difference for patients at the EOL. As one participant so poignantly stated:

But I always felt like you could make the best of the time somebody has left, even if it's only in your hour visits that you were there, the things you said, the hands you held, the hair you brushed, all those things made a difference in the memories.

Findings from this study were similar to those previously reviewed. The study by Hopkinson et al. (2002), explored six essences: (a) the personal ideal, (b) the actual, (c) the unknown, (d) the alone, (e) tension and (f) anti-tension, which they used as a central focus to increase nurses' knowledge and to assist them in being more prepared in caring for dying patients. Participants in this study also discussed the importance of obtaining knowledge in EOL care, and several participants discussed going to various conferences and continuing education programs on EOL care, to better prepare themselves.

A descriptive pilot study of ICU physicians and nurses by Hamric and Blackhall (2007) found that both physicians and nurses experienced moral distress in caring for dying patients, and that nurses also experienced a more negative ethical environment in the ICU setting than did the physicians. Nurses were the sole focus of this study, but similar results regarding moral distress were also revealed, as in the Hamric and Blackhall study. Participants also described moral distress in caring for dying patients. One participant conferred how her first experience with death was very traumatic and

frightening. Most participants recalled a particular patient whom they had grown close to and felt true sorrow as a result of their death.

Volker et al. (2004) explored the APN's role in ensuring cancer patients' sense of control at the EOL in a descriptive, naturalistic study. The results of the study revealed that through education on EOL care, APNs can assist patients in achieving greater control, particularly pain control at the EOL. As in Hamric and Blackhall's (2007) study, education was found to be crucial in any area of nursing, and in particular, EOL care, because of the uncertainty and the finality of it all. The theme of care for the caregiver, and the subgroup of professional networking, focused on tapping into other professionals, and the importance of maintaining expertise in the area of EOL as a means of improving the patient experience.

Findings from the current study also supported those of Mok and Chiu (2004), which explored how trust, achievement of goals, caring and reciprocity helped promote a positive relationship between nurse and patient in EOL care. The results of Mok and Chiu's study revealed that nurses who demonstrated a holistic approach to caring, developed a mutual relationship with the patients and often were regarded as a good friend or part of the family. The findings from the current study also revealed how nurses felt comfortable in knowing what the needs of the patients were, and how they formed many close bonds and friendships with patients and their families, in the process of caring for dying patients.

A positive attitude in EOL care, a positive relationship between professional experience and attitudes towards death, and keeping the focus on the patient were all consistent findings in the present study. This supports the findings of Dunn et al. (2005), who explored nurses' attitudes toward death and caring for dying patients and had

similar conclusions. Dunn et al. identified that nurses with professional experience with death, and those with more education had a more positive attitude than those who did not possess those traits. Several participants in the study illustrated how in the beginning of their careers, they had more uncertainty in caring for dying patients, but as they grew in their profession and gained proficiency through continuing education, they became more proficient and comfortable with EOL care.

Summary

In this chapter, demographic data, the interview process, results, and discussion of those results were presented. The three themes that arose during data analysis were: *emotional work*, *knowing and unknowing*, and *care for the caregiver*. These themes reflect the lived experiences of ONs in EOL care.

The theme *emotional work* represents a paradox for ONs in EOL care. On the one hand, the participants discussed their passion towards meeting the patients and families' physical and emotional needs. On the other hand, *emotional work* also represented the need to withdraw or detach at a certain point to maintain a professional boundary for not only the patient's well being, but more importantly the nurse's emotional health.

Knowing and unknowing signified not only the participants being knowledgeable in EOL care, but the intimate knowing, as described by the participants as an acute awareness of the patients and families' needs. *Knowing* also reflects a personal knowing of one's own personal and professional presumptions on EOL care. *Unknowing* reflects the uncertainty the participants felt in dealing with EOL care, particularly for participants early on their nursing careers. *Care for the caregiver* represents not only

the personal time the participants took for themselves to rejuvenate and prevent burnout but also the professional and personal support provided to them to gain both knowledge experience in becoming proficient in EOL care.

Parse's theory of human becoming guided this study, which supported, in particular, the three processes of illuminating meaning, synchronizing rhythm, and mobilizing transcendence.

CHAPTER V

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

Introduction

The purpose of this qualitative study was to explore ONs' experiences in EOL care. A summary of this phenomenological study that investigated the lived experience of ONs in EOL care is presented in this chapter. This chapter also includes a discussion of research conclusions; implications for nursing practice, education and administration; and recommendations for future research.

Summary of Study Findings

Cancer is the second leading cause of death in the U.S., and cancer-related deaths have a significant impact on not only the patients and their families, but also the ONs who care for them. Oncology nurses have a rich history of caring for patients in the EOL, and face many challenges related to it, such as caring for dying patients in a cure focused medical profession. Meeting the physical, psychological, spiritual and social needs of patients and their families requires knowledge, expertise and insight into the unique needs of the dying patient. The purpose of this study was to explore the experiences of ONs in EOL care, to provide a deeper meaning into the process nurses go through and how to give them the tools necessary to make the process positive for both nurse and patient. A phenomenological approach was used to examine the nurses' experiences through detailed descriptions and prolonged engagement with the participants. Parse's theory of human becoming was used as the framework that guided this study.

Six participants from northeast Wisconsin, age 28 to 55 years, who were currently practicing in the oncology setting, and had at least one year of oncology experience participated in the study. Each participated in a face-to-face interview lasting approximately 30 to 90 minutes. The researcher took meticulous field notes during the interview and data was transcribed verbatim. Data were then analyzed using Giorgi's (1985) approach to phenomenological data analysis to discover themes that effectively described the lived experiences of the participants in EOL care. Three major themes emerged from the data: (a) *emotional work*, (b) *knowing and unknowing*, and (c) *care for the caregiver*. These themes described the lived experiences of ONs in EOL care in this particular study.

The first theme, *emotional work*, represented a paradox for ONs in EOL care. On the one hand, the participants discussed their passion towards meeting the patients and families' physical and emotional needs. On the other hand, *emotional work* also represented the need to withdraw or detach at a certain point to maintain a professional boundary for not only the patient's well being, but more importantly the nurse's emotional health.

The second theme, *knowing and unknowing*, signified not only the participants being knowledgeable in EOL care, but the intimate knowing, as described by the participants as an acute awareness of the patients and families' needs. *Knowing* also reflects a personal knowing of one's own self reflections on EOL care. *Unknowing* reflects the uncertainty the participants felt in dealing with EOL care, particularly for participants early on their nursing careers.

The final theme, *care for the caregiver*, represented not only the personal time the participants took for themselves to rejuvenate and prevent burnout, but also the

professional and personal support provided to them to gain both knowledge and experience in becoming proficient in EOL care.

Conclusions

As a result of the findings of this study, the themes identified correspond with Parse's clinical practice methodology of illuminating meaning, synchronizing rhythm, and mobilizing transcendence (Figure 2). Additionally, several distinct conclusions can be drawn. First, caring for patients and their families at the EOL is emotional work that requires moving beyond the detached provider to fully meet the needs of the dying. This type of emotional work, at times, involved blurring the lines of care between professionalism and personal relationships. However, ONs do feel the need to emotionally detach from patients and their families to preserve their own emotional health and well being.

Second, being proficient in EOL care requires not only an intimate knowing of the patients needs, but also a personal knowing of the nurses own strengths, limitations and presumptions regarding death and dying. Nurses who haven't gained experience in this area, possess a sense of uncertainty and insecurity with EOL issues. These results are supported in part by Mok and Chui's (2004) study, which revealed that nurses who demonstrated a holistic approach to caring, and an intimate knowing, developed positive mutual relationships with the patients and families.

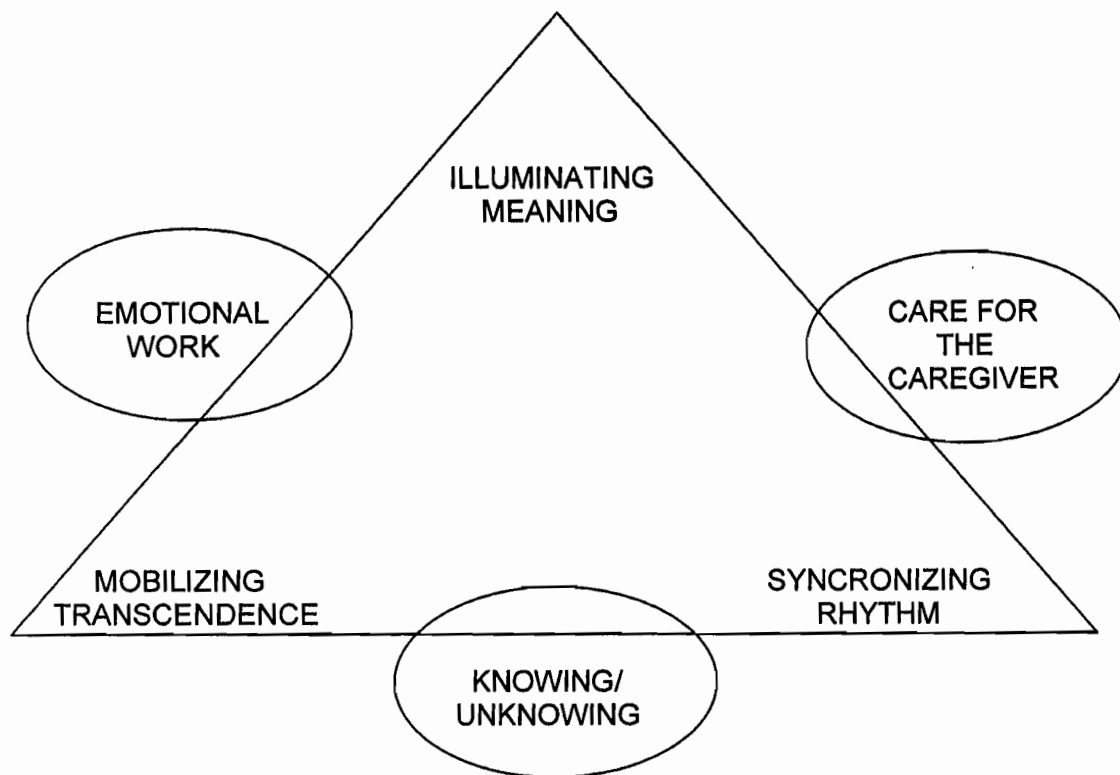


Figure 2. Parse's practice methodology.

All the participants in the study felt that more education was needed in the area of EOL care, either through formal conferences, local programs, or professional support. These results are consistent with several other studies findings, including the study by Hopkinson et al. (2002), which revealed that knowledge is an important component in ensuring that nurses are prepared to assist patients at the EOL. Similarly, the results of Mitchell's (2006) study revealed that inquiry into quality and compassionate care provided by EOL nurses, can assist nurse educators in developing curriculum for students in this area.

Implications for Nursing Practice

Nurses, and specifically ONs, often have an intimate role in assisting patients psychologically, physically and emotionally at the EOL. As a result, caring for dying patients also affects ONs professionally and personally, and ultimately becomes a fundamental part of who they are as whole human beings.

Through the exploration of their own feelings, clinicians can learn to be fully present and to put aside personal fears to attend to the needs of others" (Wessel & Rutledge, 2005, p. 213).

The process of exploring nurses' experiences in EOL care allows nurses to assess their own biases about death, and work toward finding a balance between professional and personal lives. Understanding the perspective of nurses caring for patients at the EOL is important knowledge for the profession of nursing about how to support them both professionally and personally. Advance practice nurses are leaders in the profession of nursing and possess both theoretical and research-based knowledge to provide valuable insight into EOL issues. Additionally, APNs are increasingly becoming involved in EOL care, either in the primary care or in a more specialized setting. Gaining increased

knowledge on experiences of ONs in EOL care, will assist APNs in developing strategies to facilitate their own practices.

Implications for Nursing Education

The findings from this study also have implications for nursing education. It is evident from this and other studies referenced that novice nurses working in EOL care experience more uncertainty and anxiety than more experienced and educated nurses. Nurse educators need to address EOL care more fully in their curriculum to better prepare nurses in dealing with dying patients, and enable them to have the confidence and knowledge to support patients through the experience without losing themselves.

Implications for Nursing Administration

The results of this study also have implications for nursing administrators. Results of the study clearly show that ONs felt more prepared to meet the needs of dying patients and their families, when they had more knowledge and experience. Most of the participants in the study gained the knowledge by seeking out conferences and local programs on EOL on their own. Nursing administrators can ensure that all ONs are prepared to deal with the complexities of EOL care by providing time and financial support to nurses interested in pursuing increased education. Furthermore, administrators can become more cognizant of the emotional toll nurses experience in caring for dying patients and provide professional support through making social workers and other professionals available for consultation.

Recommendations for Future Research

Based on the findings of this study, the following recommendations were developed as potential methods for future research:

1. It is evident in the review of literature that there is a paucity of both empirical and qualitative studies related to ONs' experience in EOL care. More studies with larger samples and a larger geographical area are recommended to understand this subject in greater depth.
2. Future research will also be of benefit in assisting health professionals who are involved in educating nurses, to gain a better understanding in developing curriculum to support nurses who care for dying patients.
3. Studies focusing on developing or implementing models for EOL care would be valuable to further implement evidenced based practice into this area.

Summary

This chapter provided a summary of the current study that explored the experiences of ONs in EOL care. An overview of the findings was discussed. This chapter also focused on the implications for nursing practice, education, and administration developed as a result of the findings, along with recommendations for future research. The need for exploring the experiences of ONs in EOL care was apparent and supported by the findings of the research.

APPENDIX A
Demographic Questionnaire

DEMOGRAPHIC QUESTIONNAIRE

Please complete the following information:

Date _____

Age _____

Gender:

_____ Male

_____ Female

Marital
Status _____ Ethnicity _____

Highest Education Completed:

_____ Diploma

_____ Associate Degree

_____ Bachelor Degree

_____ Other

Years of Experience as Registered Nurse _____

Current Primary Place of Employment

_____ Inpatient Oncology Unit

_____ Outpatient Oncology Unit

_____ Other

Years of Experience as Oncology Registered Nurse _____

APPENDIX B
Interview Guide

Interview Guide

1. What comes to your mind when you think end of life care?
2. What is your professional experience in end of life care?
3. Describe an experience in which you cared for a patient who was at the end of his/her life.
4. How has this experience and other similar ones impacted you professionally?
5. How has this experience and other similar ones impacted you personally?
6. How do you cope when caring for patients at the end of life?
7. What can the profession of nursing do to assist you in caring for dying patients, both professionally and personally?

APPENDIX C

UW Oshkosh IRB Approval Letter



November 8, 2007

Ms. Patricia Martins
714 Grandview Road
Hortonville, WI 54914

Dear Ms. Martins:

On behalf of the UW Oshkosh Institutional Review Board for Protection of Human Participants (IRB), I am pleased to inform you that your application has been approved for the following research: Experiences of Oncology Nurses in End-of-Life Care: A Phenomenological Study.

Your research has been categorized as NON-EXEMPT, which means it is subject to compliance with federal regulations and University policy regarding the use of human participants as described in the IRB application material. Your protocol is approved for a period of 12 months from the date of this letter. A new application must be submitted to continue this research beyond the period of approval. In addition, you must retain all records relating to this research for at least three years after the project's completion.

Please note that it is the principal investigator's responsibility to promptly report to the IRB Committee any changes in the research project, whether these changes occur prior to undertaking, or during the research. In addition, if harm or discomfort to anyone becomes apparent during the research, the principal investigator must contact the IRB Committee Chairperson. Harm or discomfort includes, but is not limited to, adverse reactions to psychology experiments, biologics, radioisotopes, labeled drugs, or to medical or other devices used. Please contact me if you have any questions (PH# 920/424-7172 or e-mail: rauscher@uwosh.edu).

Sincerely,

Dr. Frances Rauscher
IRB Chair

cc: Mary Wurzbach
1257

INSTITUTIONAL REVIEW BOARD
UNIVERSITY OF WISCONSIN OSHKOSH • 800 ALGOMA BLVD • OSHKOSH WI 54901
(920) 424-3215 • FAX (920) 424-3221
An Equal Opportunity/Affirmative Action Institution • <http://www.uwosh.edu/>

APPENDIX D
Informed Consent Document

UNIVERSITY OF WISCONSIN OSHKOSH
CONSENT DOCUMENT

Experiences of Oncology Nurses in End of Life Care:
A Phenomenological Study

Patricia Jo Martins, of the Department of Graduate Nursing in the University of Wisconsin Oshkosh, is conducting a study of the experiences of oncology nurses in end of life care. Professor Mary Ellen Wurzbach, of the Graduate Nursing Department at the University of Wisconsin Oshkosh, will serve as chair of the project. We would appreciate your participation in this as it will assist in making recommendations for improving experiences of oncology nurses in end of life care.

As a part of this study, we would like to conduct semi-structured interviews regarding your experiences in end of life care. The interview will last approximately 30-60 minutes and will be audio-taped. No identifiable information will be obtained during any portion of the research project. You will be given an opportunity for a follow-up interview to discuss findings and address any questions or concerns you may have. You will be asked to complete an anonymous demographic questionnaire prior to interview.

We do not anticipate that the study will present any medical, physical, or social risk to you. A possibility of emotional distress may exist as you discuss your personal experiences with caring for dying patients. You will have an opportunity to discuss any concerns immediately after the interview is complete and at the follow-up interview one week later. Participation in this study may not benefit you directly.

The information gathered through the demographic questionnaire and semi-structured interviews will be recorded in anonymous form. We will not release information about you to anyone else in a way that could identify you.

If you want to withdraw from the study at any time, you may do so without penalty. The information collected from you up to that point would be destroyed if you so desire.

Once the study is completed, we would be glad to give the results to you. In the meantime, if you have any questions, please ask us or contact:

Dr. Mary Ellen Wurzbach
College of Nursing Graduate Program
University of Wisconsin Oshkosh
800 Algoma Blvd.
Oshkosh, WI 54901
(920)424-2106

If you have any complaints about your treatment as a participant in this study, please call or write:

Chair, Institutional Review Board
For Protection of Human Participants
C/o Grants Office
UW Oshkosh
Oshkosh, WI 54901
(920) 424-1415

Although the chairperson may ask for your name, all complaints are kept in confidence.

I have received an explanation of the study and agree to participate. I understand that my participation in this study is strictly voluntary.

Name Date

I consent to the audio-taping of the interview for this study.

Name Date

This research project has been approved by the University of Wisconsin Oshkosh IRB for Protection of Human Participants until November 8, 2008.

REFERENCES

- American Cancer Society (2007). *Cancer facts & figures 2007*. Retrieved June 10, 2007, from www.cancer.org.
- Belcher, A., & Griffiths, M. (2005). The spiritual care perspectives and practices of hospice nurses. *Journal of Hospice and Palliative Nursing*, 7, 271-279.
- Borbasi, S., Wotton, K., Redden, M., & Chapman, Y. (2005). Letting go: A qualitative study of acute care and community nurses' perceptions of a "good" versus "bad" death. *Australian Critical Care*, 18, 104-105, 107-113.
- Caton, A., & Klemm, P. (2006). Introduction of novice oncology nurses to end-of-life Care. *Clinical Journal of Oncology Nursing*, 10(5), 604-608.
- Dunn, K., Otten, C., & Stephens, E. (2005). Nursing experience and care of dying patients. *Oncology Nursing Forum*, 32, 97-104.
- Fairbrother, C., & Paice, J. (2005). Life's final journey: The oncology nurse's role. *Clinical Journal of Oncology Nursing*, 9, 5, 575-579.
- Hamric, A. & Blackhall, L. (2007). Nurse-physician perspectives on the care of dying patients. *Critical Care Medicine*, 35, 422-429.
- Hegerty, M., Hammond, L., Parish, L., Glaetzer, K., McHugh, A., & Grbich, C. (2005). Nursing documentation: Non-physical dimensions of end-of-life care in acute wards. *International Journal of Palliative Nursing*, 11, 632-636.
- Hopkinson, J., Hallett, C., & Luker, K. (2002). Caring for dying people in hospital. *Journal of Advanced Nursing*, 44, 525-533.
- McGrath, P., & Holewa, H. (2006). Missed opportunities: Nursing insights on end of life care for haematology patients. *International Journal of Nursing Practice*, 12, 295-301.

- Mitchell, A., Sakraida, T., Dysart, D., & Gadmer, N (2006). Nurses' narratives of end-of-life care. *Journal of Hospice and Palliative Nursing*, 8, 210-221.
- Mok, E., & Chiu, P. (2004). Nurse-patient relationships in palliative care. *Journal of Advanced Nursing*, 48, 475-483.
- National Institutes of Health State-of-the-Science Conference Statement on Improving End-of-Life Care (2004). Retrieved June 10, 2007, from <http://consensus.nih.gov/2004/2004EndOfLifeCareSOS024html.htm>.
- Parse, R. (1998). *The human becoming school of thought: A perspective for nurses and other health professionals*. Thousand Oaks, CA: Sage Publications.
- Pierce, B., Dougherty, E., Panzarella, T. Le, L., Rodin, G., & Zimmermann, C. (2007). Staff stress, work satisfaction and death attitudes on an oncology palliative care unit, and on a medical and radiation inpatient radiation oncology inpatient unit. *Journal of Palliative Care*, 23, 32-39.
- Polit, D., & Beck, C. (2004). *Nursing research: Principles and methods* (7th ed.). Philadelphia: Lippincott Williams & Wilkins.
- Speziale, H., & Carpenter, D. (2007). *Qualitative research in nursing: Advancing the humanistic imperative* (4th ed.). Philadelphia: Lippincott, Williams & Wilkins.
- Tan, J., Low, J., Yap, P., Lee, A., Pang, W., & Wu, Y. (2006). Caring for dying patients and those facing death in an acute-care hospital in Singapore. *Journal of Gerontological Nursing*, 32(5), 17-36.
- Touhy, T., Brown, C. & Smith, C. (2005). Spiritual caring: End of life in a nursing home. *Journal of Gerontological Nursing*, 31(9), 27-35.