2020

NURSES' INVOLVEMENT IN END OF LIFE COMMUNICATION AND CARE PRACTICES IN ICUs

Annette Griffin
University of Rhode Island, annette_griffin@my.uri.edu

Follow this and additional works at: https://digitalcommons.uri.edu/oa_diss

Recommended Citation

Griffin, Annette, "NURSES' INVOLVEMENT IN END OF LIFE COMMUNICATION AND CARE PRACTICES IN ICUs" (2020). *Open Access Dissertations*. Paper 1143.
https://digitalcommons.uri.edu/oa_diss/1143

This Dissertation is brought to you for free and open access by DigitalCommons@URI. It has been accepted for inclusion in Open Access Dissertations by an authorized administrator of DigitalCommons@URI. For more information, please contact digitalcommons-group@uri.edu.

NURSES' INVOLVEMENT IN END OF LIFE COMMUNICATION AND CARE

PRACTICES IN ICUs

DOCTOR OF PHILOSOPHY DISSERTATION

BY

ANNETTE L. GRIFFIN

A DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT OF THE
REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY IN
NURSING

UNIVERSITY OF RHODE ISLAND

2020

DOCTOR OF PHILOSOPHY DISSERTATION

OF

ANNETTE L. GRIFFIN

APPROVED:

Dissertation Committee:

Major Professor Marlene Dufault

Katherine Paquette

Stephen Kogut

Nasser H. Zawia

DEAN OF THE GRADUATE SCHOOL

UNIVERSITY OF RHODE ISLAND

2020

Abstract

Patients with end-stage and life-threatening diseases are frequently admitted to the intensive care unit (ICU). In fact, the ICU is the place of death for one in five patients in the United States due to the acuity of this population. Despite the high frequency of death in ICUs, evidence suggests that there is a need to improve end-of-life care (EOLC) for these patients.

Additionally, advancing medical technologies have contributed to the rescue culture of ICUs and in some cases has increased the use of aggressive and ineffective life-support therapies. Since critically ill patients are often too ill to participate in EOL treatment decisions, family members are asked to speak for patients, participating in decision-making with members of the healthcare team to determine the goals of care and to make decisions regarding withholding or withdrawing life-sustaining treatments. Although these conversations with families are common in ICUs, the communication is often difficult for all those involved. While healthcare providers have become more active in the role of managing the deaths of critically ill patients, many continue report the lack of adequate preparation for these complex skills. EOL decision-making is an important issue faced by ICU nurses who are on the front lines providing care to patients and families.

Despite the frequency in which ICU nurses are required to provide EOLC, nurses report variability in the ways in which care is operationalized and the extent of their involvement. It is concerning that nurses' actual participation or level of involvement in EOL decisions in the United States remains unclear despite endorsement of their roles by professional organizations and established protocols for ICU, palliative and end-of-life care practices. Hence, there is a need to clarify role expectations in clinical practice.

While almost two decades of nursing research suggests that nurses agree about the value and importance of quality EOLC, contrasting experiences have been reported related to levels of involvement in some aspects of care and decision making in clinical practice. Thus, examination of the prevalence of nurses' involvement in EOL communication, care practices, and identification of factors that may contribute to or predict involvement may help to explain the documented variations in EOL care in ICUs. Few studies conducted in the U.S. have specifically examined ICU nurses' actual involvement in EOL decision-making. Much of the available work has identified deficiencies in communication, ethical issues, and barriers to optimal EOL care. It has been suggested that nurses are at times dissatisfied with EOL decision-making practices and the quality of EOL care provided.

Communication is the centerpiece of EOL care in the ICU from which all other aspects of care emanate. As interest grows in improving the quality of EOL care in ICUs, the impact nurses can have on ICU patients and families takes on greater significance. End-of-life care in the ICU is challenging. Studying the involvement of ICU nurses in EOL communication and decision-making will contribute to our understanding of how these roles are operationalized, increase active participation by ICU nurses within the interdisciplinary team, and enhance overall quality of EOL care.

The purpose of the studies in this dissertation was to advance understanding of the nurses' involvement in end of life communication and care practices in the intensive care (ICU) setting. This dissertation will be comprised of three separate manuscripts which will address the following aims:

Manuscript 1: To provide a systematic review of theoretical and empirical research and synthesis of the findings related to nurses' involvement in EOL care and communication in ICU settings.

Manuscript 2: To explore role theory as a potential framework for understanding nurses' involvement in EOL care in ICU settings.

Manuscript 3: To describe ICU nurses' perspectives of their involvement in EOL communication and decision making. Identify potential factors or contribute to nurses' preferences for involvement.

Acknowledgements

I would like to take this opportunity to express my sincere appreciation to several people who have supported my work throughout my doctoral work and completion of my dissertation, making this educational goal a reality. A special thank you to my major professor Dr. Marlene Dufault whose mentoring, steadfast guidance, and research expertise supported me in this journey. She always provided encouragement, and valuable insight which enriched my development in research and scholarship. Despite her full schedule and professional commitments, she always found the time to provide helpful feedback on my work. I am deeply appreciative for all of her guidance for lifting me up throughout this dissertation process. I would also like to express my gratitude to my committee members. Dr Katherine Paquette provided content expertise on palliative care and helpful edits which helped me to create my professional manuscripts and dissertation. Her professionalism, kindness, and direction provided for an enriching experience. Dr. Stephen Kogut, offered time, expertise, and knowledge of statistical processes for this research. I am deeply grateful for his willingness to answer questions, make time for meetings, and his overall commitment to move me through the completion of this dissertation. Dr. Brian Quilliam, who offered suggestions at the proposal stage. The recommendation to include focus groups in addition to the survey which provided very rich data and deeper understanding of end-of-life care in the ICU. I have been fortunate for having had the opportunity to work with four outstanding mentors throughout this educational process. I am sincerely grateful for their dedication, time, and expertise that they have contributed to this work.

I would like to express my wholehearted thanks to my dear friends and colleagues, Yolande Lockett, Kathleen Smith and Jane Williams, for their continued support, encouragement and for always believing in me. I would also like to extend my deep appreciation to my dear friend Elaine Amato-Vealey for her being a support and encouragement in achieving this goal. I would be remiss if I did not mention my dear friend and colleague, Carolyn Wood who was instrumental in reconnecting me with my educational goals and her love and support along the way. She was always a voice of wisdom and encouragement. She always helped to ground me in reality during challenging times and helped me to believe in myself. I will be forever grateful to her for connecting me with my mentor at URI, truly a pivotal in my journey towards completion of this PhD.

To all of the nursing faculty at URI that I have had the honor and a pleasure to learn from you throughout this educational experience. Your dedication to research and scholarship has been inspirational and has enriched my professional development.

The unconditional love and untiring support of my family and relatives throughout my academic journey did not go unnoticed. I simply could not have accomplished this without them. My husband, Michael, sons; Brendan, Trevor, and daughters; Kate and Allison who have made many sacrifices along the way and played many roles to support me in this journey, through sickness and health. My husband has provided proof reading, document formatting, laundry, housework, meal preparation, and various other activities to keep the house running. Needless-to-say he has worn many hats. I am truly blessed for the untiring support of my family. I would also like to thank my in-laws, Eileen and Phil for their love, support, and encouragement throughout my pursuit of my PhD. in nursing.

To my parents, Robert and Annette Couture, for the life values that they instilled in me, dedication, hard work, and the importance of education. Throughout my life they always supported my every endeavor and fostered a positive spirit which propelled me to pursue my goals. I wish my Dad was here to share this achievement, however, I know he is proudly looking down on me.

Dedication

This dissertation is dedicated to my beloved husband Michael and our beautiful family, Brendan, Kate, Allison, and Trevor, who have been beside me throughout this journey. They have all been my strength and support throughout this experience. I could never have accomplished this work without their unconditional love, devotion, and encouragement. I hope that they are somewhat inspired to work hard and never give up on their own goals, whatever they may be.

“Accomplishment will prove to be a journey, not a destination.” Dwight D. Eisenhower

Preface

End-of-life care (EOLC) is woven into the fabric of nursing practice and a significant aspect of nursing in critical care settings. ICU nurses are challenged with the responsibilities of providing complex, highly acute care, with a focus on sustaining and/or extending life, while also providing EOLC for patients and families. This can require a shift in the focus of care, presenting a unique dichotomy since the curative philosophy challenges the skillful management of dying patients and obliges refocusing from a rescue orientation. End of life care in these settings has been characterized as a complex specialty where nurses' roles and scope of practice related to EOLC has changed with the introduction of expanding role expectations in the management of dying patients.

ICU nurses are key players in the delivery of compassionate EOLC with skilled communication as a centerpiece of care. Shortcomings in care of dying patients can improve if available, evidence-based recommendations for gold standard EOLC delivery (National Consensus Project, 2018) are fully implemented in ICUs. Growing interest in improving the quality of EOLC in ICUs calls for strategies to elevate care practices and mitigate challenges for nurses. Research to better understand gaps occurring in practice settings will advance our ability to develop targeted approaches that address education and training focused on providing exemplary care that meets the needs of nurses caring for patients and families at end of life. This work is intended to contribute to the body of nursing knowledge on this important subject.

TABLE OF CONTENTS

ABSTRACT.....	ii
ACKNOWLEDGEMENTS	v
DEDICATION.....	viii
PREFACE.....	ix
TABLE OF CONTENTS	x
LIST OF TABLES AND FIGURES.....	xiii
MANUSCRIPT 1	1
1.1 ABSTRACT.....	2
1.2 INTRODUCTION	4
1.3 BACKGROUND	7
1.4 METHODS	10
1.5 DATA EVALUATION	13
1.6 RESULTS	15
1.7 STUDY FINDINGS.....	17
1.8 LIMITATIONS.....	23
1.9 CONCLUSION.....	24
1.10 REFERENCES	26
MANUSCRIPT 2	45
2.1 ABSTRACT.....	46
2.2 INTRODUCTION	47
2.3 DISCUSSION of ROLE THEORY WITHIN THE SYMBOLIC INTERACTION PERSPECTIVE.....	49

2.4 ASSUMPTIONS OF SYMBOLIC INTERACTION	51
2.5 INTEGRATION OF ROLE THEORY	52
2.6 OVERVIEW OF ROLE THEORY RELATED TO UNDERSTANDING ICU NURSES' INVOLVEMENT IN END OF LIFE CARE	56
2.7 CHANGES IN PRACTICE EXPECTATIONS	58
2.8 ROLE THEORY AND IMPROVING END OF LIFE CARE IN THE ICU: STRENGTHS AND LIMITATIONS	60
2.9 REFERENCES.....	66
MANUSCRIPT 3	69
3.1 ABSTRACT.....	70
3.2 INTRODUCTION	71
3.3 AIMS.....	74
3.4 DESIGN AND METHODS	75
3.5 SAMPLE AND SETTING	77
3.6 DATA ANALYSIS.....	78
3.7 ETHICAL CONSIDERATIONS.....	80
3.8 RESULTS.....	81
3.9 THEMES: FOCUS GROUPS.....	87
3.10 DISCUSSION.....	94
3.11 STUDY LIMITATIONS.....	98
3.12 APPLICATIONS TO NURSING PRACTICE.....	99
3.13 REFERENCES.....	102
APPENDICES.....	

APPENDIX A: IRB Approval University of Rhode Island.....	127
APPENDIX B: IRB Approval Lifespan	128
APPENDIX C: Permission for Use of Survey.....	129
APPENDIX D: End of Life Survey	130

LIST OF TABLES AND FIGURES

TABLES AND FIGURES	PAGE
Manuscript 1	
Figure 1. Systematic Records Review	36
Table 1. Literature Search Strategy.....	37
Table 2. Description of Included Articles.....	38
Manuscript 3	
Table 1. Characteristics of Participating ICU Nurses	108
Table 2. Frequency of Participating in Palliative Care Discussions.....	109
Table 3. Potential of Barriers to Involvement in Types of Palliative Care Discussions: Frequency of Agreement.....	110
Table 4. Level of Confidence in Types of Communication.....	112
Table 5a. Frequency of Nurse Participation: Comparing Years of Experience with Unit Type.....	114
Table 5b. Potential Barriers to Involvement: comparing years of experience with unit type.....	116
Table 5c. Nurse Confidence: comparing years of experience with unit type.....	119
Table 6. Focus Group Participant Characteristics.....	122
Box 1. Guiding Questions for Focus Group Discussions.....	123
Table 7. Common Themes from Focus Group Discussions.....	124

MANUSCRIPT 1

Title: Intensive care unit (ICU) nurses' involvement in end of life (EOL) care and decision- making: An integrative review of the literature.

Annette L. Griffin, MSN, MBA¹; Marlene Dufault, PhD¹; Katherine Paquette, PhD¹; Stephen J. Kogut, PhD, MBA²

¹College of Nursing, University of Rhode Island, Kingston, RI

²Health Outcomes, Department of Pharmacy Practice, College of Pharmacy, University of Rhode Island, Kingston, RI

Funding: Unfunded

Target Journal: *Journal of Advanced Nursing*

Publication Status: In preparation for publication in the Journal of Advanced Nursing

1.1 Abstract

Aim: To examine what is known about ICU nurses' involvement in end of life (EOL) communication and family meetings when a shift in focus from curative care to comfort care occurs. Identifying implications for nursing practice is especially salient during this decision-making process.

Background: Communication is the center piece of EOL care and can impact quality as well as satisfaction for all involved. There is only one opportunity to get this right in the care of a dying patient. Calls for improvement in this aspect of EOL care require a better understanding of current practice in order to recommend specific changes to better address the needs of patients and families.

Design: The integrative review methodology of Whittemore and Knafl (2005) was employed to conduct this analysis.

Data sources: A search of electronic data bases (2011-2019) yielded 13 relevant articles which included quantitative, qualitative, and mixed methods research methodology and analysis.

Results: Four overarching themes emerged during the data analysis stage: environment of care, communication/shared decision making, nurse involvement, and role ambiguity/preparedness.

Conclusion: Communication is a cornerstone of palliative and EOL care. Results corroborated prior findings regarding deficiencies in EOL care practice variation and communication deficits. Nurses' roles in family meetings for decision-making about withholding and withdrawing treatments and developing goals of care, are

frequently sparse or auxiliary in nature. The importance of nurses' active involvement is a crucial component in collaborative, shared decision models of palliative and EOL care in order to achieve high quality communication and care, and especially so in the intensive care unit.

KEYWORDS: End-of-life care, palliative care, intensive care, critical care, communication, decision making, family meetings

1.2 Introduction

Patients with end-stage and life-threatening diseases are frequently admitted to the intensive care unit (ICU) where the primary focus of care is to preserve and restore the quality of life for patients, while supporting a complex battle for survival. Despite the core goal to cure, the ICU is frequently the place of death for one in five patients, nationally and internationally (Anderson et al. 2015; Todaro-Franceschi, 2013; Treece et al., 2006). Increased availability and use of resources including technology and medical advances, have played a role in the rescue philosophy of ICUs and in some cases, intensified the use of burdensome life-support therapies which at times extend the dying process. This trend has resulted in healthcare providers becoming more active in the role of managing the deaths of critically ill patients in the ICU (Mularski et al., 2006). Despite the frequency with which this occurs, two decades of evidence and a growing body of literature suggests that quality in end of life (EOL) care in intensive care settings is suboptimal (Anderson et al., 2016; Beckstrand, Callister & Kirchhoff, 2006; Carlet et al., 2004; Clarke et al., 2003; Troug et al., 2008; SUPPORT, 1995). In particular, communication between members of the healthcare team and the patients' relatives, is frequently identified as deficient (Carson, Cox, & Wallenstein, 2016). Consequently, calls for improvement have become a national and international imperative (Hidayat, Kongsuwan, & Nilmanat, 2017; Stajduhar et al., 2017; Trankle, 2014; Troug et al., 2008).

This “transition of care” has been described as possibly the most important, yet most challenging aspect of medical and nursing practice in ICUs (Stajduhar et al., 2017; Truog et al., 2008). Transition of care in the ICU refers to a shift in the focus

and intensity of care goals. EOL care optimizes the relief of pain and suffering and managing a peaceful death rather than aggressive life prolonging therapies purported to cure. Furthermore, the fact that many ICU deaths are preceded by decisions to limit life-sustaining treatment when a transition in the focus of care is necessitated, presents significant communication considerations that occur on a frequent basis (Gutierrez, 2012; Rocker et al., 2005; White, Braddock, Bereksnyi, & Curtis, 2007). The phenomenon presents a dichotomy for healthcare providers since the philosophy of cure collides with the dual responsibility of end of life care, which makes the delivery of bad news particularly challenging for members of the healthcare team.

Additionally, the complexity of communication is intensified by the fact that critically ill patients are often incapacitated due to sedating medications, severity of illness and impaired cognitive abilities, rendering them unable to participate in EOL treatment decisions. Family meetings are often assembled for decision making at the time when a shift in the focus of care is recommended. In many cases, grieving family members are asked to serve as surrogate decision makers and speak on behalf of the patient, requiring them to collaborate with members of the healthcare team and determine the goals of care (Heyland, Rocker, O'Callaghan, Dodek, & Cook, 2003; Prochaska & Sulmasy, 2015; Stajduhar et al., 2011). The need for clear, effective, communication is imperative at this time. The consequences of poor communication may lead to increased anxiety, depression, guilt, increased levels of stress, and complicated grief for families (Davidson, Jones, & Bienvena, 2012; Lewis & Kitchen, 2010) while leaving unsuspecting families little time to prepare for the loss of a loved one (Gutierrez, 2012).

An increasing body of research and clinical literature points to the importance of timely and accurate communication that will deliver understandable prognostic information, mitigate uncertainty, and alleviate tension. ICU nurses inevitably have a pivotal role in end of life communication due to their proximity to patients and extended time spent with families at the bedside. However, the evidence suggests that operationalization of this role is currently underperformed in intensive care settings. This is concerning because of the central role the ICU nurse has in providing care and support for these patients and families. Deeper understanding of barriers to nurses' involvement in communication is necessary to bridge the gaps towards improving nurses' critical contribution to this deficient aspect of EOL care.

The purpose of this integrative review was to examine current theoretical and empirical literature regarding ICU nurses' involvement in end of life care when a shift in focus from life sustaining to end-of-life care is needed, with two foci: (a) nurses' communication practices with families and physicians; and (b) nurses' level of involvement in family meetings and/or decision making. The updated integrative review method of Whittemore and Knafl (2005) was chosen because integrative reviews are considered an effective strategy to enhance the rigor and analysis of current literature and contribute to evidence-based practice for nursing. The question explored in this analysis was: What is the theoretical and empirical evidence that describes ICU nurses' role and involvement in end of life communication and family meetings and/or decision making when a shift in focus from life sustaining care to end of life care is needed?

1.3 Background

Although conversations with families about death and EOL care are frequent in ICUs, variability and barriers exist in nurses' involvement, confidence in skilled communication, and the overall effectiveness of discussions, which often contribute to discordant experiences for all those involved (Fuoto & Turner, 2019; Harris, Gaudet, & O'Reardon, 2014; Stajduhar, 2017; Troug et al., 2001). In addition, challenges related to EOL communication in the ICU are well documented in literature that has examined perceptions of healthcare providers and relatives of dying patients (Guitierrez, 2012; Isaacson, Minton, DaRosa, & Harming, 2019).

Despite the fact that nurses identify communication as a central component to high quality care, the frequency of nurses' involvement in different types of discussions determining goals of EOL care are varied (Anderson et al., 2016; Shannon, Long-Sutehall & Coombs, 2011; White, Braddock, Bereknyci, & Curtis, 2007). Nurses report challenges to involvement which include: ambiguity in roles, limited presence in family meetings and feelings of inadequacy and/or discomfort with communication which impede the provision of skilled end of life care (Adams, Bailey, Anderson, & Docherty, 2011; Adolph, Frier, Stanislaw, Stawicki, Gerlach, & Papdimos, 2011; Bach, Ploeg, & Black, 2009). These impediments also contribute to ICU nurses' reports of inconsistencies in the ways in which their roles are operationalized, including the extent of their involvement in family meetings (Hameric & Blackhall, 2007; Wysham et al., 2017). In combination, these factors contribute to the complexity of communication with families of dying patients and have been associated with nurses' dissatisfaction regarding end of life care decision making (Fuoto & Turner,

2019; Luce, 2010). While it is clear that palliative and EOL communication and care practices in the intensive care unit are believed to be essential by healthcare providers, current assessment of quality of EOL communication in ICUs demonstrates suboptimal standards even decades after the landmark SUPPORT study (1995) identified deficits in the focus of care (Lewis & Kitchen, 2010; Nelson et al., 2013; Truog et al., 2001; Wysham et al., 2017). Poor experiences in EOL decision making have been associated with long-term negative psychological effects on both families and healthcare providers (Kisorio & Langley, 2016; Lewis & Kitchen, 2010; Schenker et al., 2013; Stajgumar et al., 2011; Truog et al., 2001) and is one of the most significant contributors in adverse patient outcomes.

Nurses have a vital role in alleviating negative outcomes for families. Nurses support patients and families through interpreting and clarifying information and providing empathy, which are vital during a time when family members are often unable to recall information provided due to emotional stress, misunderstanding, and filtering of information (Bach, Ploeg, & Black, 2009; Noome, Dijkstra, Leeuwen, & Vloet, 2016). In addition, the gravity of conversations about death and dying may also contribute to “emotional numbness” with resulting difficulties in cognition, memory and attentiveness, creating additional barriers to decision making (Maciejewski & Prigerson, 2013) while families struggle to fully understand the implications of the treatment options that are being conveyed to them (Efsthathiou & Walker, 2014; Endacott & Boyer, 2013).

Recommendations to advance nursing practice which would address the need for skilled communication and unique care needs of dying patients were developed

through the End-of-Life Nursing Education Consortium (ELNEC) beginning in the year 2000 (Ferrell, Molloy, & Virani, 2015). Through the partnership with the City of Hope, the American Colleges of Nursing (AACN) and major funding support of the Robert Wood Johnson Foundation (RWJF) the ELNEC project was initiated for the purpose of training nurses in the areas of symptom management, pain control and relief of symptoms associated with severe illness (Ferrell, Molloy, & Virani, 2015). Nurses are called upon to manage dying, critically ill patients in ICUs (ANA, 2016; Luce, 2010), however, reports of deficiencies in preparation continue to emerge (Hall, 2018; Harris, Gaudet, & O'Reardon, 2014; Todara-Franceschi, 2013). While few studies have specifically examined the extent of nurses' involvement in family meetings and end of life decision-making, examining types of communication factors will advance our understanding of current practice behaviors and illuminate progress or lack thereof in enactment of nurses' roles.

1.4 Methods

Design

The modified integrative review methodology of Whittemore and Knafl (2005) was employed to guide this analysis of literature, to address the study aims. This process was chosen because it allows for the inclusion of diverse sources of literature and provides a rigorous, comprehensive, and systematic approach. The stages included are the following; systematic approach of problem identification, search of the relevant current literature, data evaluation and reduction or classification for data management, iterative data analysis for identification of themes, presentation reported in the form of tables, and conclusions. The existing literature will serve as the data for this review (Whittemore & Knafl, 2005).

Aim

The aim of this review is to examine what is known about nurses' roles, involvement in end of life communication and family meetings when transition from curative care to comfort care is needed in order to identify implications for nursing practice.

Search methods

A systematic search of electronic data bases was conducted including: CINAHL, MEDLINE, PsychINFO and MathSci EBSCOhost. The search included qualitative, quantitative, and mixed methods, empirical research that examined nursing roles in end of life care in ICU settings with a focus on communication and decision making necessitated by a transition from curative care to comfort care. The search terms used were: end of life care, palliative care, intensive care, critical care,

communication and decision making. Multiple searches were conducted to determine if additional or different records would be produced.

The term “family meeting” was added to the terms during the searches, however zero new records resulted. Systematic reviews were not included in this analysis. A subsequent search of the search engine Google was also conducted to determine if any records were missed. Reference lists were also reviewed for any additional and relevant literature that was not captured in the database searches included in this analysis. Inclusion and exclusion criteria undertaken for this systematic review process is detailed in Table 1.

Search limits

A comprehensive review of computerized databases was conducted, using the key words, palliative care, end of life care, intensive care, critical care, communication, and family meetings during the period from January 2011 to March 2019. The flowchart of the literature review is displayed in Figure 1.

A hand search for additional articles that met the inclusion criteria was also done to determine if any supplementary records would be yielded. The search was limited to studies conducted after 2011, since a systematic review of literature for the period from 1996 to 2011 was previously published, which examined nurses’ roles in communication at end of life across all hospital settings (Adams, Bailey, Anderson, & Docherty, 2011). The full text studies were retrieved for thorough screening of contents to determine if inclusion criteria were met for this analysis.

Inclusion criteria

This review considered primary sources that examined staff ICU nurses' roles and involvement in end of life communication during transition from curative to comfort care of adult patients and family meetings. Included publications were required to be in peer-reviewed journals. Studies were included that described communication practices specifically related to decision-making and/or focused on nurses' experiences and concentrated on communication as a central component of the article discussion.

Exclusion criteria

Non-English publications, non-adult populations, and non-ICU settings were excluded from this analysis. Additionally, records that focused on ethics, organ donation, euthanasia, specific diagnoses such as sepsis, and organ donation were excluded. Finally, records related to intervention, simulation programs, and/or programs specifically teaching communications skills were also excluded. Pediatric and neonatal patient populations were not included in this analysis due to the complexity of a parent relationship and decision-making and possible differences from adult populations. The literature search strategy, including key words, inclusion and exclusion criteria is summarized in Table 1.

1.5 Data Evaluation

The initial search strategy yielded a sample set of 65 articles. The sample was then limited to peer-reviewed academic journals, further reducing the potential sample to 60 abstracts for review. After additional age limiters were added and duplicate articles removed, a sample set of 36 potential articles for screening were reviewed. Full text articles from this group of 36 were printed and read for closer examination and determination of relevance to the study focus. Applying the inclusion and exclusion criteria established for this paper, an additional 19 articles were omitted, further reducing the sample to 17 potential articles. Further review of this group of articles yielded a final sample of 13 articles published between January 1, 2011 and March 1, 2019. Figure 1 displays the Systematic Record Review.

Data reduction

The first phase of data reduction involved classifying the data categorically. Articles included in this synthesis were organized through a systematic process which included grouping the data according to subgroups based on the research methods. The final sample of articles selected for synthesis included eight studies that used qualitative methods, four studies that used quantitative methods, and one mixed methods study. There were five studies conducted in the United States, with additional studies performed in Canada, Asia, the Netherlands, Europe, UK, Australia, and Africa.

Data display

Table 2 shows the organization of data into a table format that provides an overview of the selection of studies for this synthesis. As previously noted, data from

the final sample was first grouped by research method and then organized into subcategories identifying author, country, study purpose, sample/setting, study design, data collection and main results/themes.

1.6 Results

Study designs

Eight of the studies reviewed were qualitative (Adams, Bailey, Anderson, & Thygeson, 2013; Bloomer, Endacott, Ranse, & Coombs, 2016; Brooks, Manias, & Nicholson, 2017; Holmes, Milligan, & Kydd, 2011; Kisorio & Langley, 2016; McAndrew & Leske, 2015; Noome, Dijkstra, Leeuwen, & Vioet, 2016; Ong, Ting, & Chown, 2017), one used a mixed methods approach (Dillworth et al., 2015), and four used quantitative approaches (Anderson et al., 2016; Langley, Schmollgruber, Fulbrook, Albarran, & Latour, 2013; Montagnini, Smith, & Balistieri, 2012; Sinuff et al., 2015). Among these studies, there were four relevant research studies between the years 2011 to 2014 that met the inclusion criteria and nine studies between the years 2015 through 2018, with the greatest number (4) in 2016.

The resurgence of interest in end of life care in the ICU may have been influenced by the Institute of Medicine report that was published in 2014, which reported that the US healthcare system was not currently structured to meet the needs and desires of patients and families requiring end of life care. Healthcare continues to focus on curing disease and not on providing comfort care despite the fact that it is preferred by most people at end of life (IOM, 2014). This premise was also a focus of the American Nurses' Association position paper published during this same period entitled "Nurses' roles and responsibilities in providing care and support at the end of life" (2016).

Characteristics of participants

By examining more closely the nurse participants and their roles in these studies

potential implications for nursing practice can be identified. The population samples in all studies except the Delphi study included ICU bedside nurses. Additionally, one included family members, nurses, and physicians (Adams et al., 2016), a second, included other disciplines such as physical therapy, clergy, social workers, dietitians, and “other” category (Montagnini et al., 2012) and two studies included nurses and physicians (Brooks et al., 2017; McAndrew et al., 2015). A last study included ICU bedside nurses, and/or management level nurses (Langley et al., 2013). The sample sizes for the 13 included studies ranged from one participant to 598 participants. The total overall number of participants across all of the studies utilized was 1,413.

Data comparison

Data analysis of comparisons was done using an iterative process of the final sample of articles through thematic analysis, examining potential patterns, themes and relationships between the data (Whittemore & Knafl, 2005). The purpose of this phase in the integrative review was to identify and develop patterns and themes that emerge regarding the phenomenon of nurses’ involvement in EOL communication (Kirkevold, 1997).

1.7 Study Findings

Of note, this integrative review focused on issues related to communication with the intent to examine nurses' involvement in EOL communication and family meetings during care transitions. Few studies focused specifically on communication in family meetings from the perspectives of nurses and their roles. Additionally, there is a paucity of research that specifically describes or measures nurses' involvement. The current research between January 2011 and March 2019 describes the nature of communication related to limiting, withholding or withdrawing end-of-life treatments, and barriers that have been described by healthcare providers. The studies included in this analysis were comprised of 4 in the United States, 1 in the United States and Canada, 1 in Canada only, 1 in Australia and New Zealand, 1 in Australia only, 1 in Scotland, 2 in South Africa, 1 in the Netherlands, and 1 in Singapore.

Synthesis of the literature supported prior findings of overall deficiencies in EOL communication and resulting suboptimal quality of care for dying ICU patients and their families (SUPPORT, 1995). Four themes emerged related to nurses' EOL communication with families in intensive care settings including; (1) Environment of care, (2) Communication and Shared Decision Making, (3) Nurses' Involvement, and (4) Role Ambiguity/Preparedness. It should be noted that the thirteen studies included in this analysis represented a diverse sample of intensive care nurses and physicians across eight different countries, while only four studies were conducted in the United States. Nonetheless, results of these studies demonstrate many commonalities across the four themes that emerged from the perspectives of nurses and other healthcare

providers. Each of these themes are next described in more detail.

Environment of Care

Not a conducive setting for EOL care - While nurses describe the intensive care environment as busy, lacking privacy, space, and peace for patients and families (Holmes et al., 2011; Noome et al., 2016) they also share the desire to create a more peaceful situation that allows patients and families time to participate in basic care, and say goodbye (Kisorio et al., 2016; Noome et al., 2016). Nurses also expressed feelings of high importance related to care of the dying, while describing deficits in their own ability to manage patient comfort. This was associated with lack of nurse autonomy (Ong et al., 2017), inability to consistently discuss patient care needs with physicians (McAndrew et al., 2015) and tension related to differences between nurses and physicians on perceptions of overall care (Montagnini et al., 2012). Shifting treatment goals from curative to palliative care opposes the philosophical underpinning of intensive care, creating challenges associated with timing of communication and disagreement at times among healthcare providers (Bloomer et al., 2016; Brooks et al., 2017). Additionally, tension and stress were linked to the ethos of intensive care when EOL or palliative care was delayed, and breakdowns in communication contributed to inconsistent messaging (Ong et al., 2017; Holmes et al., 2014). Nurses described discord when futile care interventions were performed, contributing to unrelieved suffering and unnecessary prolongation of life (Ong et al., 2017). Care practices that delay palliative or EOL care practices were characterized as placing a higher value on quantity than on quality of life (Dillworth et al., 2015; Ong et al., 2017).

Communication/Shared Decision-Making

What is common to nurses' descriptions of family centered care is the importance of high, quality communication. Communication is reliant on the strength of mutual understandings and the development of therapeutic relationships which are integral to nursing practice (Ranse, Yates, & Coyer, 2016). Issues related to negative communication patterns stymie our ability to move the quality of EOL care to exemplary levels. The importance of quality communication and family centered care at EOL has been positively linked to family satisfaction (Mitchell & Chaboyer, 2010; Noome et al., 2016). Recent studies identify common characteristics of excellent clinical communication skills that are necessary when discussing withholding or withdrawing care and developing goals with families. Recommendations for optimizing communication include clear, honest communication without use of medical jargon when providing an explanation of the patients' medical condition and prognosis (Adams et al., 2013; Ong et al., 2017). Strategies to optimize difficult conversations include utilizing a shared decision making model and collaborative process as an important component of family meetings (McAndrew et al., 2015; Noome et al., 2016). Conflicts do exist among doctors and nurses regarding the ways in which care practices are carried out (Montagninni et al., 2012) and nurses contend that shared decision-making is consistently not achieved (McAndrew et al., 2015).

A plethora of communication deficiencies underscore common themes of suboptimal quality EOL care in intensive care settings. Poor communication practices increase frustration and tensions nurses experience. For example, the timing of communication has been identified as a critical factor in the ability to develop goals of

care and provide adequate preparation for families to know what to expect while also supporting their need for information (Bloomer et al., 2016; Brooks et al., 2016; Kisiorio et al., 2016; McAndrew et al., 2015; Noome et al., 2016). In one study, nurses describe communication between physicians and families as “mostly superficial” (Ong et al., 2017) while another study found there were inconsistencies and mixed messages with breakdowns associated with withholding and/or withdrawing care (Holmes et al., 2011). Inconsistent messaging was associated with family denial, false hopes (Holmes et al., 2011; Kisiorio et al., 2016) ambiguous care plans and delays in the implementation of palliative or end-of-life care (Ong et al., 2017).

Nurses also reported that when communication was discordant and ambiguous that death was equivalent to unrelieved suffering and futile prolongation of life (Ong et al., 2017). In addition, poor timing of communication has been equated with “crisis decision-making,” leading to relatives’ dissatisfaction with care (McAndrew et al., 2015) and associated delays in inclusion of spiritual and religious support, as well as other disciplines such as social worker, psychologists and counselors for families (Kisiorio et al., 2016).

Nurses’ involvement

Evidence suggests that nurses’ proximity to patients in the ICU, places them in a key position to share important information and to support the needs of patients’ and their relatives during these emotionally charged, difficult conversations. In addition, shared decision models that center on collaborative communication between members of the healthcare team support nurses’ involvement. The literature indicates that nurses’ presence in family meetings is sparse and, in many cases, nurses are not present at all

(Adams et al., 2013; Brooks et al., 2016; Kisorio et al., 2016; Langley et al., 2013; McAndrew et al., 2015). Some studies suggested that nurses did not participate in family meetings because physicians did not ask for their perspectives (Anderson et al., 2016; Ong et al., 2017). Research retrieved for this analysis did not yield any studies that measured actual levels of nurses' involvement in family meetings. Self-reports regarding involvement noted that nurses would prefer "more presence" in family meetings (Holmes et al., 2011; Kisorio et al., 2016; Langley et al., 2013) and emphasized the importance of nurses' presence (McAndrew et al., 2015; Ong et al., 2017).

An ethical dilemma exists in clinical practice between the high value nurses place on quality EOL communication and care and their actual roles in EOL communication and care practices. It is notable that this incongruity and moral discord creates frustration, tension, and stress, which studies suggest may affect nursing care practices and result in feelings of helplessness, anger and/or sadness (Holmes et al., 2011). In the Noome et al. (2016) study, it was reported that nurses attend all family meetings, yet they also reported a preference for more involvement in decision-making. This discrepancy indicates that nurses who attended family meetings in this study may have been present but did not have an active role in discussions. Further, nurses' roles were described to include listening, explaining, clarifying and in family meetings, adding information if needed (Noome et al., 2016). Some of these supportive behaviors likely occurred subsequent to the family meeting. Nurses described the important role of "bringing all the parties together," providing comfort and advocacy which at times may include communicating with the physician provider and influencing changes in the treatment plan (McAndrew et

al., 2015).

Role Ambiguity/Preparedness

The issue of role ambiguity may be an important factor in the level of nurses' involvement in EOL communication and family meeting. Nurse reports in several studies indicated that they lacked confidence with their skills in difficult conversations with families (Anderson et al., 2016; Kisorio et al., 2016). Nurses also reported self-perceived deficiencies in EOL communication (Montagnini et al., 2012) due to lack of education or training in this area (Anderson et al., 2016; Bloomer et al., 2016; Holmes et al., 2014; Kisorio et al., 2016). Development of skills related to EOL communication was said to be learned primarily through observations and both positive and negative past experiences with little formal education (Costello, 2006; Holmes et al., 2014). One study also noted that since EOL communication skills were learned through experiences, it was difficult to share knowledge in this area with novice nurses (Bloomer et al., 2016).

1.8 Limitations

This integrative review only included studies that were published in English and full text articles that were available. Also, studies were included only if published in a peer-reviewed journal.

Consequently, additional relevant studies may not have been included in this analysis. The review focused on the lens of nurses' involvement in EOL communication and was therefore limited to one perspective. Studies that examined nurses' roles from other stakeholders' perspectives were not included.

These may provide a different insight into the phenomenon of EOL communication and care. Finally, all but one of these national and international reports were conducted in major tertiary academic centers. The findings may differ if smaller private hospitals were included in the sample. Major academic centers may provide a sample of ICU nurses that are more representative of emerging practice changes regarding their involvement in EOL communication.

1.9 Conclusion

The nurse's ability to communicate competently and effectively is essential in palliative and EOL care. Effective communication has been widely recognized as the "backbone of the art and science of nursing" (Bloomer et al. 2016). It is central to family centered care. Barriers and gaps in EOL communication and areas for improvement have been consistently identified in national and international literature. The findings of this modified integrative review are congruent with previous studies that have suggested poor EOL communication exists between members of the healthcare team, and between the healthcare team and families, resulting in low satisfaction with EOL care by both nurses and families (Efstathiou & Clifford, 2011). Nurses spend a considerable amount of time at the bedside which affords them unique knowledge and perspectives about the patients and families. Relationship building is known to enhance trust and understanding which provide essential insight during these difficult conversations. Optimizing nurses' EOL communication in the ICU could be effective in addressing the gaps in communication timing and clarity, lack of agreement between members of the healthcare team, and lack of compassion and empathy reported by nurses in the literature analyzed for this review. The communication strategies of active listening, clarifying, explaining, and reassuring as described by the nurses in this review have the potential to significantly improve EOL communication when nurses actively participate in family meetings.

Positive communication practices are imperative for achieving quality EOL care (Brooks et al., 2015). Collaborative practices are integral to palliative care practice models (AACN, 2016; AACN, 2006; ANA, 2016; Curtis et al., 2005; Dillworth et al.,

2015). The importance of expanding nurses' roles is a key factor in optimizing EOL care in the intensive care unit. The opportunity to improve decision- making and care practices in EOL care has the potential to enhance the satisfaction of all members of the healthcare team, facilitate necessary practice changes, and ultimately improve the quality of EOL care.

The presence of role ambiguity may be an important link in explaining some deficiencies in EOL care practices. Strategies are still needed to support education needs and clarify role expectations associated with EOL communication and care processes for experienced and novice nurses in order to operationalize quality EOL care practices in ICUs.

Nurses in the ICU are on the frontlines minute to minute and day to day caring for patients and families. Knowledge of the patient and family dynamic is crucial during EOL care conversations. Communication is an integral role of the nurse and includes education about patient care practices and clarification of goals of care. Nurses involved in family meetings regarding EOL care are in a unique position to advocate for individualized approaches to this care for their patient and family members. The importance of nurses' development of competence and confidence in EOL communication and care cannot be underestimated. It is imperative that EOL care education and ELNEC certification is integrated into the orientation and continuing education requirements of all ICU nurses. These practice changes will empower ICU nurses to become mandatory, active participants during EOL care family meetings and enhance utilization of a shared decision-making model in collaborative EOL care delivery in the ICU.

1.10 References

- Adams, J.A., Bailey, D.E., Anderson, R.A., & Docherty, S.L. (2011). Nursing roles and strategies in end-of-life decision making in acute care: a systematic review of the literature. *Nursing Research and Practice*, 2011, 1-15. doi: 10.1155/2011/527834
- Adams, J.A., Bailey, D.E., Anderson, R.A., & Thygeson, M. (2013). Finding you way through EOL challenges in the ICU using Adaptive Leadership behaviors: A qualitative descriptive case study. *Intensive and Critical Care Nursing*, 29, 329-336. doi: 10. 1016/j.iccn.2013.05.004
- Adolf, M.D., Frier, K.A., Stawicki, S.P.A., Gerlach, A.T., & Papadimos, T.J. (2011). Palliative critical care in the intensive care unit: A 2011 perspective. *International Journal of Critical Illness and Injury Science*, 1(2), 147-153.
- American Association of Colleges of Nursing, (2016). Position statement. Registered nurses' roles and responsibilities in providing expert care and counseling at the end-of-life <http://www.nursingworld.org/mainmenucategories/ethics-position-statements/etpain14426.pdf>.
- American Association of Critical Care Nurses, (2006). *Protocols for practice: Palliative Care and end- of-life issues in critical care*. American Association of Critical Care Nurses. Sudbury, MA.: Jones and Bartlett Publishers, Inc.
- ANA Board of Directors, (2016). Nurses' roles and responsibilities in providing care and support at the end of life. *ANA Position Statement*. Retrieved from <https://www.nursingworld.org/~4af078/globalassets/docs/ana/ethics/endoflife->

positionstatement.pdf

- Anderson, W.G., Puntillo, K., Boyle, D., Barbour, S., Turner, K., Noort, J.,...
Pantilat, S. (2016). ICU bedside nurses' involvement in palliative care communication: A multicenter survey. *Journal of Pain and Symptom Management*, 51(3), doi:10.1016/j.painsymman.2015.11.003
- Bach, V., Ploeg, J., & Black, M. (2009). Nursing roles in end-of-life decision-making in critical care settings. *Western Journal of Nursing Research*, 31(4), 496-512. doi: 10.1177/0193945908331178
- Badger, J.M. (2005). Factors that enable or complicate end of life transitions in critical care. *American Journal of Critical Care*, 14(6), 513-522.
- Beckstrand, R.L., Callister, L.C., & Kirchhoff, K.T. (2006). Providing a "good death": Critical care nurses' suggestions for improving end of life care. *American Journal of Critical Care*, 15(1), 38-46.
- Beckstrand, R. & Kirchhoff, K. (2005). Providing end-of-life care to patients: critical care nurses' perceived obstacles and supportive behaviors. *American Journal of Critical Care*, 14(5), 395- 403.
- Bach, V., Ploeg, J., & Black, M. (2009). Nursing roles in end-of-life decision making in critical care settings. *Western Journal of Nursing Research*, 31(4), 496-512. doi: 10.1177/0193945908331178
- Bloomer, M.J., Endacott, R., Ranse, K., & Coombs, M.A. (2016). Navigating communication with families during withdrawal of life-sustaining treatment in intensive care: a qualitative descriptive study in Australia and New Zealand.

Journal of Clinical Nursing, 26, 690-697. doi: 10.1111/jocn.13585

Brooks, L.A., Manias, E., & Nicholson, P. (2017). Communication and decision-making about end-of-life care in the intensive care unit. *American Journal of Critical-Care Nurses*, 26(4), 336-341. doi: 10.4037/ajcc2017774

Carlet, J.T., Antonelli, M., Cassell, J., Cox, P., Hill, N., Hinds, C.,...Thompson, B.T. (2004). Challenges in end-of-life care in the ICU. Statement of the 5th International Consensus Conference in Critical Care: Brussels, Belgium, April 2003. *Intensive Care Medicine*, 30(5), 770-784. doi:10.1007/s00134-004-2241-5

Carson, S.S., Cox, C.E., & Wallenstein, S. (2016). Effect of palliative care led meetings for families of patients with chronic critical illness: A randomized clinical trial. *Journal of the American Medical Association*, 316, 51-62.

Clarke, E.B., Curtis, J.R., Luce, J.M., Levy, M., Danis, M., Nelson, J., et al. (2003). Quality indicators for end-of-life care in the intensive care unit. *Critical Care Medicine*, 31(9), 2255-2262. doi:10.1097/01.ccm.0000084849.96385.85

Costello, J. (2006). Dying well: nurses' experiences of "good and bad" deaths in hospitals. *Journal of Advanced Nursing*, 54(5), 594-601. doi: 10.1111/j.1365-2648.2006.03867.x

Curtis, J.R., Engelberg, R.A., Wenrich, M.D., Shannon, S.E., Treece, P.D., & Rubenfeld, G.D. (2005). Missed opportunities during family conferences about end-of-life care in the intensive care unit. *American Journal of Respiratory Critical Care Medicine*, 171(1), 844-849. doi:

- Dillworth, J., Dickson, V.V., Mueller, A., Shuluk, J., Yoon, H.W., & Capezuti, E. (2015). Nurses' perspectives: hospitalized older patients and end-of-life decision-making. *British Association of Critical Care Nurses*, 21(2), e1-e11. doi: 10.1111/nicc.12125
- Efstathiou, N. & Clifford, C. (2011). The critical care nurses' role in end-of-life care: Issues and challenges. *British Association of Critical Care Nurses*, 16(3), 116-123. doi: 10.1111/j.1478-5153.2010.00438.x
- Efstathiou, N. & Walker, W. (2014). Intensive care nurses' experiences of providing end of life care after treatment withdrawal: a qualitative study. *Journal of Clinical Nursing*, 23(21), 3188-3196. doi: 10.1111/jocn.12565
- Endacott, R. & Boyer, C. (2013). Preparing for the unavoidable: Public and clinician expectations of death. *Nursing in Critical Care*, 18(3), 112-113. doi: 10.1111/nicc.12021
- Fuoto, A. & Turner, K.M. (2019). Palliative care nursing communication: An evaluation of the COMFORT model. *Journal of Hospice and Palliative Nursing*, 21(2), 124-130. doi: 10.1097/NJH.0000000000000493
- Gutierrez, K.M. (2012). Prognostic categories and timing of negative prognostic communication from critical care physicians to family members at end-of-life care in an intensive care unit. *Nursing Inquiry*, 20(3), 232-244. Doi: 10.1111/j.1440-1800.2012.00604.x

- Hall, M.A. (2018). Critical care registered nurses' perceptions of preparedness in the provision of end-of-life care. Widener University, ProQuest Dissertations Publishing, 2018. 10815746.
- Hamric, A.B., & Blackhall, L.J. (2007). Nurse-physician perspectives on the care of dying patients in intensive care units: Collaboration, moral distress, and ethical climate. *Critical Care Medicine*, 35(2), 422-429.
- Harris, M., Gaudet, J., & O'Reardon, C. (2014). Nursing care for patients at end of life in the adult intensive care unit. *Journal of Nursing Education and Practice*, 4(6), 84-89. doi: 10.5430/jnep.v4n6p84
- Heyland, D., Rocker, G., O'Callaghan, C., Dodek, P., & Cook, D. (2003). Dying in the ICU; perspectives of family members. *Chest*, 124, 392-398.
- Hsiu-Fang, H., Shannon, S.E., & Curtis, J.R. (2006). Contradictions and communication strategies during end-of-life decision making in the intensive care unit. *Journal of Critical Care*, 21(4), 294-304. doi: 10.1016/j.jcrc.2006.06.003
- Holmes, N., Milligan, S., & Kydd, A. (2014). A study of the lived experiences of registered nurses who have provided end-of-life care within an intensive care unit. *International Journal of Palliative Nursing*, 20(11), 549-556.
- Isaacson, M.J., Minton, M.E., DaRosa, P., & Harming, S. (2019). Nurse comfort with palliative and end- of-life communication. *Journal of Hospice and Palliative Nursing*, 21(1), 38-45.

- Kirkevold, M. (1997). Integrative nursing research – an important strategy to further the development of nursing science and practice. *Journal of Advanced Nursing*, 25, 977-984.
- Kisorio, L.C. & Langley, G.C. (2016). Intensive care nurses' experiences of end of life care. *Intensive and Critical Care Nursing*, 33, 30-38. doi: 10.1016/j.iccn.2015.11.002
- Langley, G., Schmollgruber, S., Fulbrook, P., Albarran, J.W. & Latour, J.M. (2013). South African critical care nurses' views on end-of-life decision making practices. *British Association of Critical Care Nurses*, 19(1), 9-13. doi:10.1111/nicc.12026
- Lewis, D. & Kitchen, C. (2010). The role of communication skills in end of life care. *Journal of Renal Nursing*, 2(2), 69-74. doi: 10.12968/jorn.2010.2.2.47254
- Luce, J.M. (2010). End-of-life decision making in the intensive care unit. *American Journal of Respiratory Critical Care*, 182, 6-11. doi:10.1164/rccm.201001-0071Cio
- Maciejewski, P.K., & Prigerson, H.G. (2013). Emotional numbness modifies the effect of end-of-life discussions on end-of-life care. *Journal of Pain and Symptom Management*, 45(5), 841-847. doi: 10.1016/j.painsymman.2012.04.003
- McAndrew, N.S. & Lenke, J.S. (2015). A balancing act: Experiences of nurses and physicians when making end-of-life decisions in intensive care units. *Clinical Nursing Research*, 24(4), 357-374. doi: 10.1177/1054773814533791
- Mitchell, M.L. & Chaboyer, W. (2010). Family centered care-A way to connect patients, families and nurses in critical care: A qualitative study using

telephone interviews. *Intensive and Critical Care Nursing*, 26(3), 154-160.
doi: 10.1016/j.iccn.2010.03.003

Mularski, R.A., Curtis, J.R., Billings, J.A., Burt, R., Byock, I., Fuhrman, C., et al.
(2006). Proposed quality measures for palliative care in the critically ill: A
consensus from the *Robert Wood Johnson Foundation Critical Care
Workgroup*. *Critical Care Medicine*, 34(11), S404-S411.

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D.G. (2009). Preferred reporting items for
systematic reviews and meta-analyses: The PRISMA statement. *PLoS Med.*,
6(7),e1000097. doi: 10.1371/journal.pmed.1000097

Nelson, J.E., Curtis, J.R., Mulkerin, C., Campbell, M., Lustbader, D., Monsenthal,
A.,...Weissman, D. (2013). Choosing and using screening criteria for palliative
care consultation in the ICU: a report from the Improving Palliative Care in the
ICU (IPAL-ICU) Advisory Board. *Critical Care Medicine*, 41(10), 2318-2327.
doi: 10.1097/CCM.0b013e31828cf12c

Noome, M., Dijkstra, B.M., Leeuwen, E.V., & Vloet, L.C.M. (2016). The perspectives
of intensive care nurses about the current and ideal nursing end-of-life care.
Journal of Hospice and Palliative Nursing, 18(3), 212-218. doi: 10.
1097/NJH.00000000000000221

Ong, K.K., Ting, K.C., & Chow, Y.L. (2018). The trajectory of experience of critical
care nurses in providing end-of-life care: A qualitative descriptive study. *s*,
257-268. doi: 10.1111/jocn.13882

Prochaska, M.T. & Sulmasy, D.P. (2015). Recommendations to surrogates at the end

of life: A critical narrative review of the empirical literature and a normative analysis. *Journal of Pain and Symptom Management*, 50(5), 693-700. doi: 10.1016/j.jpainsymman.2015.05.004

Ranse, K., Yates, P., & Coyer, F. (2016). Modelling end-of-life care practices: factors associated with critical care engagement in care provision. *Intensive and Critical Care Nursing*, 33, 48-55. doi: 10.1016/j.iccn.2015.11.003

Rocker, M., Cook, D.J., O'Callaghan, C.J., Pichora, D., Dodek, P.M., Conrad, W. ... Heyland, D.K. (2005). Canadian nurses' and respiratory therapists' perspectives on withdrawal of life support in the intensive care unit. *Journal of Clinical Care*, 20, 59–65.

Schenker, Y., White, D.B., Crowley-Matoka, M., Dohan, D., Tiver, G.A. & Arnold, R.M. (2013). “It hurts to know...and it helps”: Exploring how surrogates in the ICU coping with prognostic information. *Journal of Palliative Medicine*, 16(3), 243-249. doi: 10.1089/jpm.2012.0331

Shannon, S.E., Long-Suthehall, T., & Coombs, M. (2011). Conversations in end-of-life care: communication tools for critical care practitioners. *British Association of Critical Care Nurses*, 16(3), 124-129.

Sinuff, T., Dodek, P., You, J.L., Barwich, D., Tayler, C., Downar, J.,...Heyland, D.K. (2015). Improving end-of-life communication and decision-making: The development of a conceptual framework and quality indicators. *Journal of Pain and Symptom Management*, 49(6), 1070-1080. doi: 10.1016/j.jpainsymman.2014.12.007

Stajduhar, K., Funk, L. Cohen, R., Williams, A., Bidgood, D., Allan, D.,...Heyland, D.

(2011). Bereaved family members' assessments of the quality of end-of-life care:

Why is it important? *Journal of Palliative Care*, 16(1), 261-268. doi: 10.

1186/1472-684

Stajduhar, K., Sawatzky, R., Cohen, R., Heyland, D.K., Allan, D., Bidgood,

D.,...Gadermann, A.M. (2017). Bereaved family members' perceptions of the quality of end-of-life care across four types of inpatient care settings.

BMC Palliative Care, 27(4), 1-12. doi: 10. 1186/s12904-017- 0237-5

The SUPPORT Principal Investigators. (1995). A controlled trial to improve care for

seriously ill hospitalized patients. The study to understand prognoses and

preferences for outcomes and risks of treatments (SUPPORT). *Journal of*

American Medical Association (JAMA), 274(20), 1591- 1598.

doi10.1001https://insights.ovid.com/pubmed?pmid=18431285/jama.1995.03530

200027032

Todaro-Franceschi, V. (2013). Critical care nurses' perceptions of prepared and ability

to care for the dying and their professional quality of life. *Dimensions of*

Critical Care Nursing, 32(4), 184-190. doi: 10. 1097/DCC.)b)13e31829980af

Trankle, S.A. (2014). Is a good death possible in Australian critical and acute settings:

Physician experiences with end of life care. *BMC Palliative Care*, 13(41), 1-14.

doi: 10.1472-684X/13/41

Treece, P.D., Engelberg, R.A., Shannon, S.E., Nielsen, E.L., Braungardt, T.,

Rubinfeld, G.D., et al. (2006). Integrating palliative and critical care:

Description of an intervention. *Critical Care Medicine*, 34(11), S380-S387.

Truog, R.D., Campbell, M.L., Curtis, J.R., Haas, E.H., Luce, G.D.,...Kaufman, D.C.

(2008). Recommendations for end-of-life care in the intensive care unit: A consensus statement by the American College of Critical Care Medicine.

Critical Care Medicine, 36(3), 953-963. doi:10.

1097/CCM.0B013E3181659096

Truog, R.D., Cist, A.D., Brackett, S.E., Burns, J.P., Curley, M.A., Danis,

M.,...Hurford, W.E. (2001). Recommendations for end-of-life care in the intensive care unit: The Ethics Committee of the Society of Critical Care Medicine. *Critical Care Medicine*, 29(12), 2332-2348. doi: 10.

White, D.B., Braddock, C.H., Bereknyei, S., & Curtis, J.R. (2007). Toward shared decision making at the end of life in intensive care units. *Archives of Internal Medicine*, 167, 461-467.

Whittemore, R. & Knafl, K. (2005). The integrative review: updated

methodology. *Methodological Issues in Nursing Research*, 52(5), 546-553. doi: 10.1111/j.1365-2648.2005.03621.x

Wysham, N.G., Hua, M., Hough, C.L., Gundel, S., Docherty, S.L., Jones,

D.M.,...Cox, C.E. (2017). Improving intensive care unit-based palliative care delivery: a multicenter, multidisciplinary survey of critical care clinician attitudes and beliefs. *Critical Care Medicine*, 45(4), e372-e378. doi: 10.

1097/CCM.0000000000002099

Figure 1

Systematic Records Review

Figure 1 Flow diagram of study selection process. Adapted from Moher et al. (2009).

Table 1*Literature Search Strategy*

Keywords: end of life care, palliative care, intensive care, critical care, communication, nurses' roles, decision making. These Boolean operators were used to create multiple combinations of the key terms to yield a maximum number of eligible theoretical and empirical sources of current literature.

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> English Language 	<ul style="list-style-type: none"> Non-empirical literature, opinion articles, literature reviews, non-peer reviewed research or literature
<ul style="list-style-type: none"> Peer reviewed journal articles 	<ul style="list-style-type: none"> Focus on care after EOL decisions made to withdraw and/or withhold care.
<ul style="list-style-type: none"> Full text available 	<ul style="list-style-type: none"> Focus on ethical dilemmas, family bereavement, organ donation, and/or diagnosis specific.
<ul style="list-style-type: none"> ICU settings for adult patient population (18 yrs. & older) 	<ul style="list-style-type: none"> NICU, pediatric, adolescent populations because of the distinctly different nature of parental roles, concerns/emotional variables.
<ul style="list-style-type: none"> Study participants included staff nurses. 	<ul style="list-style-type: none"> Advanced practice nurses because they may have had different training or education than staff nurses.
	<ul style="list-style-type: none"> Focus on outpatient, homecare settings, and/or other non- intensive care settings.
	<ul style="list-style-type: none"> Focused on an implementation, simulation or other type of program to teach communication skills.

Table 2*Description of Included Articles*

Author (s) Country	Purpose of the study	Sample/Setting	Study design	Data collection	Main study themes
Qualitative studies					
Adams et al. U.S. (2013)	To describe the behaviors that providers use while interacting with family members facing challenges of recognizing that their loved one was dying in the ICU.	1 ICU patient with end stage illness who lacked decision-making capacity: case study	Qualitative descriptive Case study	PI recorded family members, doctors and nurses during three family conferences and conducted 1 interview with family	1 pilot case study utilized Adaptive Leadership as framework for ways individuals adapt to environmental changes. 2 types, technical and adaptive. Technical focuses on pragmatic approaches, adaptive; changes attitudes, thoughts and behaviors. 1 patient case-study, communication & illness trajectory included (1) provide clear, honest communication free of medical jargon (2) explanation of prognosis, risks & options to develop goals, (3) show compassion and empathy, supporting hope for possible outcomes, caring, and peaceful death (4) addressing what to expect, reassurance & symptom management. Nurses present in family meetings, sparse mention of the nurses' contribution to discussions. One exception, "at the end of the first family meeting the nurses fielded questions (p.333)."
Bloomer et al. Australia and New Zealand (2016)	To explore how nurses navigate communication with families during withdrawal of life-sustaining treatments in intensive care	21 critical care nurses from 2 adult intensive care units in Australia and 2 in New Zealand	Qualitative descriptive	Focus groups were conducted one in each intensive care unit	Five themes emerged; suggested effective communication multifaceted, includes skills of active listening, timely reassurance, & less tangible skills: reading cues of families to determine their understanding and information needs. 4 themes identified: (1) establishing the WHO, (2) working out HOW, (3) judging WHEN, (4) assessing the WHAT, (5) WHERE the skills learned. Nurses receive little training on communication skills, individual approaches or styles challenge sharing expertise with inexperienced nurses.
Brooks et al. Australia (2017)	To explore experiences and perspectives of nurses and physicians when initiating end-of-life care in the intensive care unit	17 critical care nurses and 11 physicians in 24 bed intensive care unit in Melbourne Australia	Qualitative descriptive	5 focus groups were conducted	5 focus groups, 3 with ICU nurses, 2 ICU physicians. 2 major themes & multiple subthemes identified, (1) communication; <i>timing of EOL care discussions, difficult conversations</i> , (2) <i>shared decision-making; EOL care planning, multidisciplinary acceptance of EOL plans, collaborative decisions with family involved</i> . Gaps identified; timing, discussions perceived by nurses and doctors occur too late, creates loss of trust, low satisfaction experienced by families. Challenges

Author (s) Country	Purpose of the study	Sample/Setting	Study design	Data collection	Main study themes
Holmes et al. Scotland, UK (2011)	To explore the experiences of ICU nurses who have provided EOLC to patients and families	5 ICU nurses working in 1 ICU in Scotland	Qualitative phenomenology	Interviews, thematic content analysis	identified; reaching agreement in care planning due to families' unrealistic expectations, health care team view expectations not based on patients' best interests. Nurses' roles in family meetings not explored. Organizational processes advocated, recommendation of framework for collaborative decision making needed to facilitate process.
Kisorio et al. Johannesburg, South Africa (2016)	To explore intensive care nurses' experiences of end-of-life care in adult intensive care units.	3 focus group discussions included 24 intensive care nurses	Qualitative descriptive focus group approach	Analysis using long table approach for thematic analysis	Focus groups yielded 5 major themes of nurses' experiences. (1) Difficulties; psychological & emotional stress, intensified if young in age or built relationship with nurses. Challenges related to care of dying; communication, stress associated with when to disclose information or not, family denial. (2) Discussion & decision making; majority of nurses reported, not involved in discussions & decision making, would prefer to be involved, "rarely attend." (3) Support for patients; associated with environmental factors; noise, need for quiet, family presence, allowing families to be involved in care, managing basic care, & promoting spiritual & religious support. (4) Support for families; interdisciplinary services, social workers, psychologists,

	Author (s) Country	Purpose of the study	Sample/Setting	Study design	Data collection	Main study themes
						counsellors, church leaders, prayer, respect of cultural practices/rituals, open visitation, privacy, and nurses' presence. Nurses not comfortable or prepared to handle family. Nurses report families not prepared days before the patient death (5) Nurse support; currently not available, counselling, debriefing sessions, and/or someone to talk to, available for staff would be helpful. When patient death occurs over a period of days, nurses would benefit if not required to care for the same patient for consecutive days. Lack of training in EOLC, how to handle patients, families, other challenges; no time to adjust after death before next admission. Communication key, though nurses indecisive whether or not to talk to families and not present in family meetings.
40	McAndrew et al. U.S. (2015)	To understand nurses' and physicians' perspectives and experiences with end of life decision making	7 nurses and 4 physicians in a large academic, Magnet designated, Midwestern hospital, intensive care units	Qualitative Grounded theory	Interviews	7 nurses and 4 physicians interviewed. Overall theme of EOL decision making as a "balancing act", 3 interacting subthemes that contribute to process of balance or imbalance. 3 subthemes included, (1) emotional responsiveness, (2) professional roles & responsibilities, (3) intentional communication & collaboration. Subtheme (1) the ability of nurses and doctors to acknowledge own emotional response and bracket emotions, to keep separate from professional responsibility. (2), nurses describe their role in EOL decision-making "bringing all parties together," provide comfort to families and to serve as advocate which may include influencing the treatment plan in separate discussions with physicians. Final subthemes, (3) intentional communication and collaboration distinguished from day to day, communication with that of shared decision-making. Noted; the goal of shared decision-making was not consistently achieved. Other factors related to communication: making "Intentional communication difficult,": uncertainty about prognosis, ambiguous documentation related to treatment goals,

Author (s) Country	Purpose of the study	Sample/Setting	Study design	Data collection	Main study themes
Noome et al. Netherlands (2016)	To determine how EOLC could be improved knowing the difference in current EOLC according to ICU nurses and the way ICU nurses would like to provide EOLC	20 intensive care nurses from 1 university hospital and 3 community hospitals, ICUs were medical, neurology, cardiothoracic and surgical	Qualitative descriptive	Interviews and thematic analysis	<p>inconsistent messaging, crisis decision-making, and timing of discussions.</p> <p>20 ICU nurses from 4 different hospitals, 1 university and 3 community participated in semi-structured interviews. 5 themes emerged from the data describing nurses' perceptions of "ideal EOLC; "(1)collaboration with other professionals, nurses' presence in multidisciplinary meetings important, (2) communication between nurse to patient and nurse to relatives. All ICU nurses attend family meetings and role described as listening, explaining and clarifying and also adding information when needed. (3) Nursing care practices not uniform in EOL care provided, consensus on wanting to create a peaceful situation. (4) Nursing care of relatives, included time to say goodbye, participate in last care, focus on patient but willing to listen give practical advice. (5) Organizational aspects of EOLC; all ICU nurses described trying to plan a family meeting about withholding treatment, recommend a guideline/checklist to guide care, believe that they should have a role in follow-up meetings after patients die to discuss & evaluate care. Optimally nurses prefer more time to spend with patient and family, more involvement/role in decision making, satisfactory communication between ICU nurses, professionals, and patients/families. Currently nurses experience little involvement in decision-making process, though feel they have pertinent, up to date information about the patient and family.</p>
Ong et al. Singapore (2017)	To understand the perceptions of critical care nurses towards providing EOLC	10 ICU nurses in a medical intensive care unit of a public tertiary hospital	Qualitative descriptive	Semi-structured interviews	<p>10 ICU nurses interviewed from MICU of tertiary hospital in Singapore. Nurses' culture and care experiences providing EOL care. Overarching theme, "Trajectory of care". 4 subthemes: (1) management and comfort, (2) tension assoc. with climate of communication; doctor to relatives, "mostly superficial", lack clear decision making, lack nurse autonomy, overall suboptimal, nurses underprepared for EOL care. Resulting in delays in care, unmet family expectations, poorly explained options and</p>

Author (s) Country	Purpose of the study	Sample/Setting	Study design	Data collection	Main study themes
					goals. (3) nurses' perceptions of discord associated with patient suffering, futile interventions, prolonging life, nurses value quality over quantity of life. (4) nurses coming to terms, seeking resolution of tension developed from experience associated with negative ICU culture of care.
Mixed method					
Dillworth et al. U.S. and Canada (2015)	To identify the most pressing palliative care & end-of-life issues & strategies and to identify association bet. nurse demographics (age, gender, race, education and experience), institutional/unit characteristics, issues	Data from GIAP survey data including 393 critical care nurse respondents from 156 hospitals in the U.S. and Canada	Secondary analysis of the NICHE Benchmarking Service data	Descriptive Statistical analysis of demographic data Quantitative data association between nurses & institutional characteristics with palliative care & EOL themes Qualitative using Dedoose	Secondary analysis to examine ICU nurses' perceptions of EOL decision-making and palliative care. Central theme of "paradox of prolonging life versus protecting quality of life". Associated with: Poor EOL communication issues, (1) lack of clear, simple and honest communication, (2) Delays in timely decision-making and palliative care referrals, (3) lack of family acceptance , care options and patient condition not clearly understood, delayed acceptance of patient prognosis, contributed to lack of family agreement on goals. All contributing to deprivation of quality time for family support with crucial information and education secondary to "stalled processes."

Author (s) Country	Purpose of the study	Sample/Setting	Study design	Data collection	Main study themes
Quantitative Anderson et al., U.S. (2016)	To describe the perspectives of intensive care bedside nurses on their involvement in palliative care communication	Data from survey including 598 critical care nurses	Quantitative descriptive and comparison analysis	Survey with descriptive statistics, Chi-squared test	598 ICU nurses w/in 5 academic tertiary centers in California. Mean ICU experience 10 years. 85% reported high importance related to discussions about prognosis, goals of care between healthcare clinicians and families. Frequency and type of nurses' involvement varied. Confidence in engaging in some aspects of palliative care communication reported by nurses, as widely varied. Associated barriers to nurse involvement in communication with either families or physicians; doctors not asking for nurses' opinions, need more training (65%), concerns about emotional toll, lack of role clarity. Nurses working day shift statistically more confidence in communication issues than nurses working primarily night shift.
Langley et al. South Africa (2013)	To examine So. African critical care nurses' experiences and perceptions of EOL care	Data form survey including 100 critical care nurses	Quantitative cross-sectional design	Survey with descriptive statistics and Chi-squared test	Data analyzed from 100 nurse surveys. Half respondents believed that withdrawing and/or withholding are ethically the same. Most reported to be involved in EOL direct care, not involved in decision making. Also, not involved in discussions with physicians, not asked to participate in family meetings. Nurses reported involvement would have positive influence on their job. Nurses supported maintenance of ET tube, oxygen (slightly reduced), nutrition, hydration, pain management and other comfort care. Two thirds of nurses advocated deep sedation.
Montagnini et al. U.S. (2012)	To describe ICU healthcare providers' self-perceived knowledge, attitudes, and behaviors related to the provision of EOL care for the purpose of planning educational interventions for ICU staff	Data from survey included 185 ICU staff members of an academic tertiary medical center	Quantitative descriptive and correlational analysis	Survey with (ANOVA) comparisons between yrs. in practice, self-perceived EOLC competencies, total types education, previous EOL education and EOL self-perceived competencies	All ICU healthcare providers at an academic affiliated tertiary VA medical center were eligible. Survey measured self-perceived knowledge, attitudes, and behaviors related to EOL care. 38 nurses, 25 physicians, other disciplines (respiratory, dietary, social work) \not statistically compared due to small sample sizes. Mean years of practice experience across all specialties 14.9 years. 70% reported some type of education related to EOL care. Years of practice correlated with self-perceived competency, not correlated with knowledge and attitudes towards EOL care, care behaviors, or 7 domains of care. Previous education correlated with self-perceived competency in decision-making and providing emotional support. Differences of means between nurses

Author (s) Country	Purpose of the study	Sample/Setting	Study design	Data collection	Main study themes
Sinuff et al. Canada (2015)	To develop quality indicators related to EOL communication and decision making	28 participants comprised a multidisciplinary panel of experts form a purposive sample from Canadian networks of healthcare professionals and researchers working in palliative or EOL care	Modified Delphi method	Four rounds of on-line surveys were used to achieve consensus of items to measure quality of EOL communication, descriptive statistics were used to describe mean, standard deviation, median and interquartile range of importance of items ranked in four categories	<p>and physicians; nurses significantly less likely than medical staff to perceive team behaviors carried out, medical staff rated EOL communication more positively than nurses (statistically significant). Overall, several deficiencies in self-perceived EOL competencies, related to communication, continuity of care, and decision-making process. Nurses and physicians differ on perceptions of how particular EOL care practices carried out in the ICU. Conflicts exist between nurses and physicians.</p> <p>Delphi method used to develop a conceptual framework for clinical settings, and indicators to measure quality related to EOL communication and decision making and develop generalizable definitions. 34 quality indicators were identified and then organized into 4 categories. The categories highlighted factors of structure, processes and outcomes associated with EOL communication and decision-making and focused on patients' values and preferences. Within the framework 3 of 4 categories focused on communication and decision-making, including advanced care planning, documentation of goals, care plans, and decisions about goals of care, the 4th category detailed organizational and system aspects such as policies and procedures, quality audits, staff access to professional development resources, etc. Measurement may inform proposals focused on improvement of quality EOL care.</p>

MANUSCRIPT 2

Title: Exploration of role theory as a potential framework for understanding nurses' involvement in EOL care: A theory analysis.

Annette L. Griffin, MSN, MBA¹; Marlene Dufault, PhD¹; Katherine Paquette, PhD¹; Donna Schwartz-Barcott, PhD¹; Stephen J. Kogut, PhD, MBA²

¹College of Nursing, University of Rhode Island, Kingston, RI

²Health Studies & Department of Kinesiology, University of Rhode Island, Kingston, RI

Funding: Unfunded

Target Journal: *Advances in Nursing Science*

Publication Status: In preparation for publication in the *Advances in Nursing Science*

2.1 Abstract

End- of-life care (EOLC) has been recognized as an emerging specialty in critical care. However, evidence suggests that quality is frequently deficient and varied in practice settings. Consistently, nurses report lack of having the requisite training necessary for clarity of role expectations related to difficult communication and care practices associated with EOLC. In this analysis, we propose using role theory as potential framework for understanding nurses' involvement in communication and care practices when providing EOLC in critical care. Whereby recommendations for EOLC may be viewed as a new role set and expectations are made explicit through education and role development.

Key words: role theory, involvement, end-of-life, critical care, ICU

2.2 Introduction

Theory is generally considered to be an abstraction utilized in research and practice to guide nurses' ability to understand, explain, and predict phenomena of interest. It is defined as a conceptualization embodying two or more related concepts in an organized manner. Existing theories are often used in nursing research to provide an organized conceptual framework. Research and theories bring essential value to the continued improvement and advancement of the discipline.

There is a need to examine the phenomenon of nurses' involvement in end-of-life care (EOLC), centered in the practice domain.¹ According to Kim, the practice domain describes approaches to examining phenomena that are encountered when doing the work of *nursing*. Kim posits that knowledge precedes action.² Consequently, it is critical to explore theoretical questions, which explain, predict, and describe how nurses deliberate or contemplate, make decisions, and actualize their activities in clinical practice. Development of a distinct body of nursing knowledge is essential in providing the foundations for the delivery of nursing care. Further research and theory development contribute to the continued empirical advancement and scholarship of nursing science.

Despite the frequency with which nurses shift patient goals from curative to palliative or comfort-oriented care in intensive care settings, variability has been reported in how this shifting focus of care is operationalized, the extent of nurses' involvement in this process,³⁻⁵ and in defining the nurse's role in shifting care orientation.^{6,7} It could be argued that the frequent use of the combined terms "nurses" and "involvement" and the implicit nature of nurses' involvement as identified in nursing literature, signifies its

importance in describing nursing activities at the center of practice and supports the need for further clarification of this phenomenon. Upon examination of the combined terms *nurses' involvement*, Griffin found that the criterion required for its categorization as a scientific concept was not met.⁸ During this analysis and review of the literature, role theory emerged unexpectedly as a potentially useful tool for examining nurses' involvement in end-of-life care (EOLC) in critical care nursing. This work also reinforced the need for further explanation of nurses' involvement to achieve concept clarity, which may inform future research and understanding regarding variations in EOL nursing care practices in the intensive care setting. The importance of nurses' involvement is intrinsic to all behavioral activities of practice and underscores the value for further development of its meaning and use. Examination of the role theory framework may provide a basis for understanding variation in nurses' involvement in aspects of EOLC, unobserved expectations of practice, and aid in operationalization of the established protocols for practice in intensive care unit (ICU) palliative and end-of-life care.⁸⁻¹¹

2.3 DISCUSSION OF ROLE THEORY WITHIN THE SYMBOLIC INTERACTION PERSPECTIVE

The tradition of interactionism originated for the intention of understanding processes within families. The preponderance of early knowledge was generated from the lessons of George Herbert Mead.¹² Although Mead's teachings were never published, research and development continued after his death. The assumptions of symbolic interaction emerged from the work of Mead's former students and associates at the University of Chicago during the 1920s and 1940s. The majority of the synthesis and interpretation of Mead's lecture notes and the work published as *symbolic interaction* was credited to Blumer.¹² The interest in this area of research has continued to evolve because the Chicago School achieved preeminence for the work using a sociohistorical context of symbolic interaction.^{13,14} The two predominantly used theoretical orientations that grew out of the earlier work are symbolic interaction¹² and role theory.^{15,16} Both theories are frequently used to guide nursing research. Burr et al.,¹² suggested that there may be an infinite set of assumptions associated with symbolic interaction which are not mutually exclusive from other theories. The assumptions identified in this discussion may not be exhaustive but will focus on an interactionist and/or role theory perspective as they relate to understanding and describing the phenomenon of nurses' involvement in EOL care.

The focus of human behavior and the context where social exchanges take place are pivotal to interactionism. ¹⁴ Recognition of the fact that interpersonal exchanges take place within social situations must be considered since individuals derive their own meaning from the symbols, language, events, and context. Also, individuals interpret

symbols throughout their lives through the processes that are continually occurring in their encounters and/or social interactions.¹³ Blumer,¹³ suggested that social encounters and context are not just occurrences, but are central influences in development of the self, thinking, intelligence, and development of meaning.¹² This is a key assumption since meanings which are shaped based on social encounters also contribute to the resultant behavioral responses.

Socialization is described as a reciprocal process, whereby the “self” does not exist separately, but rather, exists with other unique human beings and all individuals involved are mutually influenced by social exchanges.¹² In general, people live in a social context that includes many transactional relationships which occur in their day to day lives or situations. Mead differentiated between “self” and “I,” where I consists of the individual’s reaction to the attitudes of others. These beliefs provide a link between symbolic interaction and role theory, since roles exist as part of inclusive social acts, resulting in different role performances within a social structure.¹⁴

2.4 ASSUMPTIONS OF SYMBOLIC INTERACTION

“The human mind is malleable and becomes a product of the cumulative integration, interpretation, and modification of acquired values and meanings with existing ones, blending the old with the new”.¹²⁽⁴⁶⁾

This statement underpins the overall tenets of symbolic interaction theory that describes human beings on both the individual level and in a social context. A central assumption of this theory is that there are two attributes of an individual “self” and they are distinguished as the physical self or one’s body and the social self which exists in relation to society. The social self is further characterized as the entities of *me* and *I*. *Me* is used to illustrate the individual’s learned and repetitious roles in society, contrasted with *I*, the unique more spontaneous and unpredictable human entity. Through this lens, the self emerges over a lifetime of learning and processing information within the context of a dynamic culture and society. The symbols in this context may include language, words, gestures, intonation, ideas and values and help to shape symbolic meanings, evaluative judgments and the importance or worth of various phenomena.¹²

Additionally, individuals are motivated, and goal-directed and interact cooperatively with others in a purposeful manner to continuously acquire knowledge and creating meaning from symbols. As a result, individual decisions on what to do, or what not to do are based on interpretations, beliefs, and the importance or worth of various phenomena which are learned through interactions with others. Finally, the dynamic context of culture and society is thought to exist in harmony. Disruption or changes in the natural ebb and flow can produce strain and conflict in interactions¹²

2.5 INTEGRATION OF ROLE THEORY

Role theory exists within two basic traditions in the literature: the structuralist view and the social interaction perspective. This analysis is focused on role theory within the interactionist perspective. From an interactionist perspective, human behaviors emerge from an integrative process of life's experiences, on a personal level, socially, through direct and indirect communication, and modeling.¹² Interactionists also acknowledge that social variables, combined with mental influences, are utilized to interpret and explain the unpredictable components of behavior.¹² Although role expectations are considered to be somewhat prescriptive, role theorists also recognize that individuals operationalize or enact role expectations differently when they interpret "symbols" and interactions in dissimilar ways. Consequently, individuality and flexibility emerge in the articulation of roles. This notion exemplifies the necessary behaviors that involve ways in which individuals negotiate meaning from experiences and discover and enact new roles as a result.¹⁵ Through subjective appraisal, evaluation, and decisions, individuals coordinate and comport with the expectations of others in a social system. This is particularly valuable for understanding role theory and patterned behaviors associated with people who share a common identity and who are learning the role prescriptions or statuses attached to the positions within a social structure such as a professional organization.

The importance of the mind as the center of the development of "self" is a critical assumption in role development because it threads together all aspects of deliberation and intellectual processing that an individual partakes to appraise the dynamic landscape of culture and society. Each one of the previously identified assumptions about human interaction illuminates the reciprocal processes that occur. These processes are based on

meanings derived from the individual, through collective meanings that are learned, and are interpretive and flexible. Mead suggested that the "self" is not only interpreted through an individualistic lens but also incorporates the prevailing attitudes and perceptions of the organization or group of which she/he is a member. ¹⁴ The process of social interaction is the underpinning of an individuals' learning, acquisition of roles, and development of interpersonal competence. The purpose of socialization is to prepare members for the roles within the social group. Additionally, outcomes of socialization are related to statuses and roles that may be ascribed to on the basis of a social class, demographic group, professional roles, educational achievement based on occupational background.¹⁴ As a consequence, continuation in a social context requires that the members are committed to responsible participation and competence that is socially acceptable. It is also assumed that the individual will accept the requirements, responsibilities, and will develop any appropriate competencies required for the respective role.¹⁴ Meadian role theorists further suggest that socialization is necessary to facilitate role acquisition and performance. Socialization enables the development of interpersonal competence, physical and cognitive skills, and the internalization of the motives and values of the society.¹⁴ The combined use of symbolic interaction and role theory were utilized in this analysis as complementary strategies for understanding the nurse practice domain.

The term role itself is most commonly referred to as the set of recommendations or prescriptions that define the expected behaviors of members belonging to a group/society. While role theory recognizes the importance of the mediating role of the "self," it also possesses some unique properties that diverge from symbolic interaction.

For example, while the importance of subjective mental phenomena and making meaning from “mentalistic variables,” are acknowledged in role theory, the focus is directed more towards consensual and explicit phenomena.¹² This differs slightly from symbolic interaction because the focus of this theory is more on the immediate encounter than on predictability. Role theory is also deterministic and is concerned with interaction that has somewhat of a predictable nature due to scripted expectations and social norms that are easier to measure. These aspects are unique to role theory and do not overlap with symbolic interaction.¹²

Role theory is also a dynamic perspective, which recognizes individual differences in adult social role performance related to the individual’s knowledge, ability, and motivation to meet role demands. Brim¹⁷ suggested that socialization of roles is considered successful when it prepares the individual to respond to situational demands with “an appropriate amount of a given role characteristic”.¹⁴⁽⁹⁷⁾ This is significant because some variation in the operationalization of roles, due to individual differences within situations or contexts, will occur. Also, successful socialization is thought to provide a broad range of behaviors that can be enacted as the individual deliberates and can freely improvise to meet the situational role demands. While roles incorporate some socially shared expectations, there is spontaneity and latitude for individuals to enact situational differences. This is a key assumption since flexibility is required in nursing practice to meet the unique needs of a situation, directed towards the goals of the patient. Consequently, even though there are commonly held expectations of individuals in a role, there is freedom for improvisation in what is termed role making.¹²

Finally, the variable “organismic involvement” has been defined as “the proportion of a person’s concentration, effort, or engrossment that a role demands”. ¹²⁽⁵⁶⁾ This may be helpful when examining nurses’ involvement in the role of EOL care since it was described as a continuous factor that ranged from low or noninvolvement to a high degree of self-engagement. ¹²⁽⁵⁷⁾

2.6 OVERVIEW OF ROLE THEORY RELATED TO UNDERSTANDING ICU NURSES' INVOLVEMENT IN END-OF-LIFE CARE

Nurses' involvement refers to activities and behaviors in practice that are integral to nursing and are both implicit and explicit. Involvement is also a central characteristic of practice, which envelopes holistic nursing. Nurses' involvement occurs as an expression of that which is intrinsic to the very nature of nursing practice. When examining nursing practice activities, the actual definition as a concept and the nature in which nurses' involvement operationalized proved to be ambiguous and elusive, despite the regularity of the terms' use. This is problematic when examining this aspect of practice since people must be socialized in new roles to facilitate the performance of expected behaviors.¹⁵ According to role theory, role behaviors are not random and meaningless. Instead, the behaviors are patterned and somewhat predictable based on expectations that exist in the normative system. In addition, individuals negotiate emergent meanings in situations that are coordinated with actions based on appraisal, established meanings, and the articulation of courses of actions within a range of variability, expected by others enacting the same role.¹⁶ New behaviors are made explicit to provide meaning and optimize practice expectations. When expectations are not explicit and prescriptive guidelines are ambiguous or implicit, at best, a disconnect occurs between role expectations and the realities in practice.

Kim^{1,2} proposed that nursing practice activities are actualized through deliberation and enactment, while continually oriented to the client. Nurses are required to practice utilizing both mental and behavioral actions in clinical situations which necessitate intentional action to address the client goals. Kim¹ further suggests that what takes place

in clinical practice may vary based on the underlying goals and contexts in which the practice activities take place with the intent to deliver holistic care. Involvement is an implicit factor in Kim's philosophy of the processes of deliberation and enactment. While the processes of enactment are not measured on a continuous scale, nursing practice is operationalized by integrating five dimensional qualities: scientific, technical, ethical, aesthetic, and existential. These dimensional qualities typify nursing practice and center on the assumption that when integrated, they characterize the meaning of *doing nursing*.¹ Consequently, nurses' ability to perform all of these processes in practice would epitomize a very high level of involvement and role enactment.

These tents are consistent with the ways in which roles are operationalized. They recognize the normative nature of nursing practice with an emphasis on flexibility and conscious appraisal of situations that are also inherent in both symbolic interaction and role theory. Role theory also acknowledges a dynamic view of behaviors which account for an acceptable range that may occur when individuals enact the same role in response to a situation or encounter. Role theory also allows for flexibility in utilizing "clusters" of role expectations that may be utilized based on the situation.¹² This notion is consistent with Kim's¹ assumptions related to nursing practice, requiring integration of the dimensional qualities of science, technical skills, ethics, aesthetics and existential processing for enactment of the nursing role. These attributes are also actualized in varying degrees, depending on the situation or encounter. Role making "is a process which involves frequent modifications in response to changing situations and the structuring of the social interaction in such a way as to modify it, making certain aspects of the role explicit."¹⁴⁽⁶⁹⁾

2.7 CHANGES IN PRACTICE EXPECTATIONS

Nurses are members of a social position that carries expectations of what ought to be done in nursing practice situations. According to Linton,¹⁸ implicit and explicit acts and associated expectations within the social position define role behavior and validate each individual's occupancy of the position. This assumption speaks to the need for clarity in professional behaviors expected of nurses, particularly when there is a transition or change in recommendations or standards of practice.

Nursing practice expectations in critical care areas frequently require care for patients at the end-of-life. The intensive care unit has been a setting recognized for care of a complex, highly acute population where the most technologically advanced treatments are used to sustain life and, or to extend life. Additionally, the transition to an EOL focus of care presents a challenging dichotomy when the philosophy of curative care collides with the dual responsibility of end of life care. Also, it has been recognized that the management of dying patients at times, supersedes curative care in the ICU is a shift from the originally intended focus of saving lives.¹⁹ Consequently, nurses are expected to operationalize new practice behaviors that address symptom management, spiritual needs, cultural practices, pain management, emotional support, and other aspects of specialized care, requisite to quality patient care at EOL.⁸⁻¹¹ Nurses value quality EOL care, yet evidence continues to suggest the "need for improvement" and a shift in the amount of associated management of these patients, currently considered a complex specialty.¹⁹ Almost two decades of nursing research suggests that there is agreement among ICU nurses related to the value of quality EOL care.^{6,20,21} At the same time ICU

nurses acknowledge evidence of contrasting experiences pertaining to levels of involvement in specific aspects of care and decision making in practice.^{19,22,23}

2.8 ROLE THEORY AND IMPROVING EOL CARE IN THE ICU: STRENGTHS AND LIMITATIONS

The origin of symbolic interaction was discussed earlier in this analysis. The fact that empirical and theoretical research began in the early 1900s is noteworthy in examining the strength of this theory. The work by Mead at the Chicago School began with descriptive work that explored the perspectives of the subjects and was aimed at identifying their world views.¹⁴ Mead's work was focused on carefully linking emerging ideas within his empirical work. As a result, the theory has been frequently utilized and reconceptualized to enhance the connectivity of the concepts. Additionally, when considering the appropriateness of a theory as a framework for research, the theory itself must have internal consistency so there are not multiple contradictory departures in the theory's assumptions. For this reason, in evaluating theory, internal consistency is an essential criterion for determining the fit of the theory with the proposed research interest. The process of theory development used by Mead advanced a tight relationship between the theory and research. The continued use of symbolic interaction over time advanced its usefulness as a theoretical framework for examining social behaviors and continues to inform current research.¹⁴ Also, the term *role* was used extensively in Mead's writings in the social sciences and became a predominant part of scientific terminology. The frequent use of the term *role* has allowed for synthesis, clarification, and examination of the consistency of this term as a part of the conceptual framework, also essential to the overall strength for explaining nursing phenomena.

In examining potential theoretical frameworks for use in this analysis of nurses' involvement in EOL communication, decision-making, and care practices, consideration

was given to the overall fit of the interactionists' perspective of role theory. An extensive review of the literature across multiple areas of EOL in critical care was reviewed to gain an understanding of the issues associated with the phenomenon. This theory meets the criterion of usefulness because it is a good fit with the observable reality and plausibility of the phenomena that have been identified for this research and empirical testing. Consequently, after consideration of several different potential theories, role theory emerged as an appropriate theoretical framework to guide this paper.

Requisite for improving EOL care is closing the gap between scientific knowledge and clinical education related to palliative and EOL care.²⁴⁻²⁷ Significant deficiencies were documented ten years ago in EOL care education in nursing school curriculums and in nursing textbooks.²⁸ Nonetheless, deficiencies continue to be reported by nurses regarding their knowledge about the unique pain management requirements, effective communication, and relief of suffering at the end of life.²⁹⁻³² Both symbolic interaction and role theory focus on the socialization of individuals within an interactional context. Within this perspective, the individuals process information through interpretation of "symbols," from which they derive meaning. Individuals then, act based on the meaning that they attach to the situation. The derived meaning also supports their ability to perform their role in a way that is acceptable and meets the expectations of the profession or society which corresponds to the tenets of the nursing practice domain. The mindful processes of deliberation and enactment are products of reflection and meaning that are brought to a situation through interactions between the nurse and the client/family.¹ Additionally, the premise of socialization from both the individual and societal perspectives indicates that individuals acquire their skills and normative

behaviors through interactional processes that also foster learning.¹⁴ It has also been suggested that the contrary assumption is valid. There is an inverse relationship that exists between the amount of ambiguity in role expectations and role strain. Ambiguity in role expectations occurs when “implicit assumptions are not shared, unspoken rules are broken,” and unexpected failures of communication occur, which creates role strain.¹² This may facilitate our ability to explain the variability of nurses’ involvement in EOLC in clinical practice.

Evidence of ambiguity in nursing role expectations is apparent in the literature examining EOLC nursing practice. Delay in implementation of recommended care practices^{25,26,31,32} purported to improve quality of dying in intensive care settings has been observed in acute care settings.^{6,28, 32-,34} The need for additional education is apparent^{20, 28-33} despite the outreach of ELNEC training programs targeted for faculty, students and practicing nurses with the goal of improving access and quality in palliative and end-of-life care.^{29,33} The ELNEC program was developed through a partnership between the City of Hope and the American Association of Colleges of Nursing.^{20,29,33} The impetus for improvement was first identified in the hallmark SUPPORT study²⁶ and continues to be a clinical practice and research imperative endorsed by the American Thoracic Society of Critical Care Medicine,¹⁹ and several professional nursing organizations.⁹⁻¹¹ Deficiencies continue to be reported related to nurses’ knowledge about pain assessment, management, and relief for patients at end of life.^{6,22,28,35} The lack of clarity in the roles of nurses and other members of the healthcare team has been cited as a source of difficulty in provision of quality EOLC.^{3,5,6,35}

Variation in practice may be explained by role theory as it relates to the role transition creating new demands and competencies associated with managing patients at end-of-life. The ability to perform expected practice activities at a high level, according to the role approach, requires socialization and patterning to support predictable, meaningful consequences for the participants. It is not implied that enactment is a rigid vision of practice activities; however, expected behaviors should fall within a predictable range of variability among individuals enacting the same role. ¹⁴ Further, the ability to successfully perform the “prescribed” activities in the practice setting may affect role strain. Are nurses able to meet the demands that are driven by the patient/family situation, expected in this role set, if the expectations have not been socialized or made explicit?

The value that conceptualizations of symbolic interaction and role theory contribute is that they are aimed at understanding and explaining social order. Symbolic interaction and role theories jointly acknowledge that individuals actively construct and create their environment through the process of self-reflection in reciprocal social interactions. These premises are essential in connecting role theory and symbolic interaction with nursing practice and specifically EOLC. Role theory is comprised of multiple concepts and emerging sub-theories, such as role expectations, role ambiguity, role enactment, and role strain, among others, that address specific aspects of social behavior.

Recommended guidelines for the standards of end-of-life nursing care may be viewed as a new role set. The expectations of this specialty area should be made explicit through education and role development. Knowledge of expectations has a positive effect

on the ability of the individual to perform the role activities. This is consistent with Kim's² tenant that nursing practice is focused on rationality and ways of knowing that are framed as a "holistic, goal-oriented system of human actions." Rationality is the basis for actions in nursing practice and is operationalized through the five dimensions that were described earlier. How well these five rationalities are articulated contributes to the quality of nursing practice.^{1,2} In addition, the determinants of role socialization are the individual's ability to acquire the skills and norms through interactional processes of learning, including language and motor skills both from an individual perspective and societal level.¹⁴

There are few limitations associated with the use of role theory for the purpose of examining this nursing phenomenon. One limitation that may emerge is that although role theory appears to fit logically at this point, deeper analysis into the phenomenon may illuminate a lack of logical consistency with this specific clinical situation that is not currently apparent. This could occur with any theory as new concepts emerge that may not have been considered at the outset. This might create a greater risk if the researcher has limited familiarity with the study phenomenon. Such a limitation may be mitigated by additional reviews of the current literature. A further limitation may develop when expanding the study of nurses' involvement in EOLC to include the macro level within role theory. This conceptualization may illuminate additional factors to explain the phenomena that were not considered.

The opportunity to improve decision-making and care practices in EOL care has the potential to enhance the satisfaction of all members of the healthcare team and

ultimately improve the quality of EOL care. Further research is needed to examine relationships between nurses' perceptions of their preparedness and actual involvement in provision of end-of-life care in the ICU. Research framed by a parsimonious theory, as proposed in this discussion, is needed to clarify gaps in understanding of this phenomenon, advance nursing knowledge, and to design intervention programs that will improve quality and address deficits in care practices for patients at end-of-life in critical care units.

2.9 References

1. Kim H.S. The essence of nursing practice: philosophy and perspective. New York, NY: Springer Publishing Company, LLC; 2015.
2. Kim HS. The nature of theoretical thinking in nursing. 3rd ed. New York, NY: Springer Publishing Company, LLC; 2010.
3. Hamric AB, Blackhall LJ. Nurse-physician perspectives on the care of dying patients in intensive care units: Collaboration, moral distress, and ethical climate. *Cri Care Med*. 2007; 35(2):422-429. doi:10.1097/01.CCM.0000254722.50608.2D
4. Ho KM, English S, Bell J. The involvement of intensive care nurses in end-of-life decisions: A nationwide survey. *Intensive Care Medicine*. 2005;31(5):668-673. doi:10.1007/s00134-005-2613-5
5. McMillen RE. End of life decisions: Nurses' perceptions, feelings and experiences. *Intensive Crit Care Nurs*. 2008;24:251-259. doi:10.1016/j.iccn.2007.11.002
6. Anderson WG, Puntillo K, Boyle D, et al. ICU bedside nurses' involvement in palliative care communication: A multicenter survey. *Jour Pain Symptom Manage*. 2016;51(3):589-596.e2. doi:10.1016/j.painsymman.2015.11.003
7. Bach V, Ploeg J, Black M. Nursing roles in end-of-life decision-making in critical care settings. *West J Nurs Res*. 2009;31(4):496-512. doi:10.1177/0193945908331178
8. Griffin A. Analysis of the Concept: Nurses' involvement in the context of end-of-life care in ICUs. Unpublished manuscript. 2018.
9. American Association of Colleges of Nursing, (2010). Position statement. Registered nurses' roles and responsibilities in providing expert care and counseling at the end-of-life <http://www.nursingworld.org/mainmenucategories/ethics-position-statements/etpain14426.pdf>. accessed February 18, 2011
10. American Association of Critical Care Nurses, (2006). Protocols for practice: Palliative Care and end-of-life issues in critical care. American Association of Critical Care Nurses. Sudbury, MA.: Jones and Bartlett Publishers, Inc. accessed February 18, 2011
11. ANA Board of Directors, (2016). Nurses' roles and responsibilities in providing care and support at the end of life. ANA Position Statement. Retrieved from <https://www.nursingworld.org/~4af078/globalassets/docs/ana/ethics/endoflife-positionstatement.pdf> April 10, 2018

12. Burr WR, Hill R, Nye FI, Reiss IL. Contemporary theories about the family. In: Symbolic interaction and the family. vol. II. New York, N.Y: The Free Press: 1979:2-111.
13. Blumer H. Symbolic interactionism: Perspective and method. Englewood Cliffs, NJ: Prentice-Hall, Inc; 1969.
14. Hardy ME, Conway ME. Role Theory Perspectives for Health Professionals, Norwalk, CT.: Appleton and Lange; 1988.
15. Biddle BJ. Role theory: Expectations, identities, and behaviors. New York, NY: Academic Press; 1979.
16. Sarbin T, Allen VL. Role theory. In Lindsey, Aronson. 2nd ed. The handbook of social psychology. Reading, MA: Addison-Wesley Publishing Company; 1968:488-568.
17. . Brim OG. Personality development as role-learning. In: Iscoe HW, Stevenson, Personality development in children. Austin, TX: University of Texas Press; 1960:127-159.
18. Linton R. The cultural background of personality. New York, NY: Appleton-Century; 1945.
19. Luce JM. End-of-life decision making in the intensive care unit. Am J Respir Crit Care. 2010;182:6-11. doi:10.1164/rccm.201001-0071CI
20. Ferrell BR, Virani R, Grant M. Evaluation of the End-of-Life Nursing Education Consortium (ELNEC) undergraduate faculty training program. Ann Palliat Med. 2015;4(2):61-69. doi:10.3978/j.issn.2224-5820.2015.04.05
21. American Nurses Association (ANA) Professional Issues Panel & Hospice and Palliative Nurses Association (HPNA). Call for action: nurses lead and transform palliative care. 2017: <http://www.nursingworld.org/CallforAction-NursesLeadTransformationPalliativeCare>. Accessed February 19, 2018
22. Calvin AO, Kite-Powell DM, Hickey JV. The neuroscience ICU nurse's perceptions about end-of-life care. J Neurosci Nurs. 2007;39(3):143-150.
23. Rocker M, Cook DJ, O'Callaghan CJ, et al. Canadian nurses' and respiratory therapists' perspectives on withdrawal of life support in the intensive care unit. J Clin Care. 2005;20:59-65.
24. Kirchhoff KT, Spuhler V, Walker L, Hutton A, Cole BV, Clemmer T. Intensive care nurses' experiences with end-of-life care. Am J Cri Care. 2000;9(1):36-42.
25. American Association of Colleges of Nursing(AACN).Peaceful Death: Recommended Competencies and Curricular Guidelines for End-of-Life Nursing

Care, 1997. Available online:
<http://www.aacn.nche.edu/elnec/publications/peaceful-death>, accessed May 19, 2015.

26. The SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *JAMA*. 1995;274(20):1591-1598. doi:10.1001/jama.1995.03530200027032
27. White KR, Coyne PJ, Patel UB. Are nurses adequately prepared for end-of-life care? *J Nurs Scholarship*. 2001; 33(2):147-51.
28. Ferrell BR, Virani R, Grant M. Strengthening nursing education to improve end-of-life care. *Nurs Outlook*. 1999;47(6):252-256.
29. Malloy P, Ferrell B, Virani R, Wilson K, Uman G. Palliative care education for pediatric nurses. *Pediatr Nurs*. 2006;32(6):555-561.
30. Schim SM, Raspa R. Crossing disciplinary boundaries in end-of-life education. *J Prof Nurs*. 2007; 23(4):201-207. doi:10.1016/j.profnurs.2007.01.003
31. Institute of Medicine (IOM). Dying in America Improving quality and honoring individual preferences near the end of life. 2014; <http://www.nationalacademies.org/hmd/~/media/Files?Report%20/2014/EOL/Report%20Brief.pdf>. Accessed May 9, 2015.
32. Nelson, JE, Angus, DC, Weissfeld, LA, et al. & FRCPC; for the Critical Care Peer Workgroup of the Promoting Excellence in End of Life Care Project. End of life care for the critically ill: A national intensive care survey. *Crit Care Med*. 2006;34(10):2547-2553. doi:10.1097/01.CCM.0000239233.63425.1D
33. Ferrell BR, Grant M. Nurses cannot practice what they do not know. *J Prof Nurs* 2001;17: 107e108.
34. Adams JA, Bailey DE, Anderson RA, Docherty SL. Nursing roles and strategies in end-of-life decision making in acute care: a systematic review of the literature. *Nurs Res Pract*. 2011; vol 2011;(527834):1-15. doi:10.1155/2011/527834.
35. Efstathiou N, Clifford C. The critical care nurse's role in end-of-life care: issues and challenges. *Nurs Crit Care*, 2011;16(3):116–123. doi:10.1111/j.1478-5153.2010.00438.x.

MANUSCRIPT 3

Title: Nurses' involvement in EOL communication and care practices in ICUs

Annette L. Griffin, MSN, MBA¹; Marlene Dufault, PhD¹; Donna Schwartz-Barcott, PhD¹; Katherine Paquette, PhD¹; Stephen J. Kogut, PhD, MBA²

¹College of Nursing, University of Rhode Island, Kingston, RI

²Health Studies & Department of Kinesiology, University of Rhode Island, Kingston, RI

Funding: Sigma Theta Tau, Delta Upsilon Chapter

Target Journal: International Journal of Palliative Nursing

Publication Status: In preparation for publication in the International Journal of Palliative Nursing.

3.1 Abstract

Background: Skilled communication is pivotal for supporting compassionate EOLC for patients and families. Understanding ICU nurses' level of involvement is key to improving outcomes.

Aims: Describe ICU nurses' involvement in family meetings, communication for EOL decision making, developing goals of care, and role confidence.

Methods: This study utilized mixed methods to assess nurses' perceptions of involvement in EOL communication. ICU nurses from a large US medical center completed a 44-item survey. Two focus groups were conducted for deeper understanding of the phenomenon.

Findings: Forty-nine percent of eligible ICU staff nurses participated in this study. Nurses' involvement varied across levels of experience and ICU specialties. Five themes emerged from focus group discussions: communication timing and quality, nursing of patients and families, challenges and letting go, emotional toll and nursing support, experience and training.

Conclusion: ICU nurses value their roles in EOL communication and care, however deficiencies impede provision of exemplary care. Strategies are required to mitigate barriers and provide emotional and educational support focused on exemplary care.

Key Words: end-of-life care, palliative care, critical care nursing, intensive care nursing, communication

3.2 Introduction

Nurses in intensive care settings are frequently faced with life and death in clinical practice. In fact, one in five patients die while receiving care in an intensive care unit due to the high acuity of this population, complexity of care, and the use of life sustaining treatments (Lamas, 2018; Papadimos, Maldonada, Tripathi, Kothari, & Rosenberg, 2012). Among this patient population, death is frequently preceded by decisions to withdraw or withhold these treatments that extend life and at times protract death (Lamas, 2018; Godfrey, Hilton, & Bellomo, 2013). In addition, treatment decisions for these patients often require family members to perform the role of surrogate decision makers because the meetings take place when the patient is unable to participate in the discussion (White, Braddock, Berenyei, & Curtis, 2007). Consequently, communication and meetings to determine goals of care occur frequently in intensive care settings and are characterized as challenging for all those involved (Fassier & Azolay, 2010; Gutierrez, 2012; Lamas, 2018).

Palliative care and end of life care (EOLC) have been utilized as distinctly different concepts and/or as combined concepts. ICU care combines aggressive, life sustaining care and often includes the decision to withdraw or withhold treatments within a short trajectory. This study will utilize the terms palliative and EOLC interchangeably as care and supportive services of the patient and family, with advanced disease or trauma, from the time of admission, extending through the decision to withdraw or withhold treatment(s) (Latour, Fulbrook, & Albarran, 2009).

Despite the frequency of these discussions about transitioning care, nurses, physicians, and families have reported the process of decision making as stressful and as

a source of interdisciplinary conflict (Grant, 2015; Godfrey, Hilton & Bellomo, 2013; Luce, 2010; Puntillo & McAdam, 2006). These conflicts can at times result in suboptimal outcomes for families and a decreased quality of care for patients. Further, inconsistencies and conflicts in communication between physicians and nurses are considered to be a source of frustration and distress for providers (Ramos et al., 2016) and may lead to post-traumatic stress for families (Fassier & Azoulay, 2010). This is problematic since skilled communication is central to quality end of life care and is widely recognized as an important area for improvement in end of life and palliative care (IOM, 2016).

The model for practice in quality palliative and EOL care has been identified by the World Health Organization (2019) and National Consensus Project for Quality Palliative Care (NCP, 2009) as an interdisciplinary team approach. In addition, collaboration between physicians and nurses in formulating and developing plans of care for ICU patients is integral to improving quality and ensuring that decisions are based on more complete patient information (Baggs et al., 2007). ICU nurses are on the front lines of care and are positioned as key players in end of life care (Hamric & Blackhall, 2007; Oberle & Hughes, 2001; Puntillo & McAdam, 2006).

Nurses' extent of participation or frequency of involvement in EOL care communication and decisions making in the intensive care units remains unclear. This is perplexing since ICU nurses are expected to educate clients/families, communicate effectively, manage symptoms, pain, emotional distress, and provide comfort care while effectively managing the process of dying in an emotionally charged environment of care (Campbell, 2018). These expectations of care have also been delineated and promoted by

such professional organizations as the American Nurses Association (ANA) (2010) and the American Association of Critical Care Nurses (AACN) (2016) when describing role expectations in the care of patients at end-of-life. Few studies conducted in the U.S. have specifically examined ICU nurses' actual involvement in EOL decision-making (Anderson et al., 2016; Baggs & Schmitt, 2000; Puntillo & McAdam, 2006). However, much of the work pointing to deficiencies in communication (Puntillo & McAdam, 2006), ethical issues (Oberle & Hughes, 2000), and barriers to EOL care (Beckstrand & Schmitt, 2000) have revealed nurses' perceptions of dissatisfaction in EOL decision-making and the quality of EOL care provided. Thus, it remains unclear to what degree U.S. nurses initiate, participate or have any input in family meetings when the goals of end-of-life care are determined in the ICU. Additionally, there is a paucity of quantitative research in the U.S. which has specifically examined factors that contribute to ICU nurses' active involvement in EOL care and decision-making.

3.3 Aims

The aims for this study were: 1) to describe nurses' perceptions of involvement in different types of palliative and end of life communication and 2) to identify potential differences in nurses' involvement in end of life decision making and confidence in participation, comparing years of nursing, years of ICU experience, and ICU specialty. In addition, the findings provided a foundation for developing recommendations for change and improving programs of EOL care in US ICUs.

3.4 Design and Methods

For this study a mixed methods approach was utilized to better understand this phenomenon of end of life care in the ICU. A 44-item paper and pencil survey was utilized to quantitatively measure; (1) the frequency of nurses' participation in discussions with patients, families, and physicians, (2) barriers to involvement in discussions, and (3) nurses' level of confidence in the performance of tasks associated with EOL communication (Anderson, 2016).

The survey instrument was developed by a group of experts including critical care bedside nurses, advanced practice nurses in both critical care and palliative care, palliative care physicians, nurse educators, and a nurse researcher who previously studied ICU nurses' perceptions of palliative communication (Anderson et al., 2016). The instrument was pilot tested by this group of experts for content validity. Minor modifications to the survey questions were made to enhance clarification of their meaning. Subsequently, a larger study was conducted at five medical centers in California which described ICU nurses' perceptions of palliative communication, barriers, and behaviors (Anderson et al., 2016). Permission for survey instrument use was obtained from the investigators/developers in the California study prior to use for the current investigation.

Additionally, two qualitative focus group discussions were conducted for a deeper understanding and triangulation of this phenomenon in the intensive care setting. Focus group participants were personally invited by the researcher at the time of survey completion. Potential recruits were informed of the purpose and commitment of group discussions. Contact information was collected from those who expressed an interest and

were later contacted after meetings were scheduled. A total of thirteen nurses out of 22 interested nurses were available to participant on the dates and times scheduled for discussions. Two focus groups were conducted each lasting approximately forty-five minutes, one group of five and the second with 8 participants. According to Krueger, optimal focus group size is six to eight participants (1998). The discussions were conducted on separate dates, one in the morning and one in the evening, in the hospital's main cafeteria, private conference room.

The sessions were opened with brief introduction about the purpose of the study, "Describe what comes to mind when you think about an experience you had in caring for a patient at end-of-life?" This also served as an "ice-breaker" to inform participants about the ways in which the focus groups would inform this study (Morgan & Krueger, 1998). The questions used to guide the discussions are included in Box-1. The discussion allowed open sharing of individual experiences, while probing questions were used periodically for clarification and to preserve the session focus.

3.5 Sample and Setting

The study was conducted in a large tertiary care, university affiliated hospital in the Northeast. Self – report, included 44 question surveys that were divided into three subcategories including: frequency of participation, potential barriers to involvement and nurses’ confidence. Items which were measured on either a four or five level Likert scale. Human subjects’ approvals were obtained from the University and study facility, prior to the start of this study. No identifying information was included on the surveys. Submission of completed surveys implied consent to participate in this phase of the study.

The surveys were completed over a four-week period between September 2019 and October 2019. ICU nurses were recruited to participate in either the survey and or focus group on a voluntary basis. Six specialized ICUs were targeted and included; medical, surgical, trauma, cardiovascular, cardiothoracic, and neurological. Eligibility for participation included a minimum of one-year ICU experience and current direct patient care practice. ICU nurses were invited to participate at unit staff meetings and department wide critical care competency sessions. Surveys were completed by a total of 132 (49%) intensive care nurses, from a potential sample of 297. Participant characteristics are detailed in Table 1. The final sample of respondents included in the subscale analysis was 126, since 6 participants did not complete the demographic portion of the survey and therefore could not be included according to the independent variables identified for this study.

3.6 Data Analysis

Data analysis was performed using SPSS version 26. Descriptive statistics were applied to participant characteristics of years nursing experience, years ICU experience, and work setting (specialty unit). Responses for survey subscales were analyzed. Comparisons across categorical variables were assessed for significant differences in group means by performing ANOVAs for each survey subscale item. Experience categories were dichotomized for comparison of means after comparison of results using four categories. Therefore, nursing experience and ICU experience were each analyzed using low experience (1-5 years) and high experience (6 years and above).

Focus group discussions were recorded in the form of field notes by two masters prepared research assistants. These scribes were each from non-nursing disciplines thus not content experts in EOLC, however highly capable recorders of detailed field notes, without *á priori* assumptions.

Notes were comprised of participants' verbatim responses from each session. They were reviewed immediately after each group session to check for detail and accuracy. This approach enabled the researcher to moderate the discussions, remain focused on the ongoing dialog, and reflect back statements by participants for clarity and member checking to confirm accurate expression of participants' statements and increase trustworthiness of the study findings (Lincoln & Guba, 1985).

Recommended principals for focus group analysis were used to analyze the results (Morgan & Krueger, 1995). The researcher reviewed 2 sets of notes from each session and transcribed the text onto a computerized data file. Transcripts from each

session were reviewed individually and then compared between the notes of each scribe within the same focus group session to corroborate the details of the discussions and to accurately represent participants' reflections. This process was undertaken for two sets of field notes for each focus group discussion. Notes were read and reread, while annotating and highlighting key points to inspire a depth of understanding of what was shared by participants. A horizontal table was created to allow for visualization of data, to look for commonalities, and to hon in on key issues shared by both groups (Morgan & Krueger, 1998).

Thematic analysis was conducted to describe the qualitative findings of this study and provide triangulation of results. Emerging themes were identified separately by the researcher, undergraduate research assistant, and one of the research assistants who also recorded notes during the discussions. These analyses were compared to establish commonalities and identify comments that were repeated by participants. Subthemes were categorized under related predominant themes. Upon completion of these steps of analysis, five key themes emerged: Communication timing and quality, Nursing care of patients' families, Challenges and letting go, Emotional toll and nursing support, Experience and training. To ensure the rigor of this process, participants' quotes are included in this Table 7.

3.7 Ethical Considerations

Study procedures were approved by the institutional review boards at the study hospital facility and affiliated university. Survey participation was voluntary, and respondents enrolled under waiver of written consent. Nurses who submitted a completed survey were given a raffle ticket for the chance to win a \$50 VISA gift card. Focus group discussions were voluntary, with written consent obtained prior to participation. Focus group participants were each given a \$25 AMAZON gift card as a thank you for their study involvement.

3.8 Results

Communication and Involvement in family meetings and EOL decision making

One-hundred and thirty-two ICU nurses returned completed surveys. Nurses' described variation their level of involvement in different types of EOL communication depending on the focus of the discussion and to whom. Nurses indicated that they often discussed prognosis with physicians (67%) and goals of care (74%), however, they were less likely to engage in these discussions with patients' families. The frequency of nurse communication with families about prognosis occurred rarely or never (20%) and sometimes (45%). Additionally, nurses' involvement in communication with families regarding palliative care consultations was reported as occurring only sometimes (42.4%) or rarely (33.3%). Communication between nurses and physicians about palliative care consults take place more frequently, sometimes (38.6%) and often (37.1%). Variation in nurses' reports of attendance at family meetings was distributed across all categories with 39.4% who often attend and 31.8% who participate while in these family meetings.

Barriers to Involvement

Nurses responded to survey questions related to potential barriers that hinder ability to participate in discussions about prognosis, goals of care and palliative care. The responses were varied across items which described potential obstacles to participation. However, a large percent of nurses (58%) answered that they were unsure of their role in EOL discussions with families regarding prognosis, goals, palliative care or how to bring up the subject of care goals with families (57%). Additionally, nurses responded that they did not feel that their involvement in family meetings was unsupported by physicians

(57%). When asked if physicians invite nurses' input, responses varied across all levels of agreement. Nurses' perceptions were equally divided among levels with 47% in disagreement categories and 53% of respondents in agreement or neutral categories. Generally, finding time for discussing prognosis or goals of care with families, attend meetings, or the ability to obtain coverage for attending scheduled meetings were not perceived as barriers. Most nurses were aware of the when and where family meetings occurred and did not indicate that they were not invited to the meetings. The preponderance of nurses (76%), indicated that they do not feel that their involvement in discussions would be unsupported by managers. This is an important finding since manager support is a critical environmental factor related to involvement.

In this study, two predominant barriers were identified across all participants. The first barrier was in response to the need for more training in how to discuss prognosis, goals of care, and palliative care. Responses to this question were varied and differences were further analyzed to determine whether years of nursing, years of ICU or specialty unit were predictors associated with these differences in this sample population. Respondents strongly disagreed (12%) and (29%) disagreed that more training related to EOL care was needed. Conversely, (41%) of nurses reported that more training is needed. Additionally, 18% selected "neutral" which may be indicative of less confidence in this area of nursing practice. Focus group respondents provided some further clarification, stating that no protocols are in use for EOL communication or care practices and these nurses were not knowledgeable of ELNEC domains of care (National Consensus Project, 2009, 2018).

Tables 2, 3, and 4 describe the frequency distributions of involvement in palliative care, barriers to involvement and nurses' confidence in aspects of EOL care across all survey items and all study participants (n=132).

Predictors of involvement in family meetings, decision-making regarding goals of care, potential barriers, and nurses' confidence in EOL care were further examined by comparing means of experience categories and ICU specialty unit types. Variations across measures of involvement in the types of communication were associated with years of ICU, nursing experience, and ICU specialty types. Nurses with fewer years of experience in both nursing and ICU experience reported lower levels of involvement in communication measures. For example, discussions of prognosis (*low* $m=2.928$ $s=.8282$, *high* $m=3.357$ $s=.6988$ $p<.002$) and discussion of goals of care with patients' families (*low* $m=3.333$ $s=.6568$, *high* $m=3.625$ $s=.5244$ $p<.008$) were as reported lower by less experienced nurses than those with more experience. Variation was also noted in nurses' involvement in discussions with physicians for both prognosis (*low* $m=3.377$ $s=.7689$, *high* $m=3.754$ $s=.6059$ $p<.003$) and goals of care (*low* $m=3.522$ $s=.7785$, *high* $m=3.807$ $s=.4795$ $p<.017$), were associated with ICU experience. Additionally, the frequency of nurse attendance in family meetings (*low* $m=2.754$ $s=1.0059$, *high* $m=3.316$ $s=.8485$, $p<.008$) and nurse participation when present in those meetings (*low* $m=2.536$ $s=.9484$, *high* $m=3.263$ $s=.8768$, $p<.000$) was higher among more experienced nurses. Significant differences were also associated with ICU specialty types, the highest frequency of these discussions occurred between trauma nurses and physicians (*highest* $m=3.905$ $s=.3008$, $p<.001$) and the lowest between cardiothoracic nurses and physicians (*lowest* $m=3.069$ $s=.7987$). Finally, the "frequency of nurse participation," in discussions with patients'

families took place infrequently for all nurses, with all responses below “sometimes” and statistically significant across levels of ICU experience (*low* $m=2.449$ $s=.7580$, *high* $m=2.842$ $s=.8822$, $p<.008$), and ICU unit types (*lowest* CTIC $m=2.069$ $s=.7036$, highest MICU $m=3.059$ $s=.8269$, $p<.000$). Of note, was that four ICU specialty units reported involvement in discussions about palliative care with patients’ families at a level closest to “rarely” (SICU, $m=3.071$; NCCU, $m=2.900$; CCU, 3.167 ; CTIC, $m=2.750$) conversely two ICU specialty units reporting “often” as their involvement level (MICU, $m=3.765$; TICU, 3.476). These results corresponded to nurse reports of confidence in practice behaviors such as nurses’ initiatives associated with arranging palliative care meetings, being active contributors in family meetings, and defining palliative care and/or its usefulness to physicians and families.

Differences in practice behaviors were also reported across ICU specialties related to nurses’ participation in family meetings. Medical ICU nurses were more likely than cardiothoracic nurses to attend these meetings ($m=3.529$ $s=.7174$, $m=2.276$ $s=.8822$ $p<.000$). Additionally, the most significant differences in nurses’ attendance at family meetings and being active contributors to the discussions, were uncovered between the medical and trauma ICU nurses, compared with cardiothoracic ICU nurses (*high* $m=3.471$ $s=.7174$, $m=3.429$ $s=.8701$, *low* $m=2.276$ $s=.8822$ $p<.000$). Nursing and ICU experience were both important predictors of nurses’ willingness to contribute during family meetings with the healthcare team. Higher levels of experience were positively correlated with participation. Nurses’ level of experience was identified as a common barrier across survey items where variation was identified.

Levels of agreement related to confidence in performance areas were also correlated to years of nursing and ICU experience and were identified across each of the assessed items. For example, nurses with greater years of nursing and/or ICU experience were more confident in assessing a family's understanding of patient goals (*low* $m=2.760$ $s=.5911$ *high* $m=3.105$ $s=.6018$, $p<.002$). Furthermore, nurses with less ICU experience were only somewhat confident in their ability to identify a family's need for information on illness and treatment (*low* $m=2.913$ $s=.5351$ *high* $m=3.298$ $s=.6258$, $p<.000$).

Confidence in communication related to palliative care with families occurred less frequently among nurses with fewer years of experience. Similarly, the frequency and level of nurse's confidence to initiate communication with physicians about prognosis, goals of care or palliative care were also associated with years of experience however, also varied across ICU specialties. Differences identified in confidence in ability to communicate the value of palliative care to physicians were found between trauma nurses and cardiothoracic nurses, with higher confidence among the former and lower confidence among the latter specialties (*high* $m=3.238$ $s=.7003$, *low* $m=2.483$ $s=.7847$ $p<.001$). These findings are also detailed in the comparison of means for significant survey items in Table 5a, 5b, & 5c.

Focus group discussions not only validated the survey findings, these discussions provided deeper insight and meaning related to nurses' perceptions yielded in the survey results. Nurses' perceptions of their roles in EOL communication and ways in which these roles are operationalized were further explored. Two focus group sessions of thirteen nurses were conducted to gain an in-depth understanding of their perceptions about EOL communication in their specific intensive care units. Discussions lasted approximately 45

minutes and included 13 ICU nurses ranging from 1 to 24 years of ICU experience. Nurses were predominately female, with 1 male participant in the sample. Participants represented a cross-section of the specialty ICUs. Focus group characteristics are presented in Table 6. Guiding questions for these discussions can be found in Box 1.

3.9 Themes: Focus Groups

The five themes emerged related to EOL communication and care including :Communication timing and quality, Nursing care of patients' families, Challenges and letting go, Emotional toll and nursing support, Experience and training, and are located in Table 7. Each focus group session began with the questions, "What comes to mind when you think about caring for a patient at end-of-life? Describe an experience that you have had in your practice."

Communication Timing and Quality

The value of quality EOL communication was apparent throughout the discussions. Participants described their proximity to patients, amplifying the importance of role nurses' in communication, as advocate, liaison, informant, and teacher. The nurses frequently mentioned that families trust them because they spend a great deal of time with them at the bedside fostering a sense of trust. Nurses also placed a high value on the need for honest, compassionate, and respectful communication. "They really know that we are with them all of the time, they want to hear it (bad news) from us first before hearing from the physicians, they feel better." "Sometimes we are the ones who hear from the patients that they want to go home and we (nurses) know that home means a forever home." All nurses indicated that, "families need to be educated from the beginning, what to expect, what could happen, to begin processing." Nurses also discussed honesty as a core element of communication.

The nature of the nurses' roles in bedside communication were characterized as supportive, clarifying, educating, compassionate and intuitive. Understanding the needs of

families was central to “gauging the families’ readiness to hear” information about their loved one. The importance of a relationship of trust between the nurses and families was knitted in all of the discussions. Additionally, several nurses described the practice of including family members in neurological assessments and explaining the indications of signs and symptoms evidenced by the patient, while implicitly sharing the notions of “what is happening, what to expect” and facilitating the “time to process.”

Respecting the family’s wishes was also mentioned by several nurses as an important aspect of this communication. Some participants, however, suggested that families were not always realistic. Receiving mixed messages from members of the healthcare team as well as friends and relatives outside of the situation often provides input to families that can create additional conflicts in decision making. Cultural and religious reasons were also mentioned as contributing to families’ appraisal of the situation. “There was a lot of going back and forth between what the patient wanted and what the family wanted.” “Some have religious reasons, and some view their loved one as a fighter”. Nurses cited these as reasons for families to believe that the patient may survive the situation and contributing to the overall complexity of decision making.

Discord between nurses and physicians was also apparent in nurses’ descriptions of communication about end-of-life and palliative care. Two common areas for concern were the timing of the conversations and the messages that were conveyed. Several nurses indicated that they were either “not allowed to broach the subject of palliative care” or “I wish that we did a better job of consulting palliative care.....patients get lost in the situation.” In addition, the timing of conversations was not optimized, “families are given a sliver of the truth and given false hopes, they sometimes side with the doctors because

they don't really know what is going on." "Nurses can only say so much, surgeons make the decisions and we have to go along with the orders."

Nurses also described their collaborative role between families and physicians. Depending on the specialty, variation was evidenced between levels of collaboration related to EOL and palliative communication. Responses varied when participants were asked if they participate in family meetings. Nurses on some units reported frequent participation and full engagement in the discussions while others rarely participate and do not feel comfortable speaking when they attend family meetings. Particularly, novice nurses participating in the focus groups were less comfortable and less likely to participate in the conversation during family meetings.

Nursing Care of Patients' Families

Nurses expressed the importance of their supportive, caring roles, and the intuitive nature of understanding patient and family needs. "Sometimes the family is not ready to hear what you have to say, you gauge pretty quickly if they are going to shut you down." "Some families have religious reasons, and some are fighters." Participants reported that families handled the "bad news" better when it came from the nurses themselves because of the trusting relationship. "I think the families would rather hear it from us versus the physicians. They really know us; we are with them all of the time. When they hear it from us before hearing it from the physicians, they feel better. No fault to the physicians, but they are in and out and the families don't get to know them."

Nurses also described working to manage patients' pain and symptoms. Pain and symptom management was a challenging area and difficult at times. Satisfaction of quality

in this area of care was not always met. “I don’t think that sometimes the pain is being managed.” Another reported, “I took care of a patient that had an extended ICU stay, he had several wounds, I think a lot of his needs were not being met.” In terms of advocacy, nurses suggested that they often challenge physicians when necessary to open discussions of prognosis and goals of care. They work at being a voice for both patient and family, though sometimes everybody is not on the same page. “It comes down to timing and compassion.” Nurses also reported comforting families through kindness, by being available, allowing privacy, “trying to make the patient look like the person they remember, placing the monitors on “privacy screens,” “siderails down,” and “assurance of medicating if the family thinks that the patient is in pain.”

Challenges and Letting Go

Several barriers related to conflicts in communication and goals of care were identified. Conflict between physicians’ and nurses’ goals were frequently mentioned by participants as an area of contention. One nurse suggested that tensions may stem due to differences in training, “nurses are trained to look at the big picture and quality of life, physicians are trained to save a life, save a life, save a life, at all costs.” Further, “just because we have the technology/capabilities to do stuff, it doesn’t mean that we should do so every single time.” Several participants working from one ICU reported that EOL communication was very difficult on their unit because “the surgeons do not want to let go”, “they do not want to accept defeat.” The culture of the unit is such that the “only person who should have a conversation about EOL is the surgeon.” They noted that this disagreement is also found within the medical team, surgeons, attendings and physician assistants, in terms of the direction of care. While several of the nurses reported that nurses

are not listened to by physicians, some indicated that it depends on the experience of the nurse and her confidence to go “head to head”.

Conflicts also occur at times when there are discrepancies between the goals of the family and that of the healthcare team. Contributing factors reported were related to “mixed signals” often resultant from physicians of different specialties providing conflicting messages to family members, creating confusion about patient prognosis. In some situations, families are not ready to hear bad news. Nurses cited the sudden nature or onset of illness such as trauma versus a chronic medical issue and patient age as potential barriers to family readiness to process difficult news and participate in decision making about goals of care. Finally, some novice nurses reported that in certain situations they do not feel comfortable in their communication role and seek guidance from co-workers.

Emotional Toll and Nursing Support

Distress associated with care and management of patients was described throughout the discussions. When discussing patient experiences, nurses cited personal experiences of futile care as a source of emotional distress. The distress was also associated when patients' pain needs or symptom management needs were not met. Chronic patients receiving aggressive care or receiving “everything” were described as a source of angst among nurses. “I took care of a patient that was in the ICU for more than 6 months. It was difficult emotionally for the nurses, it was too much, we had to keep rotating the assignments.” Another nurse described difficulty associated with the inability to meet patients' needs and the associated “emotional toll” on staff. Several nurses indicated knowing that “the patient was not going to make it” and expressed distress over not having the ability to be honest

with families, “It is so hard to tell families, let her go with dignity and not put her through all that.”

Feelings of futile care were also identified and expressed as concern of “going through the motions” because the physician team would not “let go”. “It’s an uphill battle to get the right care for the patients”. “Doctors don’t listen to the nurses and you still have to care for them. You are causing suffering for the patient by providing the care while you know that it is not going to turn out positive...so it’s futile and that contributes to the high turnover of ICU nurses.”

In contrast, one nurse also pointed out, “once you have the chance to provide great EOL care you can see the benefit to these patients and families.” Despite the areas of distress identified, all of the nurses reported positive experiences associated with the support they provide to families.

Experience and Training

Nurses indicated that they did not have formal training in EOL of life care. In addition, EOL care protocols are not utilized in the ICUs at this facility. Experienced and novice nurses reported learning how to manage EOL communication and care practices from nurse mentors on the job. Novice nurses reported seeking guidance from other nurses when uncomfortable in a care situation. Some nurses wanted more training in this area, though several participants felt that the individual nature of the dying experience would not lend itself to the use of protocols.

While some nurses felt that no training was needed if you have the experience, one nurse reflected, “I wonder what will happen in 20 years because nurses are not staying as

long and who is going to teach the new nurses..... you have heard a lot of talk about what we learned from other nursespeople don't stay at the bedside.” Participant quotes of the most common themes that emerged can be found in Table 7.

3.10 Discussion

This research study contributes to the current literature on end of life care in ICUs and the findings identify several important implications for nursing practice. The study aimed to describe nurses' perceptions of their involvement in different types of EOL communication and identify potential differences in nurses' involvement and confidence in participation by comparing years of experience and ICU specialty. All nurses reported that discussions about prognosis and goals of care between families and clinicians are very important for quality care delivery ($m = 3.833$, $s = .4262$), as is nurses' engagement in these discussions at the bedside ($m = 3.817$, $s = .5426$). In focus group discussions, participants expressed pride in delivery of high quality EOLC and the value to families.

In ICUs, the nature of EOL communication with families about prognosis and goals of care is both formal and informal. Nurses in this study reported varying levels of involvement in EOL communication. For example, nurses with more experience were more likely to discuss prognosis and goals of care with physicians. Overall, fewer nurses were involved in family meetings to decide on goals of care. Among the nurses who attend family meetings often (37%), fewer participate in the discussions (32%). These survey results were validated in the focus group discussions.

Nurses with more experience reported higher levels of involvement in family meetings. Some of the nurses recalled attending family meetings as novice nurses and not "speaking up." All focus group participants identified challenges associated with EOL communication. Less experienced nurses described moments of uncertainty in their role and best approaches for EOL conversations with families. Consultation with colleagues helped to guide them through the process or they would "let the doctor take

over” talking with the family. They were more confident and more likely to contribute to discussions in family meetings after acquiring more experience. These findings confirm reports of prior studies which describe nurses’ lack of involvement in family meetings (Anderson et al., 2016) and communication conflicts between nurses, physicians, and families (Schwarze et al., 2016; Grant, 2015; Wujtewicz & Wujtewicz, 2015; Gutierrez, 2012).

Within the focus group discussions, there was also a great deal of variation in practice behaviors between specialty units. The surgical units were more likely to delay palliative or end of life discussions with patients. The timing of discussions with families was important to all participants, though this was also a source of conflict between nurses and physicians. Nurses felt that it was important to prepare families early and suggested that families “need to know the gravity of the situation from the beginning to allow time to process.” This was particularly important to trauma nurses who felt that often there is little time to prepare families due to the illness trajectory. Timing was also cited as a “balancing act” between preparing families early while assessing their ability “hear what you have to say.” Clarifying information and providing compassionate and honest information to family members was characterized as a critical aspect of the nurses’ role. This was important because some nurses reported that physicians often give conflicting information to families, a source of confusion for families which as times results in development of unrealistic goals. ICU nurses identified mixed messaging as a factor that contributes to inconsistent EOLC approaches.

In contrast, medical ICU nurses felt that their input in decision making about patient prognosis and goals of care was valued by the physicians. For these nurses,

attendance in family meetings was more frequent. These differences were acknowledged by nurses during the focus group discussions. Nurses were surprised by the differences in care practices between the ICUs.

The presence of emotional distress was illuminated by nurses in focus group discussions. Several nurses described frustrating patient care experiences, deficient symptom and pain management, and protracted ICU stays. Consequences of deficient EOL communication and deficient symptom management were described as “very emotionally draining” and having “negative outcomes for ICU nurses”. Further, nurses were burdened by having to carry out care that they felt was futile and “causing patient suffering.” Participants associated these situations with burnout and a reason for nurses leaving ICU care. These experiences support prior findings in nursing research (Dillworth et al., 2015; Hollyday & Buonocore, 2015; Holmes, Milligan, & Kydd, 2014) and are an important issue for future research and supporting nursing practice needs.

Finally, this study presented a dichotomy of nurses’ perceptions regarding training and education. Survey results identified variation among nurses in confidence levels and perceptions of whether more EOL training was desired. Only one focus group participant had a lecture on palliative care in her orientation. All others had not had any formal training. This is consistent with studies suggesting that many nurses have based their learning on practice experiences and role modeling of more experienced colleagues (Holmes, Milligan, & Kydd, 2014). Research findings clearly support the premise that EOL communication is a complex, learned skill, and that insufficient training or education may affect the quality of palliative and EOLC (Bach, Ploeg & Black, 2009; Luce). In addition, years of research and recommendations by professional organizations

support the benefits of practice protocols for EOLC in the ICU setting (AACN, 2016; AACN, 2010; IOM, 2014). Discussions with focus group participants illuminated many of the challenges that contribute to the complex nature of EOL communication and implicitly suggest the need for educational support. These challenges are consistent with the findings from numerous studies. It is imperative to fully understand the challenges that nurses face and the implications that impact patients and families and practicing ICU nurses regarding end of life care.

3.11 Study limitations

This research study included perceptions of nurses from a large academic medical center located in the Northeast and may differ from nurses in other hospitals across the U.S. In addition, those motivated to participate may not represent the perceptions of those who did not complete surveys. Results from self-reported behaviors may differ from observed behaviors. Therefore, the findings contribute to nursing knowledge and suggest the need for future research to expand understanding of associated phenomenon to improve clinical practice behaviors. The survey instrument was utilized in a previous study with a similar population of nurses and setting, however, the psychometric testing has been limited to content validity. In addition, potential environmental barriers were not exhaustive and were limited to those that specific to communication and attendance at family meetings which was the focus of this study.

Finally, some members of the focus groups were known to the researcher and may possibly have influenced their willingness to participate. This may have benefitted the discussions due to a level of comfort and trust in the researcher, facilitating ease of group discussions which may limit the trustworthiness of the findings.

3.12 Application to Nursing Practice

Nurses in this study place high value on quality EOL communication and on the key role that they see for themselves in assisting patients and families to have a voice in their care. Nurses in general possess basic communication skills that include assessing and listening to patients and families and are a constant presence in their care, which positions them to provide meaningful support to families that are processing information about their loved one. These fundamental communication skills, however, may provide a communication foundation but may not fully prepare ICU nurses for the complexities of active engagement in EOL communication and care. Education and training are needed to improve the frequency that nurses participate in family meetings and reduce practice variations among nurses at different levels of experience and different ICU specialties. While participants in this study expressed confidence in EOL communication and care, their own self-described practice behaviors did not always support this sentiment.

The main sources of conflicts cited by participants in this study related to the timing and quality of communication and lack of nursing presence at family meetings on a regular basis. Interdisciplinary decision making has been recommended as a standard of practice (Hamric & Blackhall, 2007), although this approach is consistently not found in practice settings (Anderson et al., 2016). More education of accepted protocols is needed to improve collaborative practice and provision of expected quality care in ICUs. EOL communication is challenging and efforts to educate nurses are essential for improving EOL communication and care and reducing frustration that may interfere with quality care, comfort and dignity at end of life.

Acknowledging and understanding the emotional burden on ICU nurses may illuminate nurses' experiences and struggles and spearhead the development of compassionate solutions that support the psychological well-being of nurses and reduce moral distress and burn out. Respondents in this study identified many patient care experiences that suggested the need for formalized support systems. Supportive interventions for nurses in ICU practice environments must be proactive and not reactive or happenstance.

From the data in this study, it was evident that nurses derive great pride in components of their roles involving advocacy, compassion, and care of patients and families at end of life. The impact of reducing variation in care practices and increasing active participation of nurses across ICU specialties and experience levels is important to improve overall EOLC and support the nurses' roles. There is only one chance for patients and families to receive high quality EOLC and it is our moral and ethical responsibility to ensure this occurs.

Although this study provided evidence of nurses' perceptions and experiences from only one health care organization setting, the findings are consistent with previous studies related to EOL communication patterns and care in ICUs. While some studies indicate that progress has been made in EOL communication in ICUs, future research is needed to evaluate and compare nurses' and physicians' perceptions of EOL decision making. In addition, research to gain a deeper understanding of nurses' emotional burden is needed to fully acknowledge the impact of this phenomenon in practice settings and to develop and implement programs that address this serious issue. While nurses in this study reported that "experience is everything when it comes to EOLC," variations in

practice provide a counter perspective. EOL care deficiencies can only improve if available, evidence-based recommendations for gold standard EOLC delivery (National Consensus Project, 2018) are fully implemented in ICU practice settings through education and training focused on providing exemplary care that meets the needs of patients and families at end of life.

3.13 References

- American Association of Critical Care Nurses, (2016). *Protocols for practice: Palliative Care and end-of-life issues in critical care. American Association of Critical Care Nurses*. Sudbury, MA.: Jones and Bartlett Publishers, Inc.
- American Association of Colleges of Nursing, (2010). Position statement. Registered nurses' roles and responsibilities in providing expert care and counseling at the end-of-life <http://www.nursingworld.org/mainmenucategories/ethics-position-statements/etpain14426.pdf>.
- ANA Board of Directors, (2016). Nurses' roles and responsibilities in providing care and support at the end of life. ANA Position Statement. Retrieved from <https://www.nursingworld.org/~4af078/globalassets/docs/ana/ethics/endoflife-positionstatement.pdf>.
- Anderson, W.G., Puntillo, K., Boyle, D., Barbour, S., Turner, K., Noort, J.,... Pantilat, S. (2016). ICU bedside nurses' involvement in palliative care communication: A multicenter survey. *Journal of Pain and Symptom Management*, 51(3), doi:10.1016/j.painsymman.2015.11.003
- Azoulay, E., Chevret, S., Leleu, G., Pochard, F., Barboteu, M., Adrie, C.,...Schlemmer, B. (2000). Half of the families of intensive care unit patients experience inadequate communication with physicians. *Critical Care Medicine*, 28(8), 3044-3049. doi:10.1097/00003246-200008000-00061
- Bach, V., Ploeg, J. & Black, M. (2009). Nurses' roles in end-of-life decision making in critical care. *Western Journal of Nursing Research*, 31(4), 496-512. doi:10.1177/0193945908331178

- Campbell, M. L. (2018). Ensuring breathing comfort at the end of life: the integral role of the critical care nurse. *American Journal of Critical Care*, 27(4), 264-269.
- Curtis, J. R., Engelberg, R.A., Wenrich, M.D., Shannon, S.E., Treece, P.D., Rubenfeld, G.D., Missed opportunities during family conferences about end of life in the intensive care unit. *American Journal of Respiratory Critical Care Medicine*, 171, 844-849. doi:10.1164/rccm.200409.1267OC
- Dillworth, J., Dickson, V.V., Mueller, A., Shuluk, J., & Yoon, H.W. (2015). Nurses' perspectives: hospitalized older patients and end-of-life decision-making. *British Association of Critical Care Nurses*, 21(5), e1-e11. doi:10.1111/nicc.12125
- Fassier, T. & Azoulay, E. (2010). Conflicts and communication gaps in the intensive care unit. *Current Opinion in Critical Care*, 16(6), 645-665. doi: 10.1097/MCC.0b013e32834044f0
- Grant, M. (2015). Resolving communication challenges in the intensive care unit. *AACN Advanced Critical Care*, 26(2), 123-130. doi: 10.1097/NCI.0000000000000076
- Godfrey, G., Hilton, A., & Belleomo, R. (2013). To treat or not to treat: with holding treatment in the ICU. *Current Opinion in Critical Care*, 19(6), 624-629. doi: 10.1097/MCC.0000000000000036.
- Gutierrez, K.M. (2012). Prognostic communication of critical care nurses and physicians at end of life. *Dimensions of Critical Care*, 31(3), 170-182. doi:10.1097/DCC.0b013e31824e0022

- Harris, M., Gaudet, J., & O'Reardon, C. (2014). Nursing care for patients at end of life in the adult intensive care unit. *Journal of Nursing Education and Practice*, 4(6), 84-89. doi:10.5430/jnep.v4n6p84
- Hanson, L., Goodell, T.T., DeHaven, & J. Smith, M. (2009). Nurses' perceptions of end of life care after multiple interventions for improvement. *American Journal of Critical Care Nursing*, 18(3), 263-271. doi:10.4037/ajcc2009727
- Hollyday, S.L. & Buonocore, D. (2015). Breaking bad news and discussing goals of care in the intensive care unit. *AACN Advanced Critical Care*, 26(2), 131-141. doi: 10.1097/NCI.0000000000000082
- Holmes, N., Milligan, S., & Kydd, A. (2014). A study of the lived experiences of registered nurses who have provided end-of-life care within an intensive care unit. *International Journal of Palliative Nursing*, 20(11), 549-556. doi:10.12968/ijpn.2014.20.11.549
- Institute of Medicine (2016). *Dying in America: Improving quality and honoring individual preferences near the end of life*. Washington, DC: The National Academies Press.
- Kisorio, L.C. & Langley, G.C. (2016). Intensive care nurses' experiences of end-of-life care. *Intensive and Critical Care Nursing*, 33, 30-38. doi:10. 1016/j.iccn.2015.11.002
- Lamas, D. (2018). Nurse-led communication in the intensive care unit. *New England Journal of Medicine*, 378(25), 2431-2432. doi: 10.1056/NEJMe1804576.

- Lincoln, Y. & Guba, E. (1985). *Naturalistic Inquiry*. Beverly Hills, CA.: SAGE Publications, Inc.
- Luce, J.M. (2010). End-of-life decision making in the intensive care unit. *American Journal of Respiratory Critical Care*, 182, 6-11. doi:10.1164/rccm.201001-0071CI
- Morgan, D.L. & Krueger, R.A. (1998). *The Focus Group Kit (Vols. 1-5)*. Thousand Oaks, CA: SAGE Publications, Inc.
- National Consensus Project for Quality Palliative Care. (2009). *Clinical practical guidelines for quality palliative care, 2nd edition*. Retrieved from <http://www.nationalconsensusproject.org/guideline.pdf>.
- National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care, 4th edition. Richmond, VA: National Coalition for Hospice and Palliative Care; 2018. <https://www.nationalcoalitionhpc.org/ncp>.
- Papadimos, T.J., Maldonado, Y., Tripathi, R.S., Kothari, D.S., & Rosenberg, A. (2011). An overview of end-of-life issues in the intensive care unit. *International Journal of Critical Illness and Injury Science*, 1(2), 138-146. doi:10.4103/2229-5151.84801
- Puntillo, K.A. & McAdam, J.L. (2006). Communication between physicians and nurses as a target for improving end of life care in the intensive care unit: Challenges and opportunities for moving forward. *Critical Care Medicine*, 34(11 Suppl), S332-S340. doi: 10.1097/01.CCM.0000237047.31376.28

- Ramos, K.J., Downey, L., Nielsen, Treece, P.D., Shannon, S.E., Curtis, J.R., & Engelberg, R.A. (2016). Using nurse ratings of physician communication in the ICU to identify potential targets for interventions to improve end-of-life care. *Journal of Palliative Medicine*, 19(3), 292-299. doi: 10.1089/jpm.2015.0155
- Reinke, L.F., Shannon, S.E., Engelburg, R.A., Young, J.P., & Curtis, J.R. (2010). Supporting hope and prognostic information: Nurses' perspectives on their role when patients have life-limiting prognoses. *Journal of Pain and Symptom Management*, 39(6), 982-992. doi:10.1016/j.jpainsymman.2009.11.315
- Schwarze, M.I., Campbell, T.C., Cunningham, T.V., White, D.B., & Arnold, R.M. (2016). You can't get what you want: Innovation for end-of-life communication in the intensive care unit. *American Journal of Respiratory and Critical Care Medicine*, 193(1), 14-16.
- Spinello, I.M., (2011). End-of-Life Care in ICU: A Practical Guide. *Journal of Internal Medicine*, 26(5), 295-303. doi:10. 1177/0885066610392697
- The SUPPORT principle investigators. (1996). A controlled trial to improve care for seriously ill hospitalized patients. *JAMA* 274(20), 1591-1598.
- Todaro-Franceschi, V. (2013). Critical care nurses' perceptions of preparedness and ability to care for the dying and their professional quality of life. *Dimensions of Critical Care*, 32(4), 184- 190. doi: 101097/DCC.0b013e31829980af
- Wujtewicz, M., Wujtewicz, M.A., & Owczuk, R. (2015). Conflicts in the intensive care unit. *Anaesthesiology Intensive Therapy*, 47(4), 360-362. doi:10.5603/AIT.2015.0055

White, D.B., Braddock, C.H., Bereknyei, S., & Curtis, J.R. (2007). Toward shared decision making at the end of life in intensive care units. *Archives of Internal Medicine*, 167(5), 461-467. doi: 10. 1001/archinte.167.5.461

World Health Organization (2019). Definition of Palliative Care.
<https://www.who.int/cancer/palliative/definition/en/>

Table 1*Characteristics of Participating ICU Nurses*

Characteristic	1-2 yrs.	%	3-5 yrs.	%	6-10 yrs.	%	11 or more	%
Number of years in nursing?	15	11.9	35	27.8	20	15.9	56	44.4
Number of years working as an ICU bedside nurse?	28	22.2	41	32.5	9	7.1	48	38.1
Primary area of work %	n		%					
Medical Intensive Care	17		12.9					
Surgical Intensive Care	14		10.6					
Trauma Intensive Care	22		16.7					
Neurological Intensive Care	30		22.7					
Coronary Intensive Care	12		9.1					
Cardiothoracic Intensive Care	29		22.0					
ICU Float	4		3.0					

^aTotal number of responses for this group of questions ranged from 126 to 132

Table 2*Frequency of Participating in Palliative Care Discussions*

Type of Palliative Care Discussion	Never (1)	%	Rarely (2)	%	Some-times (3)	%	Often (4)	%	M	SD
3.Discuss prognosis with patients' families	4	3.1	22	16.8	59	45.0	46	35.1	3.122	.7944
4.Discuss goals of care with patients' families	0	0	9	6.9	52	39.7	70	53.4	3.466	.6239
5.Discuss prognosis with patients' physicians	1	0.8	14	10.6	29	22.0	88	66.7	3.545	.7137
6.Discuss goals of care with patients' physicians	2	1.5	8	6.1	24	18.2	98	74.2	3.652	.6652
7.Attend family meetings	12	9.1	26	19.7	42	31.8	52	39.4	3.015	.9806
8.Participate in family meetings	14	10.6	31	23.5	45	34.1	42	31.8	2.871	.9839
9.Discuss palliative care consultations with families	12	9.1	44	33.3	56	42.4	20	15.2	2.636	.8495
10. Discuss palliative care consults with physicians	7	5.3	25	18.9	51	38.6	49	37.1	3.076	.8791

^aTotal number of responses for this group of questions ranged from 131 to 132.

Table 3

Potential of Barriers to Involvement in Types of Palliative Care Discussions: Frequency of Agreement, n_a (%)

Type of Palliative Care Discussion	Strgly Disagree (1)	%	Disagree (2)	%	Neutral (3)	%	Agree (4)	%	Strgly Agree (5)	%	M	SD
11. I am unsure of my role in discussing prognosis, goals of care and palliative care.	29	22	48	36.4	33	25	18	13.6	4	3.0	2.394	1.0683
12. I need more training in how to discuss prognosis, goals of care and palliative care.	16	12.1	38	28.8	24	18.2	46	34.8	8	6.1	2.939	1.1706
13. I am not sure of how to bring up prognosis and goals of care with families.	12	9.1	63	47.7	29	22	25	18.9	3	2.3	2.576	.9739
14. I do not feel that physicians support my involvement in these discussions.	21	15.9	54	40.9	29	22	16	12.1	12	9.1	2.576	1.1665
15. Physicians do not ask for my perspectives on prognosis, goals of care, and palliative care.	16	12.1	46	34.8	27	20.5	28	21.2	15	11.4	2.848	1.2200
16. I do not have time for bedside discussions of prognosis and goals of care.	36	27.3	74	56.1	14	10.6	8	6.1	0	0	1.955	.7899

Type of Palliative Care Discussion	Strgly Disagree (1)	%	Disagree (2)	%	Neutral (3)	%	Agree (4)	%	Strgly Agree (5)	%	M	SD
17. I do not have time to attend family meetings.	32	24.2	61	46.2	21	15.9	18	13.6	0	0	2.189	.9582
18. It is hard to get coverage for my patients so I can attend family meetings.	24	18.2	51	38.6	30	22.7	25	18.9	2	1.5	2.470	1.0444
19. My managers do not support my involvement in these discussions.	44	33.6	56	42.7	27	20.6	3	2.3	1	0.8	1.939	.8390
20. I do not know when or where family meetings are occurring,	37	28.2	55	42.0	20	15.3	19	14.5	0	0	2.160	.9986
21. I am not invited to family meetings.	36	27.3	45	34.1	23	17.4	26	19.7	2	1.5	2.341	1.1245
22. Engaging in these discussions is emotionally draining.	7	5.3	31	23.7	38	29.0	46	35.1	9	6.9	3.145	1.0312
23. Families have negative reactions to palliative care.	4	3.0	51	38.6	47	35.6	26	19.7	4	3.0	2.811	.8921
24. Physicians have negative reactions to palliative care.	23	17.4	48	36.4	27	20.5	20	15.2	14	10.6	2.652	1.2355

^aTotal number of responses for this group of questions ranged from 131 to 132.

Table 4*Level of Confidence in Types of Communication*

Nursing Behaviors	Not Confident (1)	%	Somewhat Confident (2)	%	Confident (3)	%	Very Confident (4)	%	M	SD
26. Assess a family's understanding of a patient's prognosis.	1	0.8	30	22.7	79	59.8	22	16.7	2.924	.6494
27. Assess a family's understanding of a patient's goals of care.	0	0	26	19.7	82	62.1	24	18.2	2.985	.6176
28. Identify a family's needs for information about a patient's illness and treatments.	0	0	18	13.6	84	63.6	30	22.7	3.091	.5984
29. Identify and respond to family members' emotional distress.	3	2.3	36	27.3	68	51.5	25	18.9	2.871	.7352
30. Elicit a physician's perspectives on a patient's prognosis.	6	4.5	33	25	68	51.5	25	18.9	2.848	.7764
31. Elicit a physician's understandings on a patient's goals of care.	4	3.1	28	21.4	72	55.0	27	20.6	2.931	.7358
32. Convey a family's communication needs to a physician.	1	0.8	10	7.6	70	53	51	38.6	3.295	.6389
33. Communicate the need for a family meeting to a physician.	1	0.8	18	13.6	63	47.7	50	37.9	3.227	.7054
34. Arrange a meeting between a patient's family and clinicians.	14	10.6	34	25.8	57	43.2	27	20.5	2.735	.9068

Nursing Behaviors	Not Confident (1)	%	Somewhat Confident (2)	%	Confident (3)	%	Very Confident (4)	%	M	SD
35. Be an active, contributing participant in a family meeting.	7	5.3	36	27.5	65	49.6	23	17.6	2.794	.7915
36. Define palliative care.	1	0.8	38	30.2	59	46.8	28	22.2	2.905	.7422
37. Communicate the value of palliative care consultation to a physician.	4	3.1	34	26.0	66	50.4	27	20.6	2.885	.7610
38. Describe palliative care and how it can be useful to a patient's family.	3	2.3	39	29.8	62	47.3	27	20.6	2.863	.7622
39. Ensure that patients and families receive palliative care when needed.	4	3.1	42	32.1	61	46.6	24	18.3	2.802	.7688
40. Use self-care practice to prevent burnout and compassion fatigue.	8	6.1	44	33.6	58	44.3	21	16.0	2.702	.8105

^aTotal number of responses for this group of questions ranged from 126 to 132.

Table 5a*Frequency of Nurse Participation: Comparing Years of Experience with Unit Type*

		NURSE EXP M		ICU EXP M			Unit Type M	
<i>Survey Item</i>	<i>Exp.</i>		sig. SD		sig. SD			sig. SD
3. Discuss prog. w/pts' family.			p<.022		p<.002			p<.000
						MICU	3.765	.4372
Low experience	1-5 yrs.	2.920	.8533	2.928	.8282	SICU	3.071	.6157
						TICU	3.476	.8136
High experience	6 yrs. & above	3.253	.7369	3.357	.6988	NCCU	2.900	.7120
						CCU	3.167	.7177
						CTIC	2.750	.7993
4. Discuss goals w/pts' family			p<.006		.008			p<.012
						MICU	3.647	.4926
Low experience	1-5 yrs.	3.280	.6713	3.333	.6568	SICU	3.500	.5189
						TICU	3.619	.5896
High experience	6 yrs. & above	3.587	.5476	3.625	.5244	NCCU	3.200	.6103
						CCU	3.091	.7006
						CTIC	3.621	.6219
5. Discuss prog. w/pts' MD					p<.003			p<.001
						MICU	3.765	.7524
Low experience	1-5 yrs.			3.377	.7689	SICU	3.571	.7559
						TICU	3.905	.3008
High experience	6 yrs. & above			3.754	.6059	NCCU	3.567	.7279
						CCU	3.750	.4523
						CTIC	3.069	.7987
6. Discuss goals w/pts' MD					p<.017			
						MICU		
Low experience	1-5 yrs.			3.522	.7785	SICU		
						TICU		
High experience	6 yrs. & above			3.807	.4795	NCCU		
						CCU		
						CTIC		
7. Attend family meetings			p<.033		p<.001			p<.000
						MICU	3.529	.6243
Low experience	1-5 yrs.	2.780	1.0160	2.754	1.0059	SICU	2.714	1.2044
						TICU	3.619	.8047
High experience	6 yrs. & above	3.158	.9245	3.316	.8485	NCCU	3.067	.8277
						CCU	3.083	.9962
						CTIC	2.310	.9298

	Exp.		sig. SD		sig. SD			sig. SD
8. Participate in family meetings			p<.004		p<.000			p<.000
						MICU	3.471	.7174
Low experience	1-5 yrs.	2.560	.9723	2.536	.9484	SICU	2.714	1.2044
						TICU	3.429	.8701
High experience	6 yrs. & above	3.066	.9428	3.263	.8768	NCCU	2.667	.8841
						CCU	3.083	.9962
						CTIC	2.276	.8822
9. Discuss Palliative w/pts' family					p<.008			p<.000
						MICU	3.059	.8269
Low experience	1-5 yrs.			2.449	.7580	SICU	2.571	.8516
						TICU	3.048	.8646
High experience	6 yrs. & above			2.842	.8822	NCCU	2.533	.6288
						CCU	2.750	1.0553
						CTIC	2.069	.7036
10. Discuss Palliative w/pts' physician					p<.000			p<.000
						MICU	3.706	.5879
Low experience	1-5 yrs.			2.754	.8644	SICU	3.143	.8644
						TICU	3.429	.7464
High experience	6 yrs. & above			3.456	.7089	NCCU	2.967	.8087
						CCU	3.333	.8876
						CTIC	2.345	.8140

Notes: Likert 4-point scale (1) never, (2) rarely, (3) sometimes, (4) often.

Nursing experience and ICU experience, both ranked on 4 levels of experience noted in column one.

Survey items with significant values listed above.

ICU types are: (1) MICU= medical ICU, (2) SICU= surgical ICU, (3) TICU= trauma ICU, (4) NCCU= neurological ICU, (5) CCU= coronary care ICU, (6) CTIC= cardiothoracic ICU.

significant (p-value < 0.05)

n=122 (for this analysis (6) participants did not identify demographic data and could not be included in IV groupings;

n= (4) participants identified ICU float, small sample size & could not attribute differences in practice since these participants work on all of the units and would not identify with specific differences by unit specialty.

Table 5b*Potential Barriers to Involvement: Comparing Years of Experience with Unit Type*

		Nurse Exp. M	sig. SD	ICU Exp. M	sig. SD	Unit Type	M	sig. SD
11. Unsure of my role in discussions					p<.029			p<.009
						MICU	2.353	1.1695
Low experience	1-5 yrs.			2.580	1.0628	SICU	2.286	1.0690
						TICU	1.714	.7171
High experience	6 yrs. & above			2.158	1.0655	NCCU	2.567	.9353
						CCU	2.250	.9653
						CTIC	2.862	1.2457
12. Need more training			p<.007		p<.012			
						MICU		
Low experience	1-5 yrs.	3.280	1.0506	3.174	1.0566	SICU		
						TICU		
High experience	6 yrs. & above	2.711	1.1980	2.649	1.2463	NCCU		
						CCU		
						CTIC		
13. Unsure how to bring up prog. w/ families			p<.004		p<.001			
						MICU		
Low experience	1-5 yrs.	2.880	.9398	2.841	.9490	SICU		
						TICU		
High experience	6 yrs. & above	2.382	.9376	2.263	.8969	NCCU		
						CCU		
						CTIC		
14. MDs don't support my involve in discussions								p<.000
						MICU	2.000	.7071
Low experience	1-5 yrs.					SICU	2.429	.8516
						TICU	1.857	.6547
High experience	6 yrs. & above					NCCU	2.200	.8052
						CCU	2.333	1.3027
						CTIC	3.897	1.0805
15. MDs don't ask my perspective on prog & goals								p<.000
						MICU	2.000	1.000
Low experience	1-5 yrs.					SICU	3.000	1.000
						TICU	2.190	.9284
High experience	6 yrs. & above					NCCU	2.667	.9942
						CCU	2.500	1.000
						CTIC	3.966	.9814
16. No time for bedside discussions on prog. & goals								p<.022
						MICU	1.765	.8314
Low experience	1-5 yrs.					SICU	2.000	.6794

		Nurse Exp. M	sig. SD	ICU Exp. M	sig. SD	Unit Type	M	sig. SD
						TICU	1.762	.8309
High experience	6 yrs. & above					NCCU	2.300	.7022
						CCU	2.167	1.1299
						CTIC	1.690	.4708
17. no time to attend family meetings					p<.029			p<.000
						MICU	2.059	.8993
Low experience	1-5 yrs.			2.377	.9867	SICU	2.000	.6794
						TICU	1.667	.7958
High experience	6 yrs. & above			2.000	.9063	NCCU	3.000	.9097
						CCU	2.333	.9847
						CTIC	1.862	.7894
18. Hard to get coverage to go these meetings								p<.000
						MICU	2.176	.8828
Low experience	1-5 yrs.					SICU	2.571	1.0163
						TICU	1.857	.7928
High experience	6 yrs. & above					NCCU	3.067	.9444
						CCU	2.250	1.1382
						CTIC	2.379	.9029
19. Managers do not support involvement			p<.002		p<.001			p<.000
						MICU	1.625	.6191
Low experience	1-5 yrs.	2.240	.9381	2.174	.9068	SICU	2.000	.8771
						TICU	1.190	.4024
High experience	6 yrs. & above	1.760	.7136	1.679	.6635	NCCU	2.233	.7279
						CCU	1.917	.9003
						CTIC	2.207	.7260
20. I don't know when meetings occur								p<.000
						MICU	2.059	.9663
Low experience	1-5 yrs.					SICU	2.429	1.0894
						TICU	1.429	.7464
High experience	6 yrs. & above					NCCU	2.000	.7428
						CCU	2.000	.9535
						CTIC	2.821	1.0203
21. I am not invited								p<.000
						MICU	2.000	1.1180
Low experience	1-5 yrs.					SICU	2.500	1.0190
						TICU	1.333	.5774
High experience	6 yrs. & above					NCCU	2.200	.8052
						CCU	2.250	1.1382
						CTIC	3.379	.9029
23. Families react negatively to palliative			p<.006		p<.001			

		Nurse Exp. M	sig. SD	ICU Exp. M	sig. SD	Unit Type	M	sig. SD
						MICU		
Low experience	1-5 yrs.	3.080	.9442	3.058	.8725	SICU		
						TICU		
High experience	6 yrs. & above	2.632	.8301	2.509	.8477	NCCU		
						CCU		
						CTIC		
24. Physicians react negatively to palliative								p<.000
						MICU	1.882	.6966
Low experience	1-5 yrs.					SICU	2.500	1.0919
						TICU	2.190	1.0305
High experience	6 yrs. & above					NCCU	2.200	.9248
						CCU	2.833	1.1146
						CTIC	3.966	1.0851

Notes: Likert 5-point scale: (1) strongly disagree, (2) disagree, (3) neutral, (4) agree, (5) strongly agree.

Nursing experience and ICU experience, both ranked on 4 levels of experience noted in column one.

Survey items with significant values listed above.

ICU types are: (1) MICU= medical ICU, (2) SICU= surgical ICU, (3) TICU= trauma ICU, (4) NCCU= neurological ICU, (5) CCU= coronary care ICU, (6) CTIC= cardiothoracic ICU.

*The abbreviation MD is substituted for physician in this table.

significant (p-value < 0.05)

Table 5c*Nurse Confidence: Comparing Years of Experience with Unit Type*

		Nurse Exp. M	Sig. SD	ICU Exp. M	Sig. SD	Unit Type	M	Sig. SD
27. Assess a family's understanding of patient goals			p<.002		p<.000			
Low experience	1-5 yrs.	2.760	.5911	2.783	.5654	MICU SICU		
High experience	6 yrs. & above	3.105	.6018	3.193	.6106	TICU NCCU		
						CCU CTIC		
28. Identify family's need for info on illness and treatment			p<.005		p<.000			
Low experience	1-5 yrs.	2.900	.5440	2.913	.5352	MICU SICU		
High experience	6 yrs. & above	3.211	.6179	3.298	.6258	TICU NCCU		
						CCU CTIC		
29. Identify and respond to family distress			p<.015		p<.001			
Low experience	1-5 yrs.	2.660	.7174	2.652	.7241	MICU SICU		
High experience	6 yrs. & above	2.987	.7393	3.105	.6991	TICU NCCU		
						CCU CTIC		
30. Elicit MD perspective on patient prognosis			p<.004		p<.019			p<.002
Low experience	1-5 yrs.	2.600	.7284	2.696	.6925	MICU SICU	3.176 2.857	.8828 .8644
High experience	6 yrs. & above	3.000	.7659	3.018	.8343	TICU NCCU	3.286 2.667	.7171 .6609
						CCU CTIC	2.917 2.483	.7930 .6336
32. Share family's communication needs to MD			p<.008		p<.000			
Low experience	1-5 yrs.	3.100	.6145	3.101	.6218	MICU SICU		

		Nurse Exp. M	Sig. SD	ICU Exp. M	Sig. SD	Unit Type	M	Sig. SD
High experience	6 yrs. & above	3.408	.6362	3.509	.6013	TICU NCCU		
						CCU CTIC		
33. Communicate need for family meeting to MD					p<.000			
Low experience	1-5 yrs.			3.000	.6642	MICU SICU		
High experience	6 yrs. & above			3.474	.6841	TICU NCCU		
						CCU CTIC		
34. Arrange meeting bet. family and clinicians			p<.000		p<.000			
Low experience	1-5 yrs.	2.280	.8816	2.377	.8762	MICU SICU		
High experience	6 yrs. & above	2.987	.7745	3.105	.7719	TICU NCCU		
						CCU CTIC		
35. Be an active, contributor in family meeting			p<.000		p<.000			p<.010
Low experience	1-5 yrs.	2.480	.7351	2.522	.6989	MICU SICU	2.941 2.643	.6587 .8419
High experience	6 yrs. & above	2.987	.7745	3.105	.7947	TICU NCCU	3.286 2.500	.7838 .8200
						CCU CTIC	3.000 2.655	.6325 .7689
36. Define palliative care			p<.004		p<.011			
Low experience	1-5 yrs.	2.660	.7174	2.739	.7205	MICU SICU		
High experience	6 yrs. & above	3.042	.7058	3.077	.7098	TICU NCCU		
						CCU CTIC		

		Nurse Exp. M	Sig. SD	ICU Exp. M	Sig. SD	Unit Type	M	Sig. SD
37. Communicate value of palliative care to MD			p<.000		p<.001			p<.001
						MICU	3.176	.7276
Low experience	1-5 yrs.	2.580	.7025	2.667	.6788	SICU	2.571	.8516
						TICU	3.238	.7003
High experience	6 yrs. & above	3.053	.7284	3.105	.7719	NCCU	2.900	.5477
						CCU	3.182	.6030
						CTIC	2.483	.7847
38. Describe palliative & how useful to family				ICU Exp. M	Sig.	Unit Type	M	Sig.
			p<.002		p<.004	MICU		
Low experience	1-5 yrs.	2.680	.6999	2.681	.7173	SICU		
						TICU		
High experience	6 yrs. & above	3.026	.7479	3.070	.7526	NCCU		
						CCU		
						CTIC		
39. Ensure palliative care received when needed			p<.003		p<.004			p<.022
						MICU	3.118	.6002
Low experience	1-5 yrs.	2.540	.7343	2.609	.7116	SICU	2.643	.7449
						TICU	3.048	.9207
High experience	6 yrs. & above	2.947	.7465	3.000	.7792	NCCU	2.733	.5833
						CCU	3.091	.7006
						CTIC	2.483	.7847

Notes: Likert 4-point scale: (1)not confident, (2) somewhat confident, (3) confident, (4) very confident.

Nursing experience and ICU experience, both ranked on 4 levels of experience noted in column one.

Survey items with significant values listed above.

ICU types are: (1) MICU= medical ICU, (2) SICU= surgical ICU, (3) TICU= trauma ICU, (4) NCCU= neurological ICU, (5) CCU= coronary care ICU, (6) CTIC= cardiothoracic ICU.

significant (p-value < 0.05)

Table 6. Focus Group Participant Characteristics

Nurse Characteristics (n=13)				
Gender				
Male	1	7.6%		
Female	12	92.3%		
	N	μ	SD	
Years of nursing experience	13	10.577	9.639	
Years of ICU experience	13	9.077	8.424	
Nurse Education	Tot.	%		
BSN	11	84.6		
ADN	2	15.4		
Primary specialty of work %	n		%	
Medical Intensive Care	1		7.7	
Trauma Intensive Care	7		53.8	
Cardiothoracic Intensive Care	5		38.5	

Box 1. Guiding Questions for Focus Group Discussions	
•	Describe what comes to mind when you think about an experience you had in caring for a patient at end-of-life?
•	Could you share some of your feelings about how EOL communication is managed with patients and families on your unit?
•	Describe any ways in which you involve family members in the care of patients at end of life?
•	Could you describe any barriers that you experience in the care of these patients?
•	Where do you think variation in nursing care practices come from?
•	Describe any ways in which you involve family members in the care of dying patients?
•	What support systems do you have for nurses caring for dying patients in the ICU?
•	Discuss any training or education that you have had on end-of-life care in the ICU?

Table 7. Common Themes from Focus Group Discussions

Communication timing and quality	<ul style="list-style-type: none"> • “Nurses have to be very honest about the seriousness of the patient’s condition.... this is what you could be faced with” • “Families need to be educated at the beginning – gives them time to process” • “it comes down to timing and compassion.” • “Physicians explain something and then the family are not quite sure, they look to you (nurse) to explain it” • “families get confused due to conflicting messages coming from different members of the healthcare team” • “In some situations I don’t really know how to go about it (approaching family) but I talk with my co-workers to get a feel for how to go about doing it.....if I don’t feel comfortable I go and get the doctors to come in and do the talking.” • “Our team is pretty good about those blunt and bold conversations.” • “when we participate in family meetings we are fully engaged” • “sometimes the nurses will ask to come to the meeting, the doctor will say you can come if you like.”
Nursing care of patients’ families	<ul style="list-style-type: none"> • “Families would rather hear it (bad news) from us (nurses), they really know us, they trust us, we’re their support system, we are with them all the time” • “Our physicians let us interject to explain things in the family meetings.... they are very comfortable with us.” • Variation by specialty unit in the frequency of participation in family meetings – some nurses often participate – other units rarely have family meetings. • “Nurses gauge pretty quickly if the family is going to hear what you have to say or if they are going to shut down” • Care also described as’ “keeping a balance of making yourself available and giving them space, may be the last time you are going to see them” • “answer families’ questions ...assurance of medicating the patient if the family thinks the patient is in pain.” • It’s our role to be a detective especially when there’s no family, to use our voice, be a little bold and stand up and advocate for the patient.” • “We get a lot of organ donation due to a younger population and I think that can sometimes help the families deal” • “Once you can provide really great EOLC it is valuable for these patients and families ... they benefit from it but it’s an uphill battle due to the difference in the training of doctors and nurses.... Nurses look at the whole picture.”

Barriers to letting go	<ul style="list-style-type: none"> • Doctors don't want to broach the topic of EOLC with patients and families" • "Surgeons are not receptive to letting a patient go" • "Doctors won't accept defeat" • Families have difficulty accepting the possibility of death, especially for a young patient" • "Some families are not ready to hear...let go" • "Mixed signals from different doctors in different specialties" • Some doctors want to wait a specified number of days to approach EOL decision making with a family, "neuro waits 72 hours here" others, "we wait until day 5" • "Depends on doctors/specialties, some are more comfortable having these conversations," "Nurses look at the big picture and QOL doctors are different, it's save a life, save a life, save a life." • "Just because we have the capabilities to do stuff doesn't mean that we should every single time." • "some physicians are wishy, washy, some are more, blunt and explain everything." • "in situations when things are not going well, I wish we used palliative care more, we look at it like it's a hard left turn, a hard stop." • The burn surgeons always have a plan of everything they are going to try.... you go to family meetings and you want to say.... just say it...just say it." "the families just go along."
Emotional toll and nurse support	<ul style="list-style-type: none"> • Care of dying patients is "very emotional – nurses need to rotate patients". • Describing a patient that had an extended ICU stay; "It was difficult for the nurses, emotionally it was too much." • "One patient I took care of had a lot of wounds, it was a continuous battle, his needs weren't being met." • "there's a level of burnout that care occur related to caring for these patients.....it's an uphill battle to get the right care for them" • "doctors don't listen to nurses and you still have to care for them and you are causing suffering to patients by providing care while you know it is not going to turn out positive....so you know that it's futile. That contributes to the high turnover of ICU nurses." • "the doctors are not hearing from the patients.... (I just want to go home) and we (nurses) know that home means a forever home to the patient." • "death is different on every unit, on some units, death is abrupt, the nature of injuries makes a difference too." • "debriefing is rare" • "we support each other, it's nurse driven" • "If somebody doesn't bring it up it doesn't happen." • "I've used a pause after a code, time to reflect and absorb what took place, the teamwork, the efforts, all aspects – allows a level of appreciation and provides clarity when a patient doesn't make it."

Experience and training in EOLC	<p>“There’s no training, it’s watching senior nurses and seeing what they do.”</p> <p>“Experience is everything”</p> <p>“Nothing can beat experience, no matter what degree.”</p> <p>“We don’t really have protocols, every patient’s death is different, what works for one patient does not work for someone else.”</p> <p>“No formal training, only from my preceptor on the job.”</p> <p>Gets better each time with experience.”</p> <p>“you do notice a difference in the nurses that haven’t had that experience.”</p> <p>“When I was a new nurse or even 5 years less than now, I would just sit in the family meetings and not say anything, just listen to the doctors and social workers talk.”</p> <p>“I feel it should be part of our orientation because it’s the nurses that have to do everything.”</p>
---------------------------------	--

APPENDIX A

IRB Approval University of Rhode Island

OFFICE OF RESEARCH INTEGRITY
70 Lower College Road, Suite 2, Kingston, RI 02881 USA
p: 401.874.4328 f: 401.874.4814 web.uri.edu/research/ondvoffice-of-research-integrity

FWA: 00003132
IRB: 00000599
DATE: April 2, 2019

TO: Marlene Dufault, PhD, RN
FROM: University of Rhode Island IRB

STUDY TITLE: Nurses Involvement in End-of-Life Communication and Care Practices in ICU's
IRB REFERENCE #: 1401671-2
LOCAL REFERENCE #: IRB1819-154
SUBMISSION TYPE: New

ACTION: DETERMINATION OF EXEMPT STATUS
EFFECTIVE DATE: April 2, 2019

REVIEW CATEGORY: EXEMPT # 2

Thank you for your submission of materials for this research study. The University of Rhode Island IRB has determined this project falls into the **EXEMPT REVIEW** category according to federal regulations 45 CFR 46. Per URI IRB policy, the project has been reviewed by either the IRB Chair or the IRB Administrator. **Approval is valid for the duration of the project.**

No changes to procedures involving human subjects may be made without prior IRB review and approval. You must promptly notify the Office of Research Integrity of any problems that occur during the course of your work using Appendix S - Event Reporting.

If you have any general questions, please contact us by email at researchintegrity@etal.uri.edu. For study related questions, please contact us via **project mail through IRBNet**. Please include your study title and reference number in all correspondence with this office.

A handwritten signature in blue ink, appearing to read "Matthew Delmonico".

Matthew Delmonico, Ph.D., MPH
IRB Chair

APPENDIX B

IRB Approval Lifespan

Research Protection Office
Office of Research Administration
CORO West, Suite 1.300
One Hoppin Street
Providence, RI 02903
Tel 401 444-6246, Fax 401 444-7960

E. P. Bradley Hospital
Rhode Island Hospital
The Miriam Hospital
Newport Hospital
Gateway Healthcare

DATE: May 22, 2019

TO: Barbara Riley, DNP

FROM: Janice Muratori, MSN, FNP-BC
Director, Research Protection Office

SUBJECT: **HUMAN SUBJECTS PROTECTION - DETERMINATION OF EXEMPT STATUS**
FWA-Rhode Island Hospital (RIH) 00001230, The Miriam Hospital (TMH) 00003538
IRB Registration #s: RIH IRB 1 - 00000396, RIH IRB 2 - 00004624, TMH IRB - 00000482

CMTT/PROJ: 004619; 45 CFR 46.104(d)(2)

TITLE: [1388853-1 and 1388853-2] Nurses' involvement in end-of-life communication and care practices in ICUs.

Your research application submitted on March 14, 2019 was reviewed and determined to be exempt from the Federal Regulation 45 CFR 46 as meeting the criteria in 45 CFR 46.104(d)(2). Projects determined to meet the exempt criteria by the IRB are exempt from continuing review by the IRB, as long as the project maintains the properties that make it exempt.

This means:

1. You do not need to renew your application annually.
2. You do not need to submit a revision application to make changes in your project unless the modification will cause the research to change from Exempt to Expedited or Full Review Status as per 45 CFR 46.

Revisions that may change the status of this determination must be submitted to the IRB for review.

This institution is in compliance with the ICH GCP as they correspond to the FDA/DHHS regulations. This review is applicable for RIH.

Please contact the Research Protection Office if you have any questions.

This document has been electronically signed in accordance with all applicable regulations, and a copy is retained within our records.

APPENDIX C

Permission for Use of Survey

APPENDIX D

End of Life Survey

Survey Instrument

(Anderson et al., 2016)

I. First, how important do you feel the following are to the quality of care for seriously ill ICU patients?

	Not Important	Somewhat Important	Important	Very Important
1. Families and clinicians engaging in discussions about patient prognosis and goals of care				
2. Bedside nurses engaging in discussions with families and physicians about patient prognosis and goals of care				

II. How often do you as a bedside nurse do the following?

	Never	Rarely	Sometimes	Often
3. Discuss prognosis with patients' families				
4. Discuss goals of care with patients' families				
5. Discuss prognosis with patients' physicians				
6. Discuss goals of care with patients' physicians				
7. Attend family meetings				
8. Participate in family meetings				
9. Discuss palliative care consults with families				
10. Discuss palliative care consults with physicians				

III. Please rate your level of agreement with the following potential barriers to your involvement in discussions with families and clinicians about patient prognosis, goals of care, and palliative care:

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
11. I am unsure of my role in discussing prognosis, goals of care, and palliative care					
12. I need more training in how to discuss prognosis, goals of care, and palliative care					
13. I am not sure how to bring up prognosis and goals of care with families					
14. I do not feel that physicians support my involvement in these discussions					
15. Physicians do not ask for my perspectives on prognosis, goals of care, and palliative care					
16. I do not have time for bedside discussions of prognosis and goals of care					

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
17. I do not have time to attend family meetings					
18. It is hard to get coverage for my patients so I can attend family meetings					
19. My managers do not support my involvement in these discussions					
20. I do not know when or where family meetings are occurring					
21. I am not invited to family meetings					
22. Engaging in these discussions is emotionally draining					
23. Families have negative reactions to palliative care					
24. Physicians have negative reactions to palliative care					

25. Please list any other factors that you feel limit your involvement in discussions about prognosis, goals of care, and palliative care:

IV. Please rate your level of confidence to perform each of the following tasks:

	Not Confident	Somewhat Confident	Confident	Very Confident
26. Assess a family's understanding of a patient's prognosis				
27. Assess a family's understanding of a patient's goals of care				
28. Identify a family's needs for information about a patient's illness and treatments				
29. Identify and respond to family members' emotional distress				
30. Elicit a physician's perspectives on a patient's prognosis				
31. Elicit a physician's understanding of a patient's goals of care				
32. Convey a family's communication needs to a physician				
33. Communicate the need for a family meeting to a physician				
34. Arrange a meeting between a patient's family and clinicians				
35. Be an active, contributing participant in a family meeting				
36. Define palliative care				
37. Communicate the value of palliative care consultation to a physician				
38. Describe palliative care and how it can be useful to a patient's family				
39. Ensure that patients and families receive palliative care when needed				

	Not Confident	Somewhat Confident	Confident	Very Confident
40. Use self-care practices to prevent burnout and compassion fatigue				

V. Finally, please tell us a little about yourself:

41. How many years have you worked as a nurse?

1 to 2 years ____ 3 to 5 years ____ 6 to 10 years ____ 11 years or more ____

42. How many years have you worked as an ICU bedside nurse?

1 to 2 years ____ 3 to 5 years ____ 6 to 10 years ____ 11 years or more ____

43. Please select the unit in which you primarily work (all ICUs at the study medical centers were listed):

Medical Intensive Care ____

Surgical Intensive Care ____

Trauma Intensive Care ____

Neurological Intensive Care ____

Coronary Intensive Care ____

Cardiothoracic Intensive Care ____