DISCUSSING END-OF-LIFE CARE IN THE EMERGENCY DEPARTMENT: TO ATTEMPT RESUSCITATION OR ALLOW A NATURAL DEATH.

by

Catherine Grace Kelly

A professional project submitted in partial fulfillment of the requirements for the degree

Master

of

Nursing

MONTANA STATE UNIVERSITY
Bozeman, Montana

April 2014
DEDICATION

This work is dedicated to my mother Martha who taught me about living a full and joyful life, and about dying well. Most importantly, she showed all who loved her that there truly is such a thing as a good death.
ACKNOWLEDGMENTS

With deepest gratitude, I wish to recognize the guidance and insight of my advisor and project chair Dr. D. Dale Mayer. During moments of doubt, she gave me reassurance and encouragement. She also challenged my intellectual abilities and held me to a high standard of performance. It was my good fortune that she agreed to be my mentor, and I greatly appreciate her effort and dedication to the completion of this work. By generously sharing her personal experience regarding end-of-life care for a loved one, she also validated the intention and purpose of my work. Many thanks also go to my project committee members Steven Glow, Deanna Brame and Lorraine Ackerman who contributed their valuable time and expertise and helped keep the project on course. It is with appreciation that I also acknowledge the honesty and candor of my patients and colleagues in sharing their stories about end of life experiences. May their sincerity help lessen the suffering of others.
# TABLE OF CONTENTS

1. INTRODUCTION ........................................................................................................... 1

2. REVIEW OF THE LITERATURE ................................................................................. 6
   - Literature Search Method .......................................................................................... 6
   - Patients in the Emergency Department Without Advance Directives ...................... 6
   - Patient Misconceptions about Attempted Resuscitation ........................................... 7
   - Terminology Used to Describe Attempted Resuscitation ........................................ 9
   - Barriers to Discussing Attempted Resuscitation ..................................................... 10
   - Facilitating Patient Understanding .......................................................................... 12
   - Identifying Patients Needing End-of-Life Care ....................................................... 13
   - Facilitating Informed Choice ................................................................................... 14

3. METHODS .................................................................................................................... 16
   - Project Design ........................................................................................................ 16
   - Participants .............................................................................................................. 16
   - Ethical Considerations ............................................................................................. 17
   - Data Collection ....................................................................................................... 17

4. FINDINGS .................................................................................................................... 18
   - Topic 1: Initiating the Discussion ............................................................................ 19
   - Topic 2: Urgency of the Situation ............................................................................ 20
   - Topic 3: Likelihood of Imminent Death .................................................................. 20
   - Topic 4: Using the Words Death, Dying, and Mortality ......................................... 21
   - Topic 5: Describing Intubation, Mechanical Ventilation, and CPR ......................... 22
   - Topic 6: Describing Medications and Comfort Care .............................................. 23
   - Topic 7: Uncertainty of the Outcomes .................................................................... 23
   - Topic 8: Validation and Acceptance of Patient Choice .......................................... 24
   - Topic 9: Addressing Resistance .............................................................................. 24
   - Topic 10: When the Patient or Family Ask Advice ............................................... 26
   - Topic 11: Using the Term *Allowing Natural Death* ............................................. 26
   - Topic 12: Open-ended Comments ......................................................................... 28
     - The Role of Nursing in End-of-Life Discussions ................................................ 28
     - A Go-To Resource for End-of-Life Care in the ED .............................................. 29

5. DISCUSSION.................................................................................................................. 30
TABLE OF CONTENTS - CONTINUED

REFERENCES CITED ..........................................................................................................................33

APPENDIX A: Interview Script: Case Study of an Acutely Decompensating
Patient in the Emergency Department ..........................................................................................37
ABSTRACT

Patients on a known dying trajectory quite frequently present to the emergency department (ED), unprepared for some of the common and inevitable crises related to their disease process, and most of them have not prepared an advance directive. Near end-of-life (EOL) patients who present to the ED with an emergent need for symptom management may instead be faced with an incongruent treatment plan focused on life-saving interventions. Time constraints, lack of prior patient-provider relationship, vague and misleading terminology, and patient misconceptions about attempted resuscitation interfere with discussions about EOL care preferences in the ED. Questions sometimes posed by ED providers such as “If your heart stops beating, do you want us to try and start it again?” or “If you stop breathing, do you want us to put in a breathing tube?” or the more loaded question “Do you want us to do everything?” are problematic because patients are offered no tangible alternatives; in essence, the choice they are presented with is between doing everything and doing nothing. Realistically, who will choose nothing? There is a growing movement toward using more precise language to discuss attempted resuscitation and allowing natural death. The purpose of this project was to explore the language used during patient-provider conversations about attempted resuscitation versus allowing natural death. A case study was used to interview emergency department physicians, nurse practitioners, and physician assistants. Twelve topics emerged during the interviews regarding how providers discuss attempted resuscitation versus allowing a natural death. The interviews revealed areas where patient-provider communication may be improved, and highlighted the need to replace ambiguous language with more frank and detailed discussions of EOL care options. ED providers need to become more comfortable discussing EOL care, and give patients and families the full benefit of making informed decisions in line with their goals of care.
INTRODUCTION

The impetus for this project began when the investigator was working as a registered nurse the emergency department. After several years a pattern emerged; patients on a known dying trajectory quite frequently presented to the emergency department, unprepared for some of the common and inevitable crises related to their disease processes. Uncontrolled pain, nausea, or shortness of breath were some of the symptoms that precipitated their visits to the emergency department (ED), and it was noted that patients with heart failure, chronic obstructive pulmonary disorder, metastatic cancer and other life-limiting illnesses often had an insufficient understanding of their diagnosis, or their prognosis, and most of them had not prepared an advance directive. This pattern has also been noted in the literature. Fernandez, Deutsch, Janeiro, and Compton (2012) and Lamba, Nagurka, Murano, Zalenski, and Compton (2012) reported similar findings that the majority of patients who die in the ED are on an anticipated or accelerated dying trajectory. Davis (2012) reported the majority of patients have no advance directive prepared at the time of their death; and of those who do, only 1 percent bring their advance directive with them to the ED.

Advance directives are a means to communicate an individual’s wishes regarding their medical treatment, allowing patients and family members to make a broad range of health care choices that can be altered at any time, and providing explicit guidance to healthcare providers when the patient is unable to make their preferences known. There are several types of advance directives including a living will, health care power of attorney, Five Wishes, Physician Orders for Life Sustaining Treatment (POLST), Allow
Natural Death (AND) as well as Do Not Resuscitate (DNR) and Do Not Attempt Resuscitation (DNAR) orders. According to the American Cancer Society (2013), an advance directive may be a comprehensive legal document, a physician’s note in the patient’s chart, or a witnessed verbal agreement. One major aspect of an advance directive is to determine whether attempted resuscitation is desired; a decision that should be made based on a clear understanding of the interventions.

When patients present to the ED with an emergent need for symptom management, and without an advanced directive, they may be face an incongruent treatment plan focused on life-saving interventions. Lamba and Quest (2011) and Chan (2004) found that 911 calls by near end-of-life (EOL) patients and their families are primarily an expression of fear and panic when they are unable to manage symptom exacerbations. Overwhelmed by distress, they activate the emergency response system, yet resuscitative interventions may not be aligned with EOL patients’ goals of care. In the life-saving milieu of the ED, it’s difficult for emergency medical providers to adequately address EOL issues that would have preferably been clarified prior to admission. The fast pace of an ED has inherent time constraints, which are compounded by communication barriers, vague and misleading terminology, and patient misconceptions about attempted resuscitation. All of these factors interfere with provider-patient discussions about EOL preferences. Fernandez, Deutsch, Janeiro, and Compton (2012) cited lack of prior patient-provider relationship as presenting a formidable barrier to communication that may lead to providers misinterpreting patient wishes regarding life-sustaining treatment. Curtis and Patrick (1997) found that physicians are often uncomfortable talking about death and
dying, and that some feel talking about EOL care could be harmful or hasten death. Krzyzanowska, Tozer, and Mazzotta (2013) found that oncologists report talking about EOL as the most distressing part of their work. Gruzden, Richardson, Hopper, Ortiz, Whang, and Morrison (2012) reported physicians also have significant medico-legal concerns about foregoing attempted resuscitation despite instances when the risks outweigh the benefits. Jezewski, Meeker, and Robillard, (2005) found that some ED nurses feel that the ED is an inappropriate setting to discuss EOL issues.

Patients and their family members may have a less than adequate understanding of what attempted resuscitation actually entails, and a limited knowledge of the full spectrum of their care alternatives. Ells (2010) discussed numerous ambiguities regarding the term resuscitation and cited a growing movement toward more precise language. Questions sometimes posed by ED providers such as “If your heart stops beating, do you want us to try and start it again?” or “If you stop breathing, do you want us to put in a breathing tube?” or the more loaded question “Do you want us to do everything?” are problematic because patients are offered no tangible alternatives; in essence, the choice they are presented with is between doing everything and doing nothing. Realistically, who will choose nothing? Patients who present to the ED without an advance directive need greater understanding of what occurs during attempted resuscitation, and a more realistic grasp of their probable outcomes. The actual clinical interventions and the success rate of attempted resuscitation are quite different from patient perceptions, which as Diem, Lantos, and Tulsky (1996) discovered, are overwhelmingly formulated from television portrayals. Unrealistic perceptions of the invasive interventions that occur, and
lack of knowledge about the likely outcomes of attempted resuscitation expose patients to interventions that if rightly understood might be found undesirable. Inappropriate and likely futile interventions attempted on patients with a high likelihood of poor outcomes and a low probability of survival to discharge, interfere with a dignified natural death. Bishop, Brothers, Perry, and Ahmed (2010) described the problem of cardiopulmonary resuscitation (CPR) or full code status as being a societal norm, yet it is often inappropriately applied to patients at the end point on a known dying trajectory. Routine discussion of advance directives should become part of all hospital admissions, and the authors further suggested that the term do not attempt resuscitation (DNAR) replace do not resuscitate to emphasize the uncertainty of the outcomes. Kaldjian, et al. (2009) and Murphy, et al. (1994) reported that patients who are frankly informed of their likely survival of attempted resuscitation are less likely to opt for CPR.

Patients need symptom management and pain relief in the end stages of their disease process; they need to know that if they opt out of more heroic measures that they are not relinquishing other forms of supportive care and palliative measures. Breault (2011) advocated for the term allow natural death (AND) to imply a course of treatment during a natural disease progression. Comfort measures, supportive care, and allowing a natural death to occur should be more explicitly presented as care options in the ED. Clarifying for patients the difference between the interventions of attempted resuscitation and those of supportive care associated with allowing a natural death could provide valuable assistance with patient care decisions in the immediate crisis, and serve as a starting point for developing more comprehensive advance directives, if and when the
immediate crisis passes. Considering the many obstacles cited above, patients and family members are not being provided with an adequate scope of possibilities to make an informed decision about their EOL care. Clear and concise patient information should be provided to patients for whom attempted resuscitation and other highly invasive procedures would likely lead to poor outcomes. Patients should be offered the unambiguous choice of aggressive symptom management to support an anticipated death on a known dying trajectory. Compared to the well-known American Heart Association Advanced Cardiac Life Support protocol for attempted resuscitation, there is no analogous care pathway or protocol for allowing a natural death in the ED.

The purpose of this project is to talk with healthcare providers - physicians, nurse practitioners, and physician assistants working in the ED - about the language they use when discussing EOL choices with patients and families, specifically regarding whether to attempt resuscitation or to allow natural death to occur. One goal of this project is to explore the language used during patient-provider conversations about attempted resuscitation versus allowing natural death in the ED. This exploration is intended to identify areas where patient-provider communication may be improved, and areas where ambiguous terminology may be replaced by more precise language. Facilitating an informed dialogue about EOL care preferences in the ED can be of great benefit to healthcare providers, and to patients and families in crisis. The ultimate objective is to help patients and families to better understand the EOL care options in the ED, to articulate their preferences to providers, and to receive EOL treatment that is aligned with their goals of care.
A comprehensive review of the literature was conducted utilizing CINAHL and MEDLINE databases with keywords *emergency department, end-of-life, advance directives, do not resuscitate, allow natural death, futile resuscitation, cardiopulmonary resuscitation, and communication*. The goal of the literature search was to identify pertinent evidence regarding EOL care discussions between patients, families, and healthcare providers in the ED setting, specifically regarding the language used to discuss attempted resuscitation versus allowing natural death. Review of the literature demonstrated a paucity of evidence on the above topic. The literature search included articles from 2003 until 2013, and the article references were hand-searched to identify earlier documents seminal to the discussion of the survivability of cardiopulmonary resuscitation (CPR). The findings of this literature search revealed that there was little guidance for providers to discuss EOL choices for decompensating ED patients on an anticipated dying trajectory.

**Patients in the Emergency Department without Advance Directives**

There are a number of circumstances identified in the literature concerning patients who present to the ED without an advance directive. Of all patients who present to the ED, Davis (2012) reported that 71 percent had no advance directive prepared at the time of hospital admission and that 99 percent of patients who presented to the ED did
not bring their advance directive with them. DeVader, Albrecht, and Reiter (2011) estimated that 36 percent of nursing home patients and only 45 percent of patients with terminal diagnoses have an advance directive. Exploring the types of patients who die in the ED, Fernandez, Deutsch, Janeiro, and Compton (2012) stated that 60 percent are on known dying trajectories. Lamba, Nagurka, Murano, Zalenski, and Compton (2012) reported similar findings that the majority of ED patients who die in the hospital are on known and accelerated dying trajectories, yet only 11 percent have an advance directive. Lamba and Quest (2011) reported that 911 calls and presentation at the ED by near EOL patients may be primarily an expression of fear or panic, and that resuscitative interventions may not fit the patient’s overall goals of care. Chan (2004) stated that families and patients on known dying trajectories activated the emergency response system when they were unable to manage symptom exacerbations, panicked, became overwhelmed by distress, or were physically or psychologically unable to further care for the patient. The core of emergency medicine is to initiate treatment in an attempt to stabilize and cure, which is a grossly incongruent model for EOL care.

**Patient Misconceptions about Attempted Resuscitation**

Giving patients adequate information is crucial for enabling them to make soundly informed decisions, avoid suffering, minimize hospitalizations, and prevent unwanted interventions. Communicating wishes to family and healthcare providers helps ensure that patients’ goals of care are established and supported. Fischer and Lyckholm (2012) discussed how common it is to encounter patients with uncontrolled symptoms in
the final stages of their disease who have not yet spoken with any medical provider about their actual prognosis. Lo, McLeod, and Saika (1986) discovered that 70 percent of patients desired to speak with their primary provider about EOL issues and life-sustaining interventions but that they preferred the physician to initiate such discussions. Ebell, Smith, Seifert, and Polsinelli (1990) determined that only half of near-EOL patients have had frank discussions about their wishes with family members. Ells (2010) suggested that CPR means different things to different people, and this concept was further clarified by the findings of Gruzden, et al. (2012) who pointed out that patients and ED providers may have very limited understanding of the full scope of palliative and supportive care options when opting out of aggressive life-saving or life-sustaining care. Von Gunten and Weissman (2004) suggested that attempted resuscitation should not be presented as an “all-or-nothing” proposition. There are serious patient misconceptions about CPR, what Scripko and Greer (2010) referred to as unrealistic optimism that is mainly driven by media images and depictions. Schonwetter (1991) reported that for 92 percent of adults over age 62, their understanding of CPR is completely derived from television portrayals. Bedell, Delbanco, Cook, and Epstein (1983) estimated that 14 percent of all patients who received in-hospital CPR survived to discharge; 44 percent achieved a return of spontaneous pulse and blood pressure but were stuporous or comatose until death. Ehlenbach, Barnato, Curtis, Kreuter, Koepsell, Deyo, and Stapleton (2009) examined Medicare data from 1997 to 2005 and reported that approximately 18 percent of Medicare recipients over age 65 survived CPR to discharge, but that there was an increased proportion of subsequent Hospice admissions. Breult (2011) analyzed figures
from 1996 to 2007 and concluded that the survival to hospital discharge rate continues to hover around 15 percent depending on a patient’s specific situation. In contrast, media portrayals of cardiac arrest survivability were reported by Diem, Lantos, and Tulsky (1996) to be roughly 75 percent.

Terminology Used to Describe Attempted Resuscitation

Bishop, Brothers, Perry, and Ahmed (2010) described the problem of default full code status for people with life-limiting conditions despite poor prognoses. Presumed CPR has become our societal norm but it’s an incongruous technological miracle inappropriately applied to people who have reached the common end point on a known dying trajectory. It is an unfortunate and inappropriate experience for individuals who experience anticipated cardiac arrest to be subjected to invasive and futile medical interventions. These authors made several recommendations regarding attempted resuscitation: First, do not attempt resuscitation (DNAR) should replace the current terminology of do not resuscitate (DNR) as it serves to emphasize the uncertainty of the interventions. Second, routine dialogue regarding desired and recommended resuscitation options should become part of all hospital admissions. Third, there must be a method for discussing and clarifying patient prognosis, proposing a possible course of action by suggesting when CPR may not be advisable, and deferring to patient preference when medical evidence and judgment are inconclusive. Kaldjian, et al. (2009) and Murphy, et al. (1994) discussed how patients are significantly less likely to opt for CPR when they are candidly informed of the probability of their survival. This evidence implies that
discussions regarding resuscitation are desired by patients, and that these discussions need to be grounded in the realistic prospect of the patients’ survival. This brings to the forefront, the concept of allowing a natural death (AND). Ells (2010) recognized numerous ambiguities concerning the term resuscitation, and described a growing movement toward using more precise terms. While the expressions DNAR or AND are essentially different names for the same aspect of an advance directive, Breault (2011) expressed a preference for using AND because the language implies a course of treatment that allows natural disease progression while simultaneously providing supportive care interventions. Regardless of the terminology, it is the overarching responsibility of providers to prevent inappropriate attempted resuscitation for those whom the burden is greater than the benefit.

**Barriers to Discussing Attempted Resuscitation**

Similar to obtaining informed consent for other invasive procedures, an order for full code status and attempted resuscitation ought to include the informed consent of the patient whenever possible, but this is a difficult task in the ED for numerous reasons. The literature is lacking information on institutional protocols or procedures that may exist for establishing advance directives in the ED. Ache, Wallace, and Shannon (2011) found that although the Patient Self-Determination Act was passed well over 20 years ago, standardized limited medical treatment forms have no consistent format and are written far above the average literacy level. There are time constraints described by Chan (2004), coupled with hastily established ED patient-provider relationships that are limited in
Sudden illness and injury leaves little time for EOL discussions in the ED regarding patient care preferences and death preparation. Most of the EOL models for preparing advance directives were developed for patients expected to die in days, weeks, or months while ED patients are frequently on much shorter dying trajectories.

Fernandez, Deutsch, Janeiro, and Compton (2012) identified how a lack of prior patient-provider relationships in the ED, compounded by acute patient decompensation, present serious communication challenges and may lead physicians to inaccurately assess patient wishes and misinterpret their desires regarding life-sustaining treatment. Gruzden, Richardson, Hopper, Ortiz, Whang, and Morrison (2012) discovered that providers have significant concerns about the medico-legal implications of foregoing treatments even when the risks clearly outweigh the benefits. The Emergency Nurses Association (2010) reported that EOL decisions in the ED are further complicated by lack of patient information, and unrealistic societal expectations. Curtis and Patrick (1997) reported that physicians are often uncomfortable talking about death and dying, and some felt discussing EOL care could be harmful or hasten the death of a patient. Granek, Krzyzanowska, Tozer, and Mazzotta (2013) reported that discussing EOL topics was reported by oncologists as the most distressing and stressful part of their work, yet they receive little specialized training on how to communicate effectively with their patients. Misunderstandings and erroneous beliefs about the appropriateness of advance directives as well as a lack of comfort or experience initiating such discussions with patients were described as posing significant barriers to physician initiated conversations about EOL care. Jezewski, Meeker, and Robillard, (2005) reported that some emergency nurses felt
that the ED setting was not appropriate for discussing EOL wishes, but Ryan and Jezewski (2012) noted, 60 percent of critical care nurses had accurate knowledge of advance directives and were able to discuss them with a moderate level of confidence. However, other nurses in this study did express some reluctance due to lack of time, low confidence or comfort, or a perceived need for specialized skills or teaching materials in this area.

**Facilitating Patient Understanding**

One approach to addressing the problem of ED patients without advance directives is to identify and promote language that could help communicate the most pertinent, sensitive, and potentially distressing information regarding attempted resuscitation options, and the corresponding likelihood of a particular patient’s survivability. Discussing care options with decompensating near-EOL patients in the ED should provide the equally weighted option of supportive care and aggressive symptom management for allowing a natural death. Presenting the opportunity for allowing natural death to occur is critical for overcoming the misperception that opting out of attempted resuscitation means giving up and doing nothing. Fischer and Lyckholm (2012) stated that nurses have been effectively educated on identifying near-EOL patients and initiating goals-of-care discussions; their views are in agreement with the Emergency Nurses Association (2010) position that emergency nurses can provide clear and accurate information about EOL choices, elicit patient and family wishes through open-ended questioning, help families make solidly informed decisions, avoid suffering, minimize
hospitalization, and thereby prevent unwanted interventions. Consistent with the findings of Kelly, Lipson, Daly, and Douglas (2006), emergency nurses are also well positioned to facilitate discussion of EOL care, due to their close contact with patients and families, and they are likewise well suited to develop the policies, procedures, and language to identify patients for whom AND status may be more appropriate and desirable than attempted resuscitation.

Identifying Patients Needing End-of-Life Care

Identifying such patients in the pressured environment of the ED can be facilitated by some standardized triggering criteria. Glajchen, Lawson, Homel, DeSandre, and Todd (2011) implemented a rapid screening tool for palliative care consults in the ED. The criteria they used to trigger the referrals were patient age over 65 meeting illness criteria of advanced dementia, severe heart failure, chronic obstructive pulmonary disorder, malignancy or acquired immune deficiency disorder, marked symptom distress, and/or significantly declining or poor functional status. The most frequent triggering diagnoses were cancer followed by heart failure, and the most common triggering symptoms were pain followed by shortness of breath, nausea, diarrhea, loss of appetite, and failure to thrive. Gruzden, Richardson, Hopper, Ortiz, Whang, and Morrison (2012) also recommended automatic palliative care consults based on predetermined criteria. Palliative measures at EOL decrease symptom burden, improve quality of life, and increase patient/family satisfaction. Clark (2008) asserted that the EOL care model should be regarded equally with the aggressive lifesaving care model in the ED, and that
emergency nurses who help patients articulate their wishes may also help them avoid interventions with little clinical benefit.

Facilitating Informed Choice

Maguire (2012) discussed use of language by ED doctors and hospitalists for more effectively dealing with difficult conversations, angry or frightened patients, and for delivering bad news. Discussions about attempted resuscitation and associated interventions must be clear and consistent so that patients and family are able to make informed decisions regarding attempted resuscitation. Specific comfort measures and supportive symptom management that allow for the natural disease progression to arrive at its anticipated end point also need to be described in order for patients to opt for AND or DNAR status. Emphasis must be placed on there being a choice between two major pathways for EOL care; 1) of attempted resuscitation and life-prolonging measures, and 2) supportive care to allow a natural death. Identifying language that facilitates these discussions can help overcome barriers including time constraints, discomfort with the topic, and lack of established protocol. Fernandez, Deutsch, Janeiro, and Compton (2012) designed an assessment tool to evaluate the skills of physicians communicating EOL issues with acutely decompensating ED patients. The assessment tool incorporates multiple domains of EOL care as identified in the literature: seeking information, assessing life values, educating and extending care, and responding to family questions and concerns [SILVER]. The SILVER tool was intended as an appraisal and a teaching tool for improving physician proficiency with EOL discussions in the ED. The SILVER
tool was the only instrument identified in the literature that addressed specific parameters for EOL conversations with acute care patients. For the purposes of this project, the SILVER tool provided valuable guidance for identifying and categorizing language to effectively discuss EOL care choices with acutely decompensating patients and their families in the ED.

Review of the literature provides a robust discussion of how patients need to have a better and more realistic understanding of EOL care options including attempted resuscitation and allowing a natural death. Studies have also demonstrated the difficulties and barriers that ED providers experience in discussing EOL choices. More candid language is called for to dispel patient misconceptions about attempted resuscitation, to present allowing a natural death as an active care pathway. Current literature supports both the integration of palliative care interventions in the ED as well as development of clinical protocols for EOL care specifically for the ED.
METHODS

Project Design

The method of investigation for this project consisted of interviews with ED healthcare providers - physicians, nurse practitioners, and physician assistants (MD, NP, PA participants) hereafter referred to as participants. The interviews were consistent within the normal scope and professional network of the researcher’s emergency nursing practice. A case study (Appendix A) was used to present a scenario describing a decompensating patient in the ED. The patient in the scenario has a life-threatening condition and urgently needs to discuss his EOL care options. He must choose between attempted resuscitation and allowing a natural death, attempted resuscitation would likely be futile, and he has no advance directive. The scenario was designed to stimulate discussion and gain input from participants familiar with EOL situations in the ED setting. The case study format was chosen to standardize the interviews, to present specific and consistent details, and to pose precise questions so that participant responses could be objectively compared. There was also a period for open-ended discussion at the end of the interview.

Participants

During this project, fourteen participants were interviewed using the case study in Appendix A. The investigator developed the case study to elicit the types of language the participants use when discussing attempted resuscitation versus allowing natural death.
with patients and families in the ED. The participants included ten emergency department physicians, two hospitalists, one emergency department nurse practitioner and one emergency department physician assistant working for six hospitals in Montana and Arizona. The hospitals where they worked comprised three regional trauma centers and three rural Critical Access Hospitals. The participants’ years of practice experience ranged from four to 32 years.

Ethical Considerations

This project received approval by the Montana State University Institutional Review Board, and by the author’s professional project committee members. All participants provided verbal consent for the interviews. Participants were de-identified, and the only demographic information collected was the participant’s credential (MD, NP, PA) and the number of years they had been in practice.

Data Collection

The investigator read the scenario in Appendix A aloud to individual participants, posed specific predetermined questions regarding how they would discuss EOL choices with the patient in the scenario, and used probing questions to further prompt open-ended dialogue. The interviews ranged from 15-30 minutes and were documented with written field notes by the investigator. The interviews were conducted from January to March 2014. The investigator began hearing similar comments at the eighth interview and conducted an additional six interviews to ensure that saturation had been obtained.
The interview began with reading aloud the first of a two-part case study about an acutely decompensating patient in the ED for whom attempted resuscitation would likely be futile. The participants were asked how they would respond in the given scenario, specifically how they would discuss attempted resuscitation versus allowing a natural death. The second part of the case study provided further information on the poor outcome of attempted resuscitation for the case study patient. Participants were asked if they would add to or change their responses based on the new information. Probing questions were rarely needed and the participants spoke freely both about the case study patient and about their general approach to discussing end-of-life choices with patients and families. The italicized phrases below are quotes taken from the participants, and they represent the essence of shared views and responses.

Twelve topics emerged during the interviews regarding how providers discuss attempted resuscitation versus allowing a natural death. The participants’ responses were sometimes focused on the patient described in the scenario and other times their answers referred more generally to their approach to discussing EOL issues with decompensating patients in the ED. There were issues concerning how to initiate patient and family discussion, how to communicate the urgency of the situation, and how to convey the likelihood of the patient’s death. There was a focus area on terminology for describing death, dying, mortality, intubation, mechanical ventilation, and comfort care. There was discussion about addressing the uncertainty of outcomes, validating choices as well as confronting resistance, and approaching patients and families who requested advice.
There was also significant dialogue about using the term *allowing natural death*, involving nurses more in EOL discussions with patients and families, and developing palliative care protocols for allowing natural death in the ED.

**Topic 1: Initiating the Discussion**

Similar approaches and preferences were noted in how participants initiated the conversation about attempted resuscitation versus allowing a natural death with an acutely decompensating patient in the ED. Participants primarily reported a preference for speaking privately with the patient and a significant other first, before including other family members. At the beginning of the conversation, the priority was to assess whether there had been any prior discussions about EOL preferences between the patient, family, and/or their primary care provider. Many of the participants communicated some level of discomfort with EOL discussions specifically related to the lack of established relationship with patients. Participants with experience as hospitalists seemed to have more confidence, and spent more time with their responses during this phase of the interview.

*At first I think it’s best to speak with the patient alone, without all the family there. It’s important to have that first conversation without an audience.*

*Whenever possible I try to limit the first interaction to the patient, spouse, and me, and keep it separate from a crowd of others. The smaller number of people is preferable.*

*I’d start with the spouse, maybe bring in an immediate or other close family member who can help with the decision, and focus the discussion on providing comfort.*
Always, the first thing I ask is about their code status, if they have a POLST, and whether they have they discussed with their primary care provider what they would want if things go badly.

None of us are super-comfortable with this when there’s no established relationship with the patient. A better conversation can happen when a relationship is established.

I think this is like many things… a large part of the battle, and it is sort of a battle, is won or lost in the first two minutes with the patient with whatever sense the patient has of the provider. Do they want to help me? Is this one warm and fuzzy or a cold technician? This is the disadvantage for the ER doc, and an advantage for the hospitalist.

### Topic 2: Urgency of the Situation

Consistent in most of the interviews was how the participant conveyed the urgency of the patient’s situation, and the need to rapidly determine what the patient would do if they should become unable to communicate their wishes.

*We need to make some decisions pretty quick. I need you to let me know now what you’d like me to do if you can’t tell me later.*

*You are very sick and this is a life or death situation. We are going to have to think about this and quickly decide what you want us to do.*

*Sir, you look fairly ill, and we need to make decisions right now about what we can do to support your breathing.*

*You will soon be faced with a decision of whether we put you on a machine or continue giving you oxygen with a mask and see how you do.*

*I need to ask you, what are your wishes if you stop breathing?*

### Topic 3: Likelihood of Imminent Death

There were two major ways that participants talked about the likelihood of the patient in the scenario surviving a life-threatening medical condition in the ED. The
approach of some participants was to give a vague approximation of the patient’s survival in terms of his poor prognosis. Others estimated the case study patient’s percent chance of surviving the current crisis.

You have lung disease with an infection on top, and this infection could be fatal; you may not recover.

We can do our best with antibiotics, fluids, and medications - morphine and anxiolytics for air hunger - but you need to be prepared to die.

You are really sick and it’s not likely that you are going to pull through regardless of the medical options.

This infection might end your life. Would you consider having a breathing tube and being put on a ventilator if you are unable to breathe on your own?

Your death could be imminent – do you want it prolonged? You have to decide if life is worth living like that.

There is a good chance that no matter what we do for him, he is going to die, whether in a few hours, a few days, or a few weeks.

If the body is ready to die, then nothing we do is going to change that, and all the attempted resuscitation we do is only going to prolong their inevitable death.

Without ventilator support there is a 95% chance you are going to die.

We are unable to predict mortality, but without ventilation the probability is extremely high, probably 100% within 24 hours.

Topic 4: Using the Words Death, Dying, and Mortality

Most of the participants used the terms death, dying, and/or mortality, but a few felt strongly about only alluding to, but not using these words directly.

I don’t use any euphemisms with families. I use the words death, dying, because that is what it is.
Keeping you here and not transferring you out we will let nature take its course. I don’t use words, death and dying but I am very specific and clarify: You will get worse, not better. In my opinion you are not going to leave this hospital in very good shape [on a ventilator].

Topic 5: Describing Intubation, Mechanical Ventilation, and CPR

Most participants described intubation, ventilation, and attempted resuscitation in similar simplified terms including: doing everything, putting a tube in your throat, a breathing machine, electric shocks, drugs, and pressing on your chest. Some further iterated their doubts that these interventions would be beneficial.

_I put a tube down his throat and into his lungs, connect him to a machine that will breathe for him._

_If their heart stops we try drugs and electric shocks to see if we can start the heart again._

_Facing the likelihood of death, I offer potential interventions like intubation if he stops breathing, or CPR if his heart stops beating._

_We could do everything possible if you stop breathing or your heart stops beating, but that would probably involve being on a ventilator. Do you want to be on a ventilator with a breathing tube down your throat? In this patient’s situation I would say, “with your type of disease, I see it would do more harm than good._

_He needs to know that it’s common when the heart stops, that we may be able to bring you back to life with CPR, but that it’s not like on TV, that the statistics are very low, less than 20% of the time does it successfully get blood back to the brain and return good neurological function._
Topic 6: Describing Medications and Comfort Care

The alternative to attempted resuscitation was typically presented as comfort care or supportive care. Some participants were specific about particular medications or treatments, while others stated they respond to specific questions or requests for more information. Reassurance about making the patient comfortable was regularly emphasized.

I offer intubation and attempted resuscitation but point out that his pulmonary function is clearly getting worse. We can do everything in our power to save your life, but there are lots of other things we can do to for comfort.

We should focus on making you comfortable.

If you want, we can give you antibiotics to try to fight the infection and we’ll make you comfortable.

I describe in detail what we would do to make him comfortable and take care of any anxiety issues.

I don’t offer a partial code status. For this patient I would say why don’t we try to make your breathing easier with an anxiolytic and nebulizer treatment. I recommend not going on the ventilator.

I have the talk about air hunger, shortness of breath, about oxycodone and other pain medicines for comfort.

Topic 7: Uncertainty of the Outcomes

After describing the potential treatment pathways, participants consistently described the uncertainty surrounding the possibility of survival and the repercussions of attempted resuscitation.

We can’t know the outcome from any of this.
You could survive with intubation but there is no survival guarantee.

It is unclear how long you might be on the ventilator; we might be able to take you off in 2 days, 2 weeks, or maybe never.

If we put you on a ventilator long-term it may be difficult to impossible to take you off the machine.

**Topic 8: Validation and Acceptance of Patient Choice**

Consistently, the participants stated they support patient autonomy and validate their choice, whatever it may be, and that ultimately the decision rests with the patient and family.

*I tell him: If you don’t want anything done, if you don’t want to be on a ventilator, we will do everything we can so that you don’t have pain, we will make you as comfortable as possible and we can continue to treat the infection.*

*I reassure them that it’s ok to let him go.*

We could try to treat you as aggressively as possible, and intubate if needed to make the transition more comfortable. But if you don’t ever want to be on a ventilator, that’s ok too.

*Ultimately it’s what you want. What do you want us to do when you can’t tell us? When do we let you go?*

**Topic 9: Addressing Resistance**

When faced with patients and families who insist on attempted resuscitation when the outcome is likely going to be futile, participants described seeking alignment with the patient and family. Participants stated they would clarify the patient’s current situation and the doubtful success of attempted resuscitation. They were often more direct in
explaining how heroic interventions are probably not going to change the likely outcome, and how attempted resuscitation will only prolong the patient’s inevitable demise, and may actually increase their suffering.

It is rare that patients, when they are by themselves, ask you to do everything. They understand that connecting you to a machine is not going to change anything. Regardless, I then bring the family together and rehash saying: We’ve had a discussion and here’s our plan. It’s hard when an individual has an audience, there’s the guilt.

I am always seeking alignment with the family, clarifying things based on my experience as a professional and a human being. It is very rare for me to have a lot of resistance.

When the patient or the family insists on doing everything, despite the fact that the body is getting ready to die, I explain everything again.

There are a few things we can do in the short term to improve your breathing. Basically, there are things we can do for you, or things we can do to you. I worry that if we do too many aggressive things that we may not actually help you.

Your prognosis is not good with this infection. Do you want us to try a lot of things that may only prolong your suffering?

You are very likely going to die from this in a few hours. I feel strongly that [intubation] is not the right thing to do and that we need to focus on comfort.

We have to be on the same page – you have to choose life or death and decide what is the goal.

The worst thing is not knowing what to do: like when I’m coding a patient after the husband says: Do everything you need to do. Then the patient’s daughter shows up and insists I stop: This is definitely not what Mom would want, Dad doesn’t know any better.
Topic 10: When the Patient or Family Ask Advice

Some participants described how patients and families sometimes ask their opinion, what they recommend, what they would do in the same situation. Participants reported they avoid giving advice on what they themselves would do in a similar situation, but may provide some input on what they would wish for a loved one.

*In cases where they don’t know what to do, they ask: What would you do [for me]? There is what we can do – ventilator, and transfer to an ICU, and there’s what I would do - antibiotics etc… and you would not go to the ICU. Often what I’ll do with more naive patients is say: Let me make sure we know what you want.*

*If they say they want everything done, I then think about re-presenting the options. These are tough decisions. I don’t tell patients what I think they should do, but I will tell you that if you were my dad, this is what I would do: Make him comfortable and not do anything aggressive. If this is still too unpalatable to them, I may go ahead and intubate him anyway, even if I don’t think it’s the right thing to do. My goal is to make sure we are not being overly aggressive and that we are in alignment with the family in getting them to see the wisdom of this.*

Topic 11: Using the Term Allowing Natural Death

Few participants reported actively using the term allow natural death (AND). Most of the participants were slightly or completely unfamiliar with the term AND, but were enthusiastic about adding it to their vocabulary for use in future patient discussions. There was considerable support for its implementation with concurrent provision of comfort care while the patient is still living, in place of do not resuscitate/no not attempt resuscitation (DNR/DNAR) orders only which apply after death. Several participants
reported they avoid speaking about death directly and favor variations of the expression letting nature take its course.

*We can do things… to extend your life, but some people also choose to allow a natural death if that’s your preference. People often communicate verbally or non-verbally that they don’t want to be connected to a machine and that they want nature to take its course.*

*It’s important to have the conversation about what we’re going to do, because the DNR kicks in after death. AND gives some clarity to the situation, and it needs to be clarified in the case of futility [of attempted resuscitation] because there is a tendency to dismiss [the patient with a DNR]. AND takes more of a look at the big picture for treatment while the person is still living.*

*AND is something I am using more and more. We need to describe it that way. I don’t use any euphemisms with families.*

*AND… that’s good, I like it, I haven’t really said it that way, but I am going to start talking about it like that. It’s a nice way to put it, so it doesn’t sound like we do nothing.*

*I wouldn’t say so bluntly that he is dying and a ventilator is only going to prolong his life. The AND language is interesting. I don’t use it now; maybe I’ll start using it when I talk to patients.*

*AND is not the term I use, but I do talk about it in terms of letting the body do what it is ready to do.*

*I tell them that it’s ok whatever they want to do, and that it’s totally ok to do nothing. But death and dying is not what I talk about, I don’t like to put it that way, and the family gets it anyway. They don’t want to hear those words.*

*Typically I don’t use the language AND. I tell him if you don’t want anything done, if you don’t want to be on a ventilator, we will do everything we can so that you don’t have pain, we will make you as comfortable as possible and we can continue to treat the infection.*

*I don’t use the words death and dying but I am very specific and clarify “You will get worse, not better. In my opinion you are not going to leave this hospital in very good shape [on a ventilator]… Death is going to be*
part of the discussion, but I am not going to be slapping them in the face with it.

Topic 12: Open-Ended Comments

Following the standardized interview questions, there was time for open-ended dialogue. Two points were made that were not directly related to the participants’ hypothetical discussion with the case study patient.

The Role of Nursing in End-of-Life Discussions

First there was general support by the participants (physicians, nurse practitioner, and physician assistant) that nurses should take a bigger role in EOL discussions. There was acknowledgment that nurses establish a rapport and relationship at the bedside that could facilitate discussions with patients and families about attempted resuscitation versus allowing a natural death. Unfortunately there was also some concern about nurses doing more harm than good, and reported cases of inpatient nurses encouraging patients to reverse their DNR status. There was a comment that nurses should not be required to have EOL discussions, but ought to be encouraged if they are comfortable with the topic. There was a recommendation that nurses achieve a better understanding of EOL care choices, and to talk more with patients about their code status.

Nurses talking about allowing a natural death, great…I think they should, they are spending way more time in the room with them. Makes total sense.

It would be good for a nurse to have this conversation because they are right there at the bedside. The ER nurses establish a relationship and a rapport that can set the stage; they can recommend the patient talk to
their family. The AND language is awesome for framing the concept that it’s ok to choose a natural path, that it’s not failure, or an absence of treatment, or a removal of treatment. AND is a different framework from the current medical forum.

It’s outstanding for a nurse to have this discussion. They key is if the nurse is comfortable having the conversation. It shouldn’t be a requirement, but I have no problem having the RN have that discussion with any patient given their comfort level. Bringing it up [the patient] with someone else [the nurse] can help clarify “He did say death didn’t he?” I’m all for it [RNs having the discussion]. It shouldn’t be a requirement, but if they are comfortable.

It would be great for nurses to have a better understanding of code status and to talk with more with patients about DNR/DNI status. However, I do see nurses who talk to DNR patients about reversing status in favor of full code.

There have been some cases of bad bedside nursing…the patient and family had agreed to no code and comfort measures after we talked about him having less than a 5/100 chance of survival. An RN had a conversation with family on the telephone, said she had a relative with the same condition who used prayer and food and had an incredible recovery. It sowed the seeds of doubt and it was a disaster, now there was all this damage control that we had to do.

A Go-to Resource for End-of-Life Care in the ED

The second point was regarding development of standing orders or a go-to resource for EOL patients in the ED. The speculation was that such an instrument could help guide care and avoid panic and escalation to likely futile attempted resuscitation in the instances where patients begin to experience distress.

Standing orders would be good, to help things keep from escalating when patients come hypoxic and in distress. Because the ER is so used to coding folks it would be helpful to have some kind of go-to resource.
The interviews conducted for this project add to our understanding of how emergency physicians, nurse practitioners and physician assistants discuss with patients and families the concepts and implications of attempted resuscitation versus allowing a natural death. The results present several implications for clinical practice among emergency physicians, nurse practitioners, physician assistants, and nurses. If participant interview responses are generally representative of ED providers, there is a need to replace ambiguous language with more frank and detailed discussion of EOL care options. ED providers need to become more comfortable discussing EOL care, and give patients and families the full benefit of making informed decisions in line with their goals of care. The key is in finding ways to make the conversations less distressing, sharing with each other – across disciplines - more effective ways to communicate about these topics. Training ED physicians, nurse practitioners, physician assistants, and nurses on better ways to have these difficult conversations gives us the opportunity to engage in more meaningful dialogue with patients and families about attempted resuscitation and allowing a natural death as alternate and equally valid pathways.

Likewise, there are opportunities to incorporate the findings of this project into nursing. Encouraging nurses to take a more active role in EOL discussions at the bedside dovetails nicely with patient teaching, and addresses one of the difficulties stated by project participants and substantiated in the literature: lack of established relationship with the patients. The nurse spends proportionately more time at the bedside, establishing trust and a rapport. The nurse is well positioned to initiate dialogue about attempted
resuscitation versus allowing natural death, and to be the sounding board as patients process new information. Preparing nurses for greater involvement in patient-family discussions about attempted resuscitation or allowing natural death could promote more thorough understanding of what supportive care looks like as an active treatment pathway. Nursing education also has the potential to make a significant impact: In addition to learning about EOL care, there’s an opportunity to teach new nurses how to talk about it the bedside. Role playing for nursing students – ideally, for all students involved in patient care - could lay the groundwork for more effective EOL conversations between future healthcare professionals, patients, and families.

The practice of palliative care in the ED is rapidly gaining ground through the strong work of the Center to Improve Palliative Care (2014), the Improve Palliative Care (IPAL) Project (2014), and the National Consensus Project for Quality Palliative Care (2013). Rosenberg and Rosenberg (2013) describe the robust approach of an integrated palliative care program piloted by the emergency department at St. Joseph’s Health Care System in Patterson, New Jersey. As resources and enthusiasm for palliative care continue to grow, a national standardized protocol should be developed to guide EOL care in the ED that is analogous to the national standardized protocol for attempted resuscitation.

Further research into the language used to discuss attempted resuscitation and allowing a natural death could help us develop and share more standardized language with ED providers. It would also be meaningful to find out what patients and families already know about attempted resuscitation and allowing natural death. What do they
want to hear? Want do they want to know in order to make informed decisions about their EOL care?

The term and the practice of allowing natural death (AND), supported with palliative care, should be presented to patients as an active intervention for a living person, and it should replace the do not resuscitate (DNR) order which applies only after a person’s heart and/or breathing has ceased. Offering supportive interventions for AND will help us move away from the ambiguous language of “doing everything” when talking about attempted resuscitation, and the implied alternative of doing nothing in the case of a DNR order. A more realistic conception of what palliative care options look like in the ED would help dispel the erroneous perception that attempted resuscitation is an all-or nothing proposition. Ultimately, fostering deeper understanding of the equally dynamic treatment pathways of attempted resuscitation or allowing a natural death can better assist patients and families to make informed decisions about end-of-life preferences which are aligned with their goals of care.
REFERENCES CITED


Center to Advance Palliative Care (2014). *Palliative care tools, training, and technical assistance*. Retrieved from http://www.capc.org/


Gruzden, C. R., Richardson, L. D., Hopper, S. S., Ortiz, J. M., Whang, C., & Morrison, R. S. (2012). Does palliative care have a future in the emergency department?


APPENDIX A

INTERVIEW SCRIPT: CASE STUDY OF AN ACUTELY DECOMPENSATING PATIENT IN THE EMERGENCY DEPARTMENT
My name is Catherine Kelly and I am a Nurse Practitioner student from Montana State University. As part of my Master of Nursing degree I am working on a professional project titled *Discussions about end-of-life care in the emergency department: To attempt resuscitation or allow a natural death*. I’m interested in understanding the language that health care providers use with patients and families to discuss end-of-life issues, specifically attempting resuscitation, and/or allowing a natural death in the emergency department.

Your involvement in the project is voluntary, your information will remain confidential, and you may refuse to continue at any time or for any reason. Are you willing to engage in a 15-minute conversation about this topic? May I have your verbal consent to participate in this project? In addition to your comments, I plan to collect demographic data about your credentials (MD, NP, PA) and years of practice experience.

The following is a scenario involving a hypothetical patient who presents to the ER. He is in respiratory distress, has a poor prognosis related to preexisting conditions, and his decompensation could precipitate intubation and attempted resuscitation. For the purpose of this case study, the assumption is that intubation and
attempted resuscitation would likely have a poor or futile outcome.

Scenario, Part I

In a rural Montana hospital, a frail 69-year old man presents to the emergency department with a fever of 40C, hypoxia with SaO2% in the mid-60s, and in profound respiratory distress. Chest x-ray shows extensive bilateral infiltrates and honeycomb markings. He is diagnosed with bilateral pneumonia with a preexisting diagnosis of interstitial lung disease as noted in his chart.

His pulmonary fibrosis was detected two years ago; he has not been to his primary provider in six months, and has not yet seen the pulmonologist who he was referred to at that time. Though he was prescribed home oxygen therapy he has not been using it. He has a 70+ pack-year smoking history and continues to smoke, however he reports that he recently cut down to one-half pack of cigarettes per day. He has Type II diabetes, hypertension, and had a right upper lobectomy for a lung abscess in 1987.

The patient is now sitting at the edge of the bed in a tripod position, anxious, and fatigued. His respiratory rate is 38. His SaO2 is 86% on 15 liters of oxygen by non-re-breather mask. He is alert and oriented, and able to answer questions appropriately. His wife is at the bedside, immediate family members are present in the waiting area, and he has many extended family members nearby in the community. You are providing care for this patient. He is becoming increasingly fatigued and your facility has no capacity to care for a ventilated patient. Transfer to a higher level of care is by air transport to a hospital 125 miles away.
Questions

When you are faced with this sort of scenario in the ED:

1) How do you describe attempted resuscitation to the patient and family members?
2) How do you describe allowing a natural death to the patient and family members?

Dialogue with participant occurs here

Scenario, Part II

You discussed care options and the patient and his wife ask for “everything to be done, because you never know how it’s going to work out” however they don’t think being on a ventilator is a good idea and decline intubation. Their son was on a ventilator once and “it was awful for him, tearing at the tube, and then they had to tie him down.” They also prefer not to be transferred to another hospital and would like to see how he feels tomorrow. Patient then requests a doctor’s note to get out of jury duty in two weeks.

Over the next 6 hours his condition worsens, his respiratory rate is 46 and he can barely maintain 80% SaO₂ on 15 liters of oxygen. The family panics; the patient is intubated and he is transferred by air to a higher level of care where he dies 36 hours later.
Questions

With the benefit of hindsight:

3) How else might you have described attempted resuscitation to the patient and family members?

4) How else might you have described allowing a natural death to the patient and family members?

Dialogue with participant occurs here

I want to thank you for your participation in this project; your insight and experience are very much appreciated.