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EXPLORING MORAL PERMISSIBILITY OF NURSE PARTICIPATION IN LIMITED
RESUSCITATION

A Dissertation

Submitted to the School of Nursing and the Graduate School of Liberal Arts

Duquesne University

In partial fulfillment of the requirements for
the degree of Doctor of Philosophy

By

Felicia Stokes

May 2022

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Felicia Stokes

2022

EXPLORING MORAL PERMISSIBILITY OF NURSE PARTICIPATION IN LIMITED
RESUSCITATION

By

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Approved April 7, 2022

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ABSTRACT

EXPLORING MORAL PERMISSIBILITY OF NURSE PARTICIPATION IN LIMITED RESUSCITATION

By

Felicia Stokes

May 2022

Dissertation supervised by Dr. Joris Gielen

This dissertation offers a novel approach to support nurses when they face conflict between clinicians and families or alternate decision-makers over potentially inappropriate end-of-life goals of care. This dissertation will provide a normative analysis of the moral permissibility of limited resuscitation, with arguments supported by analyses of families' and nurses' perspectives and actions in the EoL decision-making process. Limited resuscitation is a cardiopulmonary resuscitation effort where full pharmacologic and mechanical intervention is not used, or the length of the resuscitative effort is shortened. It is typically associated with deception because it is performed without the knowledge of patients and families. This dissertation argues nurses may participate in limited resuscitation so long as it is performed transparently and without deception, and with full disclosure to patients and alternate decision-makers. It is morally permissible for nurses to participate in disclosed limited resuscitation

because it acknowledges patients' and families' vulnerability and autonomy, establishes trust between nurses and families, and is a beneficent act that respects cultural humility and allows alternate decision-makers to have an active role in end-of-life decision-making. Nurse participation in disclosed limited resuscitation is also morally permissible because it mitigates threats to a nurse's moral identity and ethical comportment by eliminating physically intrusive acts that cause suffering, which can contribute to moral distress, and moral disengagement.

This dissertation offers to reframe limited resuscitation as a new end-of-life option that is transparently communicated to families in culturally appropriate ways to nudge family members towards the acceptance of choosing the least harmful EoL interventions that preserve dignity and avoid suffering for their loved ones. Solutions designed to promote transparency and minimize conflict in end-of-life decision-making include tailored resuscitation orders, consultation with ethics committees, family presence at the bedside, nurse's explicit commitment to nondeceptive end-of-life practice, moral leadership that fosters an ethical environment, and nurse-led time-limited trials. These interventions are all mechanisms to eliminate deception which can build trust, mitigate nurses' moral distress, preserve patient autonomy, and cultivate a shared acceptance of limited resuscitation as a morally permissible end-of-life option.

DEDICATION

This dissertation is dedicated to Mary B. Allen, who has always been my shining light of hope, love, and encouragement.

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I would like to first thank God the Almighty for allowing me to pursue this incredible journey. Our steps in life are ordered and I am blessed that God has chosen this path for me. I would also like to thank my beautiful, loving, and supportive family (including my chosen family) for your patience and understanding of my sacrifices. Thank you for always lifting me up, encouraging me, and filling me with love.

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LIST OF ABBREVIATIONS

ADM	Alternate Decision-Maker
CPR	Cardiopulmonary Resuscitation
DNAR	Do Not-Attempt-Resuscitation
DNR	Do Not Resuscitate
EoL	End-of-Life

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Chapter One: Introduction

1 Introduction

Nurses and other clinicians are responsible for delivering appropriate end of life (EoL) care and must do so within the clinical, legal, and ethical obligations of their profession. Yet, disputes among patients, surrogates, nurses, physicians, and other health care team members regarding the delivery and ethical appropriateness of EoL care have existed for years. The ethical conundrum of the appropriate use of life sustaining treatments in EoL care is pervasive in healthcare as advanced technology continues to allow humans to extend life. The clinical, ethical, moral, and legal debates around EoL care are justly scrutinized because the potential outcome of death is irreversible. The overall societal culture of “death avoidance” and extending life is simply one factor in the complex decision-making processes at the EoL. The emotional and psychological factors involved in EoL decision-making are tremendous for everyone involved, especially in cases where the patient is unable to communicate their wishes. Patients and families may present spiritual, cultural, and value-laden expectations about the EoL process which often result in demands for clinically inappropriate care as a desperate measure to keep their loved one alive.

Nurses are squarely at the crux of the dilemma, as they are in a privileged position and are highly skilled to deliver EoL care to patients and support for families. Nurses are expected to carry out clinical orders directed by physicians, yet often have little to no input into the EoL decision-making process. This can include performing repeated occurrences of cardiopulmonary resuscitation (CPR), and other procedures to initiate life-sustaining technologies such as dialysis, mechanical ventilation, and the administration of high-powered intravenous medications. Even in circumstances when the nurse’s input is considered, the health care team's EoL care plan may be

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vastly different from the family's or surrogate's expectations. Family or surrogate demands for EoL treatment often supersede the physician's recommendations, which may result in patients near the EoL experiencing treatment that is physically invasive and painful if physicians acquiesce to the demands. Intermediate efforts by clinicians to provide palliative and comfort care are often resisted by families because grief, mistrust, low health literacy, and poor communication can plague the decision-making process (Glick et al., 2018; Ladin, Buttafarro, Hahn, Koch-Weser, & Weiner, 2018; Wicher & Meeker, 2012).

Nurses who practice in areas with high exposure to death and dying- specifically perceived aggressive EoL treatment- are especially vulnerable to moral distress. Moral distress is defined as "when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action" (Jameton, 1984, p. 6). Moral distress occurs because as patient advocates, nurses may perceive that the care that is ordered is aggressive, causes suffering, and strips patients of their dignity (Ferrell, 2006; Gallagher et al., 2015). Nurses feel constrained by physicians or families who support physically invasive interventions and are distressed because they feel compelled to perform CPR in the event a patient arrests, even in patients with a poor expected outcome (Gallagher et al., 2015; Laurent, Bonnet, Capellier, Aslanian, & Hebert, 2017). A complexity of ethical issues at the EoL can lead nurses and other clinicians to perform limited resuscitation attempts that are not intended for patient survival. Limited resuscitation is a cardiopulmonary resuscitation (CPR) effort where full pharmacologic and mechanical intervention is not used, or the length of the resuscitative effort is shortened. Using practical bioethics and feminist ethics frameworks, this dissertation will argue that limited resuscitation is morally permissible under certain conditions and nurses may participate in limited resuscitation so long as it is performed transparently and without deception. It is morally permissible for nurses to

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participate in limited resuscitation because it supports patient autonomy, shared decision-making, and preserves trust in the health care relationship. Certain forms of limited resuscitation do not defy existing laws and in fact, the lack of legal clarity for families and clinicians around resuscitation supports permissibility. This dissertation will further argue that limited resuscitation is morally permissible because it mitigates nurses' moral distress by eliminating the delivery of physically intrusive acts associated with CPR, therefore interrupting the nurse's moral reasoning from distress to disengagement by minimizing patient harm and suffering.

Through case analysis, this dissertation will provide practical solutions to address limited resuscitation and determine moral permissibility in different clinical situations. Solutions such as consultation with ethics committees, family presence at the bedside, nurse's commitments to professional ethical codes, time-limited trials, and tailored physician orders for limited resuscitation are all mechanisms to eliminate deception and assure disclosure and transparency when limited resuscitation occurs. Transparent limited resuscitation occurs and should be supported in clinical practice because it supports patient autonomy, preserves nurse's professional integrity, and mitigates moral distress associated with delivering medically inappropriate care.

2 The Ethical Perspectives of Cardiopulmonary Resuscitation

The end of life is the paramount moment when a health care professional must apply knowledge and skill to provide the most optimal care for a patient. This care must be honest, forthcoming, respectful, and in the patient's best interest. It is undisputed that resuscitation will not improve a patient's prognosis. Resuscitation simply brings the patient back to their condition before the cardiac arrest or even worse, it harms the patient more. The patient's present condition remains unchanged until the underlying cause of cardiac arrest is determined (de Vos, 2001). A patient's prognosis or life expectancy is frequently known but never factually certain (Gazelle,

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1998). In some patients, chances of successful resuscitation are remote, making treatment medically inappropriate (Tíscar-González, Gea-Sánchez, Blanco-Blanco, Moreno-Casbas, & Peter, 2019). However, before the determination of medically inappropriate care is made, it is critical to weigh the benefits and burdens of treatment taking into account patient values and judgments (Tíscar-González et al., 2019).

In situations when patients are unable to express their wishes, family's or surrogate's decision-making can make resuscitation ethically complex for the health care team (Tíscar-González et al., 2019). Initially, it may also be challenging to identify the legal surrogate for decision-making, especially in cases of estranged relationships or partnerships that are not legally recognized. This is especially difficult in time limited EoL decisions requiring a rapid decision due to deteriorating clinical conditions. Clinicians usually rely on a patient's surrogate to make decisions and are prepared to override a patient's advance directive (Pope, 2013). Surrogates may advocate for treatment against the patients documented wishes or avoid decisions due to a lack of confidence in what the patient may have preferred at the EoL (Lipnick et al., 2020). In addition, surrogates may often experience anticipatory grief which is associated with impulsivity, carelessness, and avoidance in decision-making (Glick et al., 2018). As a result, surrogates are often unable to effectively problem solve and make decisions, resulting in poor communication and patient outcomes (Glick et al., 2018). Surrogates may also experience personal guilt or blame from other family members for choosing a do-not-attempt-resuscitation (DNAR) order or less aggressive measures and therefore decisions are based on personal considerations of the surrogate rather than previously documented wishes or best interests of the patient (Su, Yuki, & Hirayama, 2020). Research has found that surrogate decisions often fail to reflect the patient's values and preferences, and in situations when patients recover, surrogate-patient concordance is low

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(Mishkin, Allen, Hulkower, & Flicker, 2021). On many occasions, resuscitation is deemed unwarranted by the health care team, especially in terminally ill patients, because there are no physiologic health benefits (de Vos, 2001). As a result, negative patient and family outcomes frequently occur due to circumstances of overtreatment, prolonging the dying process, and contributing to the high cost of health care at the EoL (Mishkin et al., 2021).

In order to understand the ethical quandaries of resuscitation, it is important to summarize how the dichotomy of “to code, or not to code” evolved.

2.1 The Evolution of Cardiopulmonary Resuscitation

In the 1940s, physicians discovered the use of pharmacologic and electric rhythm interventions that could redistribute the electrical activity in the heart and restore a heartbeat (H. D. Adams & Hand, 1942). The first case of electric defibrillation was reported in 1947 after a patient’s heart had stopped beating in a normal survival rhythm for over 70 minutes (Beck, Pritchard, & Feil, 1947). This type of emergency cardiac resuscitation was rare and selective and performed in operating or recovery rooms (American Heart Association, 1980; Bjorklund & Lund, 2019). From the 19th century until 1958, patients experiencing a cardiac arrest were treated with manual pressure on the chest or back and lifting the arms to cause inhalation and exhalation (R. Fowler, Chang, & Idris, 2017). Prior to the 1960s, full components of CPR, including external compression, were rarely attempted and patients would die a natural death without any medical intervention (Hardin, 1998). Cardiopulmonary resuscitation (CPR) was officially initiated in 1960 with the intent to restart a patient’s heart that no longer had effective pumping abilities in acute events such as “myocardial infarction, drowning, electrocution, or anaphylactic shock” (Dolan, 1984; Hollingsworth, 1969, p. 43). CPR was explicitly created for patients with an acute injury,

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and not for dying patients with irreparable damage to the heart, lungs, brain, or any other vital organs (Talbot, 1965).

CPR soon became a novelty and increasing advances in medical technology created effective ways to artificially prolong life (Elkinton, 1970). Numerous studies had been conducted to measure the effectiveness of CPR with mixed results (Hofkin, 1967; Hollingsworth, 1969; Jordan, Lavin, & Hamelberg, 1964; Jude, Kouwenhoven, & Knickerbocker, 1961; H. J. Smith & Anthonisen, 1965). Yet, the practice of CPR was widely used and soon considered an accepted practice, especially in emergency and intensive care units (Dolan, 1984). These advancements in resuscitation created unintended consequences, such as moral dilemmas and confusion around criteria to allow a natural death versus interventions to prolong life (Elkinton, 1970). Some physicians advocated that an act of commission to end a patient's life was the equivalent to an act of omission to resuscitate one's life (Elkinton, 1970). In 1969, a survey of academic physicians revealed that 80% had failed to resuscitate a patient with a terminal illness and 87% favored not performing resuscitation (Elkinton, 1970; Williams, 1969). A similar survey of hospital physicians the following year found that only 50% were in favor of not resuscitating a patient with a terminal illness, but rather allowing a natural death (Brown, Bulger, Laws, & Thompson, 1970; Elkinton, 1970).

End-of-life treatment was further complicated by the development of powerful resuscitative interventions such as antibiotics, intravenous fluids, advanced CPR, and organ transplants (Elkinton, 1968). A great deal of ethical angst arose regarding the distributive justice, or fair allocation of resources used in resuscitation (Elkinton, 1970). Physicians were concerned about patient autonomy and the morally right action to carry out life-prolonging efforts (Elkinton, 1970). For some patients, the efforts to relieve suffering and die with comfort far outweighed the

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physician's duty to preserve life (Elkinton, 1968). Physicians often felt unprepared, inexperienced, and lacked professional guidance or standards (Galbally, 1973).

Public media intensified these ethical debates, due to various national and international layperson news about which patients should receive CPR and which should not (Elkinton, 1968). A news story from England captivated the public by reporting that patients over 65 or with specific diseases would not be privy to CPR or other resuscitative techniques (Elkinton, 1968). This was a critical moment for ethicists to consider how ageism and justice were weighed in end of life decision-making. The public and health care communities were further divided between when to persist in efforts to maintain life and when to desist to allow dying with dignity for those patients with intractable pain or who were terminally ill (Elkinton, 1970).

2.1.1 Unintended Consequences

As CPR evolved, the routine frequency in the application of the procedure began to be viewed as an agonizing measure. As the successful outcomes of CPR began to flourish, requests to resuscitate *any* patient dramatically increased, and the original intent for emergency treatment was lost (Dolan, 1984). Elderly patients with terminal conditions or patients with end-stage cancer and multi-organ failure were successfully resuscitated but generally remained connected to more life-prolonging technology, only to survive a short amount of time longer (Dolan, 1984). Bioethics literature soon began to delineate between circumstances when CPR was appropriate and when it was not (Goldberg, 2007). This ethical quandary caused a great deal of confusion in the health care community and posed a lack of clarity among patients and clinicians. Covert efforts were made to document the inappropriateness of resuscitation in charts, including placing hearts or stars on a patient's chart to alert other health care staff that there was an unresolved debate about end of life care (Cohn, Fritz, Frankau, Laroche, & Fuld, 2013). In the U.S., some charts had "not for the code"

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buried in the notes, and in the United Kingdom, “not for 222”, referring to the public address number called for the code team in hospitals (Cohn et al., 2013). Clinicians were not the only ones questioning the appropriateness of CPR. Many patients felt CPR only prolonged suffering and did not restore dignity or improved quality of life (Bosslet et al., 2015; Goldberg, 2007). The desire to refrain from such aggressive measures and conquer medical paternalism resulted in do-not-attempt-resuscitation (DNAR) orders.

2.1.2 Do-Not-Attempt-Resuscitation Orders

The default modus operandi of most clinical procedures is to act or take a positive step toward something (Cohn et al., 2013). Yet, in 1974, Do-Not-Resuscitate (DNR) orders were the first advance directives to withhold treatment, and have become one of the most recognizable acronyms in health care today (Burns & Truog, 2016). DNR orders were originally created to provide a transparent method to document a patient’s decision-making about resuscitation, acknowledge the informed consent obtained from the patient, and created an opportunity for health care teams to discuss and document EoL preferences in advance of an event (Burns & Truog, 2016). The original term Do-Not-Resuscitate (DNR) was informally updated to DNAR to improve the clarity of the instruction during a cardiac arrest (Cohn et al., 2013). DNR is misleading and implies to patients and families that clinicians could have resuscitated a patient, but chose not to (Cummins et al., 1997). In 2005, the AHA formally updated its policy language to DNAR to create a supportive environment to explain to patients and families that DNAR reduces the implication that resuscitation is likely (Breault, 2011). In some countries, the term not-for-resuscitation, or DNACPR is used to convey that only the CPR portion will be removed from EoL care (Cohn, Fritz, 2013). For the purposes of this dissertation, DNAR will be used. Two primary rationales supported the shift toward DNAR orders. DNAR orders became a broad movement to promote

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patient autonomy and to assure that the values of the patient would have priority over those of the clinician (Goldberg, 2007). Second, proponents argued that DNAR orders resulted in a reduction in cost for the use of high-tech and expensive life-sustaining equipment and thus an economic benefit for the health care system (Hite, 2000).

The applicability of DNAR orders varies. Research shows that 33-67 percent of patients who receive CPR have an underlying fatal disease and missed opportunities to apply a DNAR order occur 85% of the time (Cardona-Morrell et al., 2016; Findlay, Shotton, Kelly, & Mason, 2012; Willmott et al., 2016). Physicians express barriers to writing DNAR orders including deferral of responsibility, time pressures, and poor documentation structures (Levinson, Mills, Barrett, Sritharan, & Gellie, 2018). Decades later, DNAR orders remain controversial because they direct health care professionals *not* to perform an action, and thus may be perceived as a lack of care by patients and other health care professionals. Studies show that a reduced intensity of care may be provided after a DNAR order is initiated; yet, it is designed to only withhold CPR and not affect therapy otherwise (Jonsson, McNamee, & Campion, 1988). The ambiguity related to the clinical implications of DNAR orders contributes to poor acceptance and low compliance among clinicians (Tsang, 2010).

2.2 Distinguishing Basic and Advanced CPR

Cardiopulmonary resuscitation has progressed significantly from the 16th century when techniques were used to blow tobacco smoke into the mouths and rectums of drowning victims for physical stimulation (M. Olson et al., 2018). Simply stated, CPR is an emergency intervention that can help save a person's life if their breathing or heart stops (CDC, 2021). Despite efforts to standardize CPR using an algorithmic approach, ambiguity and clinical variability in the parameters of CPR exist (Hunziker et al., 2011). Research has shown that a hospital-based team

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approach to CPR is challenging when algorithms are tailored to an individual emergency response to a patient when there are no signs of life present (Hunziker et al., 2011). In addition, vague language used in CPR response algorithms, such as “limited intervention” or “futile care” result in confusion and poor performance outcomes for clinicians (Dignam, Thomas, Brown, & Thompson, 2019). Lack of clarity around the definition of CPR and resuscitation more broadly often leads to misunderstandings related to orders to limit or not attempt CPR.

When the heart stops, also known as cardiac arrest, the average patient has only approximately eight minutes’ worth of oxygen in the body (R. Fowler et al., 2017). Every minute that CPR is delayed increases the patient’s mortality by 10 percent (Ali & Zafari, 2007; Hunziker et al., 2011). There is a rapid progression toward death when the heart stops and no longer pumps oxygenated blood to organs in the body (R. Fowler et al., 2017). The American Heart Association recommends initiation of CPR within one minute after cardiac arrest (de Caen Allan et al., 2015; Panchal Ashish et al., 2020). Basic cardiopulmonary resuscitation, also known as Basic Life Support (BLS), generally involves vigorous compressions on a patient’s chest, designed to move the oxygen around to reach essential organs (R. Fowler et al., 2017). Chest compressions are an essential component of CPR that are needed at least 60% of the time to maximize patient survival (R. Fowler et al., 2017; Iyanaga et al., 2012). Unfortunately, the rigorous nature of chest compressions can result in rib fractures, a cracked sternum, hemorrhage, perforation of the lung cavity, or tears to other vital organs (Bjorklund & Lund, 2019). The American Heart Association recommends chest compression are delivered “hard” at least 2 inches into the adult patient’s cavity at approximately 100-120 times per minute with minimal interruptions (Panchal Ashish et al., 2020).

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One significant difference between Basic Life Support (BLS) and Advanced Life Support (ALS) is the establishment of an advanced airway. ALS is often performed in intensive care units or by Emergency Medical Services through an algorithmic approach that involves airway management, sometimes requiring the placement of a plastic tube down through a patient's mouth into the trachea to assist with ventilation (Panchal Ashish et al., 2020). The tube is then connected to a ventilator which can deliver pressure and oxygen to the lungs. If necessary, CPR may also involve high-powered electric shocks from a defibrillator designed to restore the heart's function and rhythm in the event it suddenly stops. ALS may also involve the placement of large central line catheters for the administration of high-powered resuscitative medications such as amiodarone and lidocaine designed to correct lethal heart arrhythmias associated with cardiac arrest, and sodium bicarbonate used to treat severe metabolic acidosis in cardiac arrest (Panchal Ashish et al., 2020). The large catheters are susceptible to infections and may cause damage to the tissue where they are placed. Additional high-powered medications known as vasoactive intravenous medications, including epinephrine, dopamine, nitroprusside, and vasopressin, are used to support the hemodynamic therapy and restore perfusion back to the tissues (Hollenberg, 2011). Despite the lifesaving potential, all of these drugs may cause irreversible damage to the heart and other organs (Bremer & Sandman, 2011).

Cardiopulmonary arrest is the end point of all human life, but not all scenarios are the same (Georgiou & Georgiou, 2019). Basic Life Support is often considered the traditional public understanding of CPR and is one event that is more simplistic (i.e., chest compressions and defibrillation) and can be performed in acute care settings, but also by trained laypersons outside of the hospital setting. On the other hand, Advanced Life Support is a continuum of CPR that is performed by clinicians in specialized areas with adequate emergency equipment (i.e., intravenous

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medications, intubation, and interventions immediate post-cardiac arrest). It is this continuum of resuscitation that becomes life-sustaining treatment, such as maintenance of mechanical ventilation and intravenous hemodynamic medication therapy.

The success rate of CPR depends on many factors such as the location of the cardiac arrest, the equipment available for resuscitation, the cause of the arrest, and the health status of the patient (Veteran's Health Administration, 2000). Even in normal circumstances, CPR is an invasive technique with a poor likelihood of success (Bosslet et al., 2015). Recent inpatient statistics give an average of 15-30% survival for adult patients who survive cardiac arrest to hospital discharge, with a decrease in survival related to comorbidities (Gershengorn, Li, Kramer, & Wunsch, 2012; Mallikethi-Reddy et al., 2017; Panchal Ashish et al., 2020). It is especially grim for adults age 70 and above, with only 11.6-18.7% surviving until hospital discharge (van Gijn, Frijns, van de Glind, C. van Munster, & Hamaker, 2014). Resuscitation is a temporary treatment in these patients and often leaves an emotional toll on the family and healthcare team. Given the low rate of success and the multiple invasive techniques used in CPR, some scholars opine that resuscitation is especially harmful to a patient who is already physically compromised due to poor health (Baumrucker, Stolick, Morris, Sheldon, & Vandekieft, 2007). In these cases, CPR is deemed medically inappropriate- potentially detrimental- and can cause irreparable harm to families or loved ones of the patient, and emotional distress for the health care team involved in the EoL care.

2.3 Role of Nursing in Resuscitation and DNAR Orders

Historically, nurses have played an integral part in the resuscitation of patients. In the 1960s, generally, senior nurses participated in CPR recovery efforts, but in some countries such as Britain, student nurses were also expected to undertake this responsibility (Clark, 1967). In the typical hospital setting, a CPR team would consist of a medical house officer, medical resident,

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anesthesiology resident, head nurse, and nursing supervisor (Hollingsworth, 1969). The nursing personnel were generally first to reach the bedside and would begin external cardiac compression (Hollingsworth, 1969). Once the physicians arrived, the nurse would administer resuscitative medication as directed by the physician (Hollingsworth, 1969).

As the prevalence of CPR increased, both physicians and nurses perceived that dying was no longer viewed as an acceptable condition or “clear cut event extinguishing all living function” (p. 27), but rather as a very serious “disease”, generally fatal, but not necessarily incurable (Clark, 1967; Galbally, 1973). Many nurses felt that the end of a life of incurable disease should occur peacefully and with dignity (Clark, 1967; Elkinton, 1968). The moral and emotional toll was distinct for nurses, who were forced to decide whether to oblige with physician orders to resuscitate where no positive result was expected, or, on the other hand, follow orders not to resuscitate which felt tantamount to euthanasia (Clark, 1967). Registered nurse Ellen Markmann explains,

Any nurse who has worked in critical care can remember patients who were resuscitated only to spend days or weeks in a lingering death. But we also remember those we thought should never have been resuscitated, who have surprised us not only by living but by returning to productive lives. (Dolan, 1984, p. 44)

The tension between a physician’s order to resuscitate a “hopeless” patient and the nurse’s reluctance to cause harm created increasing turmoil among the health care team. At the time, physicians had more exposure to cardiac arrest and resuscitation as the practice of CPR was evolving, and therefore more exposure to what was considered successful results (Clark, 1967). Nurses’ personal experiences were limited, and the numerical chances of complete success were minimal. This resulted in divergent perspectives about the appropriateness of resuscitation for many patients. Nurses desperately feared that their direct efforts to save a patient’s life could

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actually provide more harm resulting in lifelong gross impairments (Clark, 1967). Nurses felt obligated to perform CPR and often received little executive support if the physician's orders were challenged for appropriateness. This became especially challenging for nurses when families inquired about the purpose and success of CPR. Nurses felt caught in between the obligation to follow physician's orders and the preservation of trust created with families.

Once DNAR orders were created, there was hope that this would help alleviate some of the turmoil among the health care team, but the practicality of their operation was challenging. Nurses were unclear on what the DNAR actually entailed. Some hospitals had policies obligating every patient, except those with DNAR orders, to be resuscitated in the event of a cardiac arrest (Dolan, 1984). However, some hospital DNAR policies simply meant that the nurse was not to able titrate up on any medication or add any medication to the end of life care treatment plan (Spelvin, 1981). Other hospitals allowed telephone DNAR orders, but physicians were restricted from writing a DNAR order without the support and signature of another physician (Ellstrom & Bella, 1990; Spelvin, 1981). In other circumstances, incorrect information was communicated to nurses regarding patients who were resuscitated but should not have been resuscitated, and patients who were not resuscitated but who should have been (Dolan, 1984).

There was also a lack of clarity about the family's decision-making power in DNAR orders. Huttman (1982) illustrates a story of a 46-year-old patient who experienced cardiac arrest 52 times in six weeks. The patient and family pleaded with the physician to "let him go" (Huttman, 1982). The physician refused to write a DNAR order and justified a response with a fear of legal recourse such as malpractice (Dolan, 1984; Huttman, 1982). DNAR orders became an arduous and impersonal standard of care. However, as nurses became more familiar with resuscitation practices, hospital policies began to evolve with clearer legal guidelines designed to avoid hospital

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or health care professional malpractice suits (Ellstrom & Bella, 1990). Yet, this did not subdue the growing ethical dilemmas that physicians and nurses faced with deciding who could or should be resuscitated.

Even the American Heart Association (AHA), a national professional organization responsible for CPR education in the U.S, grapples with the ethical complexity of administering CPR. AHA issued guidance in 1997 that justified unilaterally withholding or terminating resuscitation if the actions were deemed medically futile (Cummins et al., 1997). The 1997 AHA guidelines also suggested that the patient's family or surrogate should be informed that CPR was not performed, but not given a choice of CPR (Cummins et al., 1997).

In 2000, AHA guidelines indicated that every in-hospital patient should receive CPR unless: (1) there is a DNAR order; (2) signs of irreversible death (i.e. rigor mortis); (3) when no physiological benefit can be expected because of deteriorating vital functions; and (4) and in newly born infants less than 23 weeks (American Heart Association, 2000). These guidelines also specified that efforts to terminate CPR rested with the treating physician and efforts should cease when there is a high degree of certainty that the patient will not respond to further efforts (American Heart Association, 2000). However, in 2010, AHA expanded the decision to limit or withdraw CPR to be decided with the agreement of the physician and family or patient surrogate (L. J. Morrison et al., 2010). Based on respect for autonomy, this was a completely reverse position from the 1997 guidelines which supported unilateral CPR decisions. In addition, AHA guidelines indicated that few criteria could accurately predict futility and in light of this uncertainty, all patients who experience cardiac arrest in the hospital setting should receive CPR, unless there is a DNAR or signs of irreversible death (L. J. Morrison et al., 2010). This marked deviation in clinical guidelines left the health care community challenged to interpret exactly what criteria was

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appropriate for withholding or performing CPR. Another notable distinction in the 2010 AHA guidelines included that “Withholding and withdrawing life support are ethically similar” (L. J. Morrison et al., 2010, p. S670), which again raised significant ethical questions regarding the initiation of CPR (often performed by nurses), and termination of CPR (decided by physicians). The 2010 guidance suggests that while ethically similar, initiation of CPR has to be performed absent a DNAR order or signs of irreversible death, but termination is up to the treating physician and can be based on several different clinical factors. This was incredibly confusing and AHA failed to address this incongruity in its most recent 2015 guidance (Mancini et al., 2015). Today, these dilemmas remain unchanged and perhaps are even more complex given the increasing number of advanced technologies to sustain life.

2.4 False Dichotomy: CPR or DNAR

Today, too often a false dichotomous choice is presented to patients. Upon hospital admission, patients or surrogates are presented with the option to undergo CPR or DNAR in the event a cardiac arrest should occur (Bjorklund & Lund, 2019). In the U.S., consent is not needed to perform CPR in the hospital setting or in the community (Georgiou & Georgiou, 2019). Yet, the option to “code or not to code” is clinically and ethically oversimplistic. “The palliative care movement has helped us to see that... dying is a process; cardiac arrest is only the final event” (Burns & Truog, 2016, p. 505). Decisions about interventions at the moment of cardiac arrest are often not the most important factors in the larger picture of EoL care (Burns & Truog, 2016). Ethicists have challenged the concept of DNAR orders for years arguing that the order alone without elaborating on the level or detail of care rarely addresses the common clinical pathways that occur at the EoL (Tsang, 2010). A DNAR order taken solely for the purpose of addressing a rare or sudden cardiac arrest does not fully address the ethical dilemmas that often arise when

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patients deteriorate to a critical level (Tsang, 2010). For example, a cardiac arrest due to a severe allergic reaction is not the same as a cardiac arrest due to a terminal condition (Georgiou & Georgiou, 2019). Cardiac arrest due to a severe allergic reaction is generally unexpected, yet easily reversible and the patient should return to the same quality of life as before the arrest. However, a patient with a terminal condition is expected to have a cardiac arrest, yet CPR will not correct or cure the underlying terminal condition that caused the arrest. A critical distinction in determining appropriateness in each situation is identifying what benefit CPR will have. Initiation of CPR that will not likely improve quality of life is at the crux of EoL decision-making. As such, a significant gap in communication, care, and understanding of EoL decision-making exists and contributes to conflict among clinicians, patients, and families leading to the potential for untoward behavior.

3 The Evolution of Slow Codes and Other Forms of Limited Resuscitation

Today, nurses are considered critical in-hospital first responders and are often part of the rapid-response code teams in acute, ambulatory, and long-term care settings (Mäkinen, Castrén, Nurmi, & Niemi-Murola, 2016; Tíscar-González et al., 2019). The dichotomy of role delineation between nurses and physicians in decision-making and treatment at the end of life is well apparent. Physicians make the treatment withdrawal or withholding decisions, and nurses are tasked with operationalizing the orders (Coombs, Long-Sutehall, & Shannon, 2010; Long-Sutehall et al., 2011). Nurses fear their actions will subject patients to undue harm and suffering and therefore violate the ethical obligation of nonmaleficence, or not to harm (Laurent et al., 2017).

The limits of a nurses' autonomy are sometimes challenged by a power imbalance from physicians and exacerbated by demands from patients and families for medical interventions in which the healthcare team determines are inappropriate (Ong, Ting, & Chow, 2017). As a result, limited or abbreviated resuscitation attempts occur, sometimes without the knowledge or consent

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from patients, families, or surrogates. Limited resuscitation is a cardiopulmonary resuscitative effort that involves a deliberate decision not to attempt aggressively to bring a patient back to life and occurs in the absence of a DNAR order (Dosh et al., 2009; Ganz, Sharfi, Kaufman, & Einav, 2018; Gazelle, 1998; J. Kelly, 2007). The inherent presumption at the beginning of the reduced resuscitation effort is that the patient will not likely survive, and the harms associated with CPR will outweigh the benefits of survival or improve quality of life (Gazelle, 1998). Limited resuscitation has been criticized as a practice that is dishonest and deliberately performed below the clinical standards of care for success, enabling poor communication with patients and families, and contributing to clinician confusion of the EoL care goal (Muller, 1992). This practice is naturally controversial, and therefore, the definitions and descriptions vary as the practice is not widely accepted or acknowledged.

Historical accounts in the literature reveal an array of misunderstandings of limited resuscitation. In 1998, a seminal *Sounding Board* commentary in the *New England Journal of Medicine* conflated slow and partial codes, by defining slow codes as CPR efforts “that involve a deliberate decision not to attempt aggressively to bring a patient back to life. Either because the full armamentarium of pharmacologic and mechanical interventions is not used, or because the length of the effort is shortened” (Gazelle, 1998, p. 467). This commentary has been cited over 60 times in various publications and led to public media attention on National Public Radio (N. Adams, 1998). The authors of this commentary acknowledged the lack of data on slow codes (Gazelle, 1998). Yet, this definition has been quoted and reshaped over several years leading to confusion and misunderstanding of the clinical intricacies of limited resuscitation.

Several authors have characterized slow codes as brief, but symbolic resuscitation efforts (Frader, Kodish, & Lantos, 2010). Some ethicists have described slow codes as partial codes

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stating this type of code “involves initiating some resuscitative measures but carrying them out slowly or omitting the most aggressive” (Forman & Ladd, 2012, p. 760). The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research also concluded that partial codes and slow codes could be used interchangeably (“President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research,” 1983). Yet other scholars consider partial codes as a clear distinction or sub-category of slow codes (Ross & Pugh, 1988). Other scholars have described partial codes as chemical codes “where either drugs might be administered without chest compressions or where resuscitation [was] initiated but drugs or intubation would be withheld” (G. P. Smith, 2000, p. 185).

Slow codes and show codes have also been mischaracterized or used interchangeably. A show code is a fake attempt at resuscitation that visually appears to be appropriate, but no clinical intervention occurs. For example, authors suggest that during a slow code, clinicians are “appearing to provide CPR while not doing so” (Chao, 2002, p. 164) or “go through the motions of resuscitation without actually conforming to the standards of good medical practice (adequate compression, ensuring oxygenation, medications to support circulation, etc.)” (Frader et al., 2010, p. 771). However, going through the motions of CPR is unclear. Are the “motions” of CPR slow or absent? This is a distinguishable factor between show codes and slow codes. Other scholars have incorrectly surmised that a show code is a short code that allows the clinician “to initiate and then proceed to stop their actions either after a few tried or a period of time predetermined” (G. P. Smith, 2000, p. 184).

As slow codes continued to exist in clinical practice, empirical research during this time attempted to clarify different types of codes in limited resuscitation. Research and first-hand

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accounts by nurses and physicians provided clarification for slow codes in clinical practice. In 1999, a physician serving in the role of a hospital ethicist described a slow code as “a code where everybody moves slower, where everything that is supposed to be done in accordance with the ACLS protocol is done in a ‘slower’ format” (DePalma, Ozanich, Miller, & Yancich, 1999, p. 90). A critical care nurse described it as, “the health care staff responding to the code take their time” (DePalma et al., 1999, p. 94). A nurse researcher described slow codes as “cardiopulmonary resuscitative efforts intentionally conducted too slowly for resuscitation to occur” (J. Kelly, 2007, p. 1989). These accounts were far less visible in the public media or cited in bioethics literature, and therefore confusion remains regarding the types of limited resuscitation. Adding to the misperceptions, the bioethics literature on limited resuscitation is rife with euphemisms for slow codes and other forms of limited interventions at the EoL. Several scholars have termed variations of limited codes as “Hollywood codes”, “Light Blue codes”, “Navy Blue codes”, “soft codes”, and “Sky Blue Codes” (Gazelle, 1998; Goldenring, 1979; G. P. Smith, 2000). The following sections will provide clarification of the many forms of limited resuscitation.

3.1 Defining Limited Resuscitation

There are various forms of limited resuscitation including chemical codes, tailored codes, partial codes, and slow codes. See Figure 1. Due to the paucity of research around limited resuscitation, the literature suggests the various types and terms are vague, synonymous, or overlapping. However, each term will be clinically and ethically distinguished below to provide clarification and elucidation of this practice.

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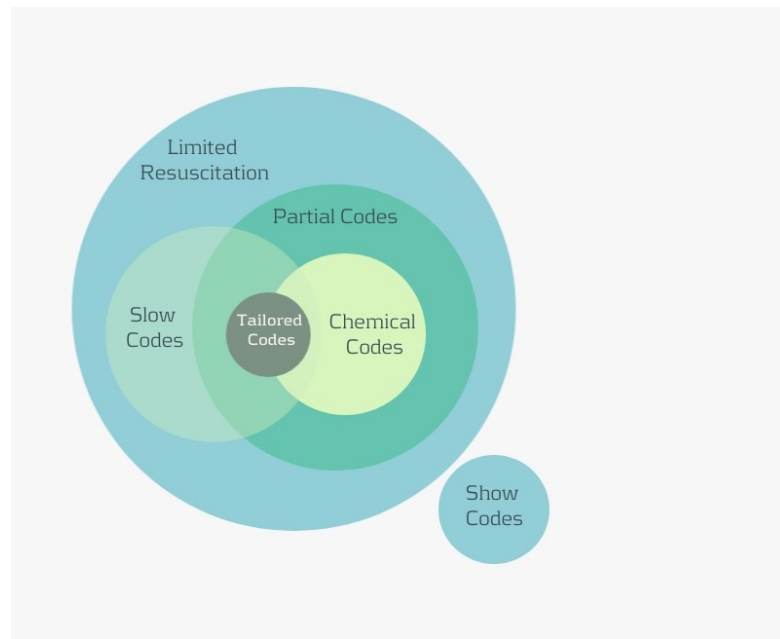


Figure 1. Types of Limited Resuscitation

3.1.1 Chemical Codes

CPR only utilizing the pharmacological components of resuscitation are known as chemical codes (M. D. Fowler, 1989). Chemical codes include the administration of high powered intravenous medications typically used in CPR, such as epinephrine, sodium bicarbonate, atropine, and other medications designed for spontaneous resuscitation of the heart function (G. P. Smith, 2000). In a study by Stokes and Zoucha (2021), nurses described chemical codes as resuscitation efforts including the delivery of lifesaving medications but lacking chest compressions which circulate the medication throughout the body. While medication administration is often documented in the patient's chart, the lack of chest compressions is not. A similar study conducted among medical residents suggests that chemical codes do not include mechanical ventilation or chest compressions but contain intravenous medications to support a patient's blood pressure and hemodynamic status if deterioration occurs (Muller, 1992).

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3.1.2 *Partial Codes*

Partial codes are often misconstrued because many of the limited resuscitation approaches can be logically classified as partial attempts at resuscitation. However, partial codes occur when full pharmacologic and mechanical interventions are not used, or the length of the resuscitative effort is often shortened (Ganz et al., 2018; Gazelle, 1998; Muller, 1992). Chemical codes are also considered partial codes because only a part of the CPR efforts is performed. However, some partial codes occur when separate varying interventions of CPR are used selectively, such as the administration of chest compressions and assisted breathing, but not medication, defibrillation, or intubation (Jonsen, Siegler, & Winslade, 2015). Therefore, not all partial codes are chemical codes. See Figure 1. Partial codes are generally documented in the patient record, often presented as a request to “Do-not-intubate or DNI”, but not DNAR (Baumrucker et al., 2014; Ross & Pugh, 1988). Clinical challenges arise when DNAR and DNI are conflated (such as in acute respiratory arrest and not cardiac arrest) and are usually seen in hospital settings where full code and DNAR are the only code status options available (Rubins, 2020).

Partial codes may also be considered “short and circumscribed” attempts of full and deliberate high-quality CPR, with the cessation of efforts determined at an appropriate time that is often shorter than traditional methods (W. Morrison & Feudtner, 2011). Meadow and Lantos (2011) proffer that CPR can be a symbolic expression of a “mutual commitment not to give up” (p. 1078), and could continue for 30 minutes, three minutes, or even three seconds. Physicians may also order “no escalation” of treatment, which is designed to prevent the initiation of life-sustaining treatment or to prevent the increase or intensity of treatment that is already in use (J. R. Curtis & Rubenfeld, 2014). Basson (1981). Van Scoy-Mosher (1982) describes a partial code as follows:

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Recently, I took care of an Hassidic rabbi. Because Hassidic Jews are very uncomfortable with DNR orders or anything that might hasten death, such a course of action was not acceptable to him. We decided that it was reasonable to make some effort to resuscitate, but not necessarily all efforts. Setting such a limit on resuscitative efforts was acceptable to the family. In this case we decided that it would not be acceptable to intubate him nor to leave him on a respirator. So, there is a way of giving what I will call a partial code-some attempt at resuscitation, but not applying everything known to man. (p. 15)

Clinicians have also questioned the value of partial codes, arguing that these acts are resuscitative façades that are paternalistic and devoid of patient autonomy (Rousseau, 2016). Scholars argue that providing patients with a list of choices that they can select or check off does not represent true autonomy and in fact can be misleading suggesting that some sort of benefit can result from an intervention (Zapata & Widera, 2016). Zapata and Widera (2016) compared offering a patient or family a litany of options for CPR akin to a chef asking a patron about their preferred proportion of ingredients in their desired entrée. “Most patrons are not highly trained in culinary arts and rely on the chef to provide a meal that fulfills basic guidelines...” (Zapata & Widera, 2016, p. 1059). In comparison, most patients or families do not know or understand the intricacies of CPR and are focused on the outcome of patient survival (Zapata & Widera, 2016). Patients and families should not be expected to understand the intricacies of CPR, especially considering the poor health literacy rate in the U.S (National Center for Education Statistics, n.d.; U.S. Department of Education, 2020). However, if performed transparently, partial codes can offer families an opportunity to actively participate and contribute in EoL decision-making. As a result, partial codes are morally permissible if they are tailored to the patient and family’s preferences, despite their potential clinical ineffectiveness.

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3.1.3 Tailored Codes

Tailored codes aim to respect patient autonomy by tailoring treatment decisions based on both the clinical picture and patient values (Ranola et al., 2015; Tang et al., 2016). Chemical, partial, and slow codes can all be considered tailored codes if they are tailored to incorporate the patient's preference. See Figure 1. While some definitions suggest a precision-medicine-like approach to CPR evaluating the clinical interventions appropriate for that individual patient (Abella, 2016), tailored codes focus on transparency and a personalized nuanced approach ensuring that patients and families have adequate information to foster shared decision-making (Ranola et al., 2015; Tang et al., 2016). Tailored codes are generally considered an ethically permissible approach to resuscitation inclusive of appropriate care individualized to patient goals of care, clinical circumstances, and other contextual features (Marron, Jones, & Wolfe, 2018). The case of the Hassidic Rabbi noted above describes a partial code, but also a tailored code, where the limited resuscitation efforts were discussed and agreed upon by the family. Lantos and Meadow (2011) published a prominent and controversial article that was a significant step in reframing the derogatory perception and unfair malign of limited resuscitation and recommending the use of the terms "tailored code" or "appropriate code," and setting standards for clinical practice. Tailored codes are ethically permissible and are the ideal approach for all types of limited resuscitation. A full analysis of tailored codes appears in Chapter 6.

3.1.4 Show Codes

Show codes differ from limited resuscitation in that no resuscitation efforts are done at all, but to a layperson, it may appear that resuscitation has taken place. Show codes are also called "Hollywood codes", to indicate the CPR attempt is a pretense or a charade. A 2017 study of ICU nurses in Singapore revealed circumstances when hierarchy and lack of communication in

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decision-making resulted in a show code (Ong et al., 2017). One of the nurse participants described, “We still bring the [emergency cart] in. I feel, it’s [to] let the family...feel better”, but they failed to actually perform CPR on the patient (Ong et al., 2017, p. 4). The nurses in this study rationalized their actions as a reasonable method to protect family members from guilt for wanting to do everything to save their loved ones (Ong et al., 2017). Acknowledgment of show codes is rare, and they have not been widely studied or investigated. One study participant describes how show codes are nonsensical, “It is all a bit ridiculous; it is that nonsense of putting off the cardiac arrest bell at 2 am. It is a crazy situation. We don’t do anything to the patient. Nothing happens. It is just a charade” (J. Kelly, 2008, p. 114). Paris and Moore (2011) describe witnessing a physician instruct residents and medical students during rounds to “simply shoot the epinephrine into the mattress” (p. 14). There are strong opponents against show codes. Frader et al. (2010) opine “Charades are not acceptable when it comes to life-and-death matters” (p. 771). Show codes are not documented in patient medical charts due to the obvious fraudulent behavior associated with them. Show codes lack transparency and are not morally permissible. Resuscitation is not limited in this scenario, it is absent. Under these circumstances, patients should have a DNAR order. Nurses should not participate in this practice and should speak up in objection if they witness this event. In this scenario, the nurse should present the morally justifiable option of a unilateral DNAR order to the physician or advanced practitioner, if appropriate. The flagrant disregard of patient and family autonomy associated with show codes can leave clinicians subject to legal liability and is tantamount to fraud.

3.2 Professional Organization Positions on Slow Codes

“Slow codes”, are another controversial type of limited resuscitation and describe a slow activation of CPR. The first mention of slow codes appeared in the health care literature in 1977

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(D. L. Berg & Isler, 1977). The authors describe a scenario when a physician tells a nurse, “If he arrests again, I guess you’ll have to call in the code- but walk v-e-r-y slowly” (D. L. Berg & Isler, 1977, p. 49). Slow codes are unwritten or undocumented and may involve all of the necessary elements which a true code possesses but in slow motion (Forman & Ladd, 2012; Gazelle, 1998; Rosen, 1998). Clinicians go through the motions of resuscitation with slow-motion effort and therefore can report to families that resuscitation was attempted, but was not successful (Mercurio, 2011). Basson (1981) describes a slow code as:

The "slow code" is a medical practice almost unknown outside medical circles. Punning on the "code/no code" decision which sums up the appropriateness of resuscitative efforts for a given patient, the slow code is applied to patients whose prognosis makes them unsuitable for resuscitation in the doctor's view while other factors necessitate at least the semblance of a resuscitative attempt. In the case presented for discussion here, for instance, a terminally ill young woman has therapeutic support withdrawn, undergoes cardiopulmonary arrest, and then dies while the "code team" moves with deliberate slowness. (p. 117)

The slow code phenomena surged into medical literature in the 1980s (K. Ellis, 1987; Huttman, 1982; Merkel, 1985; F. Quigley, 1988). The health care community was still grappling with the recent Supreme Court decision of Karen Quinlan, where the Court seemingly, shifted the right to die focus from medical paternalism to the rights and protections of privacy of a patient (D. L. Berg & Isler, 1977; "In the Matter of Karen Quinlan," 1976). In 1983, the U.S. President's Commission for the Study of Ethical Problems in Medicine recognized the existence of slow codes, however, only dedicated a few sentences in a 300-page report which stated, "...success at resuscitation is rare enough when all efforts are expended, so such limited efforts are usually

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doomed from the start” (“President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research,” 1983, p. 181). Slow codes became a significant and timely issue about life, death, quality of life, and deceit. A small number of national newspapers covered stories of patients and families who reported their loved ones were victims of the “slow code”, but the public was virtually unaware of the practice (N. Adams, 1998; Gazelle, 1998; “Slow codes, show codes and death,” 1987).

Only a small number of professional organizations have recognized slow codes. The American Heart Association, which sets the standards in resuscitation is a clear opponent of slow codes (Mancini et al., 2015), along with the American Nurses Association (American Nurses Association, 2020) and the American College of Physicians (Snyder, 2012). Research data has been inadequate regarding slow codes. Many health care professionals fear revelations of slow codes would cause public fear and possibly damage the trust in a patient-provider relationship (J. Kelly, 2008). Only a few empirical studies have focused on slow codes, despite several commentaries on slow codes. Only a few provide data on the frequency of slow codes, with a majority suggesting they are a common occurrence (K. Ellis, 1987; Ganz et al., 2018; Gazelle, 1998; J. Kelly, 2007, 2008; Lantos & Meadow, 2011; Purnell, 1998; Stokes & Zoucha, 2021). An informal study by Jeff Hardin, M.D., indicated that a majority of the medical residents at Columbia Presbyterian Medical Center had comfortably participated in some type of slow code (Hardin, 1998). A later study in 2004 reported that almost two-thirds of 85 physicians participated in a slow code during the previous year (Goldberg, 2007).

Slow codes originated in what was perceived as an absence of law regarding guidelines for EoL treatment (Van Scoy-Mosher, 1982). Clinicians were unclear when to administer CPR or whether it was appropriate to withhold CPR. Hospital policies and DNAR orders were insufficient

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to address the ethical or clinical appropriateness of CPR. Dr. Marsha Fowler describes the role of nursing at the time, “When slow codes started, they were not intended to be deceptive. Slow codes were a means at doing EoL practice without knowing what the law said. The law had not yet caught up with practice” (M. D. Fowler, 2021). Over time, both nurses and physicians concede that a factor leading to slow codes was an overbearing family who was unaccepting of what the health care team deemed an appropriate end of life care plan (J. Kelly, 2008). Slow codes occur for a variety of reasons, but one of the most common justifications for what is often considered socially unacceptable practice is the disagreement that can occur with patients, families, and the health care team regarding the end-of-life plan of care (Einav, Avidan, Brezis, & Rubinow, 2006).

Nurses and physicians have varying perspectives on the use of slow codes due to their different interactions with patients, roles in resuscitation, and hierarchy in EoL decision-making. Older research has shown that nurses involved in a slow code deem the limited resuscitation effort as futile, unconscionable, and participation undermines patient autonomy (J. Kelly, 2008). A similar study of physicians revealed that they perceived slow codes were intended to be non-harmful acts for patients who had irreversible terminal conditions (Muller, 1992). Although nurses and physicians view slow codes slightly differently, both indicated they perceived them as a violation of patient autonomy (DePalma et al., 1999; J. Kelly, 2007).

There has been a slight uptick in empirical research regarding slow codes. Ganz et al. (2018) found that a majority of nurses agreed that slow codes were ethical especially given a patient’s age, poor prognosis, and pain at the end-of-life, perhaps suggesting a shift due to time and social or contextual events. Piscitello, Kapania, Kanelidis, Siegler, and Parker (2020) reported that 69% of ICU clinicians, including nurses and physicians, reported a slow code had been conducted on a patient they had cared for in the previous year. It was also reported that the most

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common origin of a request for a slow code was by the attending physician (Piscitello et al., 2020). Similar to the outcomes in Ganz (2018), participants perceived slow codes as an ethical practice if the patient was perceived as medically futile (Piscitello et al., 2020). Stokes and Zoucha (2021) also found that the directive to nurses to participate in a slow code came from physicians, but also noted that some directives came from nurses in charge. Nurses described the decision to participate in slow codes occurred once the team agreed that no other clinical options were available, but the family was not yet willing to acquiesce to a DNAR order (Stokes & Zoucha, 2021). Nurses in this study had mixed perspectives on the ethical appropriateness of slow codes. Some nurses reported that it was justifiable to participate in slow codes based on the futility of the patient's condition, and in fact, the physical rigor of CPR was unethical (Stokes & Zoucha, 2021). Others felt strongly that slow codes were against the ethics and standards of the nursing profession (Stokes & Zoucha, 2021). Moral perspectives of all clinicians exposed to slow codes are critical in the analysis of permissibility and mitigating factors that trigger participation in limited resuscitation.

The majority view in bioethics is that slow codes are unethical because they are knowingly deceptive, regardless of the futility of the patient's condition (Gazelle, 1998; Janvier & Barrington, 2011; Kon, 2011; Lantos & Meadow, 2011; W. Morrison & Feudtner, 2011; Paris & Moore, 2011; Wreen, 2004). However, some ethicists posit that slow codes can and should be transparent, so long as consent and acknowledgment of patient or families is present (Ladd & Forman, 2011; Lantos & Meadow, 2011). Deception is not an explicit part of slow codes. Slow codes are limited resuscitation events that are deliberately slow. Slow codes can be full or partial attempts at resuscitation but are done at a reduced speed than the recommended clinical standards of care. Typically, slow codes are not end of life decisions previously discussed with the patient or family, generally because there is a disagreement over the end of life treatment of the patient (Gazelle,

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1998; Mercurio, 2011). However, patients and families can provide consent or acknowledgement for a slow code. This is rare and unlikely to occur, but it is ethically permissible for this to happen. If a slow code is performed transparently and with patient or family consent, this practice is a beneficent act for especially for patients and families who will not accept the patient's impending death unless resuscitation was attempted, despite the futility of efforts (Boisaubin, 1998; Forman & Ladd, 2012; J. Kelly, 2008; Lantos & Meadow, 2011; Muller, 1992; Purnell, 1998; Weinacker, 2011).

The literature is clear that there is a deep chasm regarding limited resuscitation. There is little to no clinical benefit for patients who are recipients of limited resuscitation. Successful outcomes after resuscitation involve all components of CPR in rapid succession previously identified above and recommended by the American Heart Association. Yet, different forms of limited resuscitation have been acknowledged in nursing and health care practice for over 40 years. Recent literature indicates that slow codes still occur in clinical practice around the world, and nurses are active participants (Ganz et al., 2018; Piscitello et al., 2020; Stokes & Zoucha, 2021). Yet, due to the secrecy of the practice, minimal research and guidance exist for nurses despite its continued existence in practice. This dissertation will ethically and clinically distinguish different forms of limited resuscitation as appropriate. This dissertation proposes that limited resuscitation in the traditional phenomena of a "slow code", occurs without patient or family consent, and is unethical and nurses should not participate in this practice. However, this dissertation also proposes that limited resuscitation, whether slow, partial, tailored, or chemical, and performed transparently by nurses and physicians, is morally permissible. This dissertation will provide ethical justifications for nurse participation in limited resuscitation and incorporate empirical research to support these findings. Also, this dissertation will provide a normative analysis of the

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moral permissibility of limited resuscitation using feminist ethics and principlism frameworks, with arguments supported by analyses of families' and nurses' perspectives and actions in the EoL decision-making process. This dissertation aims to remove the veil of silence and raise awareness for transparency towards a moral acceptance of the practice.

4 Conclusion

The clinical, ethical, moral, and legal considerations of EoL treatment are replete with debate. Patients and families present with value-laden treatment choices, which often run counter to the medical expertise of physician's treatment plans. Nurses are in the middle of the debate as patient advocates and trusted professionals and yet are obligated to carry out physician orders to perform aggressive medically inappropriate treatment at the EoL. Nurses who are repeatedly forced to participate in these aggressive measures experience moral distress. EoL treatment can be physically invasive, painful, and subject to significant suffering, and thus harm. CPR and other advanced life-sustaining treatments were not originally designed for use on terminally ill patients. As the frequency of CPR increased, ethical issues and unintended consequences lead to the creation of DNAR orders. DNAR orders were created to provide a clear and transparent mechanism for patients and families to express and document their EoL wishes. However, a dichotomy of "to code or not to code" was created, despite the complexity of the dying process. Dying is not a single clinical moment, but a trajectory of events that are not captured in a CPR or DNAR health care environment.

Nurses have historically had a pivotal role in the delivery of EoL care, often as the first clinician to respond to a "code" or cardiac arrest. As guidelines and practice culture changed over time, nurses continued to grapple with the ethical dilemmas faced when deciding who could and should be resuscitated. The lack of clarity around EoL choices has resulted in limited resuscitation

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efforts including chemical, partial, tailored, show, and slow codes. Slow codes are the most widely researched of the limited resuscitation efforts and are largely negatively viewed due to the deceptive and non-disclosed nature associated with their delivery. However, not all limited resuscitation efforts are hidden from families. Some limited resuscitation events such as partial or tailored codes are discussed with patients and families and can result in an optimal EoL care event for patients, families, and clinicians. Unfortunately, the research on limited resuscitation remains scant due to the veil of silence that exists around the practice and the deep ethical chasm that exists. Many scholars believe that an acknowledgment of slow codes could have a detrimental effect on patients and families and lead to further mistrust in the health care system. Yet, the paucity of recent studies have all shown that slow codes and other forms of limited resuscitation still persist in practice even after forty years. For these reasons, slow codes and other forms of limited resuscitation require a critical ethical analysis to determine moral permissibility in practice and specifically moral permissibility for nurse participation. Using different ethical frameworks and a case-based approach, the moral permissibility of limited resuscitation will be analyzed to foster transparency in EoL practice and to garner moral acceptance of this practice.

Chapter Two: Nurse's Ethical Comportment, Deception, and Nudging

1 Introduction

Nurses navigate complex and difficult decisions frequently in their daily practice. It is essential that the development or formation of a nurse's professional identity and practice involves virtues to act as moral agents to help them learn to "think like a nurse" (Priddy, 2018). Formation depends on taking up a professional identity with the nurse becoming what they need to be or become a good nurse. Formation in any profession is best understood from a constitutive theory that draws on the interconnections between people, their actions, and the social practices within which they perform (Benner, 2011; C. Taylor, 2016). Becoming a nurse who has a firm grounding in moral character, skillful ethical comportment, skilled know-how as a nurse, and professional identity is important when encountering complex ethical challenges in nursing practice. This chapter includes an analysis of nurses' ethical comportment, formation of professional identity, and moral identity that encompass a nurse's expectations and obligations to deliver patient care with transparency, veracity, fidelity, and beneficence using feminist ethics theory (Ballou & Bryant, 1997; Benner, 1991). Threats to a nurse's ability to practice and thrive as a "good nurse" can result in misdeeds such as deception and nondisclosure of limited resuscitation.

Professional practice involves standards of excellence, rules, and norms that a novice practitioner must rely on (MacIntyre, 2013). Practice is based on history and traditions and has internal notions of good such as excellence and effectiveness (MacIntyre, 2013). Nursing practice is also binding on the future as science, culture, and society shape the profession (MacIntyre, 2013). Godfrey and Crigger (2012) define professional identity arising out of this practice as "a sense of oneself that is influenced by characteristics, norms, and values of the

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nursing discipline, resulting in an individual thinking, acting, and feeling like a nurse.” (Godfrey & Crigger, 2017, p. 379). Nursing ethics specifically has traditionally revolved around patients and their relational nexus (M. D. Fowler, 2016). Nurses view themselves as agents who advocate for all patients through caring efforts to heal and alleviate hurt and suffering (Peter & Morgan, 2001). A nurse’s capacity to be a moral agent resides in personal integrity and the authentic expression of oneself (Robley, 1998). Nurses advocate for marginalized populations by equalizing power imbalances between physicians, patients, and nurses, and also by taking action within institutions that are bureaucratic and oppressive (Robley, 1998). Within this formation of how a nurse views herself, is the alignment of that identity with ethical behavior or comportment. Every nurse has a level of emotional, psychological, and spiritual health that impacts their nursing practice and the formation of professional identity and ethical comportment (Priddy, 2018). Nurses can make ethical choices toward or away from professional identity formation of the ethos of nursing. Nurses reflect on experiences and adopt behavior that is considered ethical and in line with professional nursing practice or bad practice that is deemed unacceptable in practice. This behavior, or ethical comportment, is embodied by the nurse as the nurses’ professional identity is formed and is exhibited through skills, knowledge, actions, and the nurse’s intent.

A brief background on feminist ethics based on the work of Lindemann and Peter, ethical comportment, in addition to traditional bioethics will be provided to formulate a normative argument for nurse participation in disclosed limited resuscitation with support from already established empirical evidence. Transparency in nursing practice preserves the notions of good internal to nursing practice, a nurses’ professional identity, and is essential to ethical comportment in nursing. This approach offers a comprehensive understanding of various ethical

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approaches to analyze deception, truth-telling, and the current climate of limited resuscitation, including context within nursing ethics and practice.

2 Ethical Compartment and Moral Identity

2.1 Principles of Biomedical Ethics

Considerable scholarship in bioethics has acknowledged how physician-patient relationships are conducted in practical situations, such as refusal or withholding of treatment, or situations when patient decision-making is discounted (Dodds, 2005). Traditional bioethics resulted from atrocities in clinical research and medical paternalism and is based on “moral philosophy, normative theory, abstract universal principles and objective problem solving, all of which focus on right and wrong ‘action’ for resolving dilemmas” (Thompson, 2003, p. 588). In 1979, Beauchamp and Childress (2019) established four principles of biomedical ethics drafted as an extension to the Belmont Report and the Nuremberg Code, including: (1) respect for autonomy; (2) nonmaleficence; (3) beneficence, and; (4) justice. Beauchamp and Childress (2019) describe these abstract principles as “general guidelines for the formulation of more specific rules” (p. 12). Bioethics has a practical application to health care practice, and clinicians can easily identify common principles such as beneficence and non-maleficence. Today, bioethics is heavily influenced by health law demonstrated through policy initiatives such as advance directives, abortion, and informed consent (G. J. Annas, 2005).

2.2 Feminist Ethics

This section will introduce feminist ethics as a framework to analyze nursing issues through a social, political, and relational approach to identify areas of oppression and vulnerability within nondisclosed limited resuscitation attempts (B. Green, 2012; Liaschenko, 1993; Peter & Liaschenko, 2013). Feminist ethics tend to share two common general

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assumptions: 1) it builds on an ontological understanding that people are connected, interdependent, uniquely situated, rational and emotional, as opposed to autonomous, independent, rational and unencumbered; and 2) building on Tronto's (1993) theory of ethics of caring as a moral orientation, relationships of care must also be political with attention to power dynamics and oppression to account for how individuals "are situated as a result of race, class, profession, gender, and so on" (Peter & Liaschenko, 2020, p. 25). Feminist ethics is not a formal branch of ethics, but rather a way of "doing" ethics (Lindemann, 2019). Feminist ethics can be applied to all three branches of ethics including metaethics, normative ethics, and practical ethics (of which bioethics is a subset) (Lindemann, 2019).

Feminist ethics is a useful framework to understand the practice of nursing, with an emphasis on the inextricable relationship between ethics and politics (Liaschenko & Peter, 2016). It is specifically useful in uncovering nursing ethical issues because the work of nurses is "deeply embedded in complex social networks involving health care professionals, patients, families, and administrators, all of whom are further nested in politics, policies, and economics" (Peter & Liaschenko, 2013, p. 339). Feminist ethics, as with any ethical theory, does not have a unified perspective but suggests that personal issues are political. It is important to note that feminist ethics not only focuses on gender differences in power imbalances, but also factors such as sociodemographic, race, class, and ability (Peter & Liaschenko, 2013). Peter (2000) suggests that care, justice, maintenance of relationships, and freedom from exploitation and oppression are moral values at the core of a feminist ethic in nursing. Nurse historians have long argued that oppressive practices and systemic hierarchical medical models contributed to the restriction of the moral freedom of nurses (Yarling & McElmurry, 1986). Nurses have often been characterized as powerless compared to other clinicians in the traditional medical model of

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health care where nurses were considered subservient to physicians (Peter & Liaschenko, 2020). This oppression results in an inaccurate perception of nurses as lacking in leadership or decision-making abilities because of subordination to physicians (Liaschenko & Peter, 2016).

Lipscomb (2016) notes that oppressive institutional structures and repeated exposure to exploitative social and systemic practices can lead to an ethical numbing where misdeeds and inadvertent attempts to act dishonestly may be encouraged. For example, organizations exploit the nursing workforce because nurses are not adequately paid or resourced and are powerless in improving their positioning in the institution. Freedom from this oppression is essential to any feminist ethic and ensures that nurses' relationships with others are not unrecognized or exploitative (Peter, 2002). Nurses exercise their power when faced with ethical conflict when they refuse to participate, act as patient advocates, or engage in constructive verbal disputes, as a result of their moral stance (Peter & Liaschenko, 2020). The consequences of this moral action vary, and nurses may face harassment, loss of employment, and retaliation (Peter & Liaschenko, 2020). Feminist ethics has the potential for transformation and therefore can be of assistance in deconstructing stereotypes of nurses to reconceptualize nursing and nursing ethics to promote a culture of ethical practice (Peter & Liaschenko, 2020).

Feminist ethics adds to practical bioethics by highlighting relationships, power differentials, and personal and social aspects of an experience (Lindemann, 2019). The significance of using feminist ethics in addition to practical bioethics principles as frameworks in this dissertation is to assist nurses with 1) competently identifying ethical dilemmas; 2) exhibiting moral courage to provide recommendations for physicians and advanced practice providers with decision-making authority, and 3) building upon the recognition of patient-focused bioethical principles and recognize the nurses' role and course of moral action to address

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the conflict. The following ethical analysis describes how a nurse's relationships are informed by ethical comportment that shapes conduct in EoL practices, such as nondisclosed limited resuscitation which may be influenced by deception, coercion, and nudging (American Nurses Association, 2015; Benner, 1991; Mitchell, 2014; Solbakk, Chadwick, ten Have, & Meslin, 2011).

2.3 Ethical Comportment

Ethical comportment is the relational and skilled know-how of being with and treating patients with respect, dignity, in the way that the nurse comports her or himself with patients (Day & Benner, 2002). Ethical comportment is essential in a practice discipline and avoids the reduction of ethics to rule-based decision-making rather than skillful practices that convey and carry out respectful, attuned care that fit the ethical demands of the situation. Ethical comportment, the embodiment of notions of good and rights of patients, includes tone of voice, active listening, attentiveness, curiosity, transparency, gestures, touch, postures, being with and assisting patients (Benner, 1991; Day & Benner, 2002). For example, a physician order written on the chart does not have more primacy or moral weight than direct communication and presence with a patient and family during the compassionate extubation of a patient when palliative comfort care is astutely and skillfully required.

Ethical comportment in nursing is a fundamental component of the formation of a nurse's professional identity. Ethical comportment defines nurses' knowledge and skills in interactions with others respectfully and responsibly to support patient concerns and establish quality clinical judgments for patient care (Benner, 1991; Benner, Tanner, & Chesla, 2009). Ethical comportment is a socially embedded knowledge gained through lived experiences and skilled know-how and is often a pre-theoretical representation of rules or principles (Day & Benner,

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2002). Ethical comportment develops through accretive experience in practice with others and becomes the basis of understandings that can enrich theoretical knowledge, revise, or add nuance to existing rules and principles (Day & Benner, 2002). The formation embodied in ethical comportment cannot rely solely on the theoretical representation of ethical principles to drive decision-making, because the development of comportment precedes the application of the rule (Benner, 1991; Day & Benner, 2002). Ethical comportment relies on a nurses' experiences and relationships, using feminist ethics to address the social and personal contexts framing these experiences (Mackenzie, Rogers, & Dodds, 2014). "Theory can inform practice, but practice is richer than theory and above all, self-sustaining practice can survive without theory while theory arises from a practice and perishes without the nourishment of a practice" (Borgmann, 2003, p. 31). Ethical comportment enables the nurse to act within the ethos of the profession (notions of good) and use ethical principles or to consider unacceptable practices and deviate from them.

Ethical comportment is manifested through a relational outcome from Early American nursing ethics literature that identified nursing's relational center. Based on these foundational nursing ethics writings, M. D. Fowler (2020) identifies several key relationships for nurses including nurse-patient, nurse-to-self, nurse-to-nurse, nurse-to-physician, and nurse-to-society. The maintenance of relationships in nursing is a moral value at the core of a feminist ethic in nursing (Peter, 2002). Cultivating relationships stems from the value of care and recognizes the vulnerability and power differences that exist in health care. A nurse's direct experiential grasp of ethical reasoning and awareness of "knowing the patient" not as a disease or illness, but as a person situated with a family, and community, allows the nurse to identify the barriers or social structures that influence health outcomes and can yield wisdom and skillful ethical comportment

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(Benner, 1991). Ethical decision-making for nurses must involve a meaningful analysis of the situation inclusive of the wisdom, narratives, and ethical comportment of nurses.

An understanding of ethical comportment is critical in the analysis of nurse participation in nondisclosed limited resuscitation because of the pivotal role that nurses have in the patient and family EoL experience. At the core of nursing practice is a skilled action grounded in a notion of good nursing practice that is continually developed when nurses experience ethical conflict. Nurses develop ethical comportment as they become aware of their own vulnerabilities when encountering a challenging or ethically complex patient situation (McAllister, Levett-Jones, Petrini, & Lasater, 2016). Ethical comportment is part of the formation of a professional nurse, yet nurses often are unable to identify ethical issues (Benner, Sutphen, Leonard-Kahn, & Day, 2008). Sometimes nurses also lack the ethical awareness or sensitivity to recognize the dilemma but emotive strong preference for what they perceive as an ideal clinical outcome (Leuter, Petrucci, Mattei, Tabassi, & Lancia, 2013; Robichaux, 2012). Ethical sensitivity “involves the skill or ability to interpret the reactions and feelings of others” (Robichaux, 2012, p. 66). It also involves the ability for nurses to identify the distress of others, including an awareness of how courses of action could affect each individual in the dilemma (Robichaux, 2012).

Nurses must identify broader and larger ethics that address advocacy and social ethics, which are both critical issues of ethical concern to nurses (Benner et al., 2008). Advocacy in nursing is a unique but expected role in nursing practice. Patients present with an illness and expect just, respectful, competent, and high-quality care, especially at the EoL. In circumstances when this fails to happen, patients look to the clinicians who have spent the most time at their bedside or have formed a connection based on the performance of humanistic and caring tasks. This is how nurses develop skills including empathy and caring and can step “into the shoes” of

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patients and advocate for their needs. Advocacy is a broad term that refers to giving patients a voice and thus empowerment, clarifying confusion about treatment options, and making sure there are no harmful clinical contraindications to treatment, and is an essential component of ethical comportment (Benner et al., 2008).

2.4 End of Life Experiences Shape Ethical Comportment

Ethical comportment is an expected and practical art of being a professional nurse. Comportment is more than just words, beliefs, or values, but also touch, orientation, presence, and action (Benner, 1991). Presence is more than the mere physical company; it involves intentional engagement and assessment of the needs and values of the patient or family and their life. Presence is designed as a powerful medium to restore health and nurture trust and caring. Being present is a learned skill and critical to the development of ethical comportment. There is a delicate balance for nurses to be present during patient and family suffering but also to be attuned to the patient's physical and emotional needs to establish comfort, but not to be intrusive (Benner, 1991). A nurse's presence during EoL care for patients and families is invaluable, even in circumstances of conflict or distress. The more exposure a nurse has to death and dying, the greater influence on ethical comportment occurs. Ethical comportment is refined through experience defined as "the turning around, the adding of nuance, the amending or changing or preconceived notions or perceptions of the situation" (Benner, 1991, p. 2). For example, the more nurses are exposed to the ethical dilemmas associated with EoL care, the more confident, comfortable, skilled, and attuned they become in discussing EoL care with patients and families (Dunn, Otten, & Stephens, 2005). Nurses continue to develop ethical comportment throughout practice as ethical considerations arise and continually shape their understanding and ethical awareness to recognize ethical distinctions in practice. The formation of ethical comportment

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allows nurses to reflect on and question standards and rules of practice. A nurse's first-hand experiences in a socially based practice, including building patient's narratives and participation in clinical patient-family dynamics, foster the development of a novice nurse to that of a skillful practitioner. For example, a novice nurse (one who is initially informed by practice rules and formal theories that do not require experience) continues to develop ethical comportment to the level of a skillful practitioner (one who has real-life experience with multiple, complex, real clinical situations complete with a narrative memory of those clinical situations to enrich, augment and replace abstract decontextualized principles) (Benner, 1991).

Ethical comportment describes how nurses embody the ability to respond and relate to others responsibly and with respect for patient dignity, but also with the personal integrity that is attuned to the particular concerns of the patient and family and the nature of the clinical situation (Benner et al., 2008). Nurses are faced with challenging ethical dilemmas that frequently test but also strengthen their ethical comportment. Patient and family inquiries regarding prognosis or opinions on treatments can be morally problematic for nurses. Patients may inquire, "do you think I should have this surgery?" or "what would you do if you were in my shoes?" This intimate reliance on nurses for their expertise and trusted connection in the nurse-patient relationship can be a quandary. In response, nurses use ethical comportment to make decisions about open and responsive communication that is based on the patient and family's concerns. Nurses acknowledge the dilemma and respond empathetically in an attuned and transparent way that is morally appropriate.

Another element of ethical comportment in nursing is meeting the patient as a person and not as a diagnosis (Benner et al., 2008). Nurses do not typically identify a patient by their illness or vulnerability. Rather nurses see the whole person, especially when medical interventions

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become invasive, sometimes disfiguring of both body and of human dignity (Benner et al., 2008). This is especially germane at the EoL when patients are reflecting on the totality of their lives, their finitude, and livelihood. Nurses strive to alleviate suffering and justly question the appropriateness of intense physically invasive interventions, such as CPR, mechanical ventilation, and other advanced technologies, when those interventions are likely to be medically inappropriate given the patient's condition. Some nurses attempt to absolve themselves of this conflict by performing less aggressive and therefore substandard actions that are not transparent and defy family demands for aggressive EoL treatment. In many cases, limited resuscitation efforts are not shared with the patient or family, and therefore deceptive EoL care occurs. Oftentimes, the intent of nondisclosure is not deceit, but it is to preserve the dignity of patients, to avoid harm to patients, and to minimize or mitigate the moral distress of the nurse. This is a protective response on behalf of the nurse to advocate for the patient to avoid or mitigate harm or suffering. Ethically, nondisclosure of information should be avoided. Special considerations for nondisclosure in cultural groups should be made and will be explored more in Chapter Three. However, the protective advocacy response is consistent with the development of the ethical comportment of the nurse, to identify a more ethically appropriate advocacy response in future clinical EoL situations (Benner, 1991).

2.5 Moral Identity

A nurse's ethical comportment continually shapes moral identity. Nurses' moral identities are fluid and relational through interactions with the health care team, patients and their families, and others that also positively and negatively shape an individual's moral identity (Peter, Simmonds, & Liaschenko, 2016). Feminist ethics builds on the premise that moral identity is central to moral life (Peter et al., 2016). As nurses encounter ethical conflict and are

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presented with the opportunity to perform deceptive acts inconsistent with characteristics of being a good nurse (such as nondisclosed limited resuscitation), moral identity can be threatened, and moral distress can result.

Theorist Lindemann (2001) outlines identity as an interaction of one's self and others' understanding of who one is, which is the underlier of how moral agency is developed. Identities are situated in historical, social, and political contexts that reflect ongoing moral experiences of what individuals care for and value (Peter et al., 2016). This continued identity formation can be threatened by practice and organizational constraints on the ability and perceived ability for a nurse to feel that they are delivering "good" care. Although several professional ethical resources guide the profession of nursing, nurses view their own individual moral identity as a fundamental manifestation of making a difference in society (Peter et al., 2016). This includes obligations to provide support, care, assistance with recovery, and advocacy for system change (Peter et al., 2016). Liaschenko and Peter (2016) posit that moral identity work is essential for nurses to exercise their moral agency to effect system change. Peter (2002) defines moral agency as a "mix of motivation and physical action directed toward some moral end" (p. 66). Moral agency is intimately connected to one's identity and is shaped by nurses' relationships with communities and institutions, especially ones in which nurses have a problematic relationship, such as health institutions that are bureaucratic or powerful (Liaschenko & Peter, 2016). Moral identity is central to moral agency and is an ongoing process arising through social contexts (Doane, 2002; Liaschenko & Peter, 2016). Moral identities are situated within particular social and political contexts that are reflective of current and future narratives (Liaschenko & Peter, 2016). Specifically, moral identity for nurses is shaped by professional group membership and historical and current relationships with others (nurse-to-nurse, nurse-to-physician, and nurse-patient)

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(Liaschenko & Peter, 2016). Moral identity includes how nurses perceive themselves, how others perceive them, and how society perceives them (Liaschenko & Peter, 2016). Therefore, deceptive acts, such as participation in limited resuscitation that is not disclosed to patients or families, can cause detrimental effects on a nurse's moral identity and erode their sense of professional integrity.

3 Deception, Coercion, and Transparency and the Ethics of Limited Resuscitation

Generally, deception leads to feelings of regret or discomfort, especially in situations where there is an established relationship of trust (J. M. A. de Vries & Timmins, 2016). Deceit associated with slow codes that are not disclosed to patients or families is contrary to a health care professional's duty to uphold the truth (Abdool, 2017; Beauchamp & Childress, 2019). This section will analyze the ethics of deception, including deception associated with nondisclosed slow codes, or any other form of nondisclosed limited resuscitation. In these circumstances, failing to tell patients or families the truth is harmful and can damage the trust expected between the nurse and the patient or family member. Deception and the lack of transparency in care are antithetical to the norms and standards established by the nursing profession. Communicating the limits and low success rate of in-hospital resuscitation are part of the truth-telling obligation related to any resuscitation.

Defining deception and lying has been a conceptual quandary for years. Bok (1978), an ethicist and author of work around lying and deception, defines deception as an attempt to make an individual believe what they themselves do not believe. Bok's (1978) work specifically highlights not only the intent of the deceiver but concerns regarding the risk of exploitation or manipulation of the people being deceived, especially when that person is deceived in a situation

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where actions depend on information from others. Some scholars classify a lie simply as using a falsification or alteration of facts to purposefully and intentionally mislead a person (Ekman, 1985; Elvish, James, & Milne, 2010). This can occur when an individual tells a partial truth or the full truth that is exaggerated with the intent that it is not believable (Ekman, 1985). There is considerable debate regarding the moral distinction between deception and lying (Tullo, Lee, Robinson, & Allan, 2015). Some scholars contend that lying and deception are morally distinct (Benn, 2001; Jackson, 2001). Yet others argue that they are both a deliberate use of manipulation and power, to get someone to believe something false, and therefore in clinical practice are ethically akin (Bakhurst, 1992; Teasdale & Kent, 1995). For this dissertation and analysis, lying and deception undermine trust and are morally equivalent (Teasdale & Kent, 1995).

Lying and deception have become part of a societal norm through news, social media, and politics (Mercurio, 2011). Lying and deception are instruments of power and are a reflection of the different modes of domination that exists within the social order in the health care environment (M. Carter, 2016). Similar to truthfulness and honesty in nursing, dishonesty and deceit are used by those who are powerful to coerce, act upon without consent, control or influence those who are powerless (M. Carter, 2016). The potential for dishonesty in nursing practice will vary based on the clinical circumstance, practice setting, power differentials, and autonomy and decision-making abilities of those involved (M. Carter, 2016). Deception often occurs in situations where nurses or other clinicians aim to minimize any additional patient distress or disruption in care. Deception occurs in a moment in time and may not be an intentional practice or act of the agent (Tuckett, 2012). Unlike a person who is a pathological liar, or who lacks integrity and truthfulness as a sustained practice, “softening” the truth to minimize harm to a patient may cloud the recognition of overt or covert deception. Deception is

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usually one of the last resorts after other reasonable measures have been taken to resolve the ethical dilemma. There are circumstances when actions by nurses are deceitful and morally and legally not permitted. Lipscomb (2016) opines “It is deceitful when knowingly and deliberately the nurse puts her name to forms with the intention of giving the impression that the contents and substance of that form have been deliberated over and/or agreed. It is dishonest when care not given is claimed as having been given” (p. 158). Falsifying patient records even in circumstances when hands-on care prevents a viable option for documentation, is dishonest, unethical, and illegal.

While most individuals would broadly agree that lying is wrong and a violation of another’s autonomy by undermining an individual’s right to make choices, some scholars support lying as a respectful act of beneficence and nonmaleficence (Strudler, 2016). There are rare circumstances when deception may be morally and often socially acceptable. In health care, the proverbial question about disclosing a grim prognosis is fraught with debate (Ling, Yu, & Guo, 2017; Schmelzer & Anema, 1988; Sokol, 2007). Clinicians may use ambiguities, euphemisms, or evasions to disclose a poor prognosis (Sokol, 2007). Titration of information given to patients is widespread in health care and can be justified in circumstances when patients become more distressed if they receive bad news (Teasdale & Kent, 1995). Nurse E. Fowler (2004) describes the effect of not fully disclosing a poor prognosis to a patient who she was caring for in an emergency department, also known as a theatre:

I first met the patient, a gentleman in his 70s, at the theatre reception. I introduced myself and carried out the routine preoperative checks. Once the checks were completed, I asked if he had any questions. At this point he looked me directly in the eyes and asked, ‘*Am I*

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going to die? Without thinking I immediately replied ‘no’. He asked no further questions and continued to chat to me about his family. (p. 448)

E. Fowler (2004) responded without thinking, despite knowing from the anesthesiologist that the patient was seriously ill, would most likely die without the operation, but was also unlikely to survive the procedure. The patient died during the procedure, and E. Fowler (2004) developed tremendous guilt for not being honest with her patient and stated that she “failed in one of the most basic nursing principles: that of honesty” (p. 448). In this reflective exercise, the nurse acknowledged her own vulnerabilities in this situation. E. Fowler (2004) pondered whether the patient was relying on her to tell him the truth, which might have allowed him an opportunity to say goodbye to his family or reconcile his thoughts. The nurse also acknowledged the patient’s reliance on her to provide the most appropriate response, yet she grappled with understanding what was the best response for the patient without knowing the patient’s social location with others. In retrospect, the nurse acknowledged that several factors limited her ability to fully assess the ethically appropriate response in this case. E. Fowler (2004) described that she had very limited knowledge about the patient’s values, cultural preferences, ability to cope with this information, and relationships with family or loved ones. Perhaps the patient did not really understand how unwell he was or perhaps he was seeking reassurance rather than “truth” about the possibility of his imminent death (E. Fowler, 2004).

This scenario presents a unique dilemma about the predictability of death. No one knows exactly when death will occur. Therefore, questions from patients about EoL expectations are often hard to adequately answer but transparency about the potentiality of death is intrinsic to good nursing practice and ethical comportment. Clinicians present probabilities and likelihoods but providing the ethically appropriate response can be challenging, and fraught with ambiguity

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and uncertainty. In this circumstance, brutal honesty may not be ethically appropriate, for example, if it undermines the patient's confidence, or escalates fear or panic. Human responses to mortality and suffering may potentially override the nurse's professional ethical obligations of honesty and veracity. A compassionate response is warranted and done to minimize emotional suffering and promote the preservation of hope for patients. The therapeutic effects of hope are well documented (E. Fowler, 2004). Although these situations can become justifiably distressing for nurses, a deliberate analysis of each case strengthens ethical comportment, ethical sensitivity, for optimal future outcomes. Openness, curiosity, attentiveness, and responsiveness on the part of the nurse or health care provider in the moment the patient's questions arise can clarify the patients' concerns, and coping needs and minimize deception.

3.1 Nursing Perceptions of Truth-telling

Nurses frequently encounter situations where they are expected to hide truths because other members of the health care team with decision-making authority have misled patients and families (Sarafis, Tsounis, Malliarou, & Lahana, 2013). They are placed in situations where truth-telling comes with considerable risk due to retaliation or employment termination, and they are forced to withhold information or tell a lie (Nasrabadi, Joolae, Navab, Esmaeili, & Shali, 2020; Sarafis et al., 2013; Valizadeh et al., 2014). The deception that sometimes occurs during nondisclosed limited resuscitation is often undiscovered unless a family member inquires about the resuscitation effort or if a lawsuit is filed. Once again nurses are placed in difficult ethical dilemmas because of their proximity to patients and families. A recent study of Chinese nurses revealed that most nurses felt it was morally right to protect patients from knowing the truth and that it was morally acceptable to lie to patients regarding a terminal illness (Ling et al., 2017). Cultural preferences heavily impact the decision to inform patients about a poor prognosis or

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terminal condition (Deem & Stokes, 2018; Ling et al., 2017). In the U.S., 98% of physicians informed patients of poor prognoses because of respect for patient autonomy, yet in some Eastern countries, only 15% of patients were informed of their diagnosis (Ling et al., 2017).

In general, nurses and nursing students believe that deception with patients is unethical and should not be an acceptable part of nursing practice, although some believe it is warranted in some cases (D. A. Curtis, Braziel, Redfearn, & Hall, 2020). A study of nurses in Italy found that 88% of nurses lie, but reported doing it minimally and only in the interest of the patient, to relieve stress, or to convince a patient to take a medication (Cantone et al., 2017). A majority of nurses in this study reported they considered the negative impact of lying and opposed lying to patients in situations that were nontherapeutic (Cantone et al., 2017). Another study found that nurses lied or deceived patients for numerous reasons including avoiding patient reactions to bad news, respecting cultural diversity, fear of diminishing hope, aligning with organizational policies, and inexperience with difficult conversations (Nasrabadi et al., 2020).

There is a strong and legitimate societal expectation that clinicians are honest and trustworthy professionals. For example, nurses remain the most trusted profession, and patients rely on this trust in the delivery of health care (Saad, 2020). This is certainly a shift from early medicine when American physician Oliver Wendell Holmes in 1871 stated,

Your patient has no more right to all the truth than he has to all the medicine in your saddle-bags, if you carry that kind of cartridge-box for the ammunition that slays disease.

He should get only just so much as is good for him. (Cone, 1982, p. 528)

Truth-telling is an expectation of patients, especially from nurses and nursing ethics codes call for honesty as a virtue (Schroeter, 2002). However, nurses value patient honesty, which leads to building trust within the nurse-patient relationship (D. A. Curtis et al., 2020).

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Lying is inconsistent with trustworthiness and affects both nurses and patients; yet human coping behavior allows individuals to subconsciously or unconsciously activate their mind and bodies to restore a sense of feeling good, despite actions that may be deceptive or dishonest (Mercurio, 2011; Olsen, 2012). A study of 250 acute care nurses and nursing students in England evaluating deception in nursing, found that some nurses who admitted using deceptive practices experienced moral distress because they contributed to the deceit and worried the trust in the nurse-patient relationship might be shattered (Teasdale & Kent, 1995). Generally, deception leads to feelings of regret or discomfort, especially in situations where there is an established relationship of trust (Mercurio, 2011). However, humans possess the ability to morally restore feelings of regret or guilt from lying through justifications that the deceptive behavior is an act of support of the individual who is being deceived, such as in nondisclosed limited resuscitation (Olsen, 2012). This will be explored further in Chapter Five.

3.2 Deception in Nondisclosed Limited Resuscitation

Nurses have a strong allegiance to honesty and transparency during EoL care discussions (Turner, Eccles, Keady, Simpson, & Elvish, 2017). Therefore, it can become morally challenging when nurses find themselves in situations where they must conceal the truth or tell an express lie to align with actions or prior statements of the health care team. The following section reflects a case-based analysis of the nurse's ethical options and responses when nondisclosed limited resuscitation has occurred.

Deception is associated with nondisclosed limited resuscitation, specifically nondisclosed slow codes and show codes because resuscitation efforts are either limited or not performed at all, yet families are sometimes under the impression that full measures were taken. Families may be given vague reports such as “everything was done, but your loved one did not survive” or a

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more specific but false report that “CPR was performed to the best of our ability, but without success”. In these circumstances, deception is two-fold. Deception occurs at the point of cardiac arrest when the health care team does not provide full efforts to resuscitate the patient yet report to the family that they were or appear to make a full effort, but it is slow or below the standard of practice. The deception continues once family members are notified of the patient’s death, and the health care team is expected to provide a unified response that fails to disclose a true account of the resuscitative efforts. Physicians are often the ones reporting this to families, but nurses are also responsible for reporting outcomes to families. Often nurses are left to respond to families who inquire “what happened?” after the physician has left the patient’s bedside. Nurses are placed in a difficult position when lying has occurred. Consider the following case example:

Vanessa is a 47-year-old patient with acute idiopathic cardiomyopathy. Her condition is irreversible, and her heart function continues to decline at a rapid rate. As a result, her lungs, liver, and kidneys have also sustained damage, and she is rapidly approaching multi-system organ failure. Vanessa’s health care team has expressed concern that she is unlikely to survive long enough to be placed on a heart transplant list, and other intermediate interventions are unlikely to provide enough support for her survival. Attending physician Richard Thomas, MD, and the remaining health care team immediately discussed Vanessa’s code status upon admission to the intensive care unit recognizing her prognosis was poor. Vanessa’s husband was adamant that he wanted “everything done,” and he did not want to change her code status to DNAR. He expressed that Vanessa was a “fighter” and had strong faith. He knew that she would not want to “give up”. Vanessa is currently in the intensive care unit supported by mechanical ventilation, intravenous vasoactive medication, antibiotics, and artificial nutrition and hydration. She is sedated and therefore unable to express her wishes. Registered nurse Javier has taken care of

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Vanessa on several occasions and developed a strong rapport with the family. He discovered that he went to the same high school as Vanessa's daughter, and he has bonded with Vanessa's husband, children, and parents. Even on days when Javier was not assigned to care for Vanessa, her family would look for him just to say hello. Over several days, Vanessa's clinical condition continued to deteriorate. Once again, Vanessa's husband and family were presented with grim medical facts but refused to change her code status from full code. However, Dr. Thomas agreed to consult with the heart transplant team for a formal review. When Javier returned to the unit he was again assigned to care for Vanessa. He could see her decline over the past few days, and he knew that her death was imminent.

During rounds, Dr. Thomas expressed that her family was not amenable to a DNR order. Her family was not present at the bedside during this time. He stated that she was at the maximum amount of support, but organs were failing. He predicted her cardiac arrest soon and indicated that the team would do a short and abbreviated round of CPR if necessary. He stated, "do not pull out all stops, she has suffered enough." Javier knew exactly what he meant. He had seen it numerous times before. Javier felt distressed because he knew the family wanted everything done. But he also knew that Vanessa did not deserve to suffer, and he would likely be the one to administer CPR, perform chest compressions, and he did not want to cause or witness additional harm. Vanessa's family was not present at the bedside and the health care team tacitly agreed that she would not be aggressively coded. Not long after his shift began, Vanessa coded. Javier called for others to come to assist with resuscitation, but the charge nurse and other staff already knew that this would not be an aggressive attempt. Vanessa had been a patient on the unit for some time, and the staff knew this day would come. No one rushed around frantically to obtain the crash cart or medications. Javier performed chest compressions but agonized over

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causing harm. He performed light chest compressions and another nurse administered one round of epinephrine. Dr. Thomas arrived within 3-4 minutes and asked the team if anyone objected to stopping. There was silence. The resuscitation effort was stopped.

Javier reflected on the slow code event. Did the team perform CPR? Technically yes. But was it consistent with the standard of care? No. The team entered Vanessa's room with the intent that she was not going to survive. Dr. Thomas indicated that the team was to perform "light CPR" and the attempt ended after 3-4 minutes. He specifically said, "don't pull out all stops, this poor woman has suffered enough". When Vanessa coded, Javier called out for assistance from his other team members, and there was a tacit yet unspoken understanding that an aggressive attempt to bring Vanessa back was not going to occur. Javier briefly and gently performed chest compressions lighter than AHA recommendations. Another nurse slowly obtained the crash cart and brought it to the room. At this point, 2-3 minutes had already passed. Another nurse pulled and prepared resuscitative medications, but only administered one dose before Dr. Thomas looked at everyone in the room and called for a termination of the code.

Vanessa's husband, mother, and father received a phone call from Dr. Thomas. Dr. Thomas informed Vanessa's family that "Her heart stopped, and all measures were taken to save her, but we were unsuccessful. We worked for quite some time to save her, but her heart was just too weak to survive. I am so sorry for your loss. Are you able to come to the hospital?" Vanessa's family rushed to the hospital and when they arrived Dr. Thomas was on another unit, and registered nurse Javier was present in Vanessa's room. Javier was prepared for the family's arrival and spiritual support services were also present. Vanessa's husband asked Javier "How could she decline this fast? Yesterday she was stable, and I thought she was going to get better. I

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thought she was going to get a heart transplant. Did you have to do CPR? Did you try all the medications that Dr. Thomas mentioned you would try? Did she suffer?”

At this moment, how should Javier respond to Vanessa’s husband in a morally appropriate way?

3.2.1 Case Study: Option One

Javier could tell the full truth with transparency. Javier could tell Vanessa’s husband that the team briefly attempted chest compressions and administered medications to save her. Javier could explain that in an effort to minimize suffering, a lengthy CPR event did not occur. It is hard to predict how these difficult conversations will be received. Ideally, Vanessa’s husband and family will accept this as a truthful statement. Despite their grief, they will be grateful for the health care team’s efforts and acceptance of the outcome. However, there is a significant risk that they will understand that not all measures of CPR were taken. Vanessa’s husband poses specific questions regarding CPR and medications. He may inquire further about why a lengthy CPR event was not done. He may interpret a short CPR event as a medical failure and demand an explanation. In times of shock and grief, emotional responses are easily triggered for families. Anger is often the frontline coping strategy for a sense of helplessness and powerlessness.

This approach could have significant consequences not only for Javier but for the entire health care team. When patient families suspect anything untoward that may have contributed to their loved one’s death, the pursuit of legal action may occur. In general, lawsuits surrounding EoL disputes are often lodged against the hospital and physicians (O’Reilly, 2018). Nurses are rarely sued, despite their intimate involvement in the circumstances (Brous, 2019; H. Singh, 2020). This is explored in more detail in Chapter Four. Ethically, Javier’s honesty and transparency minimize any threat to personal or professional integrity. Javier has communicated

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his version of truthful facts to the family related to Vanessa's death. However, Javier risks conflict with Dr. Thomas and other members of the health care team because his version differs from what they told the family. Research demonstrates that a unified approach when communicating with patients and families is optimal (Laurent et al., 2017). Deviation in communication terms or messages among the health care team can confuse patients and families and risk creating a professional divide amongst the health care team.

3.2.2 Case Study: Option Two

Javier could defer these answers to Dr. Thomas and other physicians on the health care team. This approach could involve some level of deceit because Javier is not being fully transparent by deferring the questions to Dr. Thomas, especially knowing that Vanessa's family will not likely hear the truth from the rest of the team. This is a common approach, especially for novice nurses who are not comfortable or do not feel empowered to address EoL concerns with families (Chu & Taliaferro, 2019; Hendricks-Ferguson et al., 2015). Javier's avoidance in answering the question is not an explicit lie but could be considered deceptive because the family is left to believe the lie that Dr. Thomas originally told them (that full measures were taken to save Vanessa's life). This approach preserves a unified approach to communication with the team. It could instill trust among the health care team that "we are all in this together", especially since it appears that Javier and the other nurses were complicit in participating in the slow code event. Yet, it could affect Javier's moral identity and threaten his sense of commitment to good nursing practice knowing that he was not being fully transparent, even though he was not telling an explicit lie to Vanessa's family. He was not telling an explicit lie to Vanessa's family. Vanessa's family will not hear mixed messages surrounding the events related to her death. This approach could strengthen the trust among the healthcare team. Unfortunately, this approach

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justifies the hierarchical oppressive structure in health care that purports to give authority to physicians without acknowledging the contributions of nurses. This oppression fuels nurses' feelings of lack of empowerment. Expert nurses who generally have stronger ethical comportment resulting from experience and repeated exposure to ethical issues, develop empowerment and are able to speak up and speak out. Experience has allowed these nurses to recognize the necessity for patient and family advocacy, even when it deviates from the preconceived standards in health care for nurses to simply follow the physician's direction without deliberation. This may or may not be well received by Vanessa's family. Oftentimes, families want an immediate answer to their questions, especially amid a state of shock. Timeliness of communication is critical and the longer the family is left without answers, the more challenging the situation may become. It will be incumbent on Dr. Thomas or another member of the health care team to address Vanessa's family's concerns promptly.

3.2.3 Case Study: Option Three

Javier could align his statements with Dr. Thomas and continue the deception associated with the limited resuscitation efforts during Vanessa's cardiac arrest. This approach places him in an unusually difficult situation because of the hierarchical structure of the health care team. Even if Javier has the ethical awareness and comportment to identify that this is an issue, he may not possess the requisite moral courage to take action. If Vanessa's family discovered that a slow code occurred, serious consequences, such as a reprimand, employee termination, disciplinary license repercussions, and other legal consequences are possible. Nurses are viewed as more expendable than physicians because the medical model in the U.S. does not articulate a nurse's monetary value through billing codes or procedures. Physicians, on the other hand, can demonstrate financial worth through the number of surgeries, hospital admissions, and other

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measurable medical goals (Furci & Furci, 2017). Nurses offer an immeasurable value to healing, treatment, recovery, and outcomes. However, the tasks, skills, and care delivered by nurses are not typically monetized in the U.S. health care system, and nurses are considered a cost rather than revenue-generating (Welton & Harris, 2007). Therefore, when a critical incident or possibility of legal liability occurs, nurses are often the first to be reprimanded, and physicians' toxic or unethical behaviors are tolerated (Mackusick & Minick, 2010).

Not only is the threat to Javier's professional integrity at stake, the reputations of his colleagues, including other nurses are also a consideration. He may not want to jeopardize his job, career, face legal implications, or create division among the health care team if they also face similar consequences. In this case, Javier provided nursing care for Vanessa on many occasions. A key component of ethical comportment is advocacy, and he may have a deep sense of advocacy and duty to protect Vanessa's dignity and alleviate harm and suffering. Javier may have morally reconciled that limiting the physical intrusiveness of CPR was the best avenue to protect his patient. The formation of ethical comportment in nurses who experience repeated exposure to traumatic and unnecessary harm in the dying process morphs into respect for human dignity and advocacy for a good death. Javier noted that in his role as a registered nurse, he witnessed deceptive limited resuscitation efforts in many different forms on his unit before. This may have also supported his willingness to participate in the abbreviated code. However, deception in nondisclosed limited resuscitation and nondisclosed slow codes is harmful due to the nature of the relationship between the nurse and the patient. Patients and families are already in a vulnerable situation when their loved one is receiving care at the end of life, due to the reliance on the health care team to provide safe, appropriate, and effective treatment and

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deception takes advantage of that vulnerability, damaging the trusting relationship between nurses and patients and their families (Gillon, 1985).

3.2.4 The Nurse-Patient Relationship

There are several approaches to analyzing the ethics of deception in health care. Olsen (2012) suggests a two-pronged approach evaluating the nurse-patient relationship and the patient's rights. The relationship between Nurse Javier and the patient Vanessa is one where Javier serves as a nurse advocate to minimize harm and to advocate for her values. In the analysis of the three options above, it is important to recognize the appropriate ethical virtues and relationships that contribute to a nurse's moral decision-making. Several factors contribute to whether or not nurses tell the truth in these crucial moments. Truthful communication with patients and families is key to establishing and preserving trust in the nurse-patient relationship (Ling et al., 2017). The relational aspect in Vanessa's case extends to her family. Acknowledging the family's suffering is a key factor in the development of ethical comportment. Part of Javier's ethical comportment as a nurse is viewing the patient as a whole, which includes family and community. The social encompassing of Javier's duty to care, alleviate suffering and minimize unnecessary treatment is also extended to Vanessa's family. The cultivation of the relationship between Nurse Javier and Vanessa's family is a barrier that could become a potential betrayal of the health care team if the truth is disclosed. In addition, trust is a critical part of the nurse-patient relationship, and deception, no matter how well-intentioned, may cause mistrust if discovered (Olsen, 2012). The maintenance of relationships in nursing is a moral value at the core of a feminist ethic in nursing (Peter, 2002). Cultivating relationships stems from the value of care and recognizes the vulnerability and power differences that exist in health care. A nurse's direct experiential grasp of ethical reasoning and awareness of "knowing the patient" not limited to

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disease or illness, but as a person, family, and community, allows the nurse to identify the barriers or social structures that influence health outcomes and can yield wisdom and skillful ethical comportment. Any threat to a nurse's ethical obligation to patients for veracity, or truth-telling, suggests a potential for endangering the trust in that relationship. In addition, the complexity of a nurses' responsibility to patients and families during the EoL is tremendous including providing resources and emotional support for grieving.

The challenge with the nurse-patient relationship analysis is that it fails to acknowledge the other relationships, including the nurse-physician and physician-patient relationships. Nurses do not work alone, and this is evident in early American nursing ethics literature which identifies the nurse's relationship with patients, but also a relationship with physicians and families. The challenge of deception in nondisclosed limited resuscitation is that the act itself can often be a swiftly orchestrated event that involves multiple participants and factors, such as in nondisclosed "slow codes". Especially in acute care settings where limited resuscitation frequently occurs, physicians, pharmacists, respiratory therapists, and other assistive personnel may all be part of a resuscitation event. This leaves nurses at the mercy of the physician and forced to determine allegiance with patients or with the physician when the two are in conflict. Early nursing ethics literature notes that "The atmosphere [of conflict between the physician and patient] is sometimes cleared when the nurse remembers that she owes her first allegiance to her patients" (Gladwin, 1930, pp. 105-106). This ethical tenet of the profession is still present today in the second provision of the Code of Ethics for Nurses stating, "The nurse's primary commitment is to the patient, whether an individual, family, group, community, or population" (American Nurses Association, 2015, p. 5). The medical model of health care directs nurses to follow physicians' orders. However, nurses have the professional responsibility, autonomy, and legal

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and ethical responsibility to question these orders and in fact, are accountable for all decisions and actions that are taken in the course of nursing practice (American Nurses Association, 2015).

3.2.5 Patient's Rights

The second prong of Olsen's (2012) deception analysis is determining the patients' rights. Olsen (2012) suggests that in order to ethically justify deception in practice, a nurse must be willing to bypass the patient in the decision-making process. Deception prevents voluntariness or freedom in decision-making for the patient or family. Some argue that the deception associated with limited resuscitation is ethically justified because the patient or family is unable to distinguish between the deception or avoidance of harsh truths and actions that can improve family well-being (Cantone et al., 2017). The patient and family's inability to distinguish between the truth and lies is the power gradient that demands explanation and truth-telling and disclosure to the patient and family.

Nurses and physicians both have ethical obligations to have honest communications with patients to promote trust in the clinician-patient relationship. The International Council for Nurses Code of Ethics (2012) states that nurses should exemplify honesty in communication with patients and provide adequate information about treatments. The Code of Ethics for Nurses with Interpretive Statements holds that nurses must have "honest discussions about available resources, treatment options, and capacity for self-care" (American Nurses Association, 2015, p. 5). The Code of Ethics for Nurses with Interpretive Statements (2015) also holds that nurses are expected to follow a code of ethical conduct including veracity, as well as adhering to the scope and standards of nursing practice. Physicians are held to a similar standard in the Code of Medical Ethics which states, "Open communication is fundamental to the trust that underlies the patient-physician relationship, and physicians have an obligation to deal honestly with patients at

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all times” (American Medical Association, 2015, p. 130). However, the ethical challenges that arise in practice can make honesty and disclosure difficult (Morain et al., 2017).

Despite these challenges, patients’ rights must not be circumvented in the decision-making process. Slow codes are not often explicitly ordered or discussed, and therefore communication with family’s or alternate decision-makers (ADMs) has a significant potential of being inconsistent or unclear and could lead to heightened suspicions, mistrust on the part of patients and families, and deleterious effects to staff and the health care organization due to the breach in trust and professional ethics. An alternate decision-maker refers to any person participating in decision-making for a patient, regardless of whether they are appointed through default surrogate statutes, appointed by a court, or through advance directive and will be explored more in Chapter Three (DeMartino et al., 2017). In Vanessa’s case, she was unable to express her wishes. In these circumstances, her husband, or other designated ADM step into her shoes and make these decisions. It was clear that her husband and family had expectations that full resuscitation measures would be taken. They refused a DNAR on several occasions, yet the nature of the conversations or the style of communication that led to these refusals is unclear. Regardless, full resuscitation measures were not taken, and Vanessa’s family was misled to believe they were. In addition, remaining silent demonstrated in option 2 or perpetuating the lie demonstrated in option 3, does not support a transparent relationship void of deception. Deception is unethical and neglects decision-making ability from the patient and family or ADM. Options 2 and 3 can lead to mistrust, create moral distress for Javier and other nurses, and create irreparable harm to the nurse’s sense of ethical integrity and the nursing profession. Telling the truth is ideal because it cultivates Javier’s moral courage and is in alignment with the ethical tenets of the nursing profession and preserves Javier’s moral identity. However, telling the truth

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also carries the risk for Javier to experience retaliation and isolation from his colleagues because his actions were not in line with the team. Telling Vanessa's family the truth about the resuscitation event is the most ethically appropriate option, but it does not resolve the fact that a slow resuscitation event occurred. Ideally, any type of limited resuscitation event (slow code, partial code, or chemical code) should be discussed with the family in advance of the event during EoL code status discussions. The goal is to avoid deception and effectively communicate to identify an EoL care plan that is clinically and ethically appropriate and satisfies the values and preferences of the patient-family unit. This communication is difficult and requires knowledge and skills to minimize conflict. Deception can be avoided through different styles of communication that can persuade patients and families to align their values for a common goal.

4 Nudges

A critical factor in the end-of-life decision-making process is communication. Communication is a fundamental skill that is intrinsic to good nursing practice. Communication is the transactional message creation that occurs in the context of cultural and social values and psychological conditions (Kourkouta & Papathanasiou, 2014, p. 65). Communication is essential to the mitigation of conflict in ethically complex moments when patient values are balanced against the clinical expertise of the health care team. EoL decision-making even among the health care team can be challenging in circumstances of disagreement in clinical judgment. Sound communication strategies among the health care team help build consensus and portrays unification and confidence when delivering the message and care to the patient (Laurent et al., 2017). The following sections will identify how nudging can be used by nurses and other clinicians to address EoL conflict. Nudging is an evidence-informed communication technique that may benefit how clinicians present EoL medical interventions. Nudging supports transparent

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and honest communication when full resuscitation is not medically appropriate, but limited resuscitation is an EoL option.

Research regarding challenges in communication between physicians, nurses, and patients or families is substantial (Brooks, Manias, & Nicholson, 2017; Flannery, Ramjan, & Peters, 2016; Hansen, Goodell, DeHaven, & Smith, 2009; Latour, Fulbrook, & Albarran, 2009; Özden, Karagözoğlu, & Yıldırım, 2013; Westphal & McKee, 2009). A study by Forte, Vincent, Velasco, and Park (2012) revealed that physicians with less formal education in EoL care avoid making decisions and prolong life-sustaining treatment that is medically inappropriate and thus, no longer appropriate given the patient's clinical condition. Another similar study of physicians and nurses in Italy described how physicians' lack of competence in delivering EoL communication and lack of coordination among the health care team leads to unclear and sometimes contradictory messages to patients and families (Cipolletta & Oprandi, 2014). Nurses are often hesitant or feel uncomfortable communicating with patients and families about EoL care (Davies et al., 2008; Hendricks-Ferguson et al., 2015). As demonstrated in the case of Vanessa, a failure to present EoL options in a desirable manner can lead to resistance and breakdown of trust (Cipolletta & Oprandi, 2014; Ditto, Danks, Smucker, & et al., 2001). Silence is often a difficult option, simply due to families' and patients' natural curiosity and inquiry into the diagnosis, prognosis, and treatment plan (Schmelzer & Anema, 1988). In Vanessa's case, Nurse Javier must evaluate his interpersonal values and communication skills and consider the consequences and risks of telling the whole truth.

Decision-making in general is a non-rational human process based on a cognitive psychological model known as the dual-process theory (Mortensen, Nordhaug, & Lohne, 2018; Sharif & Moorlock, 2018). One system consists of an automatic quick, instinctive, and pre-

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rational thought process (Mortensen et al., 2018; Schmidt & Engelen, 2020). During this type of decision-making, people are easily influenced, unable to resist temptation, and fail to exert willpower (Mortensen et al., 2018). This requires little energy and is unconscious and spontaneous (Mortensen et al., 2018). The second system is a slow rational thought process requiring considerable energy (Sharif & Moorlock, 2018). This second type of decision-making is a deliberate attempt to overcome emotions and routines that become barriers to rational thought (Mortensen et al., 2018). These conscious and rational decisions require the use of willpower and self-control (Mortensen et al., 2018). Suggesting that people are reduced to a mere dual process of decision-making is controversial and oversimplified, yet it provides a basis to consider how the power of influence and persuasion can significantly impact outcomes (Schmidt & Engelen, 2020). It is also problematic because it only considers the opposite poles: rational versus non-rational decision-making with no in-between terms.

Ethicists have proposed a unique way of communicating with patients and families referred to as “nudging”, which encourages indirect suggestive behavior to try and achieve compliance and influence the decision-making of an individual (Halpern, 2018; Mortensen et al., 2018; Thaler & Sunstein, 2008). Nudging is designed to target the quick and unconscious thought process, which results in the conditioning of choice-making (Thaler & Sunstein, 2008). A “choice architect” deliberately structures another individual’s decisions so that it is more likely that they make the preferred choice (Mills, 2015; Thaler & Sunstein, 2008). This is done through small and subtle details that have major impacts on behavior.

4.1 Support for Nudges

The argument for nudges is an axiom to promote a “better” choice, such as health promotion. An example of a health promotion nudge is identified in the following example:

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“Google saw a 47% increase of water consumption after placing bottled water at eye level in its fridges” (Engelen, 2019, p. 49). The less desirable items are still available yet are presented in a way that an individual’s psychological bias works to influence behavior to make a “better” decision. A review of the literature revealed targeted health behaviors subject to nudging included medication adherence, physical activity, diet, blood pressure monitoring, foot care, self-efficacy, glucose monitoring, and quality of life (Kwan et al., 2020). Of these, nudging has shown statistically significant impacts on adherence to medication, foot care practices, and quality of life (Kwan et al., 2020). Supporters of nudges posit that ideal choices are made without limiting individual freedom (Engelen, 2019). Nudges are easy to resist, therefore do not infringe on autonomy, and encourage people to make a decision that benefits themselves and society (Aggarwal, Davies, & Sullivan, 2014).

4.2 Opponents of Nudging

Others vehemently oppose nudging and suggest that the act is coercive, deceptive, disrespectful, undermines autonomy, and restricts freedom (Engelen, 2019; MacKay & Robinson, 2016). Opponents suggest that if subtle encouragement from one individual to another promotes an interest other than their own, the potential for coercion exists (M. Quigley, 2014). Individuals act autonomously and of their free will. Therefore, opponents of nudging argue that any infringement on this free will, whether through coercion, persuasion, or manipulation is considered paternalism (Mortensen et al., 2018). Paternalism is an infringement on a person’s autonomy with the intent of promoting good or preventing harm. Some scholars argue that nudges are a form of non-intrusive paternalism because choices are not blocked, and yet are still manipulative because the influencer imposes their preferential view upon the other person (Thaler & Sunstein, 2008; Vallgård, 2012; T. M. Wilkinson, 2013). Yet, Sharif and Moorlock

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(2018) posit that if the same nudge does not restrict choices- and therefore an individual has the freedom to choose from all options, then it is not coercive. Coercion is not the same as merely steering people's choices by intentionally leveraging some power over them to compel them to act in a manner that is not their own (M. Quigley, 2014). Coercion involves force or threats to influence someone to do something. Manipulation associated with nudging always involves some infringement on a person's autonomy. Opponents state that even if nudges respected freedom and promoted well-being, nudgers tap into a rational agency and therefore fail to treat people like rational human beings and deprive people of making self-chosen actions (Schmidt & Engelen, 2020). Thaler and Sunstein (2008) counter by arguing that the framing of choices is inevitable, and therefore, they should be done for the greater good.

Nudges are not without risks, but an individual is really never radically separated or free from nudges. Some options must always be initially presented or set as a default (Halpern, 2018). Human beings are always engaged and have situated possibility rather than radical autonomous freedom. Therefore, creating opportunities for desired behaviors is ideal to minimize harm to society (Blumenthal-Barby & Burroughs, 2012). Nudges make unhealthy or undesirable options less convenient, more costly to engage in, or less appealing and socially attractive (A. Carter & Hall, 2012). Although controversial, nudges are often effective and therefore their application continues to be relevant in many settings.

4.3 Translating Nudging to End of Life Care

In nursing, research reveals that nudging occurs in everyday practice, even if nurses are unaware of the theory behind it (Mortensen et al., 2018). Nudging is often applied by nurses and other clinicians without awareness (Mortensen et al., 2018). A study in 2018 found that in general, physicians and patients viewed a physicians' use of nudges to be ethical and acceptable

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(Fridman, Hart, Yadav, & Higgins, 2018). Applying nudging to influence families making critical decisions for their loved ones' EoL treatment assumes that the decision to request potentially medically inappropriate interventions is influenced by nonrational factors. An exploration into the social and behavioral factors contributing to family demands for inappropriate treatment is presented in Chapter Three. However, nurses and other clinicians must be sensitive to the bereavement and grief of families when attempting to apply nudging in EoL decision-making (Sharif & Moorlock, 2018). Using nudging to address treatment decisions is particularly relevant when patients and families are often required to address risks of survival and quality of life which can stimulate emotions such as fear and grief (Aggarwal et al., 2014). A review of the literature found that EoL options are often presented by health care professionals with merely a subtle preference for a particular course of action and there is an understanding that the family's decision will be supported (R. J. Anderson, Bloch, Armstrong, Stone, & Low, 2019). A study of patients with cancer revealed that demands for treatment came from an emotional perception of hope, despite interventions having burdensome effects and a low benefit (Gaskin et al., 1998). Deviating from life-sustaining interventions requires an active choice architect suggesting this option (Halpern et al., 2013).

Nudging can be extremely beneficial for shared decision-making in EoL conflict. Allowing families to actively participate and make technical decisions about their loved one's EoL care will help steer them away from demanding to "do everything". If families are presented with a variety of options framed as providing a benefit rather than options framed as neglecting or limiting care, they generally feel engaged and find solace in the active participation of decision-making. A study of outpatients in an oncology clinic revealed that reframing an advance directive from "I want to have life support" listed in the first three options, to initially listing the

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comfort-oriented goals, resulted in a marked difference (Halpern et al., 2013). Once each participant completed their initial advance directive, they met with the researcher to debrief about their elected choices and discussed in detail what that advance directive choice entailed. Nearly half (43%) of patients who originally chose life-sustaining interventions as a default option changed their preference to comfort care once they were informed of their choice and comfort care was changed to a default option. This suggests that people are not deeply wedded to EoL preferences but are easily influenced in decision-making during this time (Halpern et al., 2013). Nudging in EoL decision-making is akin to the organized manner that food is displayed at a salad bar, where healthier options are easily accessible, or spoons versus tongs are used to control portions (M. Quigley, 2014). This simple change in the layout will affect the decisions that are made and nudge patrons to make healthy choices.

Some scholars have proposed the formal application of nudging in critical care and EoL conversations due to its success and mediation-like approach to conflict (Fridman et al., 2018; Halpern, 2018; Wright, 2018). Wright (2018) suggests that any competent adult who decides to forego life-sustaining treatment should be deliberately nudged (through policy or referral) to make this decision in consultation with their families or other stakeholders. The goal is to reach an EoL care plan using a shared decision-making approach in an effort to minimize conflict. Families and other stakeholders should be a part of EoL planning in the beginning stages of decision-making.

4.3.1 Nurses' Role in EoL Communication

Nurses have the unique privilege of frequent and consistent communication with families. As the most trusted profession, patients and families rely on their knowledge and experience to help inform decision-making. Nurses should use this opportunity to educate families on the

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limitations and success rates of full resuscitation and the nuances of resuscitation. Nurses often have sustained contact with families and therefore can explain procedures, devices, and life-sustaining treatments. Nurses must present treatments as clearly, understandably, and bias-free as possible. Nurses should also take these opportunities to present the harms associated with what therapies are present but should be careful not to provide too much background on therapies that the patient is not yet receiving to avoid overloading families with information that may not be pertinent. Nurses with frequent exposure to death and dying, especially those with hospice or palliative care experience, can implement and bridge individualized characteristics of a good death by incorporating the patient and family's values into the clinical options that are medically appropriate for the time.

This care plan and communication must not be done in a silo, but in collaboration with physicians, and other stakeholders in the health care team. There is notable research on nurse-led EOL care interventions that reveals an improvement of EoL communication and high acceptability of the intervention (Fujisawa et al., 2020; Hickish & Roberts, 2019; Pesut et al., 2017; A. J. Tan, Yamarik, Brody, Chung, & Grudzen, 2021). Nurses are consistently able to establish rapport, trust, and reliance with families, using effective communication techniques and nurse-led EoL approaches are well received (J. A. Adams, Bailey, Anderson, & Docherty, 2011). This will be explored further in Chapter Six.

4.3.2 Case Study: Nurse Javier Using Nudging

In Vanessa's case, Nurse Javier established a strong rapport with her family through frequent contact and common life experiences. Vanessa's husband stated that he wanted "everything done". This is the perfect opportunity for Javier to present the ethically appropriate options to foster a shared EoL goal that incorporates Vanessa's values. Her husband stated that

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Vanessa did not want to “give up”, suggesting that some action should be presented rather than a non-action (such as a DNAR order). Therefore, using a nudging approach, DNAR language should be presented as one of the less ideal options because it does not appear to be consistent with Vanessa’s values. However, full resuscitation is not medically indicated and should not be recommended because of Vanessa’s terminal illness and poor prognosis. Nudging does not conceal options, rather the nudger presents the ethically appropriate options identified by the health care team in a more appealing manner. This is an opportunity to discuss limited resuscitation efforts that can be tailored to meet Vanessa’s values, mitigate moral distress for clinicians, and minimize significant harm and suffering to Vanessa. Vanessa’s husband also stated that she had a strong faith, and this is also an opportunity to explore her spiritual or religious values in collaboration with pastoral consultation. It is also important that Javier explain the purpose of the current life support devices such as mechanical ventilation and intravenous vasoactive medications. Oftentimes, families are not aware that these interventions are designed to be temporary supportive measures and eventually they may not be able to support Vanessa’s condition. These conversations are delicate, time-sensitive, time-consuming, and ideally provide some framework for families to consider in decision-making. This information is best presented in the context of ongoing clinical care so that family members can better understand the clinical indications and limitations of the therapies as they are introduced and continued. This situated approach ensures that the “informed consent” is understood contextually as the patient’s condition, and the therapies change. Nudging by nurses, especially in EoL conversations is a difficult skill to master. Nurses often feel unprepared to have these conversations or feel that it is not within their scope of practice to do (Hjelmfors et al., 2015).

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Nudging is an area of research that should continue to be explored to demonstrate the benefits or harms of this approach.

The application of nudging in EoL care cases requires a careful justification to address possible coercion or manipulation and minimize infringement on autonomy. Critical components to analyze when using nudging are the threats of coercion and domination that could erode the patient and family's right to choose. Often nudging is used in public policies and therefore governmental influence over others and is of legitimate concern. Nudging allows an entity or individual to exercise power or control over the decision-making of another often without knowledge (Schmidt & Engelen, 2020). Even if clinicians were to disclose how nudges were being used to influence behavior, it could render the nudge powerless and ineffective (Gelfand, 2016). Applying the example of supermarket positioning of unhealthy foods to the issue of domination, it is clear that nudging is being used to reduce the democratic control over choice environments (Schmidt & Engelen, 2020). There is a degree of nondisclosure, yet nudging is not deceptive because all food options are present, some are just more convenient to access than others, and while choice-making might be limited, it is not precluded or completely prevented.

The benefit of using nudges is that all of the information is presented. Nothing is withheld and individuals are free to choose among the various options available. Nudging can be extremely beneficial in situations when people may not be exclusively rational or within the conformity of their values and beliefs (Mortensen et al., 2018). People often lack adequate information and have distorted rationality when making EoL decisions. As expected, families experience grief, loss and often do not respond to complex EoL decisions with well thought out options for deliberation. Providing family members with a choice of 'yes' to a life-saving intravenous medication with a low risk of harm, or 'no' to vigorous attempts to pump the chest

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and possibly break ribs during CPR, allows time for reflection of potential harms to their loved one. Presenting the least harmful options first framed in a beneficent manner nudges the family to consider their loved one's interest over their own grief and desperation for patient survival at any cost. This tailored approach to limited resuscitation avoids the "do everything" mantra and supports an individualized plan of care that incorporates families' decision-making and frames CPR options in an inclusive manner rather than an exclusive approach. This nudging approach allows the clinician to communicate "here is everything we can do", rather than "do you want us to do everything?", and present options in a way that nudges families to perceive that everything possible has been clinically done. It does not prevent a family member from saying 'yes' to chest compressions, but, separating and describing the physically intrusive acts of CPR nudges families to choose a more compassionate resuscitation process if they are unwilling to conclude their loved one should have a DNAR.

5 Conclusion

Nurses are an essential part of the healthcare infrastructure, especially in the delivery of EoL care. A nurses' professional formation is important in the analysis of participation in limited resuscitation because of the positioning of nurses as advocates and caregivers of patients and families during the EoL process. Nurses have a level of emotional, psychological, and spiritual health that informs their nursing practice and the formation of professional identity and ethical comportment. These are knowledge and skills that are embodied within the ethos of good nursing practice and reflected in respectful interactions and compassionate presence with patients and families. Nurses are uniquely positioned to provide patients and families with resources and emotional support during the EoL process. This requires nurses to possess effective communication skills that encompass honesty and transparency, which are intrinsic to good

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nursing practice and ethical comportment. Patients and families expect and trust that information will be disclosed honestly. Deception is not characteristic of a nurse's ethical comportment, which is a foundational component of being a professional nurse. When deception occurs, nurses can feel distressed because this is not consistent with their professional identity or professional ethics. Limited resuscitation is often not disclosed to patients and families and therefore a culture of deception is associated with this practice, especially with nondisclosed slow codes. Deception is not morally permissible in the delivery of EoL care and thus limited resuscitation that occurs without being disclosed to patients and families is unethical. Deceptive acts in EoL care are threats to the nurse-patient and nurse-family relationships and do not foster trust. Alternative approaches to EoL conflict between the health care team and families can be addressed using nudging. Nurses can implement nudging when there is the potential for EoL conflict or once conflict has already been presented. Nudging is an ethically defensible approach to EoL conflict that can promote shared decision-making and disclosed limited resuscitation.

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Chapter Three: Surrogate Autonomy, Vulnerability, and Cultural Humility

1 Introduction

End of life decision making involves a significant amount of conflict management and emotional processing which can strain relationships and emotionally drain stakeholders (Laurent et al., 2017). Family demands for aggressive treatment, albeit value-laden, force physician's to face up to the limits of medicine and the technical aspects of treatments and reckon that there is no treatment available that would be of benefit to the family member's loved one (Laurent et al., 2017). As a result, physicians may reluctantly comply with a demand to resuscitate a patient to appease a family member although the physician believes it is a violation of professional ethical obligations to refrain from providing treatment that is not beneficial. Nurses are often dissatisfied with EoL decisions, because they feel forced to provide the care that's required as a result of a decision in which they did not participate, for life-sustaining treatment that can sometimes cause harm to a patient who has a poor prognosis (Laurent et al., 2017).

This chapter will focus on the numerous factors that contribute to family demands for EoL care that is perceived by clinicians as medically inappropriate. This conflict and avoidance of conflict between families and clinicians are notable factors that lead to nurses' participation in nondisclosed limited resuscitation (Baumrucker et al., 2007; J. Kelly, 2008; Stokes & Zoucha, 2021). Yet, nondeceptive limited resuscitation that is disclosed to patients and families can be an intermediate action that allows families to express and preserve their values while respecting the expertise of clinicians to deliver appropriate EoL care. Limited resuscitation does not offer the full elements of CPR that a family might request but offers a middle ground to avoid harmful interventions that likely have no medical benefit. Within this context, this chapter will identify factors to support why disclosed limited resuscitation is morally permissible such as

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acknowledgement of a family or ADM's vulnerability and autonomy, establishment of trust between nurses and families, respect for cultural humility, and it allows ADMs to have an active role in EoL decision-making.

Typically, limited resuscitation occurs in the context where patients are unable to express their wishes due to clinical conditions that limit decision-making capacity. Decision-making capacity in health care has been predominately understood using the four component model including 1) understanding information relevant to a patient's condition and the recommended treatment, 2) reasoning about the potential risks and benefits of their choices, 3) appreciating the nature of their situation and the consequences of their choices, and 4) expressing a choice (Grisso, Appelbaum, & Hill-Fotouhi, 1997). This model is not without critics who opine that it does not sufficiently attend to patient values, authenticity, or address the impact of emotions (Palmer & Harmell, 2016). The key point is decision-making capacity is an inherently context-specific construct referring to an individual's capacity to make a choice about a specific decision at hand (Palmer & Harmell, 2016). Patients who lack capacity may be unable to communicate due to a comatose, unconscious, or seriously demented condition (Jonsen et al., 2015). It is important to acknowledge that an assessment of capacity should be done on a frequent basis. Depending on the permanency of the condition, medications, or mental status changes, capacity may wax and wane (Jonsen et al., 2015). It is also important to note that although a patient may be perceived as making an ill-advised decision, does not mean an absence of decision-making capacity (Jonsen et al., 2015; Veterans Health Administration, 2002).

2 Surrogate Decision Making and Autonomy

Surrogate decision-making is a common occurrence, especially for older adults, and over half of surrogates face decisions about code status and life-sustaining treatments (Torke et al.,

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2014). One study found that 68% of older adults were faced with a major treatment decision within 48 hours of hospitalization, and of those nearly half required a surrogate decision-maker (Torke et al., 2014). However, there has been tremendous debate around who should be named as a surrogate (Allen & Shuster Jr, 2002; Lipnick et al., 2020; Pope, 2009; Rushton & Hogue, 1991).

Terminology for individuals who exercise decisional authority for incapacitated people varies in clinical practice and in statutes (DeMartino et al., 2017). For the purposes of this dissertation, alternate decision-maker (ADM) refers to any person participating in decision-making for a patient, regardless of whether they are appointed through default surrogate statutes, appointed by a court, or through advance directive (DeMartino et al., 2017). State statutes enacted to delineate default surrogate decision-making authority for patients without an advance directive vary (DeMartino et al., 2017). Some state statutes proscribe authority according to the hierarchy of family priority, such as a spouse, then parent, and then children (Jonsen et al., 2015). Twenty-three states allow a friend to be a surrogate decision-maker, but this option is low on the hierarchy and therefore is typically one of last resort (DeMartino et al., 2017). A small number of states have statutes for a default surrogate decision-maker, but do not require a priority order (DeMartino et al., 2017). Historically, patient relatives were naturally considered surrogates when patients lacked decision-making capacity. In some situations, a hospital, ethics committee or volunteer board, health care professional, caregiver, or family member may justifiably serve in the role of the surrogate (Beauchamp & Childress, 2019). However, 35 states prohibit a health care professional from serving in the role as surrogate (DeMartino et al., 2017). In extreme cases, a judge or court-appointed guardian will be appointed to make critical treatment decisions (Beauchamp & Childress, 2019).

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Individuals who exercise decisional authority for incapacitated people through an advance directive are often called a “healthcare agent”. However, the terminology for ADMs designated through a legal durable healthcare power of attorney or an advance directive also varies. Some of the most common terms used in advance directive forms include “healthcare agent”, “healthcare proxy”, “healthcare representative”, “attorney in-fact”, “healthcare surrogate”, and “patient advocate” (Mathew, Gershengorn, & Hua, 2018). In some states, a healthcare agent has more decision-making authority than a surrogate decision-maker. For example, in Maryland a health care agent has authority to withdraw life-sustaining procedures even if the patient does not have a terminal illness or is in a persistent vegetative state, unlike a default surrogate decision-maker (Frosh, 2021). The legal standard for healthcare decision-making among court appointed guardians, surrogates, and health care agents varies by state and adds to the complexity of decision-making especially at the EoL (American Bar Association, 2015).

Unless a patient has already identified a healthcare agent, generally next-of-kin or loved ones becomes surrogates, and therefore, complexities exist about which family member should make decisions (Lo, 2013). Although immediate family members have customarily been granted surrogate status through legal authority, the concept of “family” has evolved over time (Comer et al., 2018). Many nontraditional, but ethically qualified surrogates, such as grandchildren, caregivers, or long-term unmarried partners are not legally allowed to serve as surrogates without a legal document (Comer et al., 2018). These ethically qualified surrogates likely know the patient extremely well and can make decisions on their behalf. It is important for clinicians to consider the relationships that patients have with ADMs for optimal decision-making and preservation of autonomy. This chapter will outline the benefits and challenges with proscribing

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autonomy to ADMs through traditional bioethics and feminist frameworks to emphasize how each affects the vulnerability and trust in the nurse-family relationship, especially regarding EoL care.

2.1 Respect for Patient Autonomy

In a bioethics framework, Beauchamp and Childress (2019) propose three standards for surrogate decision-making including a direct continuation of a patients' autonomy or pure autonomy (for patients that once had autonomy), substituted judgment, and best interests (p. 139). The goal of this approach is twofold; to protect the patient's former autonomous preferences, or if they are unknown to advocate for their current best interests (Beauchamp & Childress, 2019, p. 139).

2.1.1 Pure Autonomy

As an initial step, it is critical for the health care team to determine if a patient expressed any specific wishes verbally or in a written advance directive prior to incapacity (Jonsen et al., 2015). Pursuing previously identified patient wishes that are trustworthy respects the patient's autonomy (Entwistle, Carter, Cribb, & McCaffery, 2010). The pure autonomy standard should apply to patients who previously had capacity and expressed clear preferences. Pure autonomy satisfies the ethical and legal purposes of informed consent by respecting the patient's right to decide if and what happens to their body. The surrogate is responsible for ensuring that these preferences are carried out (Beauchamp & Childress, 2019). Beauchamp and Childress (2019) also suggest that if a patient's preferences are unknown or they never had capacity, then the best interest's standard should apply.

Beauchamp and Childress (2019) describe a three-condition theory of autonomous choice that includes intentionality, understanding, and choice void of controlling influences

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(Beauchamp & Childress, 2019). Intentionality requires actions that comport with the individual's conception and plan for the proposed series of events to occur, even if the plan does not materialize as projected (Beauchamp & Childress, 2019, p. 102). For example, a patient diagnosed with a terminal illness who has capacity chooses to stop eating and drinking to hasten the dying process. The patient experiences a stroke that results in a comatose state and no longer possesses decision-making capacity. This was not the desired outcome, but decisions about whether to administer artificial nutrition and hydration are necessary to address the patient's care goals. Undesired outcomes are a possibility of an intentional plan, especially in the context of health care decision-making.

The second condition of autonomy is understanding. An action is not autonomous if an actor does not adequately understand it. Beauchamp and Childress (2019) argue that a full understanding is not required, but a substantial degree of understanding is necessary (p. 102). This condition is difficult to apply in clinical situations because of the numerous health literacy challenges that exist among patients and families responsible for decision-making. At what point does a clinician determine that someone understands a procedure or an illness to a substantial degree? Substantial literature exists which questions the value and purpose of informed consent when research demonstrates that no one might ever be truly informed or understand their health care interventions (Blease, Bishop, & Kaptchuk, 2017; Ghooi, 2014; Murtha & Faustino, 2020).

The third condition of autonomous choice is noncontrol. Beauchamp and Childress (2019) define noncontrol as an autonomous action that is free of controls, such as coercion or manipulation, exerted by external sources or internal states that rob the person of self-directedness (p. 102). Beauchamp and Childress (2019) hold that intentionality is not a matter of degree. Actions are either intentional or they are not. However, understanding and non-control

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are more fluid (Beauchamp & Childress, 2019). For example, a person with a mental illness may be internally influenced by their condition and therefore deemed to lack the ability to make an autonomous decision. This condition may fluctuate, and therefore, the autonomy can vary in degree (Beauchamp & Childress, 2019). Under this framework, a person should be free of controlling influences and have a substantial degree of understanding about their EoL decisions. Yet, this approach can often be impractical during EoL care due to the tremendous emotional and psychological burden that terminal illness can impose on all stakeholders.

2.1.2 Substituted Judgment Standard

Another standard for surrogate decision-making proposed by the traditional model of bioethics is substituted judgment (Beauchamp & Childress, 2019). Substituted judgment is based on the standards of individual autonomy and patient privacy (Beauchamp & Childress, 2019). Patients have a right to make decisions about their bodies and any interventions that affect their bodies, even in circumstances where capacity limits this ability to make that decision. These decisions about treatment belong to the nonautonomous patient because of their right to autonomy and privacy (Beauchamp & Childress, 2019, p. 139). In circumstances where patients lack capacity for decision-making, a surrogate decision-maker is appointed to ensure that substituted judgment for the patient's autonomy is respected by complying with the patient's previously expressed wishes, preferences and values. These cases are generally uncontroverted. Substituted judgment should only apply to patients who currently lack capacity, but at some point in the past, had decision-making ability. This is critical because if a patient never had decision-making capacity, it would be nearly impossible for the surrogate to determine that patient's views and values (Beauchamp & Childress, 2019). Beauchamp and Childress (2019) contend that a surrogate should have a sufficiently deep familiarity with the patient and if a

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surrogate cannot address what the patient would want in the circumstance and only address what the surrogate would want, then the best interests standard should be made rather than a substituted judgment standard.

2.1.3 Best Interests Standard When a patient's autonomous preferences are unknown and cannot be determined, then the best interests standard is recommended to determine the highest probable net benefit among the available options (Beauchamp & Childress, 2019). Under this standard, a surrogate acts beneficently by choosing the best option with the highest probable benefit. The best interest standards also applies where no advance directive exists, and the patient is unknown to the surrogate decision-maker, and therefore substituted judgment is not possible.

In practice, best interest includes general concepts of minimizing suffering and restoration of physical capacities drawing from what a reasonable person would want in similar circumstances (Graham, 2020). However, legally the courts have outlined seven factors are used to guide the application of the best interest standard including 1) physical and cognitive function; 2) quality of life and prognosis; 3) treatment options, side-effects, and risks; 4) degree of pain and suffering from the medical condition; 5) degree of pain and suffering caused by the treatment or medical intervention; 6) degree of pain and suffering if the intervention is withdrawn; and 7) balance of treatment benefits versus burden (Pope, 2017b). This approach is more specific, but heavily relies on the medical expertise of physician's perspective regarding prognosis and trajectory of care (Graham, 2020). In some circumstances, the best interest standard is often determined by health care professionals, and therefore, a significant degree of bias from the clinician's experience can affect the "best interest" decision.

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2.2 Surrogate Decision Maker Concerns

Surrogate decision-making is not without flaws. The bioethics hierarchical framework of surrogate decision-making is common and adopted in most legal statutes (Graham, 2020). Beauchamp and Childress (2019) acknowledge that this framework is used for law and policy. Yet in clinical practice, surrogate decision-making often departs from this framework (Graham, 2020). Pure autonomy, substituted judgment, and best interests standards do not factor in the voices or perspectives of alternate decision makers (ADM), even though they often shoulder the emotional, financial, and psychological burden of the EoL experience of their loved one. Clinical decision-making is inherently challenging, stressful, and complex (Eiser et al., 2018). Eiser et al. (2018) found that ADMs acting on behalf of older patients were often influenced by their own personal and religious values or preferences. Yet, Shalowitz, Garrett-Mayer, and Wendler (2006) determined that almost 70% of ADMs accurately predicted a patient's treatment preferences. ADMs may also consider the patient's personality, quality of life, spiritual or religious beliefs, and consider the expected burden of caring for the patient, or what the ADM would want for themselves (Graham, 2020). Often times ADMs or next-of-kin do not want to make decisions on behalf of their loved ones, and would rather the clinician decide for them (Mayo & Wallhagen, 2009). Jonsen (2011) opined that a significant number of ADMs preferred that the clinician make difficult medical treatment decisions and not the family due to tremendous burden. In addition, Kon (2011) found that many family members could not bring themselves to make treatment decisions, especially those involving a withdrawal of care.

Allowing clinicians to decide on behalf of the patient is troublesome and may not capture the patient's preference or consideration for social factors that affect the patients' quality of life or health. Typically, physicians and other clinicians in an acute setting at the EoL are not deeply

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familiar with the patient. Therefore, EoL decisions made without family or patient input are solely based upon medical knowledge, expertise, and medical experiences. In rare cases, if legally permitted in the state, a family physician or advanced care practitioner who is deeply familiar with the patient may serve as an ADM. If the goal is to respect patient autonomy, then the ADM should be adequately familiar with the patient's life and status. Much of the bioethics literature focuses on determining an acceptable hierarchy of alternate decision-makers (J. I. M. Anderson, 2012; DeMartino et al., 2017; Pope, 2009; M. L. Smith & Luck, 2014). However, the critical analysis should be on the relationship of the ADM to the patient. For example, an elderly patient may live alone and not have any next-of-kin alive or remaining to make decisions in the circumstance of incapacity. This does not mean that the patient does not have a suitable ADM. The patient may have a neighbor or church member who is most familiar with their life and preferences but legally cannot become a surrogate without a predetermination through a health care power of attorney or through some legal court appointment. These can be arduous procedures and often EoL decision-making is time sensitive. Several states prohibit an individual who is not related by blood, marriage, or adoption to make decisions on behalf of the incapacitated person (DeMartino et al., 2017). Therefore, the person who could make the best decision under the substituted judgment standard often cannot.

2.2.1 Patients Without a Surrogate Decision Maker

In some circumstances, a patient will not have a designated person appointed as a surrogate. Some ethicists have opined that patients without a surrogate decision maker do not require aggressive or burdensome treatment that would offer little prospect of survival, because there is no surrogate or family member to challenge or advocate for the patient (Lo, 2013). Individuals who lack families or ADMs, sometimes referred to as “unbefriended patients”, are

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often from marginalized populations such as those with low socioeconomic status, minorities, homeless, mental illness or substance use disorder, and individuals who suffer from social isolation (M. L. Smith & Luck, 2014; D. B. White, Jonsen, & Lo, 2012). Notably, 16% of patients have no ADM (A. M. Courtwright et al., 2014). One standard legal solution to address decision-making for unbefriended patients is to legally appoint a guardian ad litem. However, guardianship is generally considered a last resort, because hospital legal representatives are often unable to obtain guardianship for unbefriended patients in a timely manner, guardian's typically have no knowledge of the patient's morals or values, and guardians are a limited resource (Pope, 2017b).

The unbefriended are sometimes at a physical risk of being overtreated regardless if it is clinically or ethically warranted due to economic incentives to treat or in an experimental nature (Pope, 2017b) . The unbefriended are also at risk of being undertreated, because many physicians refuse to perform procedures without informed consent (Pope, 2017b) . In these situations, clinicians may forego interventions that they deem not within the patient's best interest (Lo, 2013). A clinician should not model what *they* think is in the patient's best interest simply because the clinician does not know the patient's values or wishes and is unable to find a loved one who does. Clinicians can make widely different choices when faced with a similar EoL clinical scenario because of personal characteristics of the patient and characteristics of the clinician, although the choices are purported to be "medical expertise" (D. B. White et al., 2012).

Clinicians may present personal and unconscious biases based on their clinical experiences regarding EoL treatment and subject the patient to inappropriate treatment or inappropriate withdrawal of treatment. A majority of studies have shown that a clinician's negative bias can have a major impact on how clinicians make decisions for patients (Gopal,

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Chetty, O'Donnell, Gajria, & Blackadder-Weinstein, 2021). This can result in the potential for pain, and longer periods of suffering, indignity and can increase the chance of morbidity to the patient (Pope, 2017b) . This is an alarming approach given that patients without surrogates or family members are often in historically marginalized populations, and the clinician's lack of familiarity with the patient or patients' values influences decision-making (M. L. Smith & Luck, 2014). This variation in care for individuals who lack an ADM is "ethically problematic because justice requires that patients who are similar in ethically relevant ways receive similar treatment" (D. B. White et al., 2012, p. 204).

2.2.2 Individual Autonomy

The moral imperative to respect patient autonomy in medical decision-making is widely accepted, yet the concept to achieve this imperative is highly debated in bioethics literature (Olmstead & Dahnke, 2016; F. Wilson, Ingleton, Gott, & Gardiner, 2014). The principle of autonomy gradually became part of medical practice in the later 1800s when the emergence of surgical procedures began to raise questions about informed consent (Turoldo, 2010). The rise of bioethics and the popularity of principlism occurred in 1979 when Drs. Beauchamp and Childress initially proposed the concept of respect for patient autonomy premised on acknowledging and appreciating patient values and judgments in decision-making, even when those value-based decisions appear mistaken. Beauchamp and Childress (2019) state that the respect for autonomy can be applied universally in the same way to concrete ethical dilemmas. Respect for autonomy suggests an individual with the capability to reason, resist impulses, and participate in deliberation is autonomous (Faden & Beauchamp, 1986). Therefore, if a person lacks these capabilities, they are generally presumed unable to make autonomous decisions (Peterson, Karlawish, & Largent, 2020). Notions of autonomy in bioethics are often equated with

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voluntary informed consent closely connected to privacy, or in rights-based theory framed as an individual right to make decisions. Some scholars posit autonomy as a negative right to freely make decisions without undue or paternalistic influence (Dove et al., 2017; Igel & Lerner, 2016; Woods, 2006). Under the Kantian approach, autonomy presumes the individual is capable of rational reasoning to decide what is morally right (Beauchamp & Childress, 2019). Regardless of the theoretical or legal approach to autonomy, the common concept is the rejection of influence or consideration of external factors on the decision-making process (Veshi, 2016). The reliance on another individual—especially a physician—would be considered highly suspicious (Veshi, 2016).

Such views can be seen as a reaction to earlier physician paternalism. Historically, physicians relied almost solely on their own expertise to provide a treatment plan for patients and neglected a patient's rights to make choices about care (Beauchamp & Childress, 2019). This paternalistic norm sometimes resulted in presumptuous care where patients were mandated to undergo treatment without any individual decision-making ability to accept or refuse the treatment. For example, a physician would prescribe a procedure or medication without a patient's consent, and the patient was expected to comply with the physician's decision. Some scholars opine that solely allowing health care professionals to decide what constitutes a meaningful benefit or appropriate treatment represents unwarranted medical paternalism (A. M. Courtwright et al., 2014). After a series of wrongdoings in medicine, including the revelation of Nazi medical experiments and the Tuskegee Syphilis Study— in addition to several social movements towards equality such as civil rights and second-wave feminism— Western medicine began shifting away from paternalism (Igel & Lerner, 2016). The principle of individual autonomy was raised as a pillar in clinical research ethics reflected in the Nuremberg Code and

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the construct of informed consent (Dove et al., 2017). Individual autonomy has become synonymous with the administrative and legal process of informed consent by affording patients with the ‘right to make decisions’ and legally documenting their consent to those decisions (Milligan & Jones, 2016). An individual ‘autonomous agent’ is one who makes decisions freely, understands the facts and risks, and possesses practical reasoning to come to a decision (King & Moulton, 2006). In decision-making, the ethical principle of respect for autonomy appears less paternalistic but still allows physicians to control the flow of information. Legally, a clinician’s respect for patient autonomy that manifests through informed consent can potentially absolve some responsibility or legal liability in the event that a medical error occurs because the patient has been informed of the risks and has consented to the medical intervention, and therefore expressed their ‘right to make and carry out a decision’ (King & Moulton, 2006).

While individual autonomy may be applicable to bioethical issues, it is often difficult and unsuited to the decision-making involved in health care (Dodds, 2000; Walter & Ross, 2014). The concept of the ‘autonomous self’ as an individual human being does not reflect the lived experiences or understanding of how deeply embedded decisions are made (Milligan & Jones, 2016). In health care, complexities in decision making include social dynamics of families or ADMs, grief, concern for others, distrust, cultural factors, and religious or spiritual concerns. These value-laden factors that affect decision-making are not easily discernable through an individual autonomy analysis. Individual autonomy “is both insufficient to capture the breadth of human interests and agency and inconsistent with other important values” (Dove et al., 2017, p. 151). Individual autonomy presumes decisions are isolated and characteristic of just a person’s decision (Gómez-Virseda, de Maeseneer, & Gastmans, 2020). Early feminist literature suggested that individual autonomy promoted idealist views of personhood as self-sufficient and operating

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in a vacuum unaffected by social relationships or factors (Donchin, 2001; Stoljar, 2018). Using a feminist ethics framework, the reconceptualization of autonomy is inclusive of social and political aspects, especially in EoL care when a collection of relational factors influence surrogate decision-making (Gómez-Vírveda et al., 2020). Philosophical and social movements have influenced a shift from “individual autonomy” to a more collaborative autonomy that fosters shared decision-making in dilemmas at the EoL (Rubin, 2014). The following discussion will address the application of patient autonomy that incorporates a patient’s “decision-making team” of choice resulting in alternate decision-making that factors in the perspectives and emotions of those affected by the decision.

2.3 Relational Autonomy

In the 1980s feminist ethicists began to question the individualism associated with morally acceptable decision-making (Gilligan 1982). Several years later, Mackenzie and Stoljar (2000) introduced a broader umbrella concept of autonomy from a feminist perspective expanded to include social and cultural considerations. These critical considerations are the basis for what shapes values, desires, and preferences (Deem & Stokes, 2018). Relational autonomy emphasizes the notion that people are socially embedded, and therefore, identities and decisions are influenced by many social determinants such as race, ethnicity, class, and gender (Mackenzie & Stoljar, 2000). People develop their sense of self and life plans based on the relationships they forge on a daily and long term basis (Dove et al., 2017). The fundamental piece in this theory is that humans are social beings and thus dependent and interdependent (Mackenzie & Stoljar, 2000). Both good and evil result from this interdependence, but self-actualization can only be realized relationally (Walter & Ross, 2014). Interdependence has some risks including the fact

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that socially embedded people may be subject to coercion and influence stemming from relationships with others (Braudo-Bahat, 2017).

2.3.1 Criticisms of Relational Autonomy

Naturally, there are opponents of relational autonomy including scholars who question its analytic and normative value (Dove et al., 2017). Generally, people understand that socially embedded relations are essential to human flourishing. However, the issue is whether these embedded relationships are simply a mere social fact or should have deeper normative or analytical implications to practice (Dove et al., 2017). Socialization is crucial for development, evidenced through arenas such as family, workplace, community, social media, and popular culture (Braudo-Bahat, 2017). The question of relationality, in general, is challenging for some scholars to apply in practice. For example, the ethics of care theory has normative implications for how people are treated or how they “care” for and between one another (Gilligan 1982). Others argue that relational or socially embedded decision-making lacks practical clarity (Mackenzie & Stoljar, 2000). Dove et al. (2017) question whether relational autonomy has boundaries and how to apply these boundaries in practice. “What is ‘external’ to a person if all her relations are somehow part of her?” (Dove et al., 2017, p. 154). The suggestion of boundaries on relational autonomy in itself is paternalistic and imparts another individual’s restriction on freedom of social location. Individuals create relationships among those who are socially located within their lives. The creation or establishment of relationships are a part of human flourishing and in general are not subject to infringement. How people incorporate their relationships with others into their decision-making is not something that a health care professional, researcher, or ethicist should attempt to limit. Rather in health care decision-making, any intervention applying relational autonomy should be done with cultural humility and respect of relationships.

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For some scholars, the interdependence associated with relational autonomy is perceived as a threat to individual autonomy where a person is considered autonomous only if she is free from community constraints (Nedelsky, 2011). However, no individual person is free from relationships and thus dependency on another. Relational autonomy allows for an account of imagination, emotional disposition, and attitudes in decision-making (Walter & Ross, 2014). This contradicts the presumption in 'individual' autonomy that the abstract person lacks any characteristics that affect decision-making such as age, race, gender, ability, emotions, or the liberal concept of equality in society (Braudo-Bahat, 2017). Therefore, women and underrepresented minorities whose emotions and social characteristics are not considered are viewed as less autonomous and exposed to paternalism (Braudo-Bahat, 2017). Any considerations for interventions that attempt to disconnect the physical body from emotions during decision-making could lead to less than optimal decisions (Nedelsky, 2011). For example, research demonstrates that Black women have a higher maternal mortality rate than White women due to discrimination based on racism and oppression (Admon et al., 2018; G. K. Singh, 2021). When a Black woman is provided with the option to have a natural birth versus a Caesarian (assuming that an option is medically warranted), relational autonomy does not simply take into account the woman's preference based on risks and benefits outlined by the medical team. Relational autonomy acknowledges the extreme disparity in care by a) informing the Black woman of statistically higher rates of maternal mortality and the evidence-based reasons for them, and b) strategies to mitigate these risks by adequately addressing pain and other health concerns in a timely and appropriate manner (Mohapatra & Wiley, 2019; Thachuk, 2007). Relational autonomy acknowledges the social characteristics of the patient's race and gender and how this affects decision-making and identifies ways to avoid or mitigate the potential undesired

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outcomes. Clinicians must be aware that individuals in underrepresented oppressed groups invest cognitive and emotional energy in survival and basic necessities and therefore are less able to focus on an intentional reflective decision-making process (Braudo-Bahat, 2017). As it stands, individual autonomy is “intrinsically linked to patriarchy and to the reproduction of an unjust and hierarchical social order that demean and marginalizes certain social identities” (Gauthier-Chung, 2017, p. 30).

Feminists do not suggest an abandonment of autonomy altogether. Autonomy is linked to both equality and respect to recognizing what constitutes a full-fledged agent, worthy of respect and consideration (Gauthier-Chung, 2017). Rejecting autonomy is unlikely to be fruitful in terms of alleviating the normative roots this ideal has in political society (Gauthier-Chung, 2017). However, the relational approach values emotions and rationality even if a decision is not within the confines of a socially acceptable response, such as family demands for medically inappropriate treatment (Veshi, 2016). Relational autonomy also allows for dependence and reliance on another for decision-making, which should be acknowledged and respected by the health care team. For example, an individual’s decisions will be informed by a partner or spouse’s decision because decision-making occurs within an interdependent relationship (Peterson et al., 2020). In addition, cultural considerations must be made for family-oriented health care decision-making because Western society values an individual as an autonomous agent, but that is not preferred in all cultures (Deem & Stokes, 2018). Relational autonomy does not diminish individual autonomy, rather it is necessary to address inequality, and it strengthens autonomous decision-making in a rich and social context.

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2.3.2 Relational Autonomy in EoL Decision-Making

Health care decision-making at the EOL is scientifically and emotionally complex (Igel & Lerner, 2016). Studies have shown that people make decisions based on several factors including age, gender, ethnicity, culture, professional careers, family dynamism, interpersonal relationships, and complexity of a disease (Veshi, 2016). Relational autonomy acknowledges and accentuates the highly emotional experience associated with EoL decision-making. This approach does not presume that demands for potentially inappropriate medical treatment are irrational, yet these requests stem from a place of emotional grief. Nurses, physicians, and other clinicians should see the appropriateness of an emotional response and encourage discussions and exploration of these emotions with families in a culturally appropriate manner (Walter & Ross, 2014).

Evidence suggests that family involvement in EOL care discussions can improve the quality of care (Igel & Lerner, 2016). Families are a valuable resource to help clarify EoL treatment goals in support of a relational and holistic approach to quality care (Igel & Lerner, 2016). For example, C. A. Robinson (2011) conducted a qualitative study evaluating the effect of relational autonomy on advance care planning guided by a respect for patient beliefs and values in patients with end-stage lung cancer and their designated ADM. Researchers focused the advance care planning discussions on the effects of chronic illness on the family, not just the patient or just the patient's symptoms (C. A. Robinson, 2011). Autonomy that includes considerations for a family's decisions and quality of life with a specific emphasis on relationships and patient's preferences, revealed less conflict among family members, enhanced confidence in decision-making, improved congruence in specific treatment decisions between patients and ADMs, and greater patient satisfaction with the quality of clinician communication

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(C. A. Robinson, 2011). C. A. Robinson (2011) concluded that when patients approach EoL decision-making through an individualistic approach, separate from families or ADMs, their demands for treatment may override clinicians' recommendations. This can potentially increase the risk for nondisclosed limited resuscitation because clinicians want to honor a patient's wishes but experience moral distress when inappropriate and aggressive care is delivered at the EoL. Clinicians that recognize relational autonomy are able to acknowledge the interconnectedness of patients and families who become part of the responsibility of decision-making, rather than privileging the individual (Walter & Ross, 2014). Applying relational autonomy into clinical practice is, of course, challenging for patients without intricate support systems, families, or loved ones. This has also proven challenging due to the recent COVID-19 pandemic where many health institutions have restricted visitors even in EoL situations.

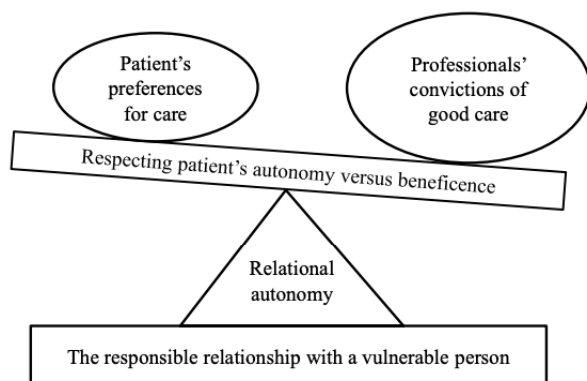
Relational autonomy also resonates with health care professionals who struggle to respect patient autonomy in clinical practice. In a recent study, researchers found that clinicians deliberated about what constituted "good care" using relational-oriented reflection to determine elements of a responsible relationship with patients as vulnerable people (Heidenreich, Bremer, Materstvedt, Tidefelt, & Svantesson, 2018). Clinicians struggled with the limits of moral justification to exert pressure on patients to influence care, as well as their obligation to frame care according to the patient's wishes (Heidenreich et al., 2018). The study participants analyzed ethical dilemmas with moral reasoning and acknowledged that patients had psychological and social difficulties, such as a lack of social support from families, economic difficulties, and psychiatric illnesses that complicated the plan of care (Heidenreich et al., 2018). The participants described this reasoning as "a seesaw of principle-based reasoning, undulating between their own professional convictions of what constitutes good care for the patient on one side, and the

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patient's wishes and preferences on the other" (Heidenreich et al., 2018, p. 474). This is shown in Figure 2 which describes the struggle for clinicians to uphold a patient's preferences balanced with a clinician's professional convictions of good care. The study found that clinicians used moral reasoning to evaluate everyday clinical practice dilemmas through principle-based and relational-oriented ethics compositions (Heidenreich et al., 2018). This was a deviation from typical case presentations where relationships and emotions are often absent (Heidenreich et al., 2018).

Figure 2

Depiction of relational autonomy in the struggle to uphold dignity in illness.



Note. The image was created to depict study participant's reasoning of what constitutes good care. Licensed under Creative Commons Attribution 4.0 from Heidenreich, K., Bremer, A., Materstvedt, L. J., Tiddefelt, U., & Svantesson, M. (2018). Relational autonomy in the care of the vulnerable: health care professionals' reasoning in Moral Case Deliberation (MCD). *Medicine, Health Care and Philosophy*, 21(4), 467-477. doi:10.1007/s11019-017-9818-6. Copyright 2017 by Springer Nature.

A key aspect of relational autonomy, as demonstrated in the study above was for nurses and other clinicians to acknowledge and establish a responsible relationship with their patients, viewing them as vulnerable people (Heidenreich et al., 2018). Every person at some point, faces vulnerability through life experiences, such as illness, hardship, oppression, or being subjected to

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violence, and the need for extra protection is critical (Heidenreich et al., 2018). Vulnerability is “a state of physical and emotional well-being that is in danger of being disturbed and destroyed due to being susceptible to harmful influences” (Boldt, 2019, p. 2). Autonomy and vulnerability are sometimes viewed as contradictory phenomena (Mackenzie et al., 2014). Yet, in the clinical practice setting, a nurse’s personal and professional emotions and convictions can outweigh the nurse’s respect for a patient’s autonomy or preferences for care (Heidenreich et al., 2018; Stokes & Zoucha, 2021). In situations when patients are most vulnerable and do not have decision-making capacity, clinicians may develop moral distress when trying to convince patients and families not to partake in interventions they judge not to be in the patient’s best interest. When this conflict arises, the potential for actions not made known to families but nurses deem appropriate may occur. For example, nondisclosed limited resuscitation may occur as nurses experience a threat to the nurse-*vulnerable* patient relationship. Nurses are easily able to recognize the vulnerability of the patient based on the need for treatment, healing, and recovery. However, vulnerability is also linked with helplessness, neediness, and victimhood, and therefore the potential for paternalistic and coercive interventions exists (Heidenreich et al., 2018). Nurses struggle with the practical interpretation of patient preferences for treatment, but also seek to accomplish optimal nursing care for vulnerable patients (Heidenreich et al., 2018).

3 Vulnerability, Trust, and Mistrust

Family or ADM demands for potentially inappropriate treatment occurs at the EoL for a myriad of reasons, such as denial about expected patient outcomes, lack of knowledge and understanding of medical conditions, religious and cultural considerations, mistrust of health care professionals, the uncertainty of death, an innate desire to fight for life, and the western culture of death as a treatable condition. Health care professionals may justifiably refuse to

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provide medical treatment at the end of life, based on the inappropriate nature of the treatments requested and on competing ethical considerations (Kon et al., 2016). A longstanding debate between what encompasses potentially inappropriate treatment is based on optional versus obligatory EoL treatment. This debate is not only a medical debate but also a moral debate (D. Kelly, Magill, & ten Have, 2013). No clear or reproducible medical guidance exists on what constitutes inappropriate treatment (Burkle & Benson, 2012; Pope, 2007). The Society of Critical Care Medicine Ethics Committee developed a policy defining potentially inappropriate treatment as, “those that have at least some chance of accomplishing the effect sought by the patient, but clinicians believe that competing ethical considerations justify not providing them.” (Kon et al., 2016, p. 1770). The committee acknowledges that this definition is not exhaustive and inappropriate treatment requests must be handled on a case-by-case basis (Kon et al., 2016). Bioethicists Veatch and Spicer argue that without clear guidance, “The real problem is not with care that clinicians believe has literally no effect. The real problem is with care that has an effect, but that clinicians believe has no benefit. This is not a judgment based on medical science. It is grounded in beliefs and values about which people inevitably disagree” (Veatch & Spicer, 1992, p. 36). Nonetheless, refusal to provide potentially inappropriate treatment, whether it is withheld or withdrawn, should be based on a patient benefit versus burden argument (Beauchamp & Childress, 2019; Jahn Kassim & Alias, 2016; Kinsella & Booth, 2007).

In many circumstances, the health care professional is best suited to frame the appropriate choices by describing the quantitative prognosis and expected quality of life. However, families or ADMs must be afforded the right to weigh these possible outcomes, especially resuscitative treatments, which may have the potential for both benefit and harm. It is “ethically untenable” to give complete authority to one party in decision-making (Bosslet et al., 2015, p. 1319). Placing

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the decision-making power solely in the hands of the health care professional neglects the fact that these decisions are not only medical or technical but value-laden decisions (Olmstead & Dahnke, 2016). Unilateral decision-making of EoL decisions by a clinician also fails to acknowledge or address the vulnerability of a person who is nearing the EoL. During these extremely emotional moments, it is essential that clinicians recognize and understand the vulnerabilities of patients and families.

3.1 Human Vulnerability

Vulnerability is complex and the definition is subject to great debate (Goodin, 1985; Held, 1987; Mackenzie et al., 2014; Nussbaum, 2006). Vulnerability is often invoked in relation to concepts such as harm, care, need, dependency, and exploitation (Mackenzie et al., 2014). Some scholars opine that vulnerability is perceived as a state of inferiority or a condition of individuals who are socially or structurally oppressed (Heidenreich et al., 2018). For example, individuals in intellectually and developmentally disabled communities may perceive a “label” of vulnerability with a negative connotation due to stigma (Fisher, Robichaux, Sauerland, & Stokes, 2020). Yet, other historically marginalized populations acknowledge and seek the designation of vulnerability to raise awareness of the lack of representation and afford opportunities and protection to communities (Luna, 2019). Within bioethics, the concept of vulnerability was originally discussed in relation to research ethics and human experimentation, for those individuals who were exposed to or unable to defend themselves from abuse, neglect, or maltreatment (ten Have & Jean, 2009). Although there are numerous normative analyses of vulnerability, one of the most notable documents is Article 8 of the Universal Declaration on Bioethics and Human Rights (UDBHR) titled Respect for Human Vulnerability and Personal Integrity. This declaration is generally applied whenever there is an advancement in scientific

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knowledge, medical practice, or where there is a possibility of exploitation of individuals (Intergovernmental Bioethics Committee, 2005). The UDBHR was proclaimed in 2005 and is a common foundational standard framework that addresses moral issues in bioethics and research science and guides scientific progress to protect human dignity globally for all people. This global perspective of vulnerability was originally written to protect the integrity and dignity of human beings due to new ethical questions as a result of advances in technology and health care (ten Have & Jean, 2009). The United Nations Educational, Scientific and Cultural Organization (UNESCO) describes vulnerability similarly by acknowledging universal human frailty but emphasizing contextual features, such as culture, economy, and relations of power that exacerbate vulnerability for certain groups who are especially vulnerable (International Bioethics Committee, 2013).

Everyone is vulnerable to some degree of harm by virtue of human existence. Vulnerability is associated with the potential for harm, not positive outcomes. For example, a person is not vulnerable to obtaining wealth or good health. Rather vulnerability is associated with a negative result that would require some action or intervention to prevent or mitigate the harm (ten Have, 2016). Therefore, it is essential to identify what creates or produces vulnerability for patients and families (ten Have, 2016). There is generally some consensus about the protections that can be offered, but there is often a misconception about which vulnerabilities are important or which protections should be afforded (Mackenzie et al., 2014). It is important to note that vulnerability should not exist as a blanket protection for a certain population but should be evaluated within individuals in the group who might have special characteristics requiring protection (Levine et al., 2004). There are various types of characteristics that can make a person vulnerable including social, political, and environmental factors (Mackenzie et al., 2014).

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Typically, vulnerable populations encompass people who are often marginalized or underrepresented based on social factors such as race, gender, ableism, socioeconomic status, among others. Then there are those groups that are particularly vulnerable, such as those who cannot give informed consent, lack capacity, or have a heightened risk of harm. Social vulnerabilities such as socioeconomic status, discrimination, gender, disability, access to health care, and a necessity for care compounded with medical vulnerabilities can become complex (Mackenzie et al., 2014). Vulnerability may also exist in having a disease whether it is acute or chronic and a scrutinized evaluation of human vulnerability should be completed for patients, including their families, at the EoL (Castaneda-Guarderas et al., 2016).

3.2 Vulnerability of Patient Families

An important component of care for nurses caring for patients at the EoL is addressing the needs of families, sometimes referred to as “hidden patients” (Norouzadeh, Anoosheh, & Ahmadi, 2019). Nurses and other clinicians may view vulnerability solely as one of the individual patient, but it may not be exclusively an individual element (ten Have, 2016). Families and ADMs may feel incredibly vulnerable when confronted with a loved one’s impending death (Ramvi & Ueland, 2017). Families of patients at the EoL are extremely vulnerable to grief and sorrow and are often in need of care themselves (Ramvi & Ueland, 2017). Critically ill patients may infringe on their family’s time, finances, and ability to care for other family members (Norouzadeh et al., 2019). Patients and families are already at risk for vulnerability because their loved one is receiving care at the EoL and therefore they must rely on the medical team to provide safe, appropriate, and effective treatment (Gillon, 1985; Ramvi & Ueland, 2017). Families experience difficult emotions during this time such as desperation, helplessness, depression, exhaustion, and hopelessness, which can severely impact decision-making that is

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requested by the health care team (Norouzadeh et al., 2019). This vulnerability may become so unbearable that they fight to retain what is left of their strength and autonomy (Ramvi & Ueland, 2017). Families strive to protect their dignity and identity by trying to control the EoL situation and manage the dying experience (Ramvi & Ueland, 2017). Families or ADMs attempting to protect their vulnerability manifest this by rejecting the nurse and trying to control the EoL situation with aggressive behavior or requests for treatment that is medically inappropriate (Ramvi & Ueland, 2017).

It is critical that nurses address and acknowledge this vulnerability to eliminate or prevent any constraint on the nurse-family relationship. “To establish relationships is to encounter vulnerability, both within oneself and within others, which calls forth every aspect of the professional’s self” (Ramvi & Ueland, 2017, p. 206). Nurses are well-positioned to strengthen families emotionally, physically, financially (by providing access to resources), and spiritually (Norouzadeh et al., 2019). Nurses should address the family’s vulnerability by providing a safe and clean environment to visit the patient and provide a supportive environment for families to say goodbye. Nurses should respond with respect, compassion, and ethical awareness to identify the conflict so that an appropriate conflict resolution strategy can be implemented. Nurses should anticipate family demands, especially when their loved one is facing impending death.

Family demands for potentially inappropriate treatment for their dying loved ones should also be approached. A nurse’s response to a family’s demand for potentially inappropriate EoL treatment for their loved one cannot be simply reduced to whether the patient would or would not want CPR. Clinicians must inquire about values and goals of care for the patient and family as a unit. This inquiry shows sensitivity to the family’s vulnerability, grief, and other emotional needs and therefore builds trust in the relationship. Trust can minimize conflict and if a family is not

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ready to accept that their loved one is dying, limited resuscitation that is made known to the family, is an option that respects the family's hope and time to process events. Offering a family *some* resuscitation interventions that are minimally invasive, rather than offering a DNAR which does not offer *any* chance of recovery, may be appealing to the emotional position of denial and hesitancy to accept their loved one's impending death. Limited resuscitation also protects a nurse's vulnerability and risk for moral distress, by eliminating the delivery of aggressive care as a means of compromise for the EoL conflict.

3.3 Nurses' Vulnerability

Nurses also experience vulnerability within the nurse-family relationship caring for a patient at the EoL. Nurses who are rejected by families are at the receiving end of anger, frustration, and resentment, which over time can result in moral distress (Ramvi & Ueland, 2017). Some nurses are able to empathize with angry family members but other nurses are not able to escape the emotional difficulty stemming from a family member's frustrations while also expecting to obey a family's demands as if they were colleagues (Ramvi & Ueland, 2017; Stokes & Zoucha, 2021). Research supports nurses feeling manipulated or controlled by families to follow their care decisions (Ramvi & Ueland, 2017; Stokes & Zoucha, 2021). Nurses are challenged by their own vulnerability in these relationships. Nurses must possess the ethical sensitivity to identify a family's vulnerability to determine if they are in need of consolation or space to process grief and suffering (Werkander Harst de & Roxberg, 2015). It is important for nurses to allow families needing consolation or emotional rest to experience these emotions and not force a transition to acceptance, so long as physical aggression or a compromise in safety is not present (Werkander Harst de & Roxberg, 2015). A display of understanding and empathy

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with families ideally should strengthen the nurse-family relationship and lead to an optimal EoL experience for the patient, family, as well as the nurse and health care team.

3.4 Trust and Mistrust of Health Care Systems and Professionals

Trust is an elusive concept without an agreed-upon definition (Alpers, 2016). Yet, it is well understood that trust is vital in the patient-provider relationships for patients to feel safe, comfortable, and willing to continue receiving care from the healthcare professional which promotes health and wellbeing. Trust is a “reliance on other’s competence and willingness to look after, rather than harm, things one cares about which are entrusted to their care” (Baier, 1986, p. 259). Other definitions of trust include “believing in each other without fear, hesitation, and suspicion to comply with ethical norms, decent and willing to deal with goodwill rather than harm, and this goodwill feeling becomes an attitude evolving in time” (Ozaras & Abaan, 2016, p. 629). Trust involves giving another an opportunity to cause harm but showing confidence that they will not and therefore establishing a belief in the goodness of another’s moral intentions (Peter & Morgan, 2001). Trust has two dimensions. The first is that trust is a fundamental characteristic of the nurse-patient relationship (Johnstone, Rawson, Hutchinson, & Redley, 2016), and is also critical in the relationships that nurses have with other colleagues, including other nurses, physicians, and assistive personnel (Peter & Morgan, 2001). This is known as interpersonal trust and exists between people on an individual level and is necessary for reliance and carrying out tasks (Ozaras & Abaan, 2016). Interpersonal trust is the mutual confidence that no party in the exchange will exploit the other’s vulnerability, and the health care professional will have good intentions and reasonable competence (Ward et al., 2017). The *Code of Ethics for Nurses with Interpretive Statements* stresses that nurses establish relationships of trust and provide care according to need, setting aside bias of prejudice (American Nurses Association,

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2015). The *Code* also outlines the nurse's role in collaboration, which intrinsically requires mutual trust, recognition respect, transparency, shared-decision-making, and open communication with all stakeholders involved in health outcomes (American Nurses Association, 2015). Trust is a key moral dimension in any nurse relationship, whether it is with ADMs or patients (Ramvi & Ueland, 2017). Patients trust that clinicians are delivering the most appropriate care within their skill and expertise and are generally able to distinguish when they are not, evidenced by failed procedures or medical mistakes.

The second dimension is institutional trust. Trust is critical at the organizational level including the public image of an organization and public willingness to seek care from an organization. This is known as institutional trust and is formed by external factors such as managing costs, health insurance, and positive patient outcomes (Ozaras & Abaan, 2016). Institutional trust includes an expectation from patients, that an institution will perform satisfactorily, meaning there will be a high service standards, expectation of consistency, and cautious decision-making (Ward et al., 2017). Trust is fundamental to a patient's positive encounter with a health care organization and its representatives (Ward et al., 2017). Institutional trust fosters patients and consumers to make informed decisions about their care. Trust should be mutual and respected by all parties.

Trust always carries some risk and trust developed over years can be lost in a moment (Ozaras & Abaan, 2016). Patients may mistrust nurses, other clinicians, and the health care system for many reasons. Mistrust by patients in the nurse-patient relationship may be caused by the patient being unaware of what the nurse is doing, or the nurses' lack of communication, mistakes in providing care, deception, making untimely decisions, behaving indifferently due to fatigue, using medical jargon, dehumanization, and lack of knowledge or skill (Ozaras & Abaan,

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2016). A failure to meet one's expectations may also create mistrust (Alpers, 2016). Family members of patients also experience mistrust of nurses, especially when there is a perception of exclusion or isolation. For example, research shows that family members experience mistrust when nurses are at the nurse's station socializing, on the computer, or engaged in collegial "chit chat" and appearing not to pay attention to patients (Underwood, 2017).

There is considerable mistrust among marginalized populations that results in adverse health outcomes. For example, one study revealed that caregivers of people with intellectual and developmental disabilities believed that nurses did not see them as human beings worthy of care, demonstrated by nonexistent communication which led to a lack of trust (Charles, 2020). Participants in this study expressed that although these were vague concepts, caring and empathy were necessary in the development of trust (Charles, 2020). Erosion of trust in health care also exists for immigrant communities in the U.S. Mistrust in health care systems among immigrant populations exists due to discrimination and fears of deportation, which result in adverse health outcomes (D'Alonzo & Greene, 2020). In the U.S., the undocumented patient population often lacks access to quality care due to ineligibility for government programs (Jaramillo & Hui, 2016). This results in delayed diagnosis and failure to obtain care in general. Patients identified as obese also report mistrust in the health care system due to the presence of stigma, reduced quality of care, and a perception among clinicians that patients fail to complete treatments and interventions (Rodríguez-Gázquez, Ruiz-Iglesias, & González-López, 2020). This is compounded by equipment and health care systems that are not adapted to this population, contributing to embarrassment and shame (Rodríguez-Gázquez et al., 2020). Pregnant women also report mistrust in clinicians during the time of birth (Lambert, Etsane, Bergh, Pattinson, & van den Broek, 2018). Women experiencing childbirth seek reassurance and rapport building, yet

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poor communication and a lack of a caring attitude lead to the development of mistrust in clinicians (Lambert et al., 2018).

Mistrust may also cause patients and clinicians to view each other as ‘the other’ instead of ‘one of the team’ or taking a unified approach to an issue (Alpers, 2016). This is called ‘othering’ and is defined as the “objectification of another person or group- or creating the other- which causes a person to put aside and ignore the complexity and subjectivity of the individual” (Alpers, 2016, p. 314). Othering is complex and is deeply rooted in both parties’ negative preconceptions often related to social processes such as stigmatization, marginalization, alienation, culturalization, and racialization (Alpers, 2016). For example, mistrust among Black Americans in the health care system is rooted in historical exploitation dating back centuries, medical experimentation in the Tuskegee Syphilis study, deplorable health conditions of slavery, racial profiling, and pervasive discrimination that remains today and has been difficult to overcome (Collins, Zoucha, Lockhart, & Mixer, 2018; Melhado & Bushy, 2011; Murray, 2015). Research demonstrates that due to mistrust, Black Americans are less likely to take the risk of depending on clinicians for care and would rather risk the unpredictability of possible future illness (Murray, 2015). Mistrust has profound negative consequences for patients, families, and health outcomes.

Discrimination and a lack of access to high-quality health care has resulted in a historical mistrust of health care professionals by minority populations and is a significant barrier for an optimal EoL experience (Isaacson & Lynch, 2017; Johnstone et al., 2016; Timmermans & Oh, 2010). Immigrant populations experience mistrust in health care professionals, especially at the EoL, because of language barriers that negatively affect quality of care, fear of deportation, and poor access to hospice care due to federal financial restrictions for uninsured patients (Jaramillo

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& Hui, 2016). Mistrust in EoL care results in significantly higher numbers of immigrants more likely to receive aggressive care and to die in an intensive care unit (Yarnell et al., 2017).

Homeless individuals, who are especially vulnerable in the health care system, also reported mistrust and skepticism over not enough care at the EoL (Tobey et al., 2017). This perception that health care professionals do not prioritize a patient's best interest is due to the historical marginalization of vulnerable populations and may result in an intense suspicion that not all interventions are being offered (Periyakoil, Neri, & Kraemer, 2015). Considerable research has been done regarding how mistrust affects Black Americans' decision-making and expectations during the EoL (Hanna et al., 2019; Kyriotakis, Francis, O'Toole, Towe, & Rose, 2014; Moss & Williams, 2014; Rhodes, Batchelor, Lee, & Halm, 2015; Sanders, Berrier, Nshuti, Tulsy, & Lindvall, 2019; Trice et al., 2009; Wicher & Meeker, 2012; Yang et al., 2020). Studies have shown that Black Americans and members of other underrepresented populations are less likely to use hospice services or advance directives than White Americans (Rhodes et al., 2015).

Typically, Black Americans are more likely to request aggressive treatments at the EOL such as mechanical ventilation, CPR, and intravenous nutrition (Rhodes et al., 2015; Wicher & Meeker, 2012). K. S. Johnson, Kuchibhatla, Tanis, and Tulsy (2008) reported that Black Americans preferred life sustaining treatments more than White Americans even in circumstances of a terminal diagnosis. Past disparities have a profound impact on Black Americans and may lead to a belief to be wary of anything less than aggressive care (Wicher & Meeker, 2012). Similar studies reveal that without aggressive life-sustaining treatment, Black Americans mistrust the health care system and feel they would be left to die (Koss & Baker, 2016; Wicher & Meeker, 2012).

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Trust, beliefs, and attitudes may play a more important role in EoL care preferences than health literacy, knowledge, access, or ability to pay. Implicitly, trust has often been described in nursing as a morally unproblematic concept, in light of nurses repeatedly considered the most trusted profession around the world (Peter & Morgan, 2001; Reinhart, 2020). Unfortunately, as Peter and Morgan conclude, “Clearly, it is not [unproblematic]. Trust relationships in nursing also need to be evaluated in order to determine their moral worthiness.” (Peter & Morgan, 2001, p. 7). Patients and families should be able to trust nurses and trust in the care they receive, especially at the EoL. Yet, EoL experiences may continue to be fraught with fear and mistrust until nurses and other clinicians understand the unique needs and vulnerabilities of patients and families. When building trust, nurses must approach relationships with humility and care, with considerations and awareness of justice, freedom from oppression, and acknowledgement of the power dimension of the relationship (Peter & Morgan, 2001). Trust involves dependence and reliance upon another and is critical to optimal patient outcomes. Clinicians caring for individuals in a vulnerable population should be aware and prepared to explore and understand their needs and values because beliefs and attitudes play a significant role in EoL decision-making (Wicher & Meeker, 2012). Until a trusting relationship is achieved, demands for aggressive measures, CPR, and life-sustaining treatment will likely continue, despite a lack of medical benefit (Wicher & Meeker, 2012).

Building trust with the patient and family unit is essential in reducing conflict in EoL care. Patients facing death must be given the opportunity not only to share their illness, but also their values in life and goals for quality of life (Martin, Williams, Haskard, & Dimatteo, 2005). Patients and families must believe that clinicians can understand their unique life experience and provide them with reliable and honest advice (Martin et al., 2005). Trust is built when patients

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and families genuinely feel/believe that their values and goals are heard and acknowledged (Zhang, Zhang, Lu, & Zhu, 2019). Patients and families who trust their clinicians have confidence in their capability to deliver quality care and a belief that their words and actions are truthful (Abel & Eford, 2013). Therefore, patients who trust their clinicians are more likely to follow medical recommendations. Research has shown that physicians who establish trust in the physician-patient relationship and express compassion for their patients, succeed in fostering cooperation with recommended treatment options (O'Malley, Forrest, & Mandelblatt, 2002). When trust is established, the risk of conflict over EoL medical interventions and goals is reduced, and therefore the potential for limited resuscitation is reduced. Ideally, patients with terminal illnesses and poor prognoses would not be exposed to additional harm and suffering caused by resuscitation. They would receive palliative care to optimize their comfort for a good dying experience. However, in circumstances when patients and family's goals of care do not align with palliative measures, then conflict occurs often. Limited resuscitation that is disclosed to the family is a morally permissible option that could be considered for situations when trust has not been established or where mistrust exists. Communication using nudging discussed above, could also help build trust through the process of explanation and empowering the family to make decisions. Disclosed limited resuscitation offers families with a means to provide the dying patient with some resuscitation efforts so that families understand that *something* was done, even if it is not medically beneficial. Limited resuscitation occurs for the benefit of the family to address their emotional needs and experiences of grief and hope.

4 Health Literacy and Decision-Making Delays

Challenges with low health literacy and the public's misperception of resuscitation drastically affect decision-making at the EoL. Approximately 52 million adults in the U.S. have

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low literacy and only 12% of U.S. adults have proficient health literacy levels (National Center for Education Statistics, n.d.; U.S. Department of Education, 2020). Limited health literacy among the majority of laypersons, combined with lack of retention of medical information can result in an inability to comprehend and make timely complex discussions at the end of life (Periyakoil et al., 2015). Health literacy continues to be an evolving concept that was first used in 1974 to describe how health information impacts different systems for children K through 12 (Parnell, 2014). Today, health literacy is considered a tapestry of skills incorporating the role of language, culture, and other social constructs (Parnell, 2014). Health literacy “entails people’s knowledge, motivation, and competence to access, understand, appraise and apply health information in order to make judgments and take decisions in everyday life concerning health care, disease prevention, and health promotion to maintain or improve quality of life during the life course” (Sørensen et al., 2012, p. 3). Health literacy is essential for the promotion and maintenance of good health to the degree that individuals have the capacity to obtain, process, and understand basic health information necessary for appropriate decision-making (Nutbeam, 2009).

Low health literacy also disproportionately affects underrepresented populations such as Latinx and Black communities, people of lower socioeconomic status, and older adults (K. de Vries, Banister, Denning, & Ochieng, 2019; Eneanya et al., 2018; Melhado & Bushy, 2011). “Poor health outcomes originating from limited health literacy are implicitly a fundamental injustice of the healthcare system” (K. de Vries et al., 2019, p. 1949). Research demonstrates that inequality related to poor health literacy stems from information that is too difficult to understand and creates a social injustice where the health care system “is organized for the most literate and powerful members of our society” (Volandes & Paasche-Orlow, 2007, p. 5). Low

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literacy levels are a result of cultural misunderstandings, language variations, and inequitable educational opportunities (J. F. Wilson, 2003).

Clinicians should provide services that are equitable to all, including marginalized communities such as ethnic minorities, immigrants, and individuals for which English is a foreign language (Sørensen, Schuh, Stapleton, & Schröder-Bäck, 2013). Similarly, other disenfranchised populations such as individuals with intellectual or developmental disabilities, mental illness, or those who are socially disadvantaged and therefore have poor access also have low health literacy issues due to infrequent interactions with the health care system (Schillinger, 2007). Health literacy is a modifiable risk factor for health disparities, and it possible to reach higher levels of literacy (Stormacq, Wosinski, Boillat, & Van den Broucke, 2020). Successful approaches to increase health literacy include effective measurement of health literacy, evaluation of communication techniques, awareness of influential and social injustices, and collaboration among stakeholders (Freedman et al., 2009; Gazmararian, Curran, Parker, Bernhardt, & DeBuono, 2005; Stormacq et al., 2020). The onus does not fall entirely on patients. Nurses and other clinicians have an “ethical responsibility to clearly communicate information that affects the public” and ensure understanding (Gazmararian et al., 2005, p. 319).

4.1 Health Literacy in EoL Decision-Making

Low health literacy extends to patient and family misperceptions about resuscitation and EoL care. Patients and ADMs who do not have training or expertise in medicine or health care may not understand the complexities of care at the EoL or what treatment is considered ordinary or extraordinary. For example, a family member may not realize that a ventilator is actually “life support” and without it, their loved one would not be able to survive. Low health literacy is often associated as a key barrier to EoL conversations (Ladin et al., 2018). Low literacy can impair

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patient and family understanding of the disease process and options for treatment (Melhado & Bushy, 2011). Literature on the ethical scope of health literacy and EoL discussions is scarce (Sørensen et al., 2013). Physicians often report that medical language may be difficult to explain in an effective way, and therefore, patients have an incomplete understanding of what interventions are possible versus medically appropriate (Periyakoil et al., 2015). Unfortunately, physicians often avoid EoL goals of care discussions (K. de Vries et al., 2019). One study revealed that despite a high mortality risk, older patients receiving dialysis only discussed EoL goals of care 13% of the time with physicians, and 25% stated that had never even considered EoL preferences and expressed difficulty raising the topic due to a lack of health terminology (Ladin et al., 2018).

Inadequate portrayals of medical interventions in the media may exacerbate challenges caused by low health literacy. This is particularly the case for CPR. Patients generally do not know what CPR entails, absent what is shown on television and movies. Many of television's most popular series have been medical dramas. Generally, people rely on these shows as a source for medical information, despite their impracticality. An observational study of 84 alternate decision-makers of critically ill patients revealed that most of the participants reported a good understanding of resuscitation techniques, but less than half could recall the core components of CPR (Almoosa, Goldenhar, & Panos, 2009). There is often an overestimation of the success of CPR caused by the portrayal of CPR in the media and overall lack of medical understanding from patients and families. Studies have shown popular television shows portray survival from resuscitation at a rate twice that of actual survival (Leonard, Doyle, & Raffin, 1999; Portanova, Irvine, Yi, & Enguidanos, 2015). In 1996, a study of CPR television scenes in hospital soap operas showed a majority of the televised cardiac arrests scenes occurred mainly in children,

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teenagers, or young adults and were caused by some form of trauma (Leonard et al., 1999). Only 28% of the cardiac arrest scenes resulted from primary cardiac failure causes or terminal illness, and approximately 67% of the patients survived the immediate cardiac arrest and appeared to have survived to hospital discharge (Leonard et al., 1999). A recent study in 2015 continued to show a significant discrepancy between media depicted CPR and actual survival rates. A review of television series portrayed a 70% immediate survival rate and a 50% survival to hospital discharge rate, significantly higher than actual rates which average between 15-30% (Gershengorn et al., 2012; Mallikethi-Reddy et al., 2017; Panchal Ashish et al., 2020; Portanova et al., 2015). Over twenty years, media depictions of CPR remain the same and contribute to poor health literacy and unrealistic expectations for patients and families. The unrealistic high rates of survival foster the misperceptions of what is appropriate EoL treatment, leading to inappropriate demands for resuscitative methods. These factors can easily contribute to a disagreement between patients and clinicians deciding what resuscitative treatment should be performed (Veteran's Health Administration, 2000).

Nurses and other health care clinicians can reduce health literacy demands on patients and families by tailoring culturally appropriate approaches for patients and families. Nurses are well positioned as advocates for patients and social justice, to provide communication that is in alignment with patient and family needs, removing literacy barriers, anticipating emotional needs, and addressing misunderstandings (K. de Vries et al., 2019). Although nurses are central to this communication, it must be a collaborative approach with support and decision-making authority provided by physicians and other members of the health care team. Death is an expected occurrence, and therefore, health policy at organizational, state, and national levels

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must also address barriers by including assessments of health literacy for the promotion of ideal EoL goals of care (Melhado & Bushy, 2011).

4.2 Decision-Making Delays

In addition to poor health literacy and mistrust of health care systems by patients and families, a lack of acceptance of impending death can cause significant delays in EoL decision-making. In acute and intensive care settings, decisions regarding the benefit or futility of life-sustaining treatment are a daily challenge (McDermid & Bagshaw, 2009). Given the multiple complexities that occur in patients in the stages of critical illness, should the onus of initiating or withdrawing life-sustaining treatment or EoL decision-making be placed on vulnerable families or ADMs? Historically, CPR was among the first medical lifesaving intervention decisions that was entrusted to patients and ADMs (Rees, Gainty, & Brauner, 2014). The insistence by health care teams that patients or ADMs decide between CPR, DNAR, and other life-sustaining treatments often in a short time frame can be awkward and confusing, especially when clinicians know that the proposed interventions may be medically inappropriate and serve no useful purpose (Ditillo, 2002).

The goal of critical care and resuscitation is to prevent unnecessary suffering and premature death by treating reversible illnesses for an appropriate period of time (Gibney, 2000). Life-sustaining treatment, such as CPR, mechanical ventilation, intravenous lines, gastric feeding tubes, and other interventions, are unquestionable when the recovery is expected to be good and eventually are no longer necessary (D. White & Meeker, 2019). Timely and appropriate life-sustaining interventions can lead to improved outcomes and lower mortality (McDermid & Bagshaw, 2009). The gray area arises when recovery is only partially good and questions about quality-of-life, appropriateness of treatment, and withdrawal arise. Due to the public expectation

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of critical care and access to modern medical technology, realistic goals are distorted and positive outcomes are overstated (McDermid & Bagshaw, 2009). Yet, critical care and life-sustaining treatments offer hope to dying patients and their families (McDermid & Bagshaw, 2009). The loss of hope can often occur for patients and families when conversations and treatment plans transition from curative to palliative care (Hughes, van Heugten, & Keeling, 2015; Löfmark, Nilstun, & Bolmsjö, 2007). It is within this transition that patients, families, nurses, and the health care team grapple with time sensitivities and the appropriateness of initiating, continuing, or withdrawing treatment.

4.3 Time Constraints at the End of Life

EoL decision-making associated with delaying, withholding, and withdrawing life-sustaining treatment is fractured by time constraints and high mortality, creating polarizing effects on families, patients, and the health care team (McDermid & Bagshaw, 2009). Patients with a terminal diagnosis or their ADM often make inappropriate demands for treatment to sustain or prolong life. Patients with decision-making capacity, who receive a terminal diagnosis, experience a gamut of emotions associated with impending loss including sorrow, fear, anger, and anxiety (J. Johnson et al., 2017). Many seriously ill individuals overestimate the amount of time remaining until death, which can lead to avoidance of planning or preparation for death (Luth, 2015). Studies show that patients with a terminal illness who are acutely aware, understand their prognosis, and reject aggressive life-sustaining interventions were more likely to have their wishes honored than those who were uniformly uncertain about their preferences (Wen et al., 2019). Those patients who did not understand their prognosis, but wanted to know and understand have a significant potential for value-discordant life-sustaining treatment at the EoL (Wen et al., 2019). Oftentimes, patients who are experiencing anticipatory grief at the EoL

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are quickly expected to make significant cogent and steadfast treatment decisions regarding care. Patients are initially hopeful for recovery but have not had adequate time to process the severity or morbidity of the diagnosis to make treatment decisions. As a result, some patients will reluctantly agree to aggressive life-sustaining treatment to satisfy the wishes of their family, despite the longing for a peaceful, pain-free, and comfortable death (Hughes et al., 2015). However, if families accepted the terminal diagnosis and poor prognosis, then it was easier for patients to make appropriate treatment decisions and get their EoL affairs in order (Hughes et al., 2015).

As phases of terminal illness progress, it is well understood that patients reevaluate their outlook and prognosis (Hitz et al., 2013). Patients who see and experience the clinical evidence of their disease or experience the symptoms are more likely to accept that death is pending (Walczak et al., 2013). A qualitative study of U.S. and Australian patients in 2013 revealed that a key precursor to readiness for EoL decision-making was acceptance and adjustment to the disease process (Walczak et al., 2013). The adjustment to the disease and poor prognosis takes time and varies for every individual. Patients in the study were able to acknowledge their impending death while balancing a realistic sense of hope and desire for a good quality of life (Walczak et al., 2013). A study in 2015 found that when participants were offered some hope of treatment for a terminal illness that might be of assistance, they became immensely focused on treatments and were unprepared for their death (Hughes et al., 2015). Yet, those participants who spent less time focusing and spending time in treatment settings were more prepared to have their affairs in order and say goodbye (Hughes et al., 2015). It is well understood that in order to make good decisions at the EoL, time, reflection, and personal maturity is necessary (Löfmark et

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al., 2007). Yet, people who are emotionally burdened by the gravity of an impending death encounter a significant distortion of time (Chochinov, 2011).

Time offers the possibility for final words, a last embrace, spiritual peace, and occasionally even reconciliation (Chochinov, 2011). For some patients, even a limited amount of quality time can provide the patient, family, and even the health care team with a multitude of benefits. Often a small, medium or large medical intervention can increase the quality of life even if for a brief moment before death, especially if there are children involved or if the patient is trying to survive for a special occasion before dying (Löfmark et al., 2007). Yet, spending money and resources to extend a lifetime on patients who are dying is only valuable to families for what it allows the patient *to be* in that moment and not what the patient *can be* in a future time (Chochinov, 2011). Providing potentially inappropriate treatment to patients at the EoL also raises an important argument regarding distributive justice as it pertains to the allocation of medical resources, given the general shortage of life-saving equipment, specialized staff to manage these devices, and the momentous financial costs to patients, families, and the health care system (Schneiderman, 2011). Distributive justice “refers to fair, equitable, and appropriate distribution of benefits and burdens determined by norms that structure the terms of social cooperation” (Beauchamp & Childress, 2019). Providing life-sustaining treatment solely to intentionally lengthen someone’s life expectancy, yet has no medical benefit occurs frequently despite arguments against the ethical appropriateness of this practice. A recent study in a large U.S. hospital revealed that 20% of patients (n= 123) were receiving potentially inappropriate treatment at the EoL amounting to almost three million dollars of excessive care over three months (Huynh et al., 2013). It is critical to acknowledge and assess equitable and appropriate distribution of life-sustaining treatment for patients at the EoL. However, violations of

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distributive justice are not the primary causes of nurses' or physicians' moral distress when caring for patients who are receiving potentially inappropriate treatment at the EoL.

4.4 Time Delays in Decision-making for ADMs

Generally, conflict over EoL decisions occurs because patients receiving life-sustaining treatments are often incapacitated and unable to make or communicate their preferences (Cochrane, 2009). Without the assistance of a clear and unambiguous advance directive, ADMs are tasked and expectedly burdened with making these decisions. In the ICU setting, ADMs (who are often family members) witness their loved one connected to multiple tubes, wires, and medical devices. This is often the first time families are witnessing their loved ones in a compromised and vulnerable state. Patients in the ICU often “were fine yesterday”, but have now experienced an acute event such as a heart attack, stroke, trauma, or devastating infection that leaves them incapacitated (Meyers, 2004). Families grapple with readiness and acceptance of this critical condition. These emotions are often combined with anxiety related to the economic impacts of the illness or death, conflict about best interests, and the fear of facing their own mortality (Meyers, 2004). It is within these polarizing moments, that the expectation to make a rational and fully autonomous decision to initiate, continue or withdraw life-sustaining efforts is expected to be made (Meyers, 2004).

Family members naturally struggle with the thought of losing a loved one. A study by MacDonald, Weeks, and McInnis-Perry (2011) revealed that families need space and time to process the series of events, but recognized that time was of the essence in EoL decision-making. Time also allows family members to physically be present with their loved ones and visualize clinical changes to better determine the consequences of their decision (MacDonald et al., 2011). However, some family members feel tremendous stress and pressure from the health care team

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when asked to make decisions for their loved ones (MacDonald et al., 2011). This is particularly true when the decision focuses on forgoing treatment. Research has shown that ADMs are reluctant to make such a decision. Research suggests that there is a contradiction between what people desire for themselves and what they desire for others (Barrio-Cantalejo et al., 2013).

When deciding for themselves, ADMs may decide to withdraw life-sustaining treatment due to a poor prognosis but are more inclined to demand these aggressive interventions for a loved one up until the end (Barrio-Cantalejo et al., 2013). A study in 2009, revealed that 32% of ADMs would continue life-sustaining treatment for a loved one that is physically invasive, can be harmful, and increase the risk of infection and other damage to vital organs, even if the health care team indicated there was less than a 1% chance of survival (Zier et al., 2009).

As a result, families may avoid making decisions or contacting the health care team at all to extend the time that their loved one stays alive. The phenomenon known as “Daughter from California Syndrome”, describes the procrastination and hesitance that families or ADMs exhibit when critical EoL decisions are requested by the health care team (Molloy, Clarnette, Braun, Eisemann, & Sneiderman, 1991). An example of this happens when an adult child who has not seen their parent for several years “appears on the scene” when critical health care options are being considered for a parent who no longer has decision-making capacity (Molloy et al., 1991). When confronted with the diagnosis of terminal illness, the adult child responds with acute denial, anger, and resentment directed towards the health care team (Molloy et al., 1991). The adult child refuses to accept the terminal diagnosis of their parent, demands medically inappropriate treatment, and impedes the management of the patient’s care (Molloy et al., 1991). This creates a delay in achieving shared goals of care and oftentimes the entire process of explaining the patient’s poor prognosis has to be revisited with the entire health care team (Ache,

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2010). Research supports that nurses often experience families requesting additional time to make EoL decisions (Beckstrand, Mallory, Macintosh, & Luthy, 2018; Stokes & Zoucha, 2021). Nurses report feeling like families intentionally stall or avoid decision-making that can last weeks and even months (Stokes & Zoucha, 2021). In similar studies, nurses report that families avoid coming to the hospital or refuse to meet with the health care team, and EoL goals of care are not discussed in order to possibly extend the time their loved one is alive (Beckstrand et al., 2018).

The actions that health care teams may take and the dimensions and perspectives of extensions of time for patients and families cannot be precisely calculated or anticipated. The time of death is unpredictable. Patients and families struggle with probabilities. As a result, patients and families may underestimate the severity of the disease and are unable to anticipate how their preferences may change throughout the illness (Aggarwal et al., 2014). What is the ethically appropriate time necessary for acceptance and readiness? When patients and families are not given sufficient time to adjust to the disease and dying process, they may become unwilling to discuss EoL care issues such as resuscitation status and withholding or withdrawal of life-sustaining treatment. In addition, poor communication, and inappropriate prognostic uncertainty leads to poorer outcomes (Mack, Weeks, Wright, Block, & Prigerson, 2010). It is critical for health care professionals to assess a patient's preferences and values rather than simply evaluating the necessity of a device or procedure when considering an extension of time. This should include an assessment of the patient's readiness for prognostic information, respect for resistance to a poor prognosis, sensitivity to the process of acceptance of accurate prognostic information, and support and resources for understanding and acceptance to make EoL care

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decisions (Wen et al., 2019). This may help eliminate the focus on time in days and weeks, but rather in moments and accomplishments.

In Western cultures, time is typically viewed as a linear construct with a beginning and an end. Life is a continuous process starting at birth and ending at death (Helman, 2005). Time is structured by business hours, deadlines, and milestones and is in limited supply (van Eerde & Azar, 2019). Other cultures interpret time based on social events and the idea of time is more flexible (van Eerde & Azar, 2019). Time is used less purposefully, and people switch between activities frequently without the guidance of clock time (van Eerde & Azar, 2019). How nurses understand and interpret time has implications for the delivery of EoL care (A. Bruce, 2007). For example, a nurse caring for a patient who interprets time with flexibility should understand that prognostication of illness may not be relevant if the patient does not consider themselves in charge of time. If time is interpreted as a linear resource that is running out, then nursing actions should be guided by values of efficiency and beneficence in assisting families to use their time with loved ones in the best way possible (A. Bruce, 2007). For example, in hospice care the conventional linear understanding of time is upended and time is tailored to the wishes of the dying patient (A. Bruce, 2007). Nurses must be supportive of and sensitive to the societal and culturally embedded notions of time understood by patients and families (A. Bruce, 2007).

5 Cultural Humility, Religious and Spiritual Values

Religious, cultural, and demographic factors contribute to the pressures that families or ADMs experience related to EoL decision-making and can add another layer of complexity to care in the acute care or ICU setting. Definitions of culture have evolved, now encompassing a more fluid nature representing values, beliefs, and behaviors, as well as changing moral and societal contexts (Hughes et al., 2015). If a health care team lacks cultural and religious

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knowledge, attitude, and skills, this can result in a breakdown in communication around EoL decision-making with a potential for negative outcomes (Chater & Tsai, 2008; Colclough & Brown, 2014; Jahn Kassim & Alias, 2016). Health care professionals involved in decision-making at the EoL must consider the cultural and religious values of the patient and the family unit.

Religion and spirituality provide the underpinning for an individual's purpose of life, including a sense of security and belonging, which naturally serves to also find meaning (Jahn Kassim & Alias, 2016). The appropriateness of medical interventions and EoL decision-making is shaped and guided by the culture. In the Catholic bioethics tradition, the withholding or withdrawing of medically inappropriate treatment is permissible if the treatment is burdensome, perilous, extraordinary, or outweighs the benefit of the expected outcome (Jahn Kassim & Alias, 2016; D. Kelly et al., 2013). Prolongation of life or death is not always a moral requirement in the Catholic religion or deemed as a good option (D. Kelly et al., 2013). Similarly, Jewish laws allow withholding life sustaining treatment at the EoL that is not beneficial or is burdensome (Jahn Kassim & Alias, 2016; Mackler, 2003). Islamic law regards saving life as one of the highest merits but recognizes those circumstances when nature must take its course. As a result, medically inappropriate treatment when death is inevitable is unacceptable (Jahn Kassim & Alias, 2016).

In some cultures, EoL and risk of harm discussions are considered harmful to the patient and therefore avoided, which can create challenges regarding life-sustaining treatment and EoL planning (Deem & Stokes, 2018). The sensitivity around disclosure combined with the nuances of inappropriate medical treatment may be extremely challenging for health care professionals who already struggle with EoL communication at baseline. Johnstone (2009) demonstrates a

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practical example of the necessity for cultural awareness in a story about a non-English speaking Greek patient with a poor prognosis. The patient's daughter begged the physician not to tell her father of his poor prognosis, citing Greek culture would not support notification of terminal illness for fear it would diminish the individual's quality of life (Johnstone, 2009). The physician disagreed citing this was an ethical obligation rather than a cultural one (Johnstone, 2009). In this situation, the physician values professional obligations of disclosure and beneficence balanced with patient and family values of nonmaleficence and respect for autonomy. Health care professionals retain a moral commitment to respect a patient's autonomy and to uphold professional ethics, which must be balanced with a patient's cultural or religious considerations (Nilsen & Malterud, 2017). In this case, the challenge for the physician is the belief that respecting the culture and preferences in the decision-making process may at times be inconsistent with the performance of professional ethical obligations of beneficence and disclosure of information (Jahn Kassim & Alias, 2016).

Research has found that cultural values and beliefs do not always fit within the assumed values of patient autonomy, truth-telling, informed decision-making, and control over the dying process (Collins et al., 2018; Torke, Garas, Sexson, & Branch, 2005). It may be morally permissible to withhold information from a patient, especially when the disclosure of information could be contrary to one's culture and therefore potentially emotionally harmful to the patient. In some cases, the respect for patient autonomy requires clinicians to accept a patient's refusal to know the truth (Zahedi, 2011). However, every case is unique and not all individuals within a single culture share the same values. The physician should communicate (with the use of a translator, if necessary) with the patient to explore his preferences around receiving medical information and diagnoses and become culturally aware of his values.

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Clinicians must be sensitive to a patient's and family's cultural needs and complete an early exploration into values and preferences to minimize harm to the patient or to the patient-provider relationship.

5.1 Cultural Considerations for Nurses and the Health Care Team

Patient and family culture shapes care relationships and “includes values, beliefs, and traditions shared in common among a group family, or populations that guide thinking, doing, and being” (Collins et al., 2018, p. 586; Gómez-Vírseda et al., 2020). Nurses and clinicians must intentionally reflect on alternative perspectives to address the cultural needs of patients and families by initiating conversations with open ended questions to foster trust and sharing (Collins et al., 2018; Gómez-Vírseda et al., 2020). Culture has implications in practice for decision-making such as truth-telling, informed consent, and advance care planning (Gómez-Vírseda et al., 2020). Cultural beliefs can result in an unwillingness to discuss EoL treatment or the appropriateness of life-sustaining treatment for health care professionals (Periyakoil et al., 2015). A study in 2015 revealed that physician's believed a lack of knowledge of a patient's cultural values caused a lack of empathy to influence EoL decisions and could severely damage the therapeutic nature of the patient-provider relationship (Periyakoil et al., 2015). Cultural considerations and accommodations for patients does not only respect patient autonomy, but supports relational autonomy (Isaacson & Lynch, 2017). Acknowledgement and willingness to learn about a patient's cultural values is essential for health care professionals who must shift their discussions from procedures and clinical interventions to goals of care and quality of life, inclusive of patient and family values and beliefs (McDermid & Bagshaw, 2009).

The U.S. is a racially, ethnically, and culturally diverse country, and normative and prescriptive EoL policies impact everyone, but preferences vary individually, and sometimes

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collectively (Wright, 2018). Some non-Western approaches to EoL decision-making rooted in a community or collective culture may value beneficence more than patient autonomy, where in Western law and medicine, the primary value is on the individual patient autonomy (Searight & Gafford, 2005). In some African societies, patients and families do not like discussing death, believe that life should be preserved at all costs, and are not likely to discontinue life-sustaining treatment once at the EoL (Ekore & Lanre-Abass, 2016). Research shows that Mexican American and Asian American cultures also approach EoL decision-making communally as a means to remove the burden away from the patient to preserve the patient's well-being (Kwak & Haley, 2005). Research also suggests that Euro Americans typically communicate EoL decisions through formal advance directives, yet African Americans are more likely to confide in family and trusted clergy (Deem & Stokes, 2018). A study of Asian Americans revealed 78% desired discussing EoL care with their families, rather than with health care professionals (Isaacson & Lynch, 2017). However, regardless of race or ethnicity, a majority of Americans believe that God influences a patient's time to die and that people (i.e. clinicians) are not God (Perkins, Cortez, & Hazuda, 2009).

Families with specific cultural needs regarding time, presence, and rituals during the dying process may feel physically constrained in the ICU setting. Often, family members express a desire to be close to or near their loved one when they are dying. This is a common desire, and unfortunately one that is often overlooked during hospital design, and therefore space constraints force families to grieve in corridors (Hughes et al., 2015). For example, some cultures prefer to be present at the bedside at multiple points in time, including imminently before death and to witness death (Perkins et al., 2009). Many times, patients deem a specific time and place "right" for acknowledging and experiencing death, and therefore, these discussions should include the

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cultural appropriateness of death and the time and place when it “should” occur (Perkins et al., 2009). It can be challenging for physicians to accommodate alternative perspectives and variability in patient preferences while also prioritizing autonomy (Wright, 2018).

Culture should not be used as a proxy for patient preferences. Clinicians should explore the values of each patient and determine how they would like to make decisions (Wright, 2018). Research has shown that nurses believe that families must be involved in EoL decision-making to strengthen trust between the family and the health care team (Ka-Ming Ho, 2016). Each EoL encounter should be assessed with respect and cultural humility. When culturally appropriate, families should be a part of the decision-making, especially for EoL goals of care. Nurses and other health care professionals must explore the cultural values and beliefs of each patient with openness and curiosity and become malleable in these circumstances by respecting the relational autonomy of the patients and families as the bedside no longer becomes a place for medical treatment but a place for dying.

There is no single concept of a good death in the literature, and the perception of a good death will likely be different for each person. The Institute of Medicine defines a good death as one that is “free from avoidable distress and suffering for patients, families, and caregivers: in general accord with patients and families’ wishes; and reasonably consistent with clinical, cultural and ethical standards” (Institute of Medicine, 2015, p. 4). Generally, characteristics shaping the death experience involve the quality of life, the quality of dying, and the quality of care at the EoL (Hutter et al., 2015). Quality of life at the EoL is impacted by a patient’s physical, mental, and spiritual well-being and body integrity (Cipolletta & Oprandi, 2014; Hutter et al., 2015). The quality of dying is heavily influenced by culture, personal, or religious preference and recognizes that patients would like to die in a way that is in accord with personal

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values (Cipolletta & Oprandi, 2014). The quality of care at the EoL is the primary indicator where a nurse's role can positively or negatively affect the outcome. Nurses must be sensitive to the needs of the patient and family as the direction of the care pendulum shifts toward their cultural identity and spiritual needs (Hughes et al., 2015). Fundamentally, the moral constructs of one culture cannot be heedlessly applied to another culture (Johnstone, 2012; Sikka, 2011). Cultural considerations around death are vast and should be assessed with cultural humility and not assumed. Cultural humility "is a process of inquisitiveness, self-reflection, critiquing, and lifelong learning" that is ongoing (Fahlberg, Foronda, & Baptiste, 2016, p. 14). Nurses and other health care professionals must be culturally aware and sensitive to patient and family needs to maneuver EoL decision-making (Periyakoil et al., 2015). Every EoL experience should be personalized with respect and an understanding of *that* patient's and family's culture and values.

5.2 Culture of Death as a Treatable Condition

Facing death as a patient, family member, or as a caregiver, can be emotional, difficult, and require time sensitive EoL care decisions. Naturally, death is often met with resistance and denial by patients and family members. Western culture supposes that health care professionals and hospitals, in general, are tasked to "save lives", simply because of the societal perception that death is bad (Solberg & Gamlund, 2016). Although death itself is a physical biologic event, the dying process is imbued with social, cultural, and political meanings (Cottrell & Duggleby, 2016). The societal psychosocial attitudes regarding death and dying are at times, feared, abhorred, and denied (Cottrell & Duggleby, 2016). Saving a life is justifiably accepted despite the reality that death is inevitable for every person. The increase in technological advances to enhance and prolong life cultivates the societal denial of death (Cipolletta & Oprandi, 2014). Death is an inevitable reality for all human beings and there is nothing that can be done to alter

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this destiny (Johnstone, 2012). The availability of life-sustaining treatments can be considered by patients in fearful and desperate moments. Yet, because a technology is available and accessible does not automatically imply that it should be utilized (Beauchamp & Childress, 2019). In cases where a health care professional has determined that life-sustaining treatment is medically inappropriate, and in fact may be harmful, patient's expectations for these treatments can cause substantial emotional and moral distress for patients, families, and health care professionals (Olmstead & Dahnke, 2016).

As early as 1967, a nurse suggested that death was no longer an acceptable outcome, but it was to be treated like a medical condition responding, "Nobody dies nowadays, they have a cardiac arrest and its permanent" (Clark, 1967, p. 65). One study revealed that nurses who care for patients whose families accepted that their loved one was dying exhibited the most supportive behaviors and fostered a favorable environment for the dying process (Ka-Ming Ho, 2016). However, nurses found it difficult to provide quality EoL care when families had not accepted the patient's prognosis and therefore displayed anger, denial, and resistance (Ka-Ming Ho, 2016). Acceptance of death is a fundamental element in attaining an optimal dying experience for patients and ADMs. Refusals or delays in acceptance of death are a significant contributing factor to EoL conflict and can become a catalyst for nurses' participation in nondisclosed limited resuscitation (J. Kelly, 2008; Stokes & Zoucha, 2021).

Limited resuscitation that is disclosed to patients and families or ADMs is an intermediate action that allows families to express and preserve their values while respecting the expertise of clinicians to deliver appropriate EoL care. It provides a middle ground that allows families to actively choose from life supporting measures (rather than taking away or refraining from an action) that may not be medically beneficial but has minimal physical harm, such as

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intravenous medication or non-invasive oxygenation. Limited resuscitation that is disclosed to patients and families is morally permissible because it acknowledges ADM's vulnerability and autonomy, establishes trust between nurses and families, and is a beneficent act that respects cultural humility and allows ADMs to have an active role in end-of-life decision-making.

6 Conclusion

End of life experiences can be good or bad. Each individual death experience is unique, due to individual values, cultures, experiences, and perceptions at the EoL. The ideal outcome is perceived as a "good death" experience primarily for the patient, but also for the family and health care team. However, a bad death experience can be fraught with anger, suffering, moral distress, and regret among patients, families, nurses, and other health care professionals. Families play a central role in their loved one's death experience, and this in itself can be challenging for the health care team. Patients and families enter the EoL decision-making with a multitude of complexities that must be acknowledged and considered in order to respect the autonomy of the patient and family. The social denial of death, which is rooted in poor health literacy about technological advances, poor communication about life expectancy, religious or cultural beliefs, and mistrust of the health care system, often results in family demands for unnecessary life-sustaining treatments (Cipolletta & Oprandi, 2014). These demands however, are value-laden considerations that can often directly conflict with the health care team's recommendations and clinical appropriateness of care. Nurses and other members of the health care team should incorporate relational autonomy into EoL decision-making to encompass the social and environmental factors that might affect these critical decisions. This includes acknowledgment of family members grief and assessing an ethically appropriate time to withdraw life-sustaining treatment with cultural humility. Transparency, effective communication, and cultural

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understanding are important steps to preserve the foundational element of trust in the nurse-patient relationship.

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Chapter Four: Legal Uncertainty of Nurse Participation in Resuscitation

There is a tremendous misunderstanding regarding legal proceedings and why and how some court cases are dismissed (Pope, 2013). Several cases are dismissed on legal technicalities and not on the merits of the clinical issue. However, the outcomes in court cases are sometimes translated to clinicians by non-legal experts and the interpretation does not include the legal intricacies of the case. In addition, legal proceedings are complex and the clinician's understanding of the law is poor (Pope, 2017a). There is also widespread confusion and legal uncertainty specifically related to EoL care among clinicians, patients, and families. Laws and court case outcomes vary significantly, and therefore, clinicians lack clarity about the legal consequences of EoL care. Content translated in media outlets and textbooks report that some nurses are determined to be legally liable for their actions when delivering care at the EoL, while others are not (Fantz, 2013; Ford, 2017; Scalpel, 2021). This leads to confusion and simply fuels the legal uncertainty that most clinicians experience. Legal uncertainty during the critical moment of cardiac or respiratory arrest may contribute to moral distress and frustration and therefore increases the potential for deceptive actions such as nondisclosed slow codes to occur.

For decades, nurses have considered the legal consequences when performing resuscitation. Over 40 years ago, a study found that critical care nurses first considered the legal consequences of their decision before the patient's preferences during resuscitation (Lawrence & Farr, 1982). It is not surprising that many clinicians often conflate ethics and law (Yakov, Shilo, & Shor, 2010). Many nursing prelicensure education courses combine ethical and legal issues, and some programs have no legal or law courses at all (Bartlett, 2013). Law and ethics are both essential to the functioning and regulation of the U.S. health care system. Although sometimes closely related, ethics and law differ most notably due to the enforcement of rules or regulations

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for health practice. Ethics is the formal study of morality that explores people's moral beliefs and practices (Lindemann, 2001). Law is the formalization of rules of action and conduct for which society is governed that is enforced by binding legal authority (Westrick, 2013). Ethics and law can conflict, typically when a law allows clinicians to participate in activities deemed harmful or unethical such as execution or torturous force-feeding. However, ethics and law can also be interconnected, especially in EoL decision-making. Ethical dilemmas can result from CPR and DNAR orders which are often legal frameworks established by state statutes.

This chapter will summarize conflicting cases that contribute to a health care professional's legal uncertainty when faced with the critical decision to resuscitate a patient. The purpose of this chapter is to provide a summary of conflicting case law and describe how disclosed limited resuscitation can contribute to the alleviation of legal uncertainty and clinician confusion about resuscitation. This chapter is not an ethical or normative analysis of law. Rather this chapter serves to provide justification for the normative argument that disclosed limited resuscitation should be permissible because of the high variability and misinterpretation of court decisions about EoL care decision-making. Recent literature on legal consequences for nurses during the decision to resuscitate is lacking. This chapter will describe some noteworthy cases featuring nurses who either failed to perform CPR when others deemed it was warranted or performed CPR when others deemed it was inappropriate. These cases demonstrate a larger systemic issue regarding EoL conflict resolution that is sometimes managed or resolved by statutes or legal courts.

1 Fear of Litigation

There is a tremendous gap of knowledge in the legal realities of clinical practice. Clinicians' perceptions of legal risks are often far greater than they actually are (Pope, 2013).

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The risk of malpractice actions against physicians are far less than what is perceived (Carrier, Reschovsky, Mello, Mayrell, & Katz, 2010; McClellan, White, Jimenez, & Fahmy, 2012), yet 85% of physicians admitted they ordered unnecessary care due to fear of being sued (Carroll, 2017). Numerous studies suggest that clinicians are often uncertain and fearful regarding laws about EoL care and therefore acquiesce to family demands for inappropriate care at the EoL (Ferrand et al., 2003; Gutierrez, 2012; Jox et al., 2010; Jox, Schaidler, Marckmann, & Borasio, 2012; Olmstead & Dahnke, 2016; Syed, Almas, Naeem, Malik, & Muhammad, 2017). Gutierrez (2012) describes physicians' "caving" into family's demands, even when their actions clearly and directly conflicted with a patient's verbal or written directives in order to avoid legal action (Gutierrez, 2012). Rarely does a physician refuse to comply with a family's demand for aggressive treatment at the EoL (Gutierrez, 2012; Stokes & Zoucha, 2021). Some health care professionals, including nurses, acquiesce to the demands, while others resist the demands for inappropriate treatment. A study in 2016 revealed that approximately 77% of the nurses admitted administering inappropriate treatment to patients at the EoL, and 28% of these nurses reported it was because of family demands (Bolt, Pasman, Willems, & Onwuteaka-Philipsen, 2016). Health care professionals are emotionally and morally affected by these actions and are fearful of the consequences of refusal (Jox et al., 2010; Olmstead & Dahnke, 2016). To avoid legal confrontation or moral adversity, clinicians often adhere to the demands and provide ineffective interventions that may be burdensome or harmful to terminally ill patients (Periyakoil et al., 2015).

2 Inconsistency in EoL Care and Decision-Making Laws

The crux of the legal debate in EoL care is determining who has the ultimate decision-making power to initiate, extend, or withdraw life-sustaining treatment (Cerminara & Cerminara,

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2011). Even in cases where the patient's wishes are known, the request for a potentially inappropriate medical intervention can lead to a legal debate. Most court cases regarding EoL care revolve around designating a surrogate decision-maker. A common approach to resolve EoL conflict in the courts is to remove or redesignate the surrogate decision-maker so that the "optimal" EoL decision can be made for the patient. Typically optimal EoL decisions are ones that seem reasonable and rational to clinicians (Zapata & Widera, 2016). However, when decisions do not appear rational, the next step is often some type of legal recourse. This can be arduous and time consuming and may require a court proceeding to establish legal decision-making authority. There are no federal laws that expressly regulate EoL decision-making. Hallmark cases such as *Quinlan* and *Cruzan* raised national awareness about death and dying, specifically about withdrawing life-sustaining interventions for patients who lack decision-making capacity ("*Cruzan v. Director, Missouri Department of Health*," 1990; "*In the Matter of Karen Quinlan*," 1976).

2.1 Variance in state laws

State laws vary and some permit EoL decisions to be made by physicians without consent, while other states defer to ADMs (G. S. C. Huffman, 2018; Parker, Goldberg, & Goldberg, 2016; Venkat & Becker, 2014). For example, Texas affords the physician authority to initiate and withdraw life-sustaining treatment when it is deemed medically inappropriate, even without the patient's consent, as long as the hospital ethics committee is in agreement ("*Advance Directives Act*," 2012). In Virginia, physicians have the authority to withdraw inappropriate life-sustaining treatment, as long as a reasonable effort has been made to notify the patient's family or ADM and no other facility will accept a transfer of care after 14 days ("*Va. Health Care Decisions Act*," 2014). Other states expressly prohibit clinicians from withdrawing life-

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sustaining treatment without consent ("Idaho Code Ann.," 2005; "Minn. Stat. Ann.," 2013; "N.Y. Pub. Health L.," 2013; "Okla. Stat. tit. 63," 2013). Idaho law states that medically inappropriate care is not required, as long as it does not violate a patient's advance directive or surrogate's direction indicating treatment, thus giving decision-making authority to patients and families ("Idaho Code Ann.," 2005). New York law states that surrogate requests for life-sustaining treatment must be granted even if clinicians do not deem it medically appropriate ("N.Y. Pub. Health L.," 2013). The variance in state laws understandably leads to confusion and hesitancy in decision-making for physicians and nurses caring for patients at the EoL, especially when family demands for treatment are often deemed medically inappropriate.

2.2 Variance in court case laws

Legal precedent by state rests on case law or laws that are formed based on court opinions. Case law regarding withholding or withdrawing life-sustaining treatment occurring without consent is abundant ("Alexander v. Scripps Memorial Hospital La Jolla," 2018; "Betancourt v. Trinitas Hosp.," 2010; "Gonzalez v. Duane," 2020; "In re Guardianship of Tschumy," 2014; "Kahn v. Kramer," 2014; "Lang v. Rogue Valley Medical Center," 2016; "Norton v. Scotland Memorial Hospital," 2016; "Strong Memorial Hosp. v. Livadas," 2008). In the absence of federal law, courts are left to interpret state statutes and ethical dilemmas about who gets decision-making authority in EoL health care with varied results. The following cases outline different court conclusions including the legal rationale for the outcome.

A famous case about an 86-year-old woman in Minnesota demonstrates the court's ruling in favor of family decision-making ("In Re Wanglie," 1991). Helen Wanglie was admitted to Hennepin County Medical Center (HCMC) from a nursing home after she fell and broke her hip. She developed respiratory failure and was placed on a ventilator but was unable to be weaned

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from the ventilator after several months. During attempts to wean her from the ventilator, she suffered a cardiac arrest resulting in severe brain damage and was diagnosed as being in a persistent vegetative state ("In Re Wanglie," 1991). Nurses caring for Wanglie contacted the HCMC Ethics Committee and expressed a consensus that continued life-sustaining treatment (i.e., the ventilator) was inappropriate (Miles, 1991). Physicians from HCMC consulted with Wanglie's husband Oliver and proposed cessation of Wanglie's treatment, but he refused the removal of the ventilator (Miles, 1991). Wanglie's EoL preferences were unknown. HCMC petitioned the Probate court to appoint Wanglie an independent guardian to determine the appropriateness of treatment. At the same time, Oliver, also an attorney, cross petitioned the court to serve as his wife's guardian. The court denied HCMC's petition and ruled that Oliver was the best person to make decisions on behalf of his wife ("In Re Wanglie," 1991). Dr. Miles, a physician serving as the HCMC ethicist in this case later explained in an article that HCMC's petition for a guardian to review its medical conclusion to withdraw the ventilator was misconstrued (Miles, 1991). HCMC should have first determined its medical obligation to provide a ventilator and determine the benefit if any to the patient (Miles, 1991). Ethicists often cite *In Re Wanglie* as a case determining medical futility, yet the Probate Court simply ruled on the "best" person to make decisions for a person who was unable to make decisions for herself (Wellman, 2005). The court supported Oliver as the best decision-maker for the patient, but this case is often misinterpreted by clinicians because, as a result, aggressive life-sustaining treatment continued. The court did not rule on whether the treatment was appropriate and coincidentally Helen Wanglie died three days after the court ruling still attached to the ventilator (Miles, 1991).

A similar notable case involved Reuben Betancourt, a 73-year-old man diagnosed with irreversible brain damage after surgery at Trinitas Hospital. A fiery legal debate ensued over

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continuing life-sustaining treatment such as mechanical ventilation, dialysis, and artificial nutrition ("Betancourt v. Trinitas Hosp.," 2010). Reuben Betancourt did not have an advance directive and his wishes were unknown. Physicians from Trinitas Hospital determined that continuing these life-sustaining treatments was not beneficial and did not follow the standard of care. The physicians terminated Betancourt's dialysis and placed a DNAR order in his chart against his family's wishes ("Betancourt v. Trinitas Hosp.," 2010). Betancourt's daughter successfully petitioned the court to prevent the physicians from removing the ventilator and withholding treatment ("Betancourt v. Trinitas Hosp.," 2010). The judge ruled that the decision regarding the proper course of treatment for Betancourt could not be made by the hospital; rather, such decisions should be made by a surrogate who could take Betancourt's "personal value systems into account when determining what medical treatment was appropriate." ("Betancourt v. Trinitas Hosp.," 2010, p. 828). Trinitas appealed the ruling, but Betancourt died before the appeals court could hear the case. Both *Wanglie* and *Betancourt* demonstrate strong evidence that courts prefer EoL decision-making to be made by ADMs or family members, not hospitals or physicians. Yet, as the court in *Betancourt* noted, it risks shifting full autonomy and decision-making about medical interventions to the family.

In some circumstances, courts have ruled in favor of the physician's medical expertise or supported findings from the hospital ethics committee. In *Gilgunn v. Massachusetts*, clinicians entered a DNAR order for a 72-year-old patient with multiple co-morbidities and a poor prognosis over the objections of family members ("Gilgunn v. Massachusetts General Hospital," 1995). Ms. Gilgunn died three days after the DNAR order was entered, and the family filed a lawsuit. The court ruled that clinicians do not have an obligation to provide care that is not medically beneficial, even when there is a demand from a surrogate ("Gilgunn v. Massachusetts

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General Hospital," 1995). A similar outcome resulted in *Bryan v. Rectors & Visitors of the University of Virginia* when clinicians refused to provide life-sustaining treatment for a patient with a poor prognosis ("Bryan v. Rectors & Visitors of the Univ. of Va.," 1996). Clinicians entered a DNAR order against the family's wishes, and when the patient had a cardiac arrest, the team did not perform CPR. The family sued the hospital for a failure to provide emergency care. The court ruled that the DNAR order was consistent with appropriate medical standards of care ("Bryan v. Rectors & Visitors of the Univ. of Va.," 1996).

Other courts have expressly stated that a courtroom is not the appropriate place to litigate profound arguments concerning the appropriateness of life-sustaining treatment ("Betancourt v. Trinitas Hosp.," 2010; "In re Guardianship of Tschumy," 2014). These clinically complex cases can also confuse the trier or triers of fact, such as a judge or jury. In *Daniels v. Hadley Memorial Hospital*, an appeals court found that the judge in the lower court ruling erroneously confused the functions of the respiratory and circulatory systems ("Daniels v. Hadley Memorial Hospital," 1977). This confusion led to a dismissal of a critical aspect of causation between the alleged actions and the patient's death. Judges are reluctant to decide critical life and death disputes that often result in the patient's death at some point during the trial. This can render the cause of action for the lawsuit moot, or no longer relevant. This can be a tremendous drain on the court system and very costly for patients, but also for clinicians who are often defending their clinical actions in a legal proceeding.

In *Wanglie* and *Betancourt*, the court found decision-making authority with the family when clinicians determined it was clinically inappropriate to perform resuscitation. Yet, *Gilgunn* and *Bryan* courts determined that clinicians were not obligated to administer medical care that was deemed inappropriate, even if the family or ADM demands it. Inconsistent rulings fuel legal

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uncertainty among nurses leaving them in a vulnerable position when deciding whether CPR is appropriate on a case-by-case basis. The following sections will analyze court cases of nurses who failed to administer CPR and then cases of nurses who did when the clinical and legal criteria for resuscitation were unclear.

2.3 Nurses Who Failed to Administer CPR

Nurses are uniquely challenged when making decisions to resuscitate a patient. Often the nurse is the first person to witness the patient in the state of cardiopulmonary arrest and must quickly determine whether the patient has a DNAR order, full code order, or a partial order such as “DNAR, but everything else done” (Tsang, 2010). Understandably, nurses are uncomfortable in making this life or death time-sensitive decision while physicians are often away from the immediate clinical scene (Tsang, 2010). Although nurses are rarely sued, they are justifiably fearful of litigation or disciplinary sanctions against their licensure (Brous, 2019).

Several cases demonstrate how nurses’ initiation or failure to initiate CPR can lead to legal action. Numerous court cases over several years involve nurses who have either administered or failed to administer CPR and other lifesaving interventions against a patient’s or family’s wishes (“Estate of Maxey v. Darden”, 2008; “Stolle v. Baylor College of Medicine,” 1998; “Underhill v. Long Beach Memorial Medical Center,” 2007). However, most cases involve a nurse’s failure or delayed intervention in administering CPR. To date, there is a gap in the literature that summarizes the legal history of cases involving nurses’ liability or culpability in these types of EoL cases. Several cases involve nurses working in the correctional practice setting. A similar case involving a nurse working in a non-clinical capacity who refused to perform CPR on a patient received national media attention (Fantz, 2013). These cases will be briefly mentioned, however, a deeper ethical analysis into a nurse’s responsibilities when she is

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acting within the scope as a nurse, but simultaneously acting in a non-clinical capacity, such as a corrections employee is necessary for those specific cases. This is not within the scope of this dissertation yet is a critical area for additional research.

In 1999, inmate Ralph Tortorci completed a suicide attempt while in the custody of the New York State Department of Corrections ("DiPace v. Goord," 2004). Tortorci's family originally sued the Department of Corrections alleging they were indifferent to Tortorci's mental illness. Upon further investigation, registered nurse Cynthia Murphy reported she originally responded to the code blue emergency and found Tortorci without a pulse ("DiPace v. Goord," 2004). Murphy reported that she used a stethoscope and was unable to hear a heart rate and noticed other obvious signs of death including lividity of the body. For these reasons, Murphy did not initiate CPR. Upon discovery of this information, Tortorci's family amended their initial lawsuit to include nurse Cynthia Murphy and other correctional officers. The lawsuit alleged that Murphy harbored ill will towards inmates and had a "personal policy against administering CPR to prisoners." When in fact, Murphy's deposition stated that she had a policy of not performing mouth-to-mouth resuscitation to inmates due to the risk of disease, but she performed CPR using the aid of the "ambu-bag" ("DiPace v. Goord," 2004). Tortorci's family was unable to establish that Tortorci was alive when Murphy arrived at the scene or that her actions constituted a violation of the Eighth Amendment's deliberate indifference. The court ruled that Nurse Murphy was entitled to immunity from the lawsuit, and Tortorci's family's motion to include Murphy in the lawsuit was denied ("DiPace v. Goord," 2004). This case demonstrates how critical the nurse is in deciding whether to resuscitate a patient. In this case, Murphy relied on her clinical judgment to determine whether to resuscitate the patient. The events in this case occurred in 1999, yet the court ruling was made in 2002. Court cases often are lengthy, costly, and can cause

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a tremendous amount of stress for those involved. This case did not reflect challenges with code status but demonstrates the legal liability that nurses face even when making clinical decisions about resuscitation. A similar question arose in England where a nurse's license was initially suspended when she failed to perform CPR on a patient who did not have a DNAR order, yet was found "waxy, yellow and almost cold" (Ford, 2017). Clinical decision-making for nurses in these cases is complex and contributes to confusion and fear of legal repercussions.

Often nurses are not immediately familiar with a patient's code status, especially if the mechanism to determine the code status is unclear. Olga Shikoski was a patient in a nursing home in Texas when she began coughing, choking, and gasping for air. Her son was present at the time and called his mother's nurses to assist ("IHS Acquisition No. 131, Inc. v. Crowson," 2010). The nurse attempted to arouse Olga but was unsuccessful. The nurse asked Olga's son if his mother "was DNR", and he replied that he did not know what that meant ("IHS Acquisition No. 131, Inc. v. Crowson," 2010). The nurse began looking for the paperwork, yet Olga was unresponsive during this time and no intervention was occurring. It is unclear how long this occurred, but any delay in the initiation of CPR can result in loss of oxygen to the body and cause brain and other organ damage. The nurse was unable to find the paperwork and began CPR. Olga was transferred to a local hospital and was diagnosed as brain dead ("IHS Acquisition No. 131, Inc. v. Crowson," 2010). Her family consented to withdraw life-sustaining treatment and she died. Olga's family sued the nursing home for negligence stating that the nursing staff failed to timely initiate CPR to resolve respiratory distress. The court case hinged on a report by an expert physician hired by Olga's family that identified the standard of care for nurses in a nursing home facility is "essentially" the same whether the patient is on a hospital floor or in a skilled nursing facility ("IHS Acquisition No. 131, Inc. v. Crowson," 2010). Notably, this case

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relied on a physician to testify to a nursing standard of care for treating a patient experiencing a respiratory arrest, calling a code, and resuscitation. The court determined that the physician's expertise and the vague description in the report was insufficient to establish a nursing standard of care for the case. The nursing home also challenged language in the report that stated the nurses failed to promptly initiate CPR but failed to define 'promptly' ("IHS Acquisition No. 131, Inc. v. Crowson," 2010). The case was dismissed based on legal technicalities surrounding the medical expert's testimony and use of vague terms such as "essentially" and "promptly". This case did not fail on the merits of the case. Nurse Olga indeed failed to initiate CPR in a timely manner consistent with AHA guidelines. The court ruled that Olga was not legally liable for her conduct based on legal technicalities related to expert testimony.

In 2001, a resident in the Omni Manor Nursing Home, "CL", was found without a pulse or blood pressure. The nurse who found CL unresponsive went to check the chart to determine CL's resuscitation status. The nurse relied on a hospital transfer form which indicated not to initiate CPR and therefore Emergency Medical Services were not contacted ("Omni Manor Nursing Home v. Thompson," 2005). The facility contacted the physician of record to inform them of the patient's status and the physician ordered that CL be transported to the local Emergency Room. CPR was never initiated. Within 15 minutes, CL's respirations ceased, and the physician then ordered CL to be transported from Omni Manor Nursing Home to the funeral home ("Omni Manor Nursing Home v. Thompson," 2005). An investigation by regulatory surveyors found that the phone calls to the Emergency Room and later to the funeral home demonstrated a lack of clarity about the DNAR order. According to Omni Nursing Homes' policy, the resident should have received CPR when found unresponsive, because the hospital transfer form did not represent a DNAR order. In this case, the court found that the nurse was not

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the subject of the lawsuit and therefore was not liable due to Omni Nursing Homes' organizational deficiencies ("Omni Manor Nursing Home v. Thompson," 2005). However, this case continues to demonstrate a pattern of legal challenges related to code status and resuscitation.

Legal uncertainty even results from cases when the EoL preferences are known and documented. Another case involving a minor child, Christian, raised critical issues regarding verbal preferences over written advance directives. In 2003, Christian was admitted to Long Beach Memorial Medical Center in critical condition due to pneumonia. Due to his condition, a nurse and physician had a lengthy conversation with Christian's parents, and it was agreed to withhold CPR and issue a DNAR order ("Underhill v. Long Beach Memorial Medical Center," 2007). A medical expert physician testified during the trial and described the DNAR conversation as:

The records indicate that Dr. Nussbaum along with two other medical personnel, a doctor and a nurse, had a lengthy conversation with both parents, Glen and Margarita Underhill wherein Christian's grave medical condition was discussed. It was recommended by Dr. Nussbaum and the parents agreed that in the event of a cardiac or respiratory arrest that no endotracheal intubation, ventilator support, CPR medications or chest compressions would be given. All other interventions were in place, i.e., nutrition, antibiotics, administration of medicines, oxygen administration. These were given to keep Christian comfortable. (para. 21)

When Christian's heart stopped beating, mechanical ventilation and chest compressions were not performed per the DNAR order. Christian's parents filed a lawsuit against the hospital for wrongful death. They stated that they never authorized the physician or nurse to withhold

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resuscitation and in fact, wanted for Christian's life to be prolonged ("Underhill v. Long Beach Memorial Medical Center," 2007). The facts of the case were undisputed, yet the legal nuances of admissible evidence resulted in this case being advanced to an appeals court. The appeals court found no evidence to suggest that the physician or nurse acted inappropriately, and the evidence suggested that Christians' parents agreed to the DNAR order. Once again, the physicians and nurses were absolved in this case, but it resulted in a four-year lengthy and costly trial for the nurses and other clinicians involved in this case.

2.4 Nurses Who Administered CPR

In the mid 1990s, a shift in the public's awareness of the legal right to refuse life-sustaining treatment grew out of a consensus that medicine was overdoing measures to prolong life (Rodriguez, 1999). Patients feared a long, lonely, and painfully drawn out death and a host of successful lawsuits arose suing physicians, hospitals, and nursing homes when treatment was provided against a patient's wishes (Rodriguez, 1999). Many years later, legal sanctions for administering unwanted treatment at the EoL are significant and growing (Pope, 2013). These sanctions include civil liability such as medical malpractice or negligence, but also licensure discipline such as probation or revocation of practice (Pope, 2013).

Legal cases arise not only when nurses fail to administer CPR, but also when CPR is administered against a patient's wishes ("Anderson v. St. Francis-St. George Hospital," 1992; Jabre et al., 2014; "O'Donnell v. Harrison," 2019; "Weisman v. Maryland General Hospital," 2016). Oftentimes, the patient's wishes are unknown or unclear to the nurse. Many hospitals and AHA guidelines default to performing CPR if a patient's code status is unknown. However, these circumstances can also carry a legal risk for the nurse when a quick decision about taking action must be made. In a bizarre case, a hospital in Texas was sued for medical malpractice by parents

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of a newborn for successfully resuscitating their child ("Stolle v. Baylor College of Medicine," 1998). Baby Mariel was born premature and survived birth although her twin sister did not. Mariel was diagnosed with a brain bleed, and therefore, her parents expressed wishes to refrain from heroic measures and they decided to initiate a DNAR order ("Stolle v. Baylor College of Medicine," 1998). At the age of four months, Mariel remained hospitalized and suffered an apneic episode and a slow heart rate after regurgitating her food. An apneic episode occurs when an individual has an irregular breathing pattern with some sustained periods of not breathing. This is not a complete respiratory arrest. An unidentified nurse administered chest compressions for 30 to 60 seconds and Mariel survived ("Stolle v. Baylor College of Medicine," 1998). The court records indicate Mariel was still alive seven years after the incident. Mariel's parents sued the Woman's Hospital of Texas for performing life-saving measures on Mariel despite the parent's wishes. This case was first heard in the trial court where the judge sided with Women's Hospital and dismissed the case without specifying a reason to do so. On appeal, the court agreed with the trial court but specified that the Texas Natural Death Act provided immunity to the hospital for their actions ("Stolle v. Baylor College of Medicine," 1998). Interestingly, the court held that Mariel's parents did not cite any authority that would have allowed the withdrawal of life-sustaining procedures lawfully ("Stolle v. Baylor College of Medicine," 1998). Although sometimes considered morally equivalent, this case was not about withdrawing life-sustaining treatment but withholding treatment in an emergent situation. The court incorrectly interpreted the clinical actions taken in this case. The court's misinterpretation of withdrawing versus withholding treatment did not have a significant bearing on the outcome of the case, but this demonstrates a misunderstanding by the court of the nuances of EoL care that are translated in a legal proceeding.

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A similar case occurring at Johns Hopkins Health System involved a 33-year-old man with AIDS who was admitted for acute renal failure ("Jeanette Wright v. Johns Hopkins Health Systems Corporation et. al," 1999). The patient, Robert Wright, contacted his mother to let her know that he would be coming home from the hospital that day after receiving his blood transfusion. Within minutes after the transfusion was completed, Wright became unresponsive and had no pulse ("Jeanette Wright v. Johns Hopkins Health Systems Corporation et. al," 1999). Dr. James Miller directed an unidentified nurse to begin CPR, and Wright was intubated for mechanical ventilation. Upon exploration, Wright's family stated that he had a written living will and expressed his wishes not to be resuscitated or intubated. Wright's mother requested that his breathing tube be removed, and he receive comfort care only. Wright had suffered 65% brain damage as a result of the events and died ten days after the cardiac arrest. Wright's family argued that he had an oral DNAR order, and his wishes should have been noted in his medical chart. They acknowledged that Wright did not have a formal written advance directive, and Wright's mother was unsure if her son ever expressed his wishes to Dr. Miller. The family argued that the clinicians who performed CPR on Wright constituted battery and failed to obtain informed consent for CPR. The court found that she lacked evidence to show Wright's wishes or DNAR preferences, and therefore, her battery claim was dismissed ("Jeanette Wright v. Johns Hopkins Health Systems Corporation et. al," 1999). The nurses involved in this case were not named in the lawsuit, and the case indicated that the attending physician directed that CPR be administered.

A medical malpractice case in New Jersey alleged that physicians and nurses at Morristown Medical Center improperly resuscitated Suzanna Stica by failing to honor her DNAR order, and she lived an additional six months before she died ("Koerner v. Bhatt," 2017). The court found that attending physician Dr. Bhatt and several members of the health care team

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resuscitated Stica when she had a cardiac arrest during a procedure believing that the DNAR order did not apply in this circumstance. The clinicians defended themselves by citing immunity, but the court determined that immunity only covered acts when patients' wishes are carried out, not when they are disregarded ("Koerner v. Bhatt," 2017). The court concluded that the clinicians were liable for Stica's unwarranted pain and suffering and were required to compensate Stica's family for the negligent failure to follow the patient's advance directive ("Koerner v. Bhatt," 2017).

These cases, among many others, are legally complex. Even if legal cases are favorable for clinicians, the cost of a defense, court and other sanctions can be financially and professionally detrimental. Nurses may face legal liability even when following clinical guidelines for the administration of CPR. Although the nurse in *Dipace* was not liable, she was still charged and had to defend her actions in court. The nurse's conduct in *Dipace* clearly fell within appropriate clinical guidelines not to perform CPR. However, when the code status of a patient who has experienced a cardiac or respiratory arrest is not clear, the default approach is to perform CPR if clinically indicated. Yet, the nurses in *IHS* and *Omni* were not legally liable although they failed to perform CPR in the absence of a DNAR order, and it was clinically indicated. In *Stolle* and *Wright*, nurses performed CPR on a patient in the absence of a DNAR order. They still faced legal challenges requiring a defense and justification for their actions. The acknowledgment of good faith attempts, or non-attempts is lacking from the analysis of all the cases. There does not appear to be any consideration for the nurse's good faith efforts to resolve the situation in the most clinically appropriate manner. Slow codes that were not disclosed originally spawned from an absence of law around resuscitation and uncertainty about resuscitation in vague hospital policies (McLennan, 2012; Van Scoy-Mosher, 1982). Legal

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uncertainty for nurses in these moments may lead to moral adversity and contributes to the moral reasoning process that drives nurses and other clinicians to participate in nondisclosed limited resuscitation that is deceptive and not transparent.

All of these cases represent a gray area where clinicians are unclear and fearful of litigation. Although courts have set case precedent resulting in policy implications, they have not resolved the emotional and moral aspects that generally underlie these EoL cases (Igel & Lerner, 2016). These situations are ripe for the practice of nondisclosed limited resuscitation, where clinicians may feel like they must “do something” but cannot morally perform full resuscitative measures. Disclosed limited resuscitation is an ideal option for clinicians and patients that mitigates legal confusion, minimizes unilateral actions by clinicians, and preserves shared decision-making for all parties, thus limiting litigation. Limited resuscitation is ethically permissible as long as it is disclosed to patients and ADMs or family members. The following sections will analyze why this disclosure should be proposed to patients and families even though legal requirements for informed consent do not need to be met.

3 Informed Consent

Informed consent is a legal concept created for patient safety and its efficacy is widely questioned (Nijhawan et al., 2013). Informed consent is a hallmark of Western medical ethics arising from atrocities documented in human experimentation such as the Tuskegee Study of Untreated Syphilis and the Nuremberg trials, but also proscribed in a foundational U.S. Court of Appeals case outlined in *Canterbury vs Spence*, (“Canterbury v. Spence,” 1972; Sedig, 2016; R. M. White, 2003). The court in *Canterbury* held that informed consent was central to a reasonable patient’s right to have risks and benefits disclosed by a health care professional (Ginsberg, 2017). The legal requirements for informed consent require the clinician (either a physician or advanced

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care provider such as a nurse practitioner or physician's assistant) to obtain the patient's agreement to the medical plan of care, explain the medical opinion about the problem or diagnosis, recommend an appropriate treatment, give a rationale for the recommendation, propose an acceptable alternative, and explain the risk and benefits of the procedure (Jonsen et al., 2015). Patient autonomy allows a patient to have opinions, make choices, and take action based on his or her personal values (Beauchamp & Childress, 2019). This includes a patient's right to accept or refuse treatment (Lo, 2013). The ethical purpose of informed consent is to protect patient autonomy and well-being (J. W. Berg & Appelbaum, 2001; Lo, 2013; Mayo & Wallhagen, 2009).

Clinicians may be skeptical of the moral argument for informed consent because most patients lack medical knowledge or expertise and poor health literacy supports the finding that most patients could never provide a true understanding of the medical treatment or benefits and risks involved in their procedure (Lo, 2013). For some clinicians informed consent is a duty or obligation; yet, patients feel that informed consent is a right (J. W. Berg, Appelbaum, Lidz, & Parker, 2001). It is the duty of both the clinician and the patient to reach a mutual agreement on the delivery of the treatment (J. W. Berg et al., 2001). Once informed consent has been granted, the patient is understood to allow the agreed-upon treatment to proceed. Despite the legal requirements and risks of medical malpractice for failure to obtain informed consent, some clinicians are reluctant to fully observe the practice due to a perception that informed consent is too time-consuming or that the patient is medically uneducated or uninterested in knowing the specific details of a procedure (Jonsen et al., 2015).

However, there are exceptions to informed consent including when patients lose or lack capacity or in emergencies; consent is assumed. If the patient is unable to make the decision or

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an ADM is unavailable, emergency treatment will commence. Herein lies the challenge of resuscitation efforts including cardiopulmonary resuscitation, because it does not require a patient's consent (de Vos, 2001). There is generally an "opt-out" mechanism through a DNAR order, but there is no opt-in, and resuscitation occurs unless there is a decision to withhold it (Bosslet et al., 2015). The assumption is that if a patient has a cardiac or pulmonary arrest in an emergent situation, then CPR must be done (Olmstead & Dahnke, 2016). It is considered a positive right that is afforded to an individual in need of emergency care, during a time when they are unable to provide consent. However, consent is required in most cases, when this right to emergency care is removed with a DNAR order. Simply stated, no consent is required to *take* action, but consent is typically required *not* to take action. This legal framework has created a dichotomy to resuscitation that has posed numerous legal and ethical dilemmas. Typically, if consent is not obtained for a DNAR order, then full resuscitation efforts are expected to be performed despite the futility of the patient's condition. Requirements for informed consent of a DNAR order minimizes the expertise and ties the hands of clinicians who have made a medical determination that resuscitation would not be medically appropriate. However, legitimate concerns by patients and families exist regarding unilateral orders to withhold resuscitation without consent in a culture where most patients are expected to be resuscitated if no DNAR order is present.

3.1 Legal Cases about Limited Resuscitation

Limited resuscitation efforts are generally unknown to patients and families unless there is express consent or a medical order to do so. Patients and families are unaware that standard resuscitation efforts are not occurring. Arguably, the elements of informed consent are not met, because limited resuscitation is typically not an option that has been discussed with patients, and

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often not even among clinicians. Generally, limited resuscitation efforts that are not disclosed occur in terminally ill patients who are admitted to academic medical centers, community hospitals, and long-term facilities (Gazelle, 1998; Piscitello et al., 2020). Patients may be in a incapacitated state, or otherwise comatose, and cardiac arrest has usually been predicted in these patients and their terminal event comes as no surprise to the clinicians (Gazelle, 1998). However, when limited resuscitation is not discussed with families, the physician does not write an order in the patient's chart, and it is not documented by any other clinicians. Nondisclosed limited resuscitation is generally decided at the time of cardiac arrest and there is no time for discussions of consent (DePalma et al., 1999).

As a result, nondisclosed limited efforts, such as nondisclosed slow codes are not litigated because families are not aware they are happening. Nondisclosed slow codes would also be extremely challenging to prove, especially in cases when all efforts appear to have been taken, and the documentation reflects an inclusive normalcy to the code. Codes are chaotic and typically a deep analysis into any type of delay is not warranted. Notably, one court case refers to a "slow code" through the testimony of the physician. In 2012, a medical malpractice lawsuit was lodged against several physicians at the Good Samaritan Hospital in New York ("Cotto v. Hegazy," 2012). The lawsuit alleges that the physician failed to prevent Maria Luna-Diaz from developing a deep vein thrombosis, causing her to suffer a massive pulmonary embolus ("Cotto v. Hegazy," 2012). Maria died in 2006 and this lengthy and costly case was heard in the Supreme Court of Puerto Rico. Terry Palatt, MD testified that he saw Maria when she was in critical condition and recommended that she have a procedure to dissolve her clots ("Cotto v. Hegazy," 2012). She recently had surgery and therefore was not a candidate for the clot-dissolving procedure. He indicated that a full code was initiated, but he arrived at the end of the code

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("Cotto v. Hegazy," 2012). Dr. Palatt stated that he ordered necessary medications and "continued with a slow code." He stated that he knew she was going to die and that he tried to keep her alive until the family could come to visit her in the hospital ("Cotto v. Hegazy," 2012). The case does not explain the terminology or significance of a slow code, and the slow code was not the cause of action of the lawsuit. It is unclear what Dr. Palatt meant by using the term "slow code". The quote simply acknowledges that the "slow code" was done in an effort to allow time for family to arrive before the patient's death ("Cotto v. Hegazy," 2012). This is often the case for limited resuscitation efforts. The intention at the beginning of the code is that the patient will not likely survive. Because of this assumption by clinicians, limited resuscitation is often hidden or not disclosed to families.

With an increase in public access to medical information, there is a potential for more cases that closely evaluate the time of cardiac arrest compared to the time of intervention. A recent case in 2019, involved a detailed review and reporting of the emergency code sheet into the lawsuit filing document. The defendants in the case alleged that the ICU nurse and resident physician failed to properly partake in and run the code and failed to begin promptly according to medical standards ("Callagy v. Sklarek," 2019). This court case is still pending and therefore could set a precedent on the legally appropriate timeliness of resuscitation depending on how the court rules. This is a common rationale expressed by clinicians who participate in nondisclosed slow codes as an adaptive response to gain control over the EoL conflict and escape what is perceived as an unethical act (McLennan, 2012).

3.2 Informed Consent and Limited Resuscitation

Death is a clinical determination, but the manner of dying remains in the values and preferences of patients and families. Limited resuscitation that is disclosed to families serves as a

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middle ground between full CPR efforts and a DNAR order (Stokes & Zoucha, 2021). It serves as a way to preserve hope for families who do not want to feel like they are giving up on their loved ones. It should be perceived as a limited form of CPR and therefore something that should be afforded to an individual who is at the EoL, not something that is taken away. For families who are adamantly opposed to a DNAR order, disclosed limited resuscitation is ethically permissible and offers some ethically appropriate medical interventions that are not deemed to cause immense suffering for patients (such as the elimination of chest compressions or defibrillation). Cardiac or respiratory arrests are considered an emergency and therefore interventions to address the emergency are done without consent and are default responses. In circumstances when full resuscitation is not clinically or ethically appropriate, clinicians must inform patients and ADMs or family members about ethically appropriate options, including DNAR orders and limited resuscitation. However, consent should not be required for limited resuscitation because it is still a clinical response to an emergency even though patient survival is not expected.

Families or ADMs may still object to limited resuscitation, just as they may reject a DNAR order. There are legal and ethical distinctions in this refusal. Legally, many jurisdictions do not allow clinicians to issue a unilateral DNAR order without the family's consent. However, no laws exist that require consent for limited resuscitation. Therefore, a legal loophole exists for limited resuscitation. As a result, a family, or ADMs refusal to agree to a DNAR order results in the delivery of aggressive care and resulting moral distress for nurses and other clinicians. Consent should not be required for limited resuscitation, and therefore, even in the event of family or ADM refusal, some attempt to resuscitate the patient would occur transparently with their knowledge and awareness, eliminating the deception associated with limited resuscitation.

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If consent was required for limited resuscitation and families or ADMs refused, the expectation for aggressive and potentially inappropriate care would remain and clinicians would continue to experience moral distress. In addition, nondisclosed limited resuscitation would likely continue to occur, and the cycle of deception and mistrust would continue. The impact of deception on a nurse's moral identity and ethical comportment could foster continual deceptive and unethical behavior. The dichotomy between full CPR and a DNAR order would be unchanged.

However, if disclosed limited resuscitation was still performed over the objections of the family or ADM, families or ADMs would be aware that some action was taken, rather than no action. In jurisdictions where unilateral DNAR orders are legal, clinicians have an option to either issue a DNAR order or provide some resuscitation even though there is no expectation for patient survival. Evidence shows that patients and families desire some action to be taken, even when they understand that their loved one is dying, but they cannot bring themselves to agree to a DNAR order. Issuing a unilateral DNAR order results in clinicians taking no action to resuscitate an individual experiencing cardiac arrest. Clinicians are not required or expected to deliver care that is medically inappropriate, and therefore, the likelihood of legal sanctions for limited resuscitation could be less than if no action was taken when a unilateral DNAR order was issued.

If families were required to consent to disclosed limited resuscitation and refused, clinicians would be in the same morally distressing situation as if the family refused a DNAR order and resuscitation would be required. Therefore, disclosure is required, but consent should not be required for limited resuscitation for the same reasons that consent for a unilateral DNAR order is not always required. Without consent for limited resuscitation, and in the absence of a DNAR order, clinicians may feel compelled to perform full CPR when it is not medically

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indicated due to fear of legal consequences or confrontation from families. However, limited resuscitation efforts are emotionally beneficial for families, and therefore *some* attempt to resuscitate a loved one is preferred and ethically permissible over *no* attempt at resuscitation (Bennett, 2016). As a result, limited resuscitation could reduce and even eliminate unilateral DNAR orders.

Although informed consent is not recommended for limited resuscitation, notice or due diligence in attempting to notify families must be a requirement. Clinicians are not required to administer treatments that are not medically beneficial or offer no reasonable hope of recovery and therefore they do not have to acquiesce to family demands to full resuscitation (American Medical Association, 2015). Autonomous decision-making does not afford patients or families with a right to whatever life-sustaining treatments they desire. However, limited resuscitation allows families with some reasonable less harmful resuscitation efforts that are proposed as opportunities to promote autonomous decision-making that do not outweigh harm or suffering to the patient. Families must be fully informed that limited resuscitation will occur and if possible, should be present when it occurs. Ideally, families and clinicians will agree on value-laden treatments that are tailored to their goals of care, but consent is not required in circumstances of disagreement. Clinicians should provide transparent and truthful information to promote trust and autonomous decision-making. Policies or state legislation proposing limited resuscitation must include that patients and families are informed of these types of resuscitation efforts. Therefore, limited resuscitation opportunities should be embraced with appropriate guidelines and legislation at the institutional, state, and national levels.

4 Policy and Legislative Approaches

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4.1 Legislation

In the late 1970s states and hospitals were grappling with the absence of legislation on CPR and DNAR orders. Hospitals had varying approaches to CPR and legislation was a desire for many institutions to create a more standardized approach to CPR efforts (Burns, Edwards, Johnson, Cassem, & Truog, 2003). Only one legislative response to nondisclosed slow codes is documented in the literature. In 1987, New York governor Mario Cuomo initiated a 23-member task force in response to the increase in public concern over EoL dilemmas. Four years later, a New York Times article published the findings from the task force's report and exposed hospitals that were initiating DNAR orders without consent and performing slow codes without consent or knowledge ("Slow codes, show codes and death," 1987). A grand jury investigation into the report found that physicians and nurses would delay resuscitation efforts so that they would intentionally fail, and the patient would die (Sullivan, 1987). The rationale for these actions was to allow the health care team to claim that everything was done to save the patient without any retribution.

As a result, New York enacted a law establishing consent requirements for DNAR orders and outlined the roles, responsibilities, and designations of surrogate decision-makers ("N.Y. Pub. Health L.," 1992). Despite the report, the New York law is silent on performing disclosed or nondisclosed slow codes. The legislative intent of the law was to end the need for nondisclosed slow codes by allowing clinicians to withhold CPR from patients who did not want it ("Slow codes, show codes and death," 1987). The law clarifies that in the absence of a DNAR order, CPR is not presumed for every patient, but will be performed according to evolving standards of care and guidelines ("N.Y. Pub. Health L.," 1992). This law was revolutionary for its time and enacted prior to the U.S. Patient Self-Determination Act. In 1991, the U.S. Patient Self-

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Determination Act (PSDA) was passed, which required all patients to be informed of their rights to advance directives (including DNAR orders) and EoL decision-making abilities ("PSDA," 1990). Before this law, scant research existed on how many patients utilized advance directives. Estimates from 20-70% suggested a wide variance of perspectives and hospital policies about the use of advance directives (Jonsson et al., 1988; Teno et al., 1997). After the PSDA passed, the numbers remain low with only 25-36% of people reporting the use of advance directives in recent years, suggesting the legislative intent has opportunities for improvement (D. W. Baker, Einstadter, Husak, & Cebul, 2003; Rao, Anderson, Lin, & Laux, 2014; Yadav et al., 2017).

Most states have enacted laws to address DNAR orders. In some states, there are laws that enable the use of unilateral DNAR orders. For example, through a Physician's Order for Life Sustaining Treatment (POLST), Maryland and Vermont allow clinicians to write DNAR orders without patient or ADM consent when efforts are deemed to be medically inappropriate (Bosslet et al., 2015). Unilateral DNAR orders are unilateral decisions made by physicians to withhold or withdraw life-sustaining treatments based on a lack of medical appropriateness of treatment without patient, family, or ADM consent (C. R. Bruce, Bibler, Childress, & Fedson, 2018; Manthous, 2007). In some circumstances, unilateral DNAR orders are implemented, and families are not made aware. It should be noted that not all hospitals use the term "unilateral" because it denotes an adversarial relationship between patients and clinicians and implies that patient preferences are being ignored, when the intent behind the policies are to maximize beneficence and respect for patients during the dying process (Courtwright, Brackett, Cadge, Krakauer, & Robinson, 2015).

There is understandably a deep legal and ethical chasm over unilateral DNAR orders. Supporters of unilateral DNAR orders argue that it is within the right of physicians to exercise

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medical judgment and expertise to provide a treatment plan for patients and withhold resuscitation in circumstances when it is medically inappropriate (Beauchamp & Childress, 2019; C. R. Bruce et al., 2018). Unilateral DNAR orders are created to protect seriously and terminally ill patients from harm at the end of their lives (Courtwright et al., 2015). However, opponents suggest that a unilateral approach to EoL care violates “due process, compassion, and patient autonomy” (C. R. Bruce et al., 2018, p. 459), and represents unwarranted medical paternalism (A. M. Courtwright et al., 2014). Although unilateral DNAR orders do not appear to give patients or families any decision-making authority, the process to implement one typically involves an ethics committee or disinterested party to approve the order (Casarett & Siegler, 1999). Unilateral DNAR orders are a less desirable option to manage EoL conflict but are sometimes ethically appropriate when families or ADMs demand life-sustaining treatments that are harmful to patients and morally distressing to clinicians. Unilateral DNAR orders may be the optimal EoL goal of care for patients with debilitating conditions, poor prognoses, and high-mortality illnesses.

The prevalence of unilateral DNAR orders is unknown. Some older research identifies that these decisions are rare, unusual, and limited by individual state laws (Fine, 2009; Pope, 2007; Swig et al., 1996), while other research suggests that it occurs on a more frequent basis (Waisel & Truog, 1995). Such decisions are often avoided because they can leave the physician subject to risks of legal and disciplinary sanction, as well as damage to the professional reputation (Georgiou & Georgiou, 2019; Pope, 2007). In circumstances when unilateral DNAR orders are implemented, physicians write the order, but it is often nurses who are forced to carry out the order. At the moment of cardiac arrest, the weight of failing to perform an action for which the outcome is most certainly death is tremendous and contributes to moral distress. The

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outcome of the physician's medical decision directly impacts not only the patient but is done without the ethical consideration of the nurse's duty to care. Unilateral DNAR orders are one medical approach to resolve EoL care conflict between clinicians and ADMs. However, these orders do not account for the risk of psychological harm to nurses and other clinicians who are complicit in the practice. Unilateral DNAR orders are distinguishable from limited resuscitation by the failure to take *any* action to preserve life versus taking *some* action even if it is minimal, especially in circumstances when families have not provided consent for a unilateral DNAR order. Alternatively, limited resuscitation offers families some relief of knowing that resuscitation attempts were made, even if it is a modicum of effort. States must be innovative and rethink approaches to EoL care that reimagine the dichotomy of DNAR and CPR.

4.2 Policy

Opinions on nondisclosed slow codes on a national level oppose the practice. The U.S. President's Commission on Bioethics briefly acknowledged nondisclosed slow codes in a 1983 report ("President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research," 1983). The report was clear that nondisclosed slow codes were deemed unethical and should not be performed. In Ontario, Canada a recent policy also suggests that physicians avoid the use of nondisclosed slow codes but requires that full CPR be performed "in good faith" when patients or families request it, even when the physician deems that it is medically inappropriate (Hawryluck, Oczkowski, & Handelman, 2016). The European Resuscitation Council has also denounced nondisclosed slow codes, associating the practice with deception but suggesting alternatives such as tailored codes (Mentzelopoulos et al., 2021). Nondisclosed slow codes continue to be associated with deception in the literature based on the primitive understanding that they are performed without patient or family knowledge, thus

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opposition to the practice continues to manifest in policies. However, slow codes that are disclosed to patients and family members or ADMs should not be considered deceptive. Family members may not yet accept that their loved one is dying and have some hope of recovery. Clinicians can propose a slow code as a minimal effort to resuscitate the patient, but also acknowledge an understanding that the patient will not likely survive. Some family members are aware that their loved one is dying yet cannot bring themselves to agree to a DNAR order (Lantos & Meadow, 2011). It is unlikely that a patient or family member would request a slow code at the EoL, but it is certainly possible and ethically reasonable if a request was made and the health care team approved (Piscitello et al., 2020). A mixed methods study found that 50% of alternate decision-makers of critically ill patients would continue life-sustaining efforts for their loved ones even if the patient only had less than one percent or no chance of survival (Zier et al., 2009). Disclosed limited resuscitation, including disclosed slow codes can become a tailored limited resuscitation effort that meets the needs of the patient and family, but also does not put undue hardship on clinicians to provide aggressive care with the expectation of patient survival. Because of opposition to nondisclosed slow codes, there is little to no guidance on how to respond to them or address them when they occur. It is unreasonable to expect that clinicians will know and understand or keep up to date with the numerous EoL cases and decisions that can affect whether or not CPR should be obtained without the introduction of national guidelines or federal law.

Clinicians are not expected to interpret the law. However, many organizations' EoL care policies are drafted by lawyers and clinicians in compliance with the law. For example, in the state of Washington, the Virginia Mason Hospital EoL policy 'Shared Decisions for Life-Sustaining Treatment' incorporates the Washington State Natural Death Act and other relevant

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statutes about informed consent and guardianship (Center, 2019). This policy specifically outlines criteria to follow when conflict is present in the EoL treatment plan of care, including limited resuscitation. The policy also requires that an ethics consultant be a part of the process and in agreement that it is ethically permissible to limit EoL interventions (Center, 2019). Policies that allow disclosed limited resuscitation in various forms should be considered at the institutional level as long as the resuscitation efforts are known to the patient and family. See Table 1. Ideally, limited resuscitation is tailored in a way that involves patient or family decision-making. Formal implementation of disclosed limited resuscitation in hospitals must include a committee that reflects stakeholders affected by the practice including nurses, physicians, ethicists, chaplains, social workers, and most importantly patient representatives.

Policies on disclosed limited resuscitation should first define different variations of limited resuscitation to help clinicians with correct terminology and avoid nebulous or vague terms that contribute to confusion and misinterpretation. Policies must also include educational opportunities for clinicians to improve communication techniques using empirically-based EoL life conflict management techniques. For example, in a quasi-experimental study of surrogate decision-makers, Chen et al. (2021) reported a higher level of satisfaction after nurses initiated the COMFORT communication model to discuss EoL interventions. COMFORT is a validated communication model consisting of seven principles (Connect; Options; Making meaning; Family caregivers; Openings; Relating; Team) (Chen et al., 2021). Another study conducted as a part of a larger randomized control trial by A. J. Tan et al. (2021) found a high patient engagement rate when nurses were trained in refined communication skills in a palliative care program. Both studies were determined to be feasible options designed to improve communication skills and minimize conflict. It is critical that safeguards are in place to address

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concerns of coercion, deception, or that other systemic injustices are not disproportionately affecting one population over another. A frequent review of cases where limited resuscitation has taken place must occur to review how factors such as race, age, ability, sexual orientation, and socioeconomic status affect the prevalence and outcomes of limited resuscitation. Healthcare teams must also debrief after limited resuscitation has occurred to evaluate goals and outcomes. Implementation of disclosed limited resuscitation must also include continued review and evaluation of outcomes and goals supported by empirical research with patients, families, and clinicians. Limited resuscitation policies must require an intentional effort at reframing the positive actions afforded to dying patients and their families. Any hospital or organizational policy must comply with its respective state and federal laws.

Table 1.

Recommendations to Include in a Policy on Limited Resuscitation

<ul style="list-style-type: none">• Stakeholder's committee• Define types of limited resuscitation• Education for clinicians on limited resuscitation communication skills• Identify safeguards against coercion, deception, and systemic injustices	<ul style="list-style-type: none">• Mandatory notification of family or alternate decision-maker• Debrief when limited resuscitation occurs• Periodic review and evaluation• Comply with state and federal laws
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5 Conclusion

Clinicians are not legal experts and often have minimal education in legal aspects of health care. This can be very challenging when health care and law intersect, especially during the conflict at the EoL. Many clinicians fear legal sanctions or lawsuits if they do not comply with family requests to deliver interventions that are deemed medically inappropriate. Although nurses are rarely sued and physicians are sued at a much lower rate than perceived, legal uncertainty about whether to resuscitate a patient contributes to moral distress and negatively affects the moral reasoning process for clinicians. Most court cases regarding EoL care revolve

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around the conflict in life-sustaining medical interventions and designating the appropriate ADM. Court case outcomes vary and therefore it should not be expected that clinicians would have clear guidance when patients have a cardiac or respiratory arrest, and the code status is unclear. Nurses, especially, have a challenging time when they are often excluded from the EoL discussions and informed consent process, yet are present when the patient arrests or are expected to follow medical orders for life-sustaining interventions that they feel are medically inappropriate. The dichotomy of CPR versus DNAR has created a legal quagmire. Due to this confusion, disclosed limited resuscitation again serves as a reasonable and morally permissible approach to address this conflict. Limited resuscitation, if it is done transparently and with the patient and family's knowledge, can be a novel approach that could minimize lawsuits and unilateral approaches to DNAR orders. Implementation of disclosed limited resuscitation must be done purposely with formal policies and the promotion of a positive right that is afforded to patients and families.

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Chapter Five: Nurse's Moral Reasoning and Ethical Approach to Limited Resuscitation

The delivery of health care by nurses, specifically at the EoL requires a comprehensive approach to address decision-making, appropriateness of life-sustaining interventions, the impact of caregiving, addressing family grief over loss, and other ethical concerns, such as insufficient resources to provide quality care and poor communication among the health care team (Kanno et al., 2019; Lewis, 2019). Naturally, conflict and stress can arise as nurses are aggressively treating the physical, emotional, and spiritual needs of not only patients but also families (Mu et al., 2019). Nurses experience a host of emotions during conflict in the EoL care of patients, and this can have an impact on the moral agency and professional identity of the nurse. Repeated exposure to conflict when caring for patients at the EoL can be a notable threat to a nurse's moral identity and misdeeds such as nondisclosed limited resuscitation may occur. Limited resuscitation, such as slow codes, often occurs as a medium between families unable to accept the impending death of a loved one and the health care team that views full resuscitation as medically inappropriate (Piscitello et al., 2020). Limited resuscitation that is not disclosed and thus becomes deceptive to patients and families, can be a significant threat to a nurse's moral identity and jeopardize professional integrity. When a nurses' moral identity is threatened through conflict, constraint, tension, or dilemmas, moral distress may also arise (Morley, Bradbury-Jones, & Ives, 2020). The chapter will argue that nurse participation in disclosed limited resuscitation is morally permissible because it mitigates threats to a nurse's moral identity by eliminating physically intrusive acts that cause patient suffering, which can contribute to moral distress and moral disengagement.

1 Threats to Moral Identity

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Unresolved conflict resulting in moral distress profoundly affects a nurse's moral identity and can negatively define their interactions with relevant people and influence the personal narrative, or description of the nurse's experience (Doane, 2002). For example, a nurse's personal narrative often reflected a larger grand narrative that was evident in the culture of nursing. A personal narrative is an individual's story or experience described in first-person language, compared to a grand narrative which describes a broader connection between the story or experiences to make sense in a historical context (Lyotard, 1984). Doane (2002) found that nurses' personal moral identities were constructed through narratives of past events where they considered their actions ethical or unethical. Nurses described the grand narrative of how the organizational challenges of scarce resources did not affect their personal narrative of being an ethical nurse but included an assumption that the nurse was absolved for quality care due to these constraints (Doane, 2002). This is a common theme for nurses, especially when caring for patients at the EoL, when nurses hold tightly to personal narratives of moral agency, despite the feelings of powerlessness due to organizational forces.

A significant history exists between threats to nurses' moral identity and the organizational constraints nurses encounter from hospitals and institutions (Liaschenko & Peter, 2016). When nurses' experience threats to their moral identity from organizational constraints, they typically hold firm in the assertion and subjective position of a moral agent, despite the powerlessness in working in immoral conditions such as a work environment that lacks adequate resources for the delivery of high quality care (Doane, 2002). This study revealed that more than the "rightness or wrongness of an action"... "it was often the fittingness or unfittingness of an action" that seemed to determine whether nurses perceived themselves as moral agents (Doane, 2002, p. 629). Therefore, nurses were not "wrong" for providing poor quality care, rather their

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actions were fitting because institutions did not provide sufficient resources for quality care— and therefore nurses maintained themselves as moral agents. This fittingness between nurses' moral identity and action is described as the narrative that nurses construct in an attempt to provide reason and justification for their actions (Doane, 2002).

However, not all nurses in the study by Doane (2002) could uphold their own narrative of moral identity when threats arose. The narratives they created were inconsistent with their examples in practice and demonstrated that they did not feel like they were practicing ethically (Doane, 2002). One nurse described her moral distress from an inability to 'do good' or 'do enough' due to systemic forces on the health care system which made it difficult for nurses to act ethically. She encountered a 102-year-old patient experiencing a cardiac arrest who required CPR because he was a full code. She described her inner conflict of not knowing the patient's preferences for CPR and her personal objections to performing CPR on a patient who was of advanced age. The inner dialogue that this nurse had within herself demonstrates the tensions felt when an outside authority controls a situation, such as a full code designation. This nurse knew that she was required to provide CPR because the patient did not have a DNAR order but questioned the clinical and ethical appropriateness of such an invasive intervention for a gentleman of advanced age. Subsequently, she questioned her own identity and ability to "do good" or practice in an ethical manner. She initially thought the ethical thing to do was to run the code because she did not know the patient's values and respected the organizational obligation to perform CPR. However, she quickly began to question her "ethically right" decision by replacing the patient's values with her own values and preferences to determine what she thought was the best decision for the patient. The moment a nurse must decide to initiate or not initiate CPR is a pinnacle moment when personal and professional considerations affect the nurse's moral identity

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and are often made in seconds. Nurses are often left feeling conflicted and dissatisfied with their actions leading to moral distress, burnout, and moral disengagement.

2 Moral Distress

Moral distress is pervasive in nursing. Moral distress was first identified as a philosophical term and was initially defined as “when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action” (Jameton, 1984, p. 6). Since that time, literature and research have grown exponentially resulting in numerous definitions. In 2002, Dr. Mary Corley clarified that moral distress threatened nurses’ moral agency because of external constraints that are particular to the work environment. Daily external constraints include power imbalances, unequal hierarchies within the institution, lack of resources, complex patient and family expectations, excessive technology and documentation requirements, and conflict among the health care team (Deschenes & Kunyk, 2019). Admittedly, moral distress remains an ambiguous concept as researchers have identified competing or closely aligned concepts such as moral injury, moral residue, and burnout (Dall’Ora, Ball, Reinius, & Griffiths, 2020; Epstein & Delgado, 2010; Hossain & Clatty, 2020). Some scholars have proposed that moral distress is multidimensional including moral constraint, moral tension, moral conflict, and moral uncertainty (C. Fourie, 2015, 2017; Morley et al., 2020).

2.1 Defining Moral Distress

Moral distress is not the same as the conflict that occurs in a traditional ethical dilemma. In an ethical dilemma, there are more than one mutually exclusive and ethically justifiable options, and both have potential benefits and risks (Epstein & Delgado, 2010). For example, an elderly patient with dementia is no longer able to swallow effectively and continues to develop aspiration pneumonia as a result. Several attempts have been made to insert a feeding tube, but

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the patient pulls them out despite the family's insistence on its placement (Epstein & Delgado, 2010). Continuing to replace the feeding tube is physically invasive, costly, and appears to be distressing to the patient. However, it is providing nutrition to support and potentially prolong life. Removing the feeding tube will likely cause the patient to experience continued aspiration pneumonia and would likely accelerate his transition to EoL care (Epstein & Delgado, 2010). Neither option is ideal, and the best ethically justifiable action is unknown and must be weighed and determined.

Moral distress differs from ethical dilemmas because the nurse assumes that she knows the ethically justifiable action, but the nurse is unable to take the ethically justifiable action and thus feels powerless to implement the ethically appropriate action (Epstein & Delgado, 2010; Evans, Jonas, & Lantos, 2020). Contrast the last example with this one. An elderly patient with dementia is often combative with staff, and two clinicians have been physically assaulted requiring emergency medical care. The patient's wife (who is also the ADM) refuses to allow the patient to receive medication to sedate him to control his behavior (Epstein & Delgado, 2010). The nurses are confident that they will be able to provide enough medication for safe care, and it will not prevent the patient from being aware of his surroundings. However, the physicians are responsible for prescribing the medication and have not yet witnessed the combative behavior due to limited exposure to the patient (Epstein & Delgado, 2010). The physicians are present for approximately 15 minutes per week and acquiesce to the patient's wife's refusal to allow any medication to address his behavior. Despite numerous pleadings by several frontline nurses and nurse managers, the physicians refused to prescribe the medication. The nurses do not want to abandon the patient but are fearful of being injured while caring for him. The nurses know the ethically appropriate action for the patient— provide the medication. Yet, they are powerless in

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this situation because they are unable to order the medication to keep themselves and the patient safe. The inability for nurses to voice their feelings and be heard due to the hierarchy of authority in health care creates a sense of loss of autonomy or powerlessness when dealing with ethical dilemmas (Georges & Grypdonck, 2002). This is moral distress.

Nurses are often unfamiliar with the term “moral distress” and therefore are unaware that they are experiencing it (Deschenes & Kunyk, 2019). Moral distress can cause a range of negative emotions including anxiety, depression, anger, guilt, misery, dread, and loss of self-worth (Morley et al., 2020). Many nurses are unaware that it can also cause physical symptoms including loss of appetite, nausea, diarrhea, headaches, and heart palpitations (Deschenes & Kunyk, 2019). Nurses who are repeatedly exposed to triggers of moral distress, such as insufficient staffing, limited autonomy in the patient plan of care, and delivering medically inappropriate care, can result in subsequent anxiety, stress, burnout, and patient avoidant behaviors (Lewis, 2019). Moral distress extends beyond the nurse and can negatively affect patient care and the health system as a whole (Deschenes & Kunyk, 2019).

A nurses’ feelings of powerlessness in conflicting ethical dilemmas or feelings that their concerns are being ignored can be a key source of moral distress and eventually increase the risk of emotional disconnection and burnout (Aghabarary & Nayeri, 2017; Gallagher et al., 2015; Hinderer, 2012). Moral distress is also a contributing factor to nurses exiting the profession and can detrimentally affect recruitment and retention within nursing (Epstein & Delgado, 2010; Pauly, Varcoe, & Storch, 2012).

2.2 Moral Distress and the Relationship with End-of-Life Care

Overwhelming research demonstrates that moral distress is realized in nurses and physicians caring for patients perceived to be receiving potentially inappropriate treatment at the

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EoL (Gallagher et al., 2015; Olmstead & Dahnke, 2016; Rostami & Jafari, 2016). Moral distress is reported more often in nurses than physicians (Olmstead & Dahnke, 2016). In many settings, nurses are most often the first ones to encounter a cardiac arrest and provide resuscitation or administer life-saving medication (McMeekin, Hickman, Douglas, & Kelley, 2017). A study by Mobley, Rady, Verheijde, Patel, and Larson (2007) found the highest level of moral distress in nursing was experienced by nurses delivering aggressive care, despite the realization that it was simply prolonging the patient's death. As patients and families struggle with the challenges in EoL decision-making, nurses experience moral distress related to the delivery of what they perceive as inappropriate and aggressive care around the world (D. White & Meeker, 2019). Borhani, Mohammadi, and Roshanzadeh (2015) conducted a large cross-sectional study of nurses in Iran and found a meaningful and positive relationship between moral distress and potentially inappropriate care.

A study conducted in Denmark showed that there was a consensus among both nurses and physicians that nurses were most likely to realize at what point treatment was inappropriate given a patient's poor prognosis (Jensen, Ammentorp, Johannessen, & Ording, 2013). Therefore, nurses are especially vulnerable to the erosion of moral identity and professional integrity due to the close proximity of care provided to patients at the EoL (Ferrell, 2006; Olmstead & Dahnke, 2016). A nurse's repeated exposure to feeling compelled to provide treatment that is perceived as inhumane, unbeneficial, and even potentially harmful, conflicts with ethical obligations to do no harm or cause unnecessary suffering (American Nurses Association, 2015; Mohammed & Peter, 2009; Olmstead & Dahnke, 2016). Institutional and professional roles, such as carrying out physician's orders for aggressive treatment, may be contrary to one's belief and therefore detrimental to a nurse's moral identity. Nurses struggle to balance competing obligations, and

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this contributes to high levels of moral distress that nurses experience when caring for individuals receiving potentially inappropriate treatment at the EoL (Ferrell, 2006; Gallagher et al., 2015; Mohammed & Peter, 2009).

Nursing literature portrays a family's resistance to medical paternalism as a significant causative factor in patient and family demands for potentially inappropriate treatment while viewing nursing advocacy as a method to resolve this conflict (Ferrell, 2006; Mohammed & Peter, 2009; Olmstead & Dahnke, 2016; Pfeifer & Kennedy, 2006). This is problematic because nurses are viewed as "third parties" between patients and physicians, which fosters the already existing boundaries between patient requests and physician's discomfort in EoL decision making (Flannery et al., 2016; Mohammed & Peter, 2009). A nurse who perceives a lack of respect or that their concerns are ignored can be a key source of moral distress and eventually increase the risk of burnout (Gallagher et al., 2015; Halcomb, Daly, Jackson, & Davidson, 2019; Laurent et al., 2017).

McMillen (2008) and Hinderer (2012)'s two smaller studies also revealed that ICU nurses felt unheard or lacked a voice, which contributed to substantial emotional and moral distress. However, in McMillen's (2008) qualitative study of ICU nurses in England, some nurses reported that they felt as if they were patient advocates, despite the delivery of potentially inappropriate care. The profound obligatory feeling to perform inappropriate care, balanced with the conflicting role as a patient advocate, could lead some nurses to become morally disengaged and perform deceptive nursing practices, such as nondisclosed slow codes (J. Kelly, 2008; F. Robinson, Cupples, & Corrigan, 2007, p. 307).

Physicians and nurses can naturally become divided during these emotionally charged circumstances, contributing to underlying moral distress. A 2017 study of ICU nurses in

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Singapore revealed circumstances when hierarchy between physicians and nurses, and the lack of communication in decision-making resulted in deceptive resuscitation practices (Ong et al., 2017). Nurses expressed a perception of tension between themselves and physicians due to physicians often having an authoritative voice over the nurse, which negatively impacted the nurse's ability to influence care planning (Ong et al., 2017). One of the nurse participants described how the conflict with physicians who acquiesced to family demands resulted in deceptive resuscitation because the nurses felt powerless to make decisions and rationalized their actions as reasonable and ethical due to uncontrollable outside authoritative factors (Ong et al., 2017).

Death and the dying experience encompass a myriad of factors for the person who is dying, loved ones, caregivers, and the health care professionals involved in the dying process. Families and loved ones going through the dying process may have never experienced this before. Yet, the clinicians delivering care at the end of life, witness and participate in these moments repeatedly. Witnessing death and dying can be detrimental for nurses, especially those in practice areas with repeated exposure to death, such as hospice, palliative care, intensive care, and emergency medicine (Mohammed & Peter, 2009). In these highly complex and emotion-laden settings, nurses are typically the clinicians who interface with the patient and family more frequently and commonly develop feelings of responsibility, helplessness, lack of autonomy or voice, fear, and apprehension during EoL decision-making (Lewis, 2019). In addition to these challenges, dying patients have distressing symptoms such as pain, shortness of breath, and delirium (Kanno et al., 2019). As a result, the repeated and often relentless demands on nurses caring for people at the EoL, along with demands to deliver inappropriate treatment can lead to feelings of distress, anger, resentment, frustration, and nurses may become morally disengaged

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from their own personal and professional morals and values (Pavlish, Brown-Saltzman, Hersh, Shirk, & Rounkle, 2011). A morally disengaged nurse is able to perform nondisclosed limited resuscitation without guilt or reservation. This disengagement stems from moral distress and burnout, and therefore the nurse can justify her actions as one of beneficence, despite the action being considered morally objectionable.

In this way, nurses may decide to participate in nondisclosed limited resuscitation, such as a nondisclosed slow code. However, this is objectionable because these acts are intentionally ineffective, not intended for patient survival, and not disclosed to the patient or family member. These acts are more symbolic of an appearance that “everything possible” was done to save their loved one (Frader et al., 2010).

3 Defining Moral Disengagement (Eight Mechanisms)

Moral disengagement is a central construct of Bandura’s (1991) social cognitive theory of moral thought and action. In 1986, psychologist Albert Bandura developed the Social Cognitive Theory (SCT) which suggests that every person’s learning is affected by behavioral, cognitive, and environmental factors (Bandura, 1991). SCT describes observational learning as not just an imitative process, but one involving human agency, self-regulation, and self-efficacy (Bandura, 1991). Bandura’s SCT occurs when an individual can exercise control over personal thoughts and behaviors of moral action through a self-regulatory process (Bandura, 1991). Bandura related the SCT with moral agency to develop the theory of moral disengagement. Moral disengagement is the disengagement of moral self-sanctions from inhumane or socially unacceptable conduct (Bandura, 1999). Bandura (1999) further posits that the disengagement of moral agency can actually be controlled through self-regulation, self-organization, pro-action, and self-reflection. These factors are important in the development of moral conduct, which in

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the early phases of life are dictated by external circumstances and social approval (Bandura, 1991). Within this moral agency, lies the potential for individuals who may normally behave in socially acceptable and appropriate ways, to engage in behavior that is deemed unethical and inhumane, but is devoid of guilt or shame (Risser & Eckert, 2016). Some people are more predisposed to moral disengagement, yet no person or group can be immune to its effects (C. E. Johnson, 2014).

People are generally good-natured and strive to minimize the gap between their morality and actions (Shu, Gino, & Bazerman, 2011). When moral disengagement is self-activated, a psychological discomfort drives the behavior. The initial trajectory of moral disengagement begins with moral distress. As previously stated, moral distress is pervasive in EoL care. Once moral distress is experienced, then the discomfort associated with cognitive dissonance leads to moral disengagement (Epstein & Delgado, 2010). See Figure 3, which depicts the trajectory of moral distress to moral disengagement.

Figure 3

Depiction of the trajectory of moral distress to moral disengagement.



Note. Adapted from Hyatt, J. (2017). Recognizing moral disengagement and its impact on patient safety. *Journal of Nursing Regulation*, 7(4), 15-21. [https://doi.org/10.1016/S2155-8256\(17\)30015-7](https://doi.org/10.1016/S2155-8256(17)30015-7). Copyright 2017 by Elsevier.

Cognitive dissonance occurs when a person's beliefs are at odds with behavior (e.g. a nurse's moral identity is threatened when she is unable to deliver quality care) (Shu et al., 2011). Dissonance is thought to be associated with behavior that is internal and personal to autonomy

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(Shu et al., 2011). Yet, cognitive dissonance is when an individual internalizes behavior and psychological discomfort results. This discomfort motivates internal efforts to reduce or eliminate the discomfort (J. M. A. de Vries & Timmins, 2016). Simply put, cognitive dissonance emerges to maintain consistency between thoughts, values, and behavior (J. M. A. de Vries & Timmins, 2016). Hyatt (2017) proposes that cognitive dissonance is a precursor and potential predictor of moral disengaging behavior. Therefore, a substantial degree of moral disengagement is possible given the magnitude of moral distress, cognitive symptoms, and behaviors of nurses dealing with the challenges of the overall health system. Several mechanisms in moral disengagement develop as a way to silence or trivialize the inconsistencies, thus leading to conduct deemed morally objectionable or unacceptable.

Under normal circumstances, most people care about being moral agents and behaving ethically, and abstain from intentionally behaving dishonestly (Shu et al., 2011). Yet, under certain varied circumstances, people are able to turn off or self-regulate their moral compass and participate in actions that are deemed socially unacceptable (such as nondisclosed slow codes). For example, moral disengagement has been commonly studied as a predictor of white-collar offending (Barsky, 2011), corporate harm (J. White, Bandura, & Bero, 2009), sport-doping (Boardley, Grix, & Harkin, 2015), and cyberbullying (Robson & Witenberg, 2013). Yet, the association of moral disengagement within the context of ethical decision-making for health care clinicians is in its early stages (Lee, Segal, Kimberlin, Smith, & Weiler, 2014). Lee et al. (2014) were the first to analyze moral disengagement in health care professionals and examined pharmacists' decisions not to counsel certain patients due to conscientious objections without resulting in guilt or shame. Two years later, Fida et al. (2016) examined self-regulation and moral disengagement in nurses concluding that nurses "sometimes resort to moral

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disengagement in their daily practice, bypassing moral and ethical codes that would normally prevent them from enacting behaviours that violate their norms and protocols” (p. 548). The following sections will outline how moral disengagement can develop in nurses when dealing with conflict caring for patients at the EoL and provide ethical justification for limited resuscitation as a mitigation strategy to address moral distress for nurses and other clinicians.

Bandura's theory of moral disengagement describes eight interrelated mechanisms of moral disengagement that can be activated and deactivated: (1) moral justification; (2) euphemistic labeling, (3) advantageous comparison, (4) displacement of responsibility, (5) diffusion of responsibility, (6) disregarding or distorting the consequences, (7) dehumanization, and (8) attribution of blame (Bandura, 1999). The first three mechanisms describe the cognitive processes of interpretation of socially unacceptable or reprehensible behavior that supports a view that is morally acceptable (Detert, Treviño, & Sweitzer, 2008). The next three mechanisms occur when a person attempts to conceal the effects of the harmful actions (Detert et al., 2008). Lastly, dehumanization and attribution of blame, reduce the identification of the recipient of the harmful act, thereby disengaging the moral sanction (Detert et al., 2008).

Each mechanism of moral disengagement will be defined to provide support to understand the moral reasoning and transition from moral distress to moral disengagement that occurs when nurses consider participation in limited resuscitation. Although closely related, each mechanism can individually contribute to or cause moral disengagement. However, moral disengagement is not ethically permissible in every situation. For clarity, the morally objectionable action resulting from moral disengagement is the act of nondisclosed limited resuscitation, including nondisclosed slow codes. Nondisclosed slow codes are considered morally objectionable because they are deceptive and purport an appearance to a family that

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“everything possible” was done to save a patient’s life (Piscitello et al., 2020; Stokes & Zoucha, 2021).

3.1 Moral Justification

Moral justification describes a person’s ability to cognitively reconstruct behavior in order to justify to themselves the morality of their harmful actions (Bandura, 1999). An individual is able to perceive socially unacceptable behavior into one that is serving a socially worthy or moral purpose, thereby making it morally permissible (Bandura, 1999). For example, support for companies that hire young children overseas to make products may be justified, because, without such work, the children are exposed to dangerous lifestyles or trafficking to support their families (Detert et al., 2008). In nursing, nurses view themselves as ethical when participating in a nondisclosed slow code because they are powerless in the ability to control a patient’s code status. Moral justification explains the preservation of a person’s view of themselves as a moral agent while inflicting or witnessing harm occurs to another person (Bandura, 1999).

In EoL care, moral justification can be activated for nurses and other health care professionals during the actual process of saving a life and other formal CPR methods. Clinically, CPR requires management of the dying person’s airway, which may involve placing a tube down the throat to assist with ventilation. CPR can also require electric shock and vigorous compressions on a patient’s chest, which can result in rib fractures or perforation of the lung cavity. A patient’s skin color may change, and signs of pain or suffering such as gasping, vomiting, and other bodily excretions, are present which is perceived as stressful for nurses (McMeekin, Hickman, Douglas, & Kelley, 2017). Yet, when a person’s heart or lungs have ceased functioning and active resuscitation is required (in the absence of a DNAR order), it

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immediately becomes a moral imperative to perform these physically rigorous and painful tasks in order to save someone's life. Outside of the context of terminal illness, these vigorous and invasive actions are violent, yet socially acceptable and unquestioned during lifesaving attempts. When nurses feel compelled to perform CPR and other aggressive treatments on people with a poor prognosis, they are sometimes unable to deactivate the moral justification to support the permissibility of these actions, leading to moral distress. The resulting moral distress that nurses feel, occurs when these unquestioned lifesaving attempts are performed when clinicians perceive them as medically inappropriate (Robinson, 2002).

The repeated exposure of performing CPR and other aggressive saving techniques in what is perceived as medically inappropriate circumstances, such as terminal illness or a poor prognosis, can potentially transform a nurse's moral distress into moral disengagement (Hyatt, 2017; Zhao & Xia, 2019). Moral disengagement, specifically moral justification, is activated due to the procedural requirement to resuscitate a person's life, especially if a DNAR order or another advance directive is not available or honored. Cognitive dissonance develops and becomes a coping mechanism to deal with witnessing the pain, suffering, and accompanying feelings of guilt associated with the delivery of these medical interventions. Nurses attempt to minimize these feelings of guilt and discomfort— i.e., preserving their moral identity— by limiting full resuscitation efforts even if families are not informed of the practice.

For example, one study found that nurses described slow codes that were not disclosed to patients or families as a compassionate way to meet the needs of a family insisting on aggressive care of their loved ones and to protect patients from the physical rigor of CPR (Stokes & Zoucha, 2021). Nurses in this study stated that they felt justified in their actions during a deceptive slow code, despite the lack of transparency with families of what was really happening, as well as

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understanding that the limited resuscitation effort was not intended for patient survival (Stokes & Zoucha, 2021). Another study of clinicians in the U.S found that more than half believed that slow codes were ethically permissible if a family member requested CPR and the clinician believed the intervention was medically inappropriate (Piscitello et al., 2020). Participants in this study believed that slow codes should be disclosed to family members or ADMs (Piscitello et al., 2020).

Moral justification is one part of the moral reasoning process of nurses who participate in nondisclosed or deceptive slow codes without any remorse or guilt, despite the majority view that they are morally unacceptable (Einav et al., 2006; Mentzelopoulos et al., 2018). Despite the moral distress that nurses experience in these situations, not all nurses experience moral disengagement. In fact, Stokes and Zoucha (2021) found that those nurses who felt that slow codes were unethical described professional obligations to be truthful and forthcoming with patients, and declared that if participation in nondisclosed and deceptive slow codes occurred it would be because of a physician order to do so. Moral justification protects a nurse's moral identity, transforms moral distress, and supports the moral agency of the nurse that she is doing the most ethically appropriate and beneficent action in the situation.

3.2 Euphemistic Labeling

The second mechanism in moral disengagement is euphemistic labeling. Sanitizing words used to describe unpleasant activities or socially unacceptable actions is often done without conscious thought (Bandura, 1999). Health care is filled with euphemisms, such as “above average weight” instead of obese, or “emotional wellbeing” instead of mental health. The euphemistic language described within moral disengagement can camouflage an inhumane or egregious activity or even confer a respectable status by using morally neutral language to make

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the conduct seem less harmful (Detert et al., 2008). Euphemisms are often used to avoid moral implications. However, nurses may use euphemistic language not as a justification for their actions, but as a means of mitigating conflict and providing a positive framing for less aggressive EoL options. There are several examples within EoL care that reflect either how words can transform an act to one of respect and dignity or can mask the reprehensible nature of an act and allow a health care clinician to disengage with personal and professional morals, simply by softening the words used to describe it. A report by The Hastings Center in 2004 highlighted challenges in end-of-life care, noting that they are often related to language and semantics (Cohen, 2004). This report suggested that the use of euphemistic language can reduce the emotional conflict at the EoL and ensure appropriate care is delivered (Cohen, 2004).

3.2.1 From hospice and palliative care to comfort care

There is great debate within the bioethics community over the use of terms hospice, palliative, and comfort care at the EoL (Vickroy, 2018). This debate fuels underlying confusion among patients and families and contributes to misunderstandings about ethically appropriate care at the EoL. Hospice focuses on individualized compassionate care that maximizes a person's quality of life by addressing not only physical, but also the psychological, psychosocial, and spiritual needs of terminally ill people (Crusse & Messler, 2014). Hospice is a subset of palliative care that is available to patients with a terminal illness, defined as a prognosis of six months or less (Vig, Starks, Taylor, Hopley, & Fryer-Edwards, 2010). Hospice is available to older and low income adults through the U.S. Medicare program, but bureaucratic barriers to reimbursement results in hesitancy and confusion in enrollment (Dillon & Basu, 2016). Palliative care is distinguished from hospice care because it can be provided concomitantly with curative treatment and focuses on quality of life. In addition to curative treatment, the goals of palliative

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care include decreasing the negative physical and psychological symptoms associated with dying, increasing quality of life, and optimizing therapies to achieve these goals (Maciasz et al., 2013). Despite these benefits, hospice and palliative care are sorely underutilized resources in the U.S. (Vig et al., 2010). A patient's ability to utilize hospice and palliative care simultaneously is a common misunderstanding by patients and clinicians and therefore can act as a barrier to early patient referrals (Maciasz et al., 2013). Maciasz et al. (2013) found that over half of patients did not know what palliative meant, which was consistent with findings from a study showing the public's lack of familiarity with the term. Maciasz et al. (2013) explain that patients often mistake palliative care to be hospice care when it is given so late in their disease course.

Clinicians also confuse hospice and palliative care. A small sample study of oncology nurses who specialized in palliative care, revealed that nurses were unable to distinguish between hospice and palliative care (Mahon & McAuley, 2010). These nurses incorrectly believed that palliative care was only appropriate for patients nearing the EoL once curative treatments were stopped (Mahon & McAuley, 2010).

Patients and families may be reluctant to consider hospice for their loved ones due to denial of impending death and misunderstandings of when to use hospice and what hospice entails (Vig et al., 2010). Nursing has a pivotal role in these conversations. Vig et al. (2010) and Maciasz et al. (2013) suggest avoiding the word "hospice" and reframing EoL care to words such as support or supportive care. They further suggest framing these services as an opportunity to talk about fears or allow for quality time with loved ones. In this example, euphemistic labeling is used to promote non-aggressive treatment at the EoL. In addition, the promotion of using the words "comfort care" rather than hospice removes the negative and sometimes frightening stigma associated with death and restores respect and dignity to the practice. Nurses and other

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clinicians may avoid using the words “hospice” or “palliative care” to avoid rejection of these interventions.

The perceptions associated with euphemistic language at the EoL might suggest enabling the culture of denial of death and dying. Nurses should allow emotional space for the family to grieve, but also help them realize the clinical signs and symptoms of the dying process (Vig et al., 2010). It should be noted that although considerations for religion and culture may also contribute to the challenges in EoL communication, research suggests that nurses find that approaching EoL is difficult in any culture (A. Green, Jerzmanowska, Green, & Lobb, 2018). Euphemistic language can also be considered avoidant behavior, or behavior that fosters a lack of full disclosure (Tuckett, 1998). This can be dangerous in EoL conflict if patients and families discover that euphemistic terms have been used to disguise an intervention that they are not supportive of doing. For example, if a patient has agreed to proceed with “comfort care”, it might be alarming when the Hospice Service Consultant presents EoL options, and the patient is unaware that “comfort care” equates to hospice services. This can lead to feelings of distrust and result in a breakdown of communication between families and the health care team. Clinical experience and research support that families remember the compassion, honesty, and empathy demonstrated when delivering bad news or having difficult conversations about goals of EoL care (Evans et al., 2020). Nurses and other clinicians should use a personalized approach when communicating with patients and families that encompasses an appropriate health literacy level and cultural considerations.

3.2.2 Do-Not-Attempt-Resuscitation to allow natural death.

Another example of euphemistic language that contributes to EoL care conflict is the true meaning of do-not-attempt-resuscitation (DNAR) orders. Families’ or ADMs’ demands to “do

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everything” are a common occurrence in clinical practice. However, “do everything” is often broad, vague, and misinterpreted. In the absence of “do everything”, “do nothing” is often associated with DNAR orders. The challenge within the culture of denial of death and dying is the misunderstanding and negative reactions associated with DNAR orders. A DNAR order is a term of narrow scope that conveys to health care professionals that CPR will *not* be performed (Schlairet & Cohen, 2013). Many patients and families incorrectly believe that once a DNAR order is in place, no treatment will be delivered, and therefore, symptoms associated with dying will be ignored. Some bioethicists have proposed that the use of the euphemistic words “Allow Natural Death” (AND) as a replacement for “Do-Not-Attempt-Resuscitation” (DNAR) is more acceptable to patients and families in EoL decision-making (Miljković, Emuron, Rhodes, Abraham, & Miller, 2015). AND allows a natural process for EoL care for patients and families rather than highlighting what measures will *not* be taken (Wittmann-Price & Celia, 2010). AND orders must still be signed by physicians, documented in the health care record, and medical interventions still have to be specified (Schlairet & Cohen, 2013; Wittmann-Price & Celia, 2010). AND orders clearly articulate to families what interventions will be implemented and what will be withheld, and thus creates a plan of care, rather than an order, at the EoL (Schlairet & Cohen, 2013).

AND was originally created with the intent to increase the number of terminally ill patients who die with dignity, without aggressive medical interventions (Miljković et al., 2015). Research supports the preference for patients and ADMs to choose AND rather than DNAR (Venneman, Narnor-Harris, Perish, & Hamilton, 2008). The word “allow” gives power and autonomy to the patient or alternate decision-maker. Yet, “do-not” is negative and suggests a failure to do something (Venneman et al., 2008). In addition, negative phrases are less clear for

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patients and families. The use of “resuscitation” in DNAR, rather than stating the axiom of “death” in AND, minimizes the misunderstanding around these EoL options (Wittmann-Price & Celia, 2010). Traditional DNAR orders are not considered a care plan. They simply outline what clinicians ought “not” do and can lead to conflict, suffering, and inappropriate care (Schlairet & Cohen, 2013; Venneman et al., 2008). More than 100 hospitals, hospices, and long-term care facilities are using AND rather than DNAR (Wittmann-Price & Celia, 2010). The euphemistic language associated with allowing a natural process can alleviate the guilt and stress that patients or ADMs may experience with DNAR orders and overall EoL decision-making (Schlairet & Cohen, 2013). Again, it is critical that patients and families have a clear understanding of the types of interventions and intended outcomes.

Euphemistic labeling in EoL conflict must be used in consideration of preexisting health literacy challenges that many patients and families possess. Any attempts to conceal interventions are morally unacceptable and should be avoided. The EoL examples noted above are not deemed to be morally objectionable so long as they do not conceal the clinical interventions or intended outcomes for care. An alternative method to addressing these delicate EoL options is through nudging, which provides full disclosure of information but through a tailored approach, discussed in Chapter 2.

3.3 Advantageous Comparison

Advantageous or exonerating comparison is another mechanism of moral disengagement that uses the comparison of morality or harm to exonerate the individual perpetuating harm or allowing harm to occur without action or intervention (Bandura, 1999, 2011). Bandura (2011) characterizes a person’s behavior by what it is compared against to transform the perception of wrongdoing to one of moral acceptance. Exonerating comparison relies on moral justification so

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that the socially unaccepted or reprehensible act can be made righteous (Bandura, 2011). For example, torture used by governments to elicit information from suspected terrorists is considered inhumane by many people. However, moral disengagement can be activated to transform acceptance of violent torture as morally acceptable behavior in certain circumstances, when compared to the potential harm or possibility of more human suffering that a terrorist could impose (Bandura, 2011). A strong utilitarian component exists within advantageous comparison. Generally, nonviolent actions are judged to be ineffective to achieve desired goals and are thus removed from consideration (Bandura, 1999). In addition, a utilitarian analysis of advantageous comparisons affirms harmful actions are perceived as merciful if they prevent additional human suffering (Bandura, 1999).

Approaching families with a recommendation for a DNAR order or “comfort care” in patients with a poor prognosis or who are terminally ill are not always well received. Miscommunication about ethically appropriate options such as choosing between CPR, DNAR orders, and other life-sustaining treatments can be awkward and confusing especially when clinicians know that some of the proposed interventions are potentially inappropriate and will serve no useful purpose (Ditillo, 2002). When a terminally ill patient has an order for full resuscitation, the desired goal of a peaceful death is not achieved. In advantageous comparison, nurses typically desire a utilitarian type of goal for a patient’s peaceful death, which is balanced with the ineffectiveness of aggressive treatment in the absence of a DNAR order. This ultimately can lead to moral distress and moral disengagement for clinicians who are forced to participate in the administration of what they deem inappropriate treatment. In moral disengagement, a failure to perform full resuscitation in the absence of a DNAR order, or the failure to inform a family or ADM that limited resuscitation has occurred, is thus viewed as a beneficent act in furtherance of

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a good death and prevents additional human suffering, although it defies professional ethical codes supporting patient autonomy, and veracity (American Medical Association, 2015; American Nurses Association, 2015).

Advantageous comparison closely aligns with moral justification. In advantageous comparison, nurses attempt to protect their moral identity by comparing harms: “I am going to do this harmful and deceptive slow code to you now which should result in a more peaceful death, to avoid you experiencing physically invasive full CPR– and my actions are merciful (I am ethical).” A nurse or other clinician involved in a nondisclosed limited resuscitation, or nondisclosed slow code effort also deems resuscitation as a beneficent act for families who physicians believe would not accept the patient’s death unless resuscitation was attempted, despite the futility of CPR efforts (J. Kelly, 2008). The advantageous comparison of limited resuscitation which is intentionally designed to be ineffective and most likely will result in death, versus the physically invasive and harmful components of CPR, minimizes and sometimes even eliminates any guilt or shame the participating clinician may experience (Stokes & Zoucha, 2021). Under this view, limited resuscitation is not viewed as deceptive or unethical, rather as non-maleficent acts toward terminally ill patients and therefore comport with the nurse’s moral identity, thus reducing moral distress.

This is consistent with research that demonstrates a majority of nurses and other clinicians believed that nondisclosed slow codes were ethical especially given a patient’s age, poor prognosis, and pain at the EoL (Ganz et al., 2018; Piscitello et al., 2020; Stokes & Zoucha, 2021). In moral disengagement, the cognitive restructuring of the harmful action is the nurse’s psychological protective mechanism to support actions to save the patient from additional pain and suffering typical in resuscitation. This suggests that nurses who participate in limited

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resuscitation do not require freedom from self-sanction associated with moral disengagement, because the act is not viewed as reprehensible or morally objectionable, and therefore no guilt or shame is associated with the practice. The ability for nurses to participate in nondisclosed deceptive slow codes and other forms of limited resuscitation with high moral purpose, such as beneficence and nonmaleficence, not only eliminates self-censure but fosters self-approval and social acceptance (Bandura, 1999).

3.4 Displacement of Responsibility

Another mechanism of moral disengagement is the displacement of responsibility, which is particularly relevant to the hierarchical decision-making authority that exists in health care. Displacement of responsibility allows an individual to disown harmful actions if a legitimate authority accepts responsibility for the conduct (Bandura, 1999). Displaced responsibility allows an escape from personal accountability because persons who displace responsibility do not perceive themselves as the actual agent of their actions (Bandura, 1999). Self-exemption is often understood in mass atrocities such as genocide, where prison commanders divest themselves of responsibility by claiming governmental order dictated their actions (Bandura, 1999). There is a critical component of duty or obligation to one's authority in the displacement of responsibility. Not only does a person feel a lack of responsibility for the harmful conduct that occurs, but there is a strong duty to authority that prevails in the socially unacceptable action (Bandura, 1999).

The dichotomy of role delineation between nurses and physicians in decision-making and treatment at the EoL is well apparent. Traditionally nursing has provided more of a caring role than a curative role, sympathizing with patients, families, and other health care professionals (Gallagher et al., 2015). Nurses spend more time with patients and families and the confidential relationship that results, allows nurses to be more attuned to patients' decisions (Gallagher et al.,

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2015). A study of nineteen ICU nurses evaluated the perceptions of nurses' professional and ethical obligations in caring for patients at the EoL (Calvin, Lindy, & Clingon, 2009). Nurses expressed obligations to promote family presence in EoL decision-making but acknowledged the pressures to respect physician authority and "walk the fine line" between the family's and the physician's expectations (Calvin et al., 2009). Nurse-physician decision-making at the EoL can be extremely difficult due to competing professional ethical missions and different moral obligations (Laurent et al., 2017). A study by Mani and Ibrahim (2017), revealed that nurses felt like they "know the patients best", yet are often not involved in the decision-making process (p. 719). Research has also shown that even families believe that the responsibility of the dying patient is in the hands of the nurse (Rafii, Nikbakht Nasrabadi, & Karim, 2016).

However, nurses attempt to absolve themselves of responsibility for EoL treatment, especially interventions that contribute to the patient's pain or suffering. Nurses fear their actions will subject patients to undue harm and suffering and therefore strip patients of a peaceful death and human dignity (Laurent et al., 2017). Raus et al. (2014) reported that nurses viewed themselves in a more advisory role in end-of-life decision-making and therefore decreased their decisional closeness in the EoL process. Nurses were able to hold on to this view because physicians make treatment withdrawal or withholding decisions and nurses are tasked with operationalizing the orders (Coombs et al., 2010; Long-Sutehall et al., 2011). Nurses viewed physicians as having the ultimate responsibility for the decisions and outcomes surrounding EoL care (Raus et al., 2014).

While physicians also perceive themselves as the ultimate individual responsible for the outcome, nurses may develop an alliance with patients and families because of the innate ability to relate to suffering and pain (Laurent et al., 2017). Nurses may even become the spokesperson

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for the family when communicating with the physician (Laurent et al., 2017). Because of this alliance, nurses are often viewed as mediators between patients and physicians in situations of patient and family demands for inappropriate treatment in EoL decision making (Flannery et al., 2016; Laurent et al., 2017; Mohammed & Peter, 2009). This perceived authority of the physician does not disregard nursing's pivotal role in relieving suffering and providing comfort at the EoL, but many studies demonstrate that nurses are excluded from the decision-making process, and therefore they can separate themselves from personal accountability for aggressive or inappropriate care at the EoL (Calvin et al., 2009; Laurent et al., 2017; Lind, Lorem, Nortvedt, & Hevrøy, 2012; McAndrew & Leske, 2014).

3.5 Diffusion of Responsibility

Diffusion of responsibility is similar to displacement, but it describes diminishing personal agency by diffusing responsibility of harmful actions among many people (Bandura, 1999). Diffusion of responsibility is exemplified through “group-think” or group decision-making. Bandura (1999) posits that “when everyone is responsible, no one really feels responsible” (p. 198). Collective actions of harmful conduct can weaken moral agency and self-activate moral disengagement (Bandura, 1999). The lack of personal responsibility allows people working in groups to act more inhumanely, and the harm can even be more detrimental on repeated occasions (Bandura, 1999). For example, Osofsky, Bandura, and Zimbardo (2005) describe diffusion of responsibility within the context of lethal execution. Diffusion of responsibility exonerates any single juror from accountability or any member of the larger justice or correctional system from experiencing personal responsibility for the death of a person (Osofsky et al., 2005). Osofsky et al. (2005) suggest that lethal execution is inhumane and described reactions from correctional employees responsible for strapping down the inmate.

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Under the supervision of a leader, each member straps down one particular part of the body: therefore, group responsibility minimizes and perhaps eliminates any guilt or shame associated with participation in the execution process (Osofsky et al., 2005).

Nurses are at an increased risk of diffusion of responsibility because there is a gap in nursing knowledge of ethical pitfalls. For example, nurses commonly follow orders for the delivery of patient care, even when those orders come from an unacquainted physician, involve an unfamiliar medication, or are a recommendation for an intervention outside of the standard of care (Starck & Holeman, 2014). Nursing continues to struggle for power in the health care hierarchy and decision-making among the health care team or nursing staff (Christensen, 2019; Longo, 2013). This is evidenced in the common phrase by nurses that “I am just the nurse”, suggesting that the clinician may feel less empowered and therefore have a reduced responsibility for outcomes (Christensen, 2019). Nurses are also often pressured to follow group norms. Research has shown that nurses tolerate and therefore become complicit in poor patient care standards to garner acceptance from health care team members out of fear of endangering a sense of belonging (Christensen, 2019). Diffusion of responsibility is especially risky during group settings with a rotation of health care professionals, many of whom are rotating in cycles, such as attending physicians, resident physicians, and other consulting providers (Christensen, 2019).

Diffusion of responsibility is especially prominent in resuscitation efforts that often involve a full team of clinicians working together in an emergency. CPR is a group activity with group responsibility that begins with the decision to perform the intervention. Although roles and responsibilities vary by practice setting, generally nurses, physicians, and other health care professionals actively participate in the resuscitation of patients. Each person has a designated

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role in the process, including a person who gathers supplies, delivers lab tests, performs chest compressions, documents the health record, among many other things. Although CPR— a potentially lifesaving measure— directly contrasts to Bandura’s example of execution and death, the diffusion of responsibility is similar. In certain settings, such as long-term care or intensive care units, nurses are most often the first ones to encounter a cardiac arrest and provide resuscitation or administer life-saving medication (McMeekin et al., 2017). The initial response and decision to act is individual until other clinicians join in the resuscitative efforts to establish group responsibility.

The activation of moral disengagement through group responsibility also contributes to the veil of silence regarding some forms of deceptive limited resuscitation including slow codes that are not disclosed to patients and families. Some research suggests that nondisclosed slow codes are not decided in advance of the resuscitation event (DePalma et al., 1999). They are decided at the time of the cardiac arrest by clinicians who symbolically appear to provide full resuscitation efforts but do so in a slow and inefficient manner because they feel that the efforts are medically inappropriate (Piscitello et al., 2020). Some studies suggest that physicians initiate nondisclosed slow codes, and others suggest that nurses initiate it (Cheraghi, Bahramnezhad, & Mehrdad, 2016; Ganz et al., 2018; Piscitello et al., 2020; Stokes & Zoucha, 2021). Because it is a group activity, participation in limited resuscitation that is not disclosed to families varies among the types of clinicians who initiate or authorize the practice. For example, W. Morrison and Feudtner (2011) describe a nondisclosed slow code as a halfhearted effort where the nurse takes their time when drawing up medications and the medical resident takes a one minute pause in between chest compressions. This collective approach to intentionally administer ineffective CPR minimizes personal agency among the health care team.

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Not all nurses' moral reasoning includes moral disengagement. Moral disengagement is not activated in all nurses in this situation. In some circumstances nurses may defy the group diffusion of responsibility and vocalize their opposition to the care delivered when experiencing moral distress due to feeling forced to participate in inappropriate treatment or CPR on a terminally ill patient. Objections to diffusion of responsibility as a group, however, are not the norm and most health care professionals, including nurses, acquiesce to the patient or family demands. It is also important to note that the self-regulation of moral disengagement can be activated and deactivated. This flexibility of moral ability in nurses has been widely studied (Georges & Grypdonck, 2002). The concept of sovereignty suggests that some nurses are able to demonstrate a 'sovereign' mode of reasoning and others demonstrate an 'accommodating' mode of reasoning (Georges & Grypdonck, 2002). Sovereign nurses use individual reasoning, regardless of group decisions or group responsibility. These nurses are often identified as having the moral courage to voice their opinion or objection during ethical dilemmas and moral conflict. Moral courage will be analyzed in depth in Chapter Six.

3.6 Disregarding or Distorting the Consequences

Disregarding or distorting the consequences continues to describe the mechanisms of moral disengagement that conceal or minimize harmful conduct towards social acceptance. When harmful conduct occurs, people initially attempt to minimize the harm. The moral disengagement theory suggests that if minimization is ineffective, then overlooking or distortion of harm is reasoned (Bandura, 1999, p. 199). Bandura (1999) posits that it is easier to act inhumanely when the consequences of suffering are not visible (p. 199). When hiding or concealing of harm occurs, the ability for self-censure is not activated (Bandura, 1999, p. 199). For example, distorting the consequences occurs when a nurse fails to administer a medication,

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but considers this as a small or slight error, because in that case, no harm is done to the patient (Fida et al., 2016). This mechanism of moral disengagement focuses on the outcome locus of the harm, rather than the behavior of the actor demonstrated in the first three mechanisms. In general, an omission of medication administration would not likely cause significant consequences such as death and therefore the harms, if any, associated with the failure to administer a medication may not be visible. However, in the circumstances of “show codes”, the result is always death due to an intentional failure to provide any intervention. Show codes differ from limited resuscitation in that no resuscitation efforts are done at all (J. Kelly, 2008). Clinicians create an artificial appearance that resuscitation is occurring so that families will believe that wholehearted efforts were made to save their loved one. Show codes are intentionally deceitful, fraudulent, and thus unethical. Regardless of a nurse’s moral reasoning when she is struggling to balance the EoL conflict and tension created when administering aggressive care, nurses must never participate in show codes or distort their actions in a way that suggests that some resuscitative effort was done, when nothing was done. This can result in a breach of trust in the nurse-patient-family relationship and in the nursing profession.

3.7 Dehumanization

The dehumanization mechanism of moral disengagement shifts the focus onto the characterization of the people subject to harm. Bandura (1999) suggests that the perception and understanding of joy and suffering elicits an empathetic emotional reaction, and thus a social obligation to humanity. Even if those suffering are strangers, the empathy that is aroused is due to the human qualities that person demonstrates (Bandura, 1999). Once a person is no longer viewed as having human qualities, they are perceived as people devoid of hopes, feelings, or concerns (Bandura, 1999). Moral disengagement is activated, and the ability to intentionally

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cause harm with a diminished sense of personal responsibility is possible. For example, dehumanization occurs in online cyberbullying, where negative content about someone is posted after the perpetrator creates a negative persona (Fernández-Antelo & Cuadrado-Gordillo, 2019). The ability to reduce a person's identification allows for rapid development of us-versus-them reasoning (Detert et al., 2008). Herbert Kelman describes dehumanization as an act excluding a person or group of people from our moral community of "an interconnected network of individuals who care for each other, who recognize each other's individuality and who respect each other's rights" (Kelman, 1973). Once this exclusion from the moral community occurs, it becomes possible to act inhumanely towards them without invoking any sense of self-reproach (Kelman, 1973, p. 48).

Dehumanization in EoL care is associated with repeated exposure to dying and death, which can result in negative psychological consequences, such as postcode stress, moral distress, post-traumatic stress disorder (PTSD), and burnout (McMeekin et al., 2017; Mohammed & Peter, 2009; Olmstead & Dahnke, 2016). Nurses who are unable to cope with the stress and emotional demands of their profession, such as witnessing suffering and death, are able to lower the human status of patients as a coping mechanism (Trifiletti, Di Bernardo, Falvo, & Capozza, 2014). When possible, some nurses will refuse to take care of the patient if the EoL care plan does not align with what the nurse perceives as the best interest of the patient (Stokes & Zoucha, 2021). If that reassignment is not possible, research suggests that nurses avoid feeling emotionally overwhelmed through the dehumanization of patients (Trifiletti et al., 2014; Vaes & Muratore, 2013). Vaes and Muratore (2013) found that physicians and nurses working with oncology patients protected themselves from stress and burnout by perceiving them as less than human without ration or morale. Stokes and Zoucha (2021) found that nondisclosed slow codes

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could occur when a patient is considered lifeless on admission. A nurse described how the health care team treated a patient who was “practically dead,” and team declared amongst themselves that they would perform a limited resuscitation effort even before the patient experienced a cardiac arrest. It is important to acknowledge that “practically dead” is a subjective dehumanizing description but could possibly suggest that the patient was without a heartbeat. The American Heart Association has outlined policy implications for emergency transportation of pulseless patients who are unsuccessfully resuscitated prior to or on the way to a hospital (American Heart Association, 2000). Transportation to a hospital for further evaluation or intervention is considered a futile effort and CPR should be discontinued when the patient cannot be resuscitated, yet literature suggests it happens due to families’ unwillingness to accept termination of CPR efforts and insistence on transportation to a hospital (G. P. Smith, 2000).

Dehumanization as a cause or trigger for nondisclosed or deceptive limited resuscitation can be analyzed through different approaches. A nurse described what she perceived as a limited resuscitation situation without acknowledging any human characteristics of the patient. She also described the team approach to limited resuscitation which outlines clear limitations of resuscitation efforts, despite the clinical outcomes of the initial effort. One could argue that nurses who experience moral distress and perceive EoL as aggressive, and physically harmful participate in nondisclosed slow codes to prevent harm presuming full resuscitation is more harmful than nondisclosed limited resuscitation. Under this approach, nurses are not dehumanizing the patient but are in fact humanizing the patient and protecting them from unnecessary suffering at the EoL— even at the cost of deceiving family members because full resuscitation measures are not administered. This presumes that the intended harm is the act of CPR on the patient and therefore it outweighs any harms associated with not disclosing the truth

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or leading a family to believe that full resuscitation attempts were taken to save their loved one. On the other hand, failing to view the person as nonhuman, or worthless, could be considered as a “green light” to let the individual die because limited resuscitation begins without the intent of survival. If a person is viewed as if their life is devoid of value, then nondisclosed limited resuscitation efforts are supporting the argument that moral disengagement creates a pseudo assumption of moral standing— who deserves CPR and who does not. This can become ethically dangerous if criteria or conditions are placed on those who should survive and those who shouldn't. This ethical analysis often occurs when assessing the need for life-sustaining treatment based on age. Naturally, people idealize a greater sense of hope in children and young adults for the potential to live longer than older adults. Within health care, this is evident in the decreased use of life-sustaining treatment in older populations than younger, with some scholars even suggesting the risk of ageism (Jericho, 2018). Older adults are more likely to adjust to a life-limiting illness than younger patients due to the limits of acceptance skills in younger patients (Walczak et al., 2013). Conversely, discussions about life-sustaining treatment in the pediatric and neonate populations are extremely difficult and the consistency of communication varies vastly by health care institution, race, age, health coverage, and diagnosis (Jericho, 2018).

Dehumanization appears to have some positive effect on clinicians, yet potentially negative effects on patients (Trifiletti et al., 2014; Vaes & Muratore, 2013). Denying humanity to patients through self-regulation may be temporarily functional for clinicians, but the long-term effects for patients could result in increased stress (Trifiletti et al., 2014). The self-regulatory aspects of dehumanization are similar and supported by research to have the same characteristics as depersonalization. Depersonalization involves feelings of detachment from others and having an impersonal response toward patients (Liao, Yeh, Lin, & Wang, 2020). These behaviors are

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associated with psychological strain and occur when clinicians face challenging moral issues (Nantsupawat, Nantsupawat, Kunaviktikul, Turale, & Poghosyan, 2016; H. Wilkinson, Whittington, Perry, & Eames, 2017). Depersonalization is a key component of burnout and is reflected in personal detachment from patients and the work environment (Boerner, Gleason, & Jopp, 2017).

Nurses can disengage themselves from patients, families, and the EoL process in a protective compensatory manner (Rivera-Romero, Ospina Garzon, 2019). Even in situations where clinicians reported lower burnout and felt supported by ethics committees and debriefing opportunities, characteristics of depersonalization still existed (Pattison, Droney, & Gruber, 2019). Depersonalization can manifest through cynicism, unprofessional comments, or callousness (Pattison et al., 2019). For example, nurses experiencing depersonalization express sentiments such as, “I don’t really care what happens to some patients” (Pisanti et al., 2015, p. 6). Specifically, clinicians who deal with EoL frequently use depersonalization to cope and process grief (Pattison et al., 2019). A study of nurses working in a front-line public community hospital revealed two-fifths reported high levels of depersonalization (Nantsupawat et al., 2016). In a study by Stokes and Zoucha (2021), nurses described the expectations to compartmentalize their feelings of sadness, anger, and frustration when delivering aggressive EoL care, and quickly prepare for the next event (Stokes & Zoucha, 2021). Nurses also cope by acknowledging that a general degree of emotional distance is required in order to work in intensive care settings with high exposure to death (Stokes & Zoucha, 2021). Raus et al. (2014) also identified an obligatory feeling for nurses and physicians to remain professional to reduce the emotional bond they felt with dying patients. Research has shown that clinicians who experience or witness repeated grief and are cognitively motivated to avoid grief are more likely to exhibit depersonalization

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(Boerner et al., 2017). This is critical in EoL care and may be an important predictor to address burnout and moral disengagement.

Because nurses often consider themselves as mediators and advocates for their patients, they develop an emotional connection with patients and families (Gallagher et al., 2015; Mohammed & Peter, 2009). Physicians and other clinicians may also experience a connection, but emotional closeness was stronger in nurses who are more immersed in the daily care of patients (Raus et al., 2014). In practice, nurses are the ones that generally have to maintain a relationship with the terminally ill patient and family, while physicians' continuity of care may vary due to schedules and rotation in clinical services (Cipolletta & Oprandi, 2014). As a result, nurses are left carrying out the directives for EoL treatment, which can be rigorous and invasive, and potentially exacerbate pain and suffering; all of which may lead nurses to compartmentalize their feeling through cognitive dissonance and experience moral distress. This reasoning process from moral distress to moral disengagement is logical as nurses strive to cope with the repeated trauma associated with dying and aggressive care.

3.8 Attribution of Blame

Bandura's (1999) last mechanism of moral disengagement is the attribution of blame and one of the most common circumstances where people attempt to self-exonerate themselves by blaming others, including the person subject to harm (pg. 203). Bandura (1999) posits that shifting the blame toward others, not only self-exonerates the harmful conduct but can even make the perpetrator feel self-righteous (pg. 203). For example, in the 1980s the tobacco industry blamed smokers for inhaling cigarettes too deeply and denied that nicotine addiction was a contributing factor (J. White et al., 2009).

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In EoL care, attribution of blame is widespread. The limits of a patient's autonomy are sometimes challenged by demands from patients and families for medical interventions in which the healthcare team determines are inappropriate interventions (Weijer, Singer, Dickens, & Workman, 1998). A physician has an ethical obligation to respect the autonomy of their patients. Nonetheless, this obligation must be weighed with the duty to consider the physiological well-being of the patient and the duty to provide medically appropriate care (Beauchamp & Childress, 2019; Weijer et al., 1998). Physicians have a critical responsibility to frame a patient's treatment with respect, within the scope of that which is medically realistic (Gazelle, 1998). When a physician submits to an ADM's demand for inappropriate treatment, the physician not only compromises the patient's autonomy but fails to meet their responsibility to avoid doing harm (Gazelle, 1998). The Code of Medical Ethics' policy states no obligation to offer a patient non-beneficial treatment or treatment that offers no reasonable hope of recovery or improvement (American Medical Association, 2015).

Physicians and nurses can naturally become divided during these emotionally charged circumstances. Communication gaps play a significant role in the breakdown of trust and increase in decisional conflict among the health care team, patients, and families. Nurses blame physicians for poor and dishonest communication with families regarding a patient's prognosis (Dillworth et al., 2016). Physicians blame institutional bodies for not having enough time to discuss EoL issues with patients and families (Jericho, 2018). Attribution of blame, however, suggests that the blame for the harmful action lies with the victim, supposing that the victim brought these circumstances upon themselves (Bandura, Caprara, Barbaranelli, Pastorelli, & Regalia, 2001).

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Attribution of blame also extends to patient families. Overwhelming research demonstrates a disdain from nurses for families who override patient wishes for non-aggressive treatment at the EoL (Beckstrand et al., 2018; Mu et al., 2019; I. H. F. Taylor, Dihle, Hofsø, & Steindal, 2020; D. White & Meeker, 2019). Physicians also blame families when they feel forced to submit to a demand for inappropriate treatment (Ćurković et al., 2021). Nurses and physicians have a shared goal, which is to help patients and families gain acceptance of their decision in terms of the EoL care plan. Yet, in cases of attribution of blame, families become the victims because it is perceived that they have the power of decision-making in the EoL treatment plan for the patient (Stokes & Zoucha, 2021). This is indeed a perception. Stokes and Zoucha (2021) found that only one study participant considered refusing a family's demands for aggressive care. The majority believed that there was no other choice but to acquiesce to family demands for aggressive care.

Once a person is able to cast blame upon another for the actions or outcomes that are taking place, the individual casting blame is more likely to be able to avoid feeling guilty or responsible for what is deemed a morally unacceptable action. At the EoL, nondisclosed slow codes occur typically due to family conflict with the health care team over EoL goals of care. Numerous studies have identified that nondisclosed slow codes, which typically occur without the patients' or families' knowledge, arise when families have not accepted that death is imminent and refuse to agree to a DNAR order (Assarroudi, Nabavi, Ebadi, & Esmaily, 2017; DePalma et al., 1999; J. Kelly, 2008). Slow resuscitation, which can never be fully effective, symbolically occurs to give non-healthcare family members the impression that all has been done to save their loved one (J. M. A. de Vries & Timmins, 2016). The attribution of blame

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against families as the victim results in clinicians performing nondisclosed slow codes without remorse to give families comfort and assuage their guilt (Ong et al., 2017; Piscitello et al., 2020).

In some circumstances, nurses' and physicians' attribution of blame resulted in the refusal to allow families to be part of the decision-making process. In a study of perceptions of slow codes by Ganz et al. (2018), some physicians refused to incorporate the family in EoL decision-making if there was no benefit of treatment (Ganz et al., 2018). This study found that almost 30% of patients' families were not consulted regarding EoL treatment because physicians felt that families would not understand that resuscitation would be clinically ineffective (Ganz et al., 2018). Although these findings are rare, it demonstrates the ease for clinicians to activate moral disengagement and disregard their professional values. By attributing blame, moral disengagement frees clinicians from feeling guilt, responsibility, or shame associated with the delivery of inappropriate care and the inability to alleviate suffering at the EoL.

4 Analyzing Ethical Approaches to Limited Resuscitation

When a nurse's moral identity is threatened and she feels like she is practicing unethically because she is unable to provide good patient care, she may emotionally and morally disengage with the patient and family (D. M. Huffman & Rittenmeyer, 2012). Coping mechanisms and workarounds are prevalent in this stage. Nurses and other clinicians may begin bending the truth, telling small lies, or hiding knowledge consistent with moral disengagement (Turner et al., 2017). These behaviors help to reduce the cognitive dissonance because lying is not generally ethically permissible from a personal perspective (Turner et al., 2017). Lying is inconsistent with honesty and being ethical. Nurses may feel an even larger burden or moral heaviness when lying, given the prestige and public acknowledgment of the ethical and honest nature of the nursing profession (Reinhart, 2020). Nurses' moral reasoning is developed by the

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cognitive dissonance between moral distress and their own moral identity, as well as between burnout and the challenges of the health care environment (Pattison et al., 2019). All of these factors in the development of this moral reasoning process contribute to the transformation from moral distress to moral disengagement (Hyatt, 2017). The time and resource constraints in health care inevitably lead to shortcuts. The mental anguish that occurs when clinicians are unable to provide the care they feel patients need, fuels the continued transformation of distress to dissonance to moral disengagement. Therefore, a substantial degree of moral disengagement is possible given the cognitive symptoms and behaviors supported by the challenges of the overall health system.

This chapter outlines numerous ways that nondisclosed limited resuscitation efforts are triggered due to moral disengagement. Nondisclosed limited resuscitation is not morally permissible. In a recent study on slow codes, 85% of the participants, including nurses, believed that although slow codes were ethical, the primary decision-maker needed to be informed that resuscitation would be limited (Piscitello et al., 2020). This dissertation argues that *transparent* limited resuscitation that is disclosed to patients and families can serve as a method to mitigate or interrupt the moral reasoning process of moral distress to moral disengagement that nurses experience when repeatedly dealing with aggressive EoL due to family and clinician value-laden conflict. Disclosed limited resuscitation should disrupt the reasoning process of moral distress to moral disengagement by reducing the moral distress in nurses associated with the delivery of aggressive care and support the empathetic bond and trust associated with the nurse-patient-family relationship. The goal of disclosed limited resuscitation is to remove the physically harmful components of CPR, therefore promoting comfort and compassion and preserving a nurse's moral identity. Limited resuscitation that is disclosed to patients and families or ADMs

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could also minimize conflicts about the goals of care at the EoL by giving them ethically appropriate choices of actions that are less harmful or invasive resuscitation efforts to their loved ones.

5 Conclusion

In general, people behave in an ethically appropriate manner, but there is a common tendency to disengage from personal and professional morals to justify harmful behavior and distance themselves from their ethics (Shu et al., 2011). Moral disengagement embodies eight mechanisms that deactivate moral self-regulation and can result in dishonesty or harmful behavior as a means of coping with ethically challenging situations. This is especially applicable when dealing with EoL issues among clinicians, patients, and families. This delicate and highly stressful time can be emotionally taxing for everyone involved. Clinicians, such as nurses and physicians, are particularly vulnerable due to repeated exposure to death and dying. The negative psychological consequences associated with EoL care such as moral distress and burnout can lead to participation in nondisclosed slow codes, dehumanization of patients, and a breakdown of trust within the health care team. Moral disengagement can allow clinicians to deviate from their personal and professional values as a coping or protective mechanism to avoid emotional stress and burnout.

Chapter Six: Solutions to Address Limited Resuscitation

1 Introduction

A myriad of strategies have been proposed and implemented to address disputes in EoL care, but there is a paucity of recommendations to deal with eliminating or justifying limited resuscitation efforts. The following sections will include recommendations specific to nurses and other members of the health care team, and organizational policies designed to effect change. The first recommendation is for resuscitation that is specifically tailored to the patient-family unit preferences. The next recommendation highlights family presence at the bedside, which is an already existing practice that could be beneficial to the elimination or reduction of nondisclosed limited resuscitation. The following recommendation is for ethics consultation and includes the role of ethics committees, which are essential to mitigating EoL conflict between families and the health care team. The last two recommendations focus specifically on nurse-specific interventions to exhibit moral leadership and implement time-limited trials for life-sustaining treatments. Each proposed strategy will be considered using a risk-benefit analysis for patients, families, or alternate decision-makers (ADM), nurses, other clinicians, and the organization, if appropriate.

1.1 Shifting Moral Acceptance

Many of the recommendations described below are non-traditional and with any level of change, some resistance is anticipated. The ultimate goal of each approach discussed below is to avoid deception and provide transparency to interventions— even if those interventions do not provide any clinical benefit. Most patients with an advanced illness would forgo aggressive life-sustaining treatment once they learn about all of the options and would prefer comfort measures (Chang et al., 2019). Therefore, it is crucial that limited resuscitation occurs with the ADM's or

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family's knowledge and understanding in situations where the patient no longer has decisional capacity.

It is important to acknowledge that limited resuscitation, even when disclosed to patients and families, is not the optimal solution for EoL conflict, but an outcome of a larger systemic problem. Limited resuscitation is the product of complex health system challenges morally akin to several other controversial issues such as abortion or medical aid-in-dying. Arguably, there is no morally right choice for abortion or medical aid-in-dying, and therefore, they will always be subject to debate. These are complex moral issues that are nuanced, and therefore, general categorical statements about moral permissibility are challenging. Yet, the crux of these issues lies within challenges of larger social and health care systemic issues, including inadequate symptom management at the EoL, and lack of education and access to preventative reproductive health care.

This moral analogy does not suggest that the beginnings or endings of life are simplistic. They are not. They are fraught with social stigma and systemic challenges that trickle down to an individual level where patients and families are left to decide the best approach to achieve their desired goals in a complex health system. The shift in societal acceptance of complex moral issues is demonstrated in increased legal and policy interventions allowing for greater autonomy for patients (Brenan, 2021; Collier, 2017). Yet, with many controversies in society, change in moral perception takes years, and sometimes decades. There are numerous examples of social change in history such as legalization of marijuana, seat belt usage, and increased moral acceptability of premarital sex, interracial marriage, and non-nuclear families (Saad, 2019). Each of these issues met resistance to change, and many issues are still considered controversial today due to varying moral beliefs and degrees of acceptance.

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1.2 Shifting Moral Perceptions of Limited Resuscitation

A pivotal ethical question regarding the use of life-sustaining technologies is, “Should we extend life just because we can?” In acute and critical care settings, there is an implicit notion that if a problem exists, action must be taken to fix it, and therefore if a technological intervention is possible, then it must be attempted (VanKerkhoff, Viglianti, Detsky, & Kruser, 2019). At some point, life-sustaining technology is no longer able to sustain life, and every individual will succumb to death. Yet, oftentimes patients and families demand that all technologies be deployed to “save their loved one”, when in fact the technology is simply extending life, but not improving quality of life. In some circumstances, life-sustaining interventions are making the quality of life worse, and arguably wasting resources that are beneficial to another patient with a greater likelihood of success. Nonetheless, this conflict over which EoL interventions are appropriate and for how long continues to plague the health care environment with profoundly negative impacts on the economy, patients, families, clinicians, health care organizations, and society. Multiple approaches to address the conflict that occurs in EoL care should be considered and utilized if appropriate.

Limited resuscitation that is disclosed to patients and families is a controversial, yet ethically justified approach to disputes in EoL care. Disputes in EoL care have existed for years and are exacerbated by continued advancements in technology designed to extend life. As far back as 1976, Massachusetts General Hospital published one of the first statements regarding limited resuscitation dividing patients into categories where “maximum therapeutic efforts will be attempted”, “limited therapeutic measures will be attempted”, and lastly, “no therapeutic measures will be attempted” (Ross & Pugh, 1988). The category for “limited therapeutic measures” directed physicians to consider limiting resuscitative medical interventions in patients

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with multisystem organ failure (Ross & Pugh, 1988). In 1992, Jessica Muller proposed limited resuscitation as a method of “negotiation of an intermediate ‘code’ effort which falls somewhere between full CPR and DNR order” specific for resident physicians (Muller, 1992, p. 886). Muller (1992) acknowledged the controversy and societal resistance associated with limited resuscitation but identified the cultural meaning of limited resuscitation as a response to the problematic dichotomy of DNAR and CPR. Limited resuscitation is obviously morally challenging because it does not provide an adequate clinical benefit to patients but rather an emotional benefit for families. Limited resuscitation does not fulfill the intentions of full resuscitation, which is patient survival. However, not providing any resuscitative efforts is also problematic because it does not provide *any* chance of recovery, despite the likelihood that a patient would not survive. Both options are poor, and therefore, limited resuscitation serves to mitigate the best of both options.

Lantos and Meadow (2011), proponents of disclosed limited resuscitation, present a strong argument— yet acknowledge the potential resistance to their recommendations. Lantos and Meadow define slow codes as partial or abbreviated resuscitation efforts that are not disclosed to patients or family members. They argue that limited resuscitation, specifically slow codes, are morally permissible if CPR is unlikely to be successful, the family or ADM understands that death is inevitable, yet they are unable to bring themselves to agree to a DNAR order.

We do not advocate this approach naively or frivolously. We are aware of, and take seriously, the many powerful arguments against slow codes. We value honesty and oppose lying. We realize that any explicit sanction of deception would put us on a very slippery slope, poised for a long downward slide toward unbridled paternalism or unanchored moral relativism. We are not triumphalist in our defense of the slow code. It is not an optimal solution. But it may be the least bad solution to a problem that has only undesirable options. Our claim is a modest one: that, in some limited situations where

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every option is problematic, “tailored” resuscitative efforts may be a better option than the others, and ought to at least be considered and examined. (pg. 8).

Although not ideal, nondisclosed slow codes and other forms of limited resuscitation have existed for decades. No successful intervention or strategy to eliminate nondisclosed slow codes has been noted in research in the literature, and due to the negative ethical perceptions of the practice, little research exists. The history and prevalence of nondisclosed slow codes and other forms of limited resuscitation strongly suggest that they are not going away—arguably their prevalence has increased since the first mention in the literature in 1977 (D. L. Berg & Isler, 1977; Ganz et al., 2018; Piscitello et al., 2020). Clinicians, researchers, and ethicists must address slow codes and other forms of limited resuscitation to better understand them. This begins with awareness, acknowledgment of the practice, research, and implementation of recommendations to address the multitude of factors that contribute to their existence. Clinicians must continue to communicate effectively and zealously advocate for appropriate patient care while preserving personal and professional integrity. The recommendations below are another attempt to influence the moral perceptions of limited resuscitation to gain a societal acceptance of the practice as a means of compromise to mitigate the complexities in EoL decision-making conflict.

2 Tailored Resuscitation

Tailored resuscitation efforts tailor treatment decisions based on both the clinical picture and patient values. Tailored codes focus on transparency and strive for a personalized nuanced approach ensuring that patients and families have adequate information to foster decision-making (Ranola et al., 2015; Tang et al., 2016). As such, any form of disclosed limited resuscitation can be considered a tailored code if it is carried out according to the patient and family or ADMs preferences. See Figure 1 in Chapter 1 which describes all forms of limited

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resuscitation. Tailored approaches to health care, in general, support shared decision-making, relational autonomy, and strive to directly consider and implement patient's goals of care.

Tailored orders in EoL care—specifically resuscitation, have evolved as a middle ground between family's requests for medically inappropriate care and clinician's recommendations based on evidence and health expertise (Stokes & Zoucha, 2021). CPR is no longer a one size fits all intervention (Ranola et al., 2015). It is important for patients and families to consider a broader approach than just a “full code” or a “DNAR order” (Ranola et al., 2015). Tailored resuscitation orders are not a new concept. Stokes and Zoucha (2021) found that nurses reported a majority of orders specifically tailored for the patient were documented in the chart, even though they limited full CPR in some way. In addition, tailored code orders prescribed by the physician or advanced practitioner were deemed morally acceptable by nurses who objected to participation in limited resuscitation without an order (i.e., nondisclosed slow codes). Due to the risk of discordance with goals of care, tailored codes must be properly documented in the patient's health record.

2.1 Documentation

Tailored codes must be documented in a written order by health care professionals leading the patient's care. At the national policy level, the U.S. Department of Health and Human Services identified documenting and honoring a patient's EoL preferences as a major objective in improving quality patient care (Bates & Bechtel, 2013). Health and nurse informaticists also encourage a standardized and transparent approach to the documentation of EoL care treatment, not only resuscitation, but also including specific values for “preferences regarding mechanical ventilation, artificial hydration and nutrition, and the use of antibiotics and cardiovascular medication (such as epinephrine)” (Lehmann, Petersen, Bhatia, Berner, &

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Goodman, 2019, p. 180). Unfortunately, specific advance directives, including code status, are documented infrequently or inconsistently (Jain, Greco, & Kaelber, 2017; Weinerman et al., 2015). Research suggests that 20% of patients report discordance in code status, where the patient reports having a resuscitation order for a full code or DNAR, but the clinician understands and documents their code status differently (K. A. Young, Wordingham, Strand, Roger, & Dunlay, 2017). The discordance in code status speaks to a larger issue of miscommunication and misinterpretation when discussing EoL care. This quality gap in EoL care provides a rich opportunity for improvement at the organizational level. The standardization of EoL options in the electronic health record can foster transparency, reduce bias, and trigger reminders for physicians, nurses, and other clinicians to address EoL goals of care with all patients and families. This is a prime opportunity for nurses to engage in corporate and organizational decisions about creating and sustaining health information technology (IT) usability for tailoring or implementation, customization, evaluation, and optimization of the health IT infrastructure (Staggers, Elias, Makar, & Alexander, 2018).

Although documentation of EoL options should be standardized, EoL interventions can and should be tailored to each individual patient respective of clinical appropriateness, patient values, and preferences. Currently, numerous EHR platforms lack the functionality to support this documentation leading to a hodgepodge approach in advance directive documentation. The American Medical Informatics Association (AMIA) Ethics Committee proposes a minimum data set for all electronic health records (EHR) to adequately capture EoL goals of care (Lehmann et al., 2019). Although the AMIA documentation proposal includes required fields such as proxy contact information and the patient's ability to consent, it allows flexibility in code status to include limited resuscitation (Lehmann et al., 2019). These limitations include but are not limited

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to withholding antiarrhythmic medications, vasoactive medications, defibrillations, chest compressions, etc. (Lehmann et al., 2019). See Table 2 for an example of an EoL care code status used in the EHR at Vanderbilt University Medical Center for clinicians to complete patient EoL goals of care (Bhatia et al., 2015).

Table 2.

Description of the end-of-life care code (Code Status) in the electronic health record

Code	Description	Orders
Undocumented	Not provided by patient. [Would default to “FULL_CODE”.]	
FULL_CODE	Take every measure to resuscitate the patient	
DNR	Do not resuscitate	
DNR_DNI	Do not resuscitate and for impending respiratory failure, do not Intubate	
LIMITED	The DNR is limited NOT to take one or more of the following steps/actions as requested by patient. WITHHOLD Antiarrhythmics WITHHOLD IV Vasoactive Drugs WITHHOLD Defibrillation/Cardioversion WITHHOLD Chest Compression WITHHOLD Ventilation by Mask WITHHOLD Endotracheal Intubation WITHHOLD Mechanical Ventilation	X X

Note. Adapted from Bhatia, H. L., Patel, N. R., Choma, N. N., Grande, J., Giuse, D. A., & Lehmann, C. U. (2015). Code status and resuscitation options in the electronic health record. *Resuscitation*, 87, 14-20. doi:10.1016/j.resuscitation.2014.10.022. Copyright © 2014 Elsevier Ireland Ltd.

In practice, the advanced care clinician leading EoL goals of care discussions would initially review the list of EoL options for medical or clinical appropriateness and discuss this with the health care team involved with the patient’s care. If an intervention is not determined to be medically appropriate, then it will not be offered and will be “grayed” out in the electronic health record. This standardized approach provides transparency and clarity for the full health care team to understand what EoL care options are deemed clinically appropriate for that patient. There may be circumstances when a family requests or demands CPR when the health care team

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has determined that is not medically beneficial, nor clinically appropriate to offer this intervention. The health care team must be intentional in documenting these delicate conversations but are not required to perform physiological medically inappropriate treatments and potentially harmful interventions. Several healthcare organizations have clear policies outlining procedural actions (including the ability for a family to obtain a second opinion or transfer the patient to another hospital) to address disagreements over the implementation of CPR (Boston Children's Hospital, 2012).

The Code Status Chart described in Table 2 is the beginning step to more comprehensive documentation of EoL goals of care discussions including easy-to-access links to policies for each status (i.e., full code, DNAR, etc.), reasons for code status discussion, patient decision-making capacity, and documentation of who performed the code status discussion and who was present for the discussions (Bhatia et al., 2015). Patients should not be given a list of items or interventions that they can check off because it can lead patients to assume that it can offer some modicum of clinical benefit (Zapata & Widera, 2016). Respecting the relational autonomy of patients and families requires a deeper dive into the goals, preferences, and motivations for EoL care preferences. Preferences can be influenced by numerous factors such as gender, religion, culture, ethnicity, personality, age, and social location (Halvorsen, Førde, & Nortvedt, 2009). The emphasis of EoL conversations should not be centered around medical interventions, defibrillation, chest compressions, or vasopressors (Zapata & Widera, 2016), rather these conversations should be conducted in a way that is understandable to the patient and family or ADM that includes EoL goals and the preferential journey to reach these goals. Memorial Kettering Cancer Center in New York has implemented a “values tab” in their EHR designed to enrich the patient experience with summary information about goals of care, understanding of

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treatment, social history, and language, culture, spirituality, communication, and EoL preferences (Desai et al., 2021). This is another exemplar demonstrating the implementation of express and easy-to-access documentation of values and goals of care.

2.2 Clarity of Tailored Medical Orders

Tailored codes must clearly delineate the omission of elements of CPR or provide only certain elements of CPR (Ross & Pugh, 1988). Tailored codes should be preplanned and agreed upon by the patient or alternate decision-maker when appropriate. Some health care organizations already have varying degrees of DNAR orders in use. For example, The Cleveland Clinic in Ohio has options for a DNRCC, DNRCC-Arrest, and DNR Specified orders. DNRCC is used for comfort care measures only, DNRCC-Arrest permits the use of life-saving measures, and DNR Specified is tailored by a physician (Cleveland Clinic, 2020). In New Jersey, a DNR-B order means that the patient will continue to receive all existing treatment except in the event of a cardiac arrest (Sultan, Mansour, Shamieh, Al-Tabba, & Al-Hussaini, 2021). These multiple acronyms and designations can be complex and confusing for patients and families (Jain et al., 2017). The intent of these orders is a remarkable change from traditional practice. However, all of these orders are designated as DNAR orders. The public perception of a “do not” type of order emphasizes an omission or a negative right. Options for tailored resuscitation orders must be communicated in a way that promotes personal choice, and not in a way that emphasizes limiting medical interventions. Nudging strategies are also appropriate for clinicians to use by presenting the most ideal option before the least optimal option. Lastly, tailored orders should be tailored by the health care team, patient, and family through shared decision-making. It should not be simply an order tailored by the physician. Nurse-led EoL communication programs have proven successful and will be discussed in detail in the next section.

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Tailored codes can also include orders “not to escalate treatment”, meaning that the current interventions remain in place, but no additional interventions will be added (J. R. Curtis & Rubenfeld, 2014). It is important to note that “no escalation clauses” can become clinically complex when life-sustaining intravenous medication such as vasopressors are used to maximize hemodynamic support for patients. In these circumstances, nurses typically are given medical orders to titrate these vasopressors using a sliding scale to maintain hemodynamic stability (i.e., titrate according to the numerical parameters of the patient’s blood pressure) (Davidson et al., 2021). When nurses’ titration efforts reach the maximum support at the top of the sliding scale, they may no longer escalate the titration of medication. Nurses describe this phenomenon as “maxed out”, which occurs when the patient is literally at the maximum amount of medication that can safely be administered to sustain their life (Stokes & Zoucha, 2021). Nurses have expressed concern over continuing aggressive interventions such as CPR when patients have reached the maximum amount of support to live. Some nurses feel like these efforts strip patients of their dignity and often fail to respect patients’ wishes (Stokes & Zoucha, 2021). Nurses often feel helpless when patients reach this point because families have not yet accepted that their loved one is terminally ill, death is imminent, and the nurse is left with no additional medical options to sustain a patient’s life (Stokes & Zoucha, 2021).

“Maxing out” can occur when a safe dosage is no longer effective, but also if a medical order includes a provision not to escalate care. “No-escalation orders” end the nurse’s ability to save the patient’s life through titration of vasoactive medication to a higher dose. In either situation, failure to escalate vasopressors could, and most likely will result in death without an additional measure of support or intervention. Research suggests that no-escalation orders are not uncommon. A study by Morgan, Varas, Pedroza, and Almoosa (2014) found that no escalation

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orders were present in 30% of ICU patients. No escalation orders can cause confusion, inconsistency, and lead to a clinician's lack of objectivity and thus bias in decision-making. No escalation orders are unethical if they are used to frame the argument to families that the patient is receiving medically effective treatment when in fact they are not (J. R. Curtis & Rubenfeld, 2014). Clinicians must be clear and honest with patients and families that no escalation orders prevent the addition of medication to the current regimen. It is also important for nurses to reframe perceptions of medically ineffective treatment as nonbeneficial. A deliberate effort to reframe perceptions of medically ineffective treatment as holistically beneficial for the patient and family as emotional and psychologically beneficial should improve the work environment (Schwarzkopf et al., 2017). Nurses acknowledge that aggressive life-sustaining care is often delivered for the benefit of families, not the patient (Stokes & Zoucha, 2021). Nurses who deliver life-sustaining treatment that they perceive as nonbeneficial or aggressive, can develop moral distress and burnout (Schwarzkopf et al., 2017). Therefore, efforts designed to reduce moral distress must include a shift in the acceptance that emotional support for patients and families is through the delivery of nonmedically effective care and is beneficial and morally acceptable.

Some scholars suggest that tailored approaches to CPR and EoL care are unrealistic due to the low health literacy of the majority of the population, and clinicians may not be able to practically implement tailored interventions "in the moment" (Abella, 2016). Tailored codes should require reflection upon the patient's values and preferences by the family or ADM. This is often difficult for family members or ADMs in the moment of resuscitation when decisions are made within seconds or minutes. These are important considerations for patients and families that should be reflected upon before an EoL decision-making occurrence. To address health

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literacy, consumer messaging regarding EoL options should be advanced at a national level. Organizations such as the Centers for Disease Control and Prevention, American Heart Association, and AARP should have bipartisan campaigns to address EoL conflict between clinicians and families, provide education to consumers about EoL options, and most importantly highlight the numerous options that may be available for themselves or loved ones. Public opinion and education are highly influenced by media campaigns. These types of campaigns should highlight the availability of tailored EoL options with clear messaging that each option will be situational. Patients and families should no longer rely on mainstream television shows for education on EoL options. Patients and families must understand that EoL options consist of “more than just CPR”.

Tailored code orders are not solely presented by the health care team. Patients and families may also request a personalized approach to EoL care interventions (Lantos & Meadow, 2011). W. S. Tan, Bajpai, Ho, Low, and Car (2019) found that the majority of individuals with chronic health conditions do not prefer life-sustaining treatments once death becomes imminent, yet there is still a strong preference for some form of limited intervention to preserve hope in survival. This less vigorous option may be a significant factor in allowing families to feel like they are not giving up, but also prevents clinician moral distress caused by the potential for inciting significant patient harm and suffering (Bosslet et al., 2015). Tailored limited resuscitation may be a more ethically tenable option than full CPR or DNAR, due to the inclusion of family and transparency in medical treatment.

Every clinical scenario is different. In some circumstances withholding, continuing, or initiating life-sustaining treatment may be ethically justified. The health care team needs to know, communicate, and understand the decision-making rationale for the decision to intervene

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or withhold treatment. For example, intubation might be withheld in a patient with a terminal illness because the patient refused, or the health care team has determined that it will be ineffective. It is important to understand if intubation is withheld because of the invasive nature of the endotracheal tube— which generally requires the patient to become sedated and thus unable to communicate— or it is withheld in respect of a decision to transition to comfort care. The latter rationale can result in an alternate and less invasive form of ventilation to address challenges with breathing and oxygenation. Institutional policies regarding tailored codes and limited resuscitation should include the statement of the objectives of each treatment, delineation of prescribed and prohibited care, description of the decision-making process, documentation procedures, and include a periodic review (Ryden & Miles, 1987).

3 Family Presence at the Bedside

Family presence at the bedside during resuscitative efforts has become increasingly common over recent years. Family presence during resuscitation first became a known issue in 1982 at Foote Hospital in Jackson, Michigan, when a spouse demanded to be at her husband's bedside during resuscitation (Doyle et al., 1987). Traditionally, family members were not allowed in the room during the time of cardiac arrest due to concerns that they may interfere with efforts or increase exposure to legal liability (Petty et al., 2013; Zavotsky et al., 2014). Pre-existing power and authority existed among clinicians who were able to claim ownership of the patient and patient care area, with little resistance from family (Giles, de Lacey, & Muir-Cochrane, 2016). Over time this became a challenge, especially when family members were present and possibly participated in a pre-hospital arrest but were excluded from being present once their loved one arrived in a hospital. In 1987, a survey of family members revealed that 72% of participants preferred being present with their loved ones during resuscitation (Doyle et

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al., 1987). This study was a catalyst that resulted in several health care institutions initiating or revisiting policies on family or visitor presence during health emergencies. Several professional associations, including the American Association of Critical Care Nursing, the Emergency Nurses Association, the American College of Emergency Physicians, and the American Heart Association, are in firm support of family presence during resuscitation (American College of Emergency Physicians, 2020; Zavotsky et al., 2014). A continuing trend is evident in research that families desire being present with their loved ones during resuscitation and feel that they have a right to do so (De Stefano et al., 2016; Twibell, Siela, Riwitis, Neal, & Waters, 2018).

Benefits and risks associated with family presence have been widely studied with mixed findings. Yet, overwhelmingly studies have demonstrated a greater benefit to families when they are present during resuscitation efforts including closure and confidence that everything was done (Compton et al., 2011; Jabre et al., 2014; Pasquale, Pasquale, Baga, Eid, & Leske, 2010; Vardanjani et al., 2021). Observing the resuscitation was noted as the beginning of the grieving process of the loss of their loved one and is the genesis of understanding that their loved one is dead (De Stefano et al., 2016). However, not all family members prefer to be present and are concerned that their presence could be a physical barrier or detrimental to the patient's resuscitation efforts (Toronto & LaRocco, 2019). Some clinicians are concerned that families witnessing resuscitation may have negative psychological consequences, but research shows that they have reduced anxiety and depression than those who do not (Giles et al., 2016; Powers & Reeve, 2020). Family presence during resuscitation promotes family well-being and reduces feelings of hopelessness and inaction (Park & Ha, 2021).

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3.1 Substantial Debate over Family Presence During Resuscitation

The debate over the appropriateness of family presence during resuscitation has been ongoing for decades and spans across the globe. As a result, there has not been widespread acceptance of family presence (Lowry, 2012). In non-Western countries, family presence is rarely utilized due to strong opposition to the practice (Powers, 2017). Clinicians in South and Central America are especially unsupportive of family presence during resuscitation (Asencio-Gutiérrez & Reguera-Burgos, 2017). Reviews of the literature have found that a majority of nurses and physicians do not want family members present at the bedside during resuscitation (De Robertis, Romano, Hinkelbein, Piazza, & Sorriento, 2017; Walker & Gavin, 2019). However, in the U.S., over 75% of clinicians allowed this practice to occur in support of patient and family advocacy (Lederman & Wacht, 2014). Some clinicians view family presence during resuscitation as an interruption or disruption in care, and therefore their presence can create anxiety for the health care professional (Vincent & Lederman, 2017). Clinicians feel that family presence during resuscitation can result in a lack of focus, decreased confidence, and nervousness (Hassankhani, Zamanzadeh, Rahmani, Haririan, & Porter, 2017). Citolino, Santos, Silva, and Nogueira (2015) found that 67% of nurses believed that family presence during resuscitation adversely affected the quality of CPR. Nurses felt that families caused physical space constraints, and nurses often felt like they were under a microscope and could not perform CPR effectively (Ganz & Yoffe, 2012; McClement, Fallis, & Pereira, 2009; Powers & Reeve, 2020). Nurses also felt that the family's presence made the decision to stop CPR more difficult and that CPR would likely be prolonged (Köberich, Kaltwasser, Rothaug, & Albarran, 2010). Several studies noted concern over nurses' safety because sometimes families' responses to grief manifest through aggression and physical violence (Hassankhani et al., 2017; Powers, 2017;

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Twibell et al., 2018). One nurse reported being beaten by family members two times after resuscitation (Hassankhani et al., 2017). The lack of physical security and instability in these highly emotional circumstances suggests that the presence of a family facilitator is necessary to support grieving families (Hassankhani et al., 2017).

Clinicians have also expressed grave concern over protecting the patient's autonomy and right to privacy. Opponents of family presence argue that their primacy is to the patient, and this includes protecting health information—even in an emergency (Brasel, Entwistle, & Sade, 2016). Opponents also suggest that family presence during resuscitation without consent of the patient risks confidentiality breaches and ignores the wishes of the patient especially during an emergent situation when diagnoses, lab values, and sensitive health information are often verbally and openly discussed (Brasel et al., 2016). Clinicians and hospital administrators have also expressed concerns over legal liability for potential risks to family members, such as exposure to blood-borne pathogens or needles (Brasel et al., 2016). These are important and valid issues that should be addressed in organizational policies for family presence during resuscitation. However, there are no lawsuits related to family presence during resuscitation, and families may be less likely to sue when they witness everything being done to save their loved one (Jabre et al., 2013; Twibell et al., 2018).

3.2 Family Presence During Resuscitation Should Be Allowed

Family presence during resuscitation should be afforded to family members as long as there are no public health (i.e., pandemic) or safety concerns, and the patient has not objected. Patient consent is typically not required and should not be required for family presence, but if a patient with decision-making capacity has objected to family presence during resuscitation, then that request should be honored. When the patient has not objected, family presence should be an

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option given to families and not a requirement. Patients should have autonomy over how they die and thus who should be allowed to be present (Vincent & Lederman, 2017). Family presence at the bedside supports the concept of relational autonomy by acknowledging and supporting the interconnected role that families should play. Families should no longer be treated as “hospital visitors”, but essential partners in the patient’s health care (Lederman, 2019). In circumstances where the patient’s preference around family presence during resuscitation is unknown, family presence during resuscitation should be allowed. Additionally, if there is no evidence of prior objection, family presence at the bedside is supported by relational autonomy. Relational autonomy supports family-centered care and recognizes that the family is interconnected in a larger social construct and patients are influenced by these relationships (Lederman, 2019). In nursing, family-centered care includes reassurance from nurses, emotional and decision-making support, and acknowledgment of a family’s contributions to care (McAndrew, Schiffman, & Leske, 2020).

The presence of family members can provide emotional well-being and physical comfort for the patient, which outweighs perceived concerns by nurses regarding the risk of negative psychological consequences related to witnessing resuscitation. Again, strong empirical evidence supports the conclusion that the benefit and right for a family member to be present during this EoL emergency intervention outweighs the risk of detrimental harm (Vincent & Lederman, 2017). Evidence does not support the argument by nurses and other clinicians that family presence disrupts the resuscitation event or negatively affects patient care. The benefit for families to know that everything possible was done to save their loved one establishes trust and confidence in the health care team, and potentially the health care institution. This far outweighs the perceived risk by nurses that family presence limits physical space to conduct resuscitation or

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causes an interruption in care. Although there is a paucity of evidence to suggest that family presence can cause a delay in the initiation of resuscitation (Goldberger et al., 2015), overwhelming evidence suggests that family presence does not impede patient care.

A risk-benefit analysis of the legal risks of a family member's exposure to bloodborne pathogens or needles is largely outweighed by the benefit of providing closure and instilling trust in the EoL care given to patients. The risk of needle or blood exposure to health care workers is high and is notably underreported (Mengistu, Tolera, & Demmu, 2021). Nonetheless, clinicians accept this risk, but family members do not. However, it would be an unreasonable burden on a family member to sign a waiver to be present, when oftentimes, in-hospital arrests are unpredictable. Lastly, the safety of nurses and other clinicians is paramount. Therefore, accommodations for families to assist with grief responses and the potential for aggressive or violent behavior should be mitigated by support staff to ensure the benefit of family presence during resuscitation is respected and promoted.

Family presence during resuscitation has also proven to reduce conflict and increase family satisfaction (Hassankhani et al., 2017). Research suggests that family presence at the bedside can mollify the EoL experience and often results in the cessation of the resuscitation event (Porter, Cooper, & Taylor, 2015; Zavotsky et al., 2014). Family presence should be individualized to each situation and may be especially helpful for patients who are receiving potentially inappropriate EoL care and at risk of being subjected to an uninformed and nondisclosed limited resuscitation event (Powers & Reeve, 2020). Limited resuscitation is generally performed under the guise of secrecy without a family member or ADM witnessing the act and is considered a deceptive practice that could be exposed through observation of practice and technique. As a result, there is a potential deterrence of nondisclosed limited resuscitation, if

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a family member or ADM was present during the time of a cardiac arrest. Family members who are present during resuscitation wanted to emotionally support their loved one but also wanted to see the resuscitation efforts by clinicians. They should be invited, encouraged, and supported by nurses and other clinicians through appropriate policies and guidelines.

3.3 Education and Resources to Support Clinicians

Family presence during CPR is typically determined and offered by nurses or other clinicians (Park & Ha, 2021; Powers & Candela, 2017). Powers and Reeve (2020) found that a majority of nurses believed that an absence of policy on family presence was a barrier to inviting families to participate. In addition, multidisciplinary training, and guidelines on family presence during resuscitation have shown an increase in clinicians' level of acceptance of family presence during resuscitation (Flanders & Strasen, 2014). Formal training on family presence during resuscitation might equip nurses and physicians to prepare for the uncertainty surrounding resuscitation, including the emotional volatility of families, the risk of breaching patient confidentiality, or clinicians' feelings of discomfort or being judged based on performance in an emergency situation (Porter et al., 2015).

Therefore, it is recommended that certain policies or procedures include a staff support person directly assigned to families and individuals during resuscitation to help them grieve and answer immediate questions, to minimize the risk of interruption that may impede the resuscitation process. Several national guidelines for family presence suggest the role of a family facilitator, as well as prohibitions against family members who demonstrate aggressive or violent behavior, or behavior consistent with an altered mental status (AACN, 2016; ENA, 2001). There is high variability in culture and values that occur at the EoL, and these factors must be considered, addressed, and respected. Policies on family presence must also address issues such

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as bias, access, and any other historically systemic injustices for patients and families. These often manifest through screening policies, such as the prohibition of family members who do not speak English in the room during a resuscitation (Brasel et al., 2016). Variations in screening and practice can result in inequitable patient care (Flanders & Strasen, 2014). Screening criteria for family presence during resuscitation vary because different health care organizations have separate policies. This is a critical issue to address and an area ripe for research.

Some family presence policies are narrow and limit the number of family members that can be present at a time (Al Mutair, 2017; Emanuel-Hayes, 2018). This can be challenging if hypothetically only two members are present, but one would have to remain outside of the hospital unit and the other family member would be present in the room. This could be emotionally disruptive for family members who could not provide each other “in the moment” emotional support. Ideally, the family member who is present is the legal health care decision-maker and can provide answers, if needed, related to the continuation of resuscitation efforts (Al Mutair, 2017). Obtaining a patient’s consent (when possible) is another component of a family presence policy but is not a requirement. This should be done as far in advance as possible. Some researchers suggest that patient consent for family presence during resuscitation should be part of an advance directive (Herron, 2014). Although patient consent should not be required, obtaining consent in an advance directive provides a clear expression of the patient’s preferences that serves to eliminate any confusion at the time of resuscitation. Policies should include language that allows for some flexibility at the health care team’s discretion.

Although some health care professionals are reluctant and unsupportive of families at the bedside during what is often a chaotic and adrenaline-filled activity, research has demonstrated that presence allows family members to witness extraordinary efforts to save their loved one, as

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well as provide an opportunity to grieve and accept death (Porter et al., 2015). Family presence during resuscitation may also deter clinicians' participation in limited resuscitation that has not been discussed with the patient or family in advance. It can also minimize conflict when family members witness everything that CPR entails. Family presence can result in stress for some clinicians, but it can also naturally result in compliance with standards of practice for full resuscitation or any other medical orders previously agreed upon. Therefore, limited resuscitation can occur with family present, but it should be transparent and family members would be informed of what to expect during the event of cardiac arrest. Family presence during resuscitation can have a profound impact on the prevalence of nondisclosed limited resuscitation. Deceptive acts such as nondisclosed limited resuscitation are less likely to occur when clinicians are being observed. This is also an area that could benefit from empirical exploration into clinicians' perspectives and behaviors when families are present during limited resuscitation efforts.

4 Ethics Consultation and Leadership

It is important for organizations to acknowledge the underlying potential for conflict between families who advocate for preserving life and the health care team armed with medical knowledge and experience to determine poor or terminal patient outcomes. Organizations must be responsible in managing this conflict through mediation and conflict resolution to preserve the model of shared decision making which is inclusive of patient and family perspectives (Choong et al., 2010). Naturally, families are interested in preserving life and want their loved one to be perceived as a whole person (MacDonald et al., 2011). Families must be given the opportunity to express the broad and holistic view of their loved one's life to the health care team, and not a mere specific incident that lead them to this medical moment (MacDonald et al., 2011).

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One obvious but underutilized and underfunded resource to manage conflict for nurses and other clinicians are ethics committees, ethics consultants, and other ethics supports opportunities (Hyatt, 2017). In the early 1980s, only 60% of U.S. hospitals had ethics committees (E. F. Baker, Geiderman, Kraus, & Goett, 2020). However, regulatory mandates passed in the 1990s required hospitals to have some type of ethics consultation mechanism provided by an individual, team, or committee to help identify and analyze ethical dilemmas in practice (Gordon & Hamric, 2006; Joint Commission on Accreditation of Healthcare Organizations, 1992). Today, almost every acute care hospital, teaching hospital, or federal hospital has some form of ethics service or mechanism to address ethical dilemmas (E. F. Baker et al., 2020). Hospital ethics committees are structured to ensure due process, minimize conflicts of interest, provide mediation, and limit any potential bias based on demographic factors (A. Courtwright et al., 2014). Committees generally consist of multidisciplinary professions such as nursing, medicine, social work, chaplaincy, clinical ethics, respiratory therapy, case management, and community members (A. Courtwright et al., 2014). Some healthcare institutions have regional ethics committees, and some have tele-ethics programs when local resources are limited (Subramanian et al., 2020).

An important function of the hospital ethics committee is to conduct ethics consultations in circumstances where a hospital has limited individual ethicists (rather than a full-time ethics consultant), and therefore the committee periodically reviews issues that are generated by the consultations (Gaudine, Lamb, LeFort, & Thorne, 2011). Most hospital ethics committees convene once per month to discuss special ethics clinical cases, and some meet on an ad-hoc basis (E. F. Baker et al., 2020). Ethics committees provide support for ethics consultants on difficult ethical dilemmas and consider ethical implications for patients, families, and the

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members of the health care team. Ethics committees are especially critical in EoL conflict, including disputes over goals of care. The ethics committee is not designed to resolve the conflict but facilitate discussions that are necessary to reach a mutual conclusion. Ethics committees serve as a mechanism for reinforcing shared decision making between clinicians and patients, not for enforcing unilateral decisions. Overall, ethics committees can provide education and dispute resolution strategies for clinicians and families that facilitate discussions about mutual goals of care.

4.1 The Role of the Ethics Consultant

The role of the ethics committee and the success of ethics consultation is essential for minimizing conflict. Clinical or hospital ethicists are responsible for providing an ethics consultation. Most health care organizations have a small number of clinical ethicists to conduct consultations. These consultations occur between the formal ethics committee meetings and typically occur in the clinical setting (E. F. Baker et al., 2020). It is important for ethics consultants to help patients and families identify their own values and support the identification of shared values with the appropriate decision-maker in an ethically and legally appropriate manner (Tarzian & Force, 2013). Nurses and physicians articulate that the patient, first and foremost, should be involved in EoL decision-making (Brooks et al., 2017). Yet, this shared decision-making model is strained when patients, especially those in the intensive care unit, lack advance directives or are unable to express their decisions due to the gravity of their condition (Brooks et al., 2017). Therefore, it is critical for the ethics consultant to give family members a “voice” and allow them to express the value and meaning of the patient’s life in order to humanize the decision-making process (MacDonald et al., 2011; Tarzian & Force, 2013).

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Generally, ethics consultants follow a prescribed process, outlined in the American Society for Bioethics and Humanities Guidelines, evaluating conflict such as the appropriateness of life-sustaining treatment at the EoL (Force, 2011). Ethics consultants gather information about the patient's clinical condition, patient preferences, quality of life and broader contextual features and assess any ethical issues involved with their care (E. F. Baker et al., 2020). One of the top ethical issues for ethics consultations is disputes between patients/family members and clinicians over EoL treatment (Breslin, MacRae, Bell, Singer, & the University of Toronto Joint Centre for Bioethics Clinical Ethics, 2005). When the patient does not have decision-making capacity, the ethics consultant is tasked with swiftly creating a safe and trusting environment to allow families to discuss the values, preferences, and cultural considerations for their loved ones (MacDonald et al., 2011). A study by MacDonald et al. (2011) demonstrated the value of the clinical ethicist by helping families feel supported in their decision-making. Families expressed concerns over finding a time to meet with the physician and a lack of consistency in messaging from the nurses and the physicians (MacDonald et al., 2011). The ethicist was viewed as a neutral collaborator, in addition to being able to skillfully provide objective feedback to the family (MacDonald et al., 2011). The ethics consultant is not the decision-maker and should not purport to give specific recommendations about ethically justifiable options without a formal consultation process (Tarzian & Force, 2013). A significant challenge that occurs in nursing practice is the limited availability of ethics consultation services. As a result, frequent requests by health care professionals, as well as patients and families are unmet to support their ethical dilemmas (Leuter et al., 2013).

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4.2 Nursing Barriers to Ethics Consultation

Ethics consultations are periodically requested by nurses (Hajibabae, Joolae, Cheraghi, Salari, & Rodney, 2016), but can be requested by any clinician involved in a patient's care (E. F. Baker et al., 2020). Research shows that nurses are typically willing and eager to participate in ethics consultation or ethical advice (Leuter et al., 2013; Lillemoen & Pedersen, 2012; Poikkeus, Numminen, Suhonen, & Leino-Kilpi, 2014). In practice settings with frequent exposure to death, a majority of nurses believe that an ethics committee or consultant should be assigned to address ethical conflicts (Palda, Bowman, McLean, & Chapman, 2005). An intervention, such as mediation, in these stressful circumstances is not straightforward, and ethics committees can be a tremendous asset. Nurses heavily rely on ethics consultation to provide a neutral party to guide the resolution process (Stokes & Zoucha, 2021).

On average, nurses report experiencing more ethical issues than physicians and perceive their ethical dilemmas are more important to themselves than to physicians (Jansky, Marx, Nauck, & Alt-Epping, 2013). Nurses are sometimes the only health care professionals with sustained contact with patients and families and are therefore optimally positioned to notice emerging issues (Milliken & Grace, 2015). However, many nurses are unaware of ethics consultation or committees and lack ethical awareness to identify what consists of an ethical dilemma (Leuter et al., 2013; Robichaux, 2012; Scherer, Alt-Epping, Nauck, & Marx, 2019). A study of 374 nurses revealed that 66% did not have knowledge of an ethics consultation service in their practice setting, 30% had never studied ethics, and 75% reported rarely requiring consultation to handle dilemmas (Leuter et al., 2013). Other studies suggest that nurses are able to recognize the value of systematically dealing with ethical challenges and providing support for moral reasoning and analysis of ethical dilemmas (Lillemoen & Pedersen, 2012; Poikkeus et al.,

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2014), but nurses do not perceive ethics consultations as having any effect on clinical outcomes or provide new reflections for clinical decision-making (Jansky et al., 2013; Poikkeus et al., 2014).

Nurses must be aware that an ethical dilemma exists in order for an ethics consultation to be availed. Ethical sensitivity includes the nurse's "skill or ability to interpret the reactions and feelings of others" (Robichaux, 2012, p. 66). Ethical sensitivity can be challenging for nurses especially in the intensive care setting, which is often focused on the efficient, economical, and procedural aspects of patient care at the EoL (Robichaux, 2012). Ethical dilemmas, in often-fast paced environments, can escalate into intense negative emotions, moral distress, and threaten an ethical work environment (Hamric & Wocial, 2016). Ethical sensitivity is, also, included in Rest's Four-Component Model, which describes the actions necessary for adequate moral reasoning (Rest, 1986). These components are ethical sensitivity, ethical judgment, ethical motivation, and ethical action (Rest, 1986; Robichaux, 2012). Although there is no hierarchical structure to the components, ethical sensitivity and awareness of an ethical dilemma are necessary to even begin deliberation of each component (Milliken & Grace, 2015). However, every component is reliant upon the reasoning of other components. For example, if a nurse lacks the requisite education or knowledge for ethical competence, then the nurse cannot make sound ethical judgments. Even if a nurse possesses ethical sensitivity to recognize the ethical dilemma, in addition to ethical judgment and motivation, the nurse may not possess the moral courage to act due to fear of reprisal or lack of organizational support (Robichaux, 2012). Ramos et al. (2016) also propose a similar model evaluating ethical sensitivity for nurses, defining ethical sensitivity as the ability to perceive that something of moral significance is happening. This sensitivity requires knowledge to identify the conflict, but also the professional capacity to

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distinguish the common dilemma from a moral dilemma and extract the value-laden narratives in the dilemma (Caram, Peter, & Brito, 2019). The lack of the ability to act or reason through ethical dilemmas can lead to moral distress, clinician burnout, and eventually, nurses leaving the profession (Borhani et al., 2015). An additional strategy to support nurses and potentially families is the implementation of a moral distress consultation service (Hamric & Epstein, 2017). During this specialized process, the consultant strives to create a safe space for participants to openly discuss and frame the ethical challenges often resulting in a conflict with personal and professional values (Hamric & Epstein, 2017).

Not all nurses are supportive of ethics consultation and perceive that ethics consultants have a bias towards families. Therefore, nurses experience frustration when the outcome of the consultation does not change the trajectory of inappropriate EoL care (Stokes & Zoucha, 2021). Some studies demonstrate a preference for nurses to deliberate on ethical conflicts among themselves, or within their profession, and sometimes even with friends or family on a regular basis and foregoing the consultation process (Jansky et al., 2013; Scherer et al., 2019). This is understandable given the practice authority hierarchy in health care, which nurses also experience in decision-making within an interdisciplinary ethics committee or during ethics consultations (Scherer et al., 2019). Gordon and Hamric (2006) raise concerns for nurses over the broader political and sociocultural context when requesting an ethics consultation. Requesting an ethics consultation is a form of speaking up about a perceived ethical concern in practice. Some nurses may be retaliated against or viewed as disloyal to the team because they are raising a concern about an ethical issue (Gordon & Hamric, 2006). Power dynamics can also create inequity in gaining access to an ethics consultation or committee. Institutions vary, but some organizations do not have a mechanism for a nurse to request a consultation because it is

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viewed as a medical order, similar to cardiology or surgical consultation. This barrier reinforces the hierarchical structures and subcultures that perpetuate barriers for nurses to exercise moral agency and advocate for patients (Gordon & Hamric, 2006). It is critical that these types of barriers are addressed and removed to create equity among clinicians for easy access to ethics consultation. Ethical dilemmas that are not brought forth for consultation, even though a consultation mechanism was available, can cause even more distress for nurses (Jansky et al., 2013). There are other scholars outside of the nursing profession who are not supportive of ethics consultations and believe that most ethical disputes are due to poor communication and can be resolved by listening to the patient and family (G. Annas & Grodin, 2016). This simplistic approach, however, does not appreciate the values of the health care team, institutions, and other competing factors that may be contributing to the ethical dilemma.

Nurses who are opposed to ethics consultation or do not perceive the conflict resolution mechanism valuable, must not attempt to enmesh themselves in conflict without proper ethical competence to manage the conflict (Cusveller & Schep-Akkerman, 2015). Unfortunately, ethics education and ethical preparation in nursing practice are extremely lacking, and nurses often express feeling unprepared to manage ethical dilemmas (Milliken, 2018). There is a desperate need for programs such as clinical residencies in ethics and other intense didactic education programs specifically designed to focus on increasing the nurse's ability to detect and prevent emerging ethical issues, lead ethics rounds, and serve as liaisons on their respective units (Morley, Field, Horsburgh, & Burchill, 2021; E. M. Robinson et al., 2014). Nurses who lack access to request an ethics consultation may benefit from proactive unit-based approaches facilitated by a clinical ethicist such as nursing ethics huddles, moral distress consultation service, and semi-structured discussions about ethical disputes designed to clarify decision-

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making and strengthen communication, all of which have demonstrated some improvement in nurse's moral distress and moral reasoning (Hamric & Epstein, 2017; Morley et al., 2021; Wocial et al., 2017).

Ethics consultation can be a valuable asset to the health care team when clinicians have participated in, witnessed, or are considering nondisclosed or disclosed limited resuscitation. Ethics consultants can provide education to clinicians about limited resuscitation and identify any hospital policies on limited resuscitation, if they are available (Center, 2019; Munson Healthcare, 2016). Ethics consultants are often consulted after an event has occurred. They may serve as a resource for debriefing after a limited resuscitation event and can provide support for clinicians to examine the root causes of why the limited resuscitation occurred. Disclosed limited resuscitation may also be an option that ethics consultants can offer patients and families when there is conflict regarding potentially inappropriate treatments or DNAR orders. Ideally, ethics consultants assist with establishing mutual goals of care for the health care team and patients, so that limited resuscitation does not occur. However, if this is not feasible, and families are not yet ready to agree to a DNAR order, then ethics consultants can work with clinicians to address moral distress or burnout.

5 Moral Leadership

There are several evidence-based approaches to minimize moral distress in nursing, but only a paucity of research to minimize or eliminate moral disengagement (Fida et al., 2016; Morley et al., 2021). For example, facilitated discussion, self-reflections, narrative writing, multidisciplinary rounds, and consultation service programs are all interventions that target the reduction of nurses' moral distress. However, research is needed to better understand those nurses whose moral reasoning process does not include moral disengagement and those who are

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able to withstand moral disengagement. Even in adverse situations, poor ethical environments, or unethical leadership climates, these nurses can exhibit moral heroism.

5.1 Moral Heroism

As previously discussed, the moral reasoning that drives moral disengagement, and thus the deception in nondisclosed limited resuscitation is a cognitive behavior (Raus et al., 2014). The situation (the group approach to nondisclosed limited resuscitation) often overpowers the individual (the nurse), especially with repeated exposure to the trigger causing the shift in cognitive behavior (the delivery of potentially inappropriate care for patients near the EoL) (Bandura 1999). The process of moral disengagement can be gradual, and people's vulnerability to it is hard to reverse (Damon & Colby, 2015). Shu et al. (2011) found that a morally permissive environment that allows unethical conduct increases moral disengagement, and people seize the opportunity to participate in harmful conduct. The nature of the individual moral agent who triumphs over "compelling situational pressures to behave" is described by Bandura as "moral heroism" (Bandura, 1999, p. 11). Moral heroism occurs when people take responsibility for their actions, remain sensitive to others' suffering, and may even sacrifice their personal well-being when upholding their convictions (Bandura, 1999).

Bandura (1999) proposed that people create social situations, and therefore the circularity associated with the outcomes of these situations can be controlled, especially by people who are strongly attached to their moral convictions and possess the power to resist, thereby changing the outcome. For example, an air force pilot defied commanding orders to massacre women and children during the Mỹ Lai massacre of South Vietnamese civilians in the Vietnam War (Bandura, 1999). Instead, the soldier risked his life to rescue and save as many remaining people as he could. A similar concept exists in nursing known as moral courage (Lachman, 2007). Dr.

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Vicki Lachman defines moral courage as the ability to speak out against something that one considers unethical and does so in the context of fear of reprisal (Lachman, 2007).

Several noteworthy stories of moral heroism exist in nursing all involving zealous patient advocacy that has placed the nurse in danger of physical harm, retaliation, or damage to one's professional reputation. For example, moral heroism was evident when a military nurse who in response to military orders, participated in repeated force-feeding of a detainee at Guantanamo Bay who was participating in a hunger strike (Olsen & Gallagher, 2014). This navy nurse admitted their role in force-feeding but no longer felt that forcing this procedure against another human being was ethical and participation did not align with the professional code of ethics for nurses (Olsen & Gallagher, 2014). This nurse was at risk of disobeying military orders, and thus facing dishonorable discharge from the military ("Nurse who refused to force feed at Guantanamo back to duty," 2016).

Another nurse, Dawn Wooten, filed a whistleblower complaint with a U.S. federal agency after numerous attempts to change the culture in her practice environment (Narea, 2020). Nurse Wooten reported a high number of hysterectomies were occurring against immigrants detained in U.S. Immigration and Customs Enforcement facilities (Narea, 2020). An investigation into this allegation proved that several women had undergone unnecessary gynecological procedures against their consent (Narea, 2020). Wooten faced retaliation through demotion after these complaints. Many of these moral heroism examples involve nurses advocating on behalf of an at-risk population and come with tremendous risk to a nurse's personal and professional reputations. Hamric, Arras, and Mohrmann (2015) describe some of the negative consequences that nurses have faced when speaking up for what they deemed was the morally right action including angry reactions from colleagues, threats of employment

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termination, and alienation in communications with the health care team. This resulted in nurses being ostracized and feeling isolated which fosters a dysfunctional team (Hamric et al., 2015).

Another example of moral heroism occurred in a long-term care facility in North Carolina. Nurse Krista Shalda called the police when a resident in her facility reported that one of the staff sexually assaulted her (B. Ellis & Hicken, 2017b). Despite warnings from Nurse Shalda's manager not to call the police, she adhered to her moral convictions and reported the allegation to the police. Yet, she also acknowledged that she had heard of a similar report against her coworker in the past but took no action (B. Ellis & Hicken, 2017b). Nurse Shalda refused to remain silent even if it meant risking her job. Her moral heroism resulted in an investigation, arrest, and conviction of a staff member found guilty of six sexual offenses against patients (B. Ellis & Hicken, 2017a). However, heroism is not without cost. Nurse Shalda was terminated from her position and remains entangled in legal challenges to resume her employment ("Krista Shalda, Plaintiff v. SSC Waynesville Operating Company, LLC, d/b/a Brian Center Health and Rehab, Defendant," 2019). In each of these cases, harm to patients was evident, yet steeped in an unethical environment and culture accepting of the behavior. Each one of these nurses acknowledged the role they played in the situation yet risked their well-being and professional reputation in response to their patient's suffering. They were able to defy the situation by holding onto their moral convictions and acting on their courage to prevent further harm to their patients. Due to the risk associated with moral heroism, there is a degree of reluctance among nurses to challenge an unethical culture. However, moral heroism serves as an exemplary response for nurses when faced with moral adversity such as participation in deceptive practices.

It is important that individuals at the lower end of the hierarchical chain, such as nurses, are supported by their leaders who exemplify ethical behavior. Nurses who are used to doing

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what their supervisors ask of them and are not encouraged to raise concerns, experience oppression and often lack the courage or psychological safety to speak up (Y. Ma et al., 2021). This is especially important in circumstances where the ethical issues appear to be part of the culture or stem from multidisciplinary challenges. The ethical climate of the work environment that nurses are working in has a significant impact on their moral reasoning (Kyzar, 2016; Sanagoo & Jouybari, 2021). This is supported by Zhoa's and Xia's (2019) work that suggests that exposure to ethical leadership embodying integrity and altruism, reflects accountability in nurses who have a tendency toward moral disengagement to become less likely to use it as a coping strategy.

In an ideal setting, moral heroism or moral courage should not be necessary beyond what is normally expected for good quality care of patients (Hamric et al., 2015). Health care institutions should foster environments that are supportive of doing the right thing and any circumstances when this does not occur should be assessed for unjust power hierarchies or dysfunctional systems (Hamric et al., 2015). Ethical leadership is critical in these environments. Leadership is influential and contributes to an ethical climate and culture and therefore moral heroism is often not needed if the morally right action is already an accepted practice (L. L. Olson, 1998).

5.2 A Pledge for Honesty and Transparency

A pledge for honesty is one approach to eliminate nondisclosed limited resuscitation that is a simple, yet evidence-informed solution for nurses. This is exemplified through a professional code or declaration to morally commit to providing care that is transparent to prevent deception traditionally associated with limited resuscitation (Shu et al., 2011; Zhao & Xia, 2019). A pledge for honesty requires a nurse to sign, pledge, or declare a commitment to ethical behavior. This

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pledge or commitment to honesty may be a modest, but valuable alternative if an ethics committee or other conflict resolution mechanism is unavailable. Shu et al. (2011) found that an intervention as simple as exposure to a moral code or pledge reduces dishonest or harmful behavior because it reminds an individual to expressly connect with and profess their moral convictions. The use of oaths or promise scripts has also proven successful in other fields such as economics (Qin, 2020). Furthermore, simply signing a moral or professional code or declaration to morally commit to ethical behavior (or not to commit unethical behavior) can completely eliminate dishonesty and deception (Shu et al., 2011). For example, nurses could sign or join a pledge online to commit to the nondeceptive care of patients nearing the EoL in an attempt to directly interrupt the moral reasoning process before moral disengagement and ensuing unethical practice can take place. A nurse would pledge, “I commit to delivering EoL resuscitation that is disclosed to patients and families. I will not participate in unethical behavior that is deceptive or hides care or interventions from patients or families”. This pledge of honesty does not suggest that nurses would not commit to transparent and honest delivery of care for other patients or settings but expressly calls out EoL care because it is widely understood to cause significant moral distress in nursing, thus causing the beginning of the cascade of moral reasoning to participation in deceptive EoL care. This recommendation appears simplistic, but it is evidence-based and can be broadly applied in nursing and health care to address the deception that can occur during resuscitation.

6 Recommending Time-Limited Trials

Time-limited trials are a reasonable approach to EoL disputes, and nurses can promote them through transparent communication with families. Dr. Timothy Quill proposed the concept of time-limited trials (TLT) as a mechanism to address disputes in EoL care (Quill & Holloway,

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2011). TLTs are agreements between clinicians and patients or ADMs that set a defined time period for specific medical therapies (Quill & Holloway, 2011). TLTs are broadly advocated in health care and used for life-supporting medical interventions such as mechanical ventilation, enteral feeding, and dialysis (C. R. Bruce et al., 2015). TLT's typically apply to patients with a limited quality of life and a low likelihood of functional recovery (Vink, Azoulay, Caplan, Kompanje, & Bakker, 2018). TLTs involve a five-step framework that includes 1) defining the patient's acute prognosis; 2) defining patient's goals; 3) identifying markers for improvement or deterioration; 4) proposing a defined time frame for re-evaluation; and 5) defining actions for consideration at the end of the trial (C. R. Bruce et al., 2015; Quill & Holloway, 2011).

Although there is minimal empirical evidence on TLT, most TLT's have been studied and implemented by physicians to determine the length of time for a medical intervention to remain. For example, George et al. (2018) studied emergency physicians' use of TLT when initiating emergency intubation. Fung, Slesnick, Tamura, and Schiller (2016) studied medical directors' recommendations for TLT for patients needing dialysis with a poor prognosis, and Chang et al. (2019) studied patient outcomes when physicians implemented a default approach to TLT protocols in the ICU. Notably, research on nurse participation or promotion of TLT's is lacking. C. R. Bruce et al. (2015) studied barriers to initiating and completing TLTs in a multidisciplinary population in the critical care setting, but only 3 advanced practice nurses were studied out of 30 health care professionals.

6.1 Challenges of TLT

TLT's are not widely and formally used for many reasons. Determining the time frame outlined in the fourth step can be ethically complex. This time frame could range from a few days to a few months depending on the patient's prognosis (C. R. Bruce et al., 2015). Vink et al.

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(2018) proposed a TLT framework that is considerate of pre-existing conditions and uses predictive analysis of life-limiting conditions to demonstrate an average time needed for a patient to respond to the treatment. Quill and Holloway (2011) also offer some suggestions for the amount of time for the TLT based on the medical intervention. However, some of them are based on patient preference such as regaining the ability to eat, but most suggest medical variables such as regaining pupillary or brainstem responses (Quill & Holloway, 2011). This measure of function and clinical outcome may be difficult for patients and families to reconcile and contribute to increased decisional conflict in the TLT. VanKerckhoff et al. (2019) found that physicians readily acknowledge the difficulty in establishing the most appropriate time frame for the TLT. Implementing a TLT that is too long can create an emotional burden on families and moral distress in clinicians responsible for delivering care (Vink et al., 2018). Yet, implementing a TLT that is too short risks families feeling rushed to make a decision (likely resulting in death) and clinicians experiencing feelings of providing inadequate care (Vink et al., 2018).

TLT's can also become problematic when there is disagreement among the health care team. EoL decision-making even among the health care team can be challenging in circumstances of disagreement in clinical judgment. Clinicians do not always agree on initiating a TLT, and some may have a disagreement over the amount of time needed for the trial (C. R. Bruce et al., 2015). In a study of multidisciplinary professionals, an advanced practice nurse described her experience with other specialties that have competing interests using TLT's. The nurse stated, "Surgeons...want their patients to survive because they need their numbers to look good." (C. R. Bruce et al., 2015, p. 2540). This quote highlights the challenges in decision-making among the health care team, especially when hierarchical power imbalances exist. Nurses—even advanced practice nurses—typically do not have decision-making authority when

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competing with a surgeon's interests. Sound communication strategies among the health care team help build consensus and portray unification and confidence when delivering the message and care to the patient (Laurent et al., 2017). In addition, families may not be receptive to a proposed timeline for decision-making and may feel pressured or guilty, which can cause more harm to the relationship (C. R. Bruce et al., 2015).

It is important that communication, consistency, and continuity are part of the TLT process. Unfortunately, in many health care settings, these can be barriers to a successful TLT because attending physicians, residents, and clinicians with decision-making authority frequently rotate among hospital units (C. R. Bruce et al., 2015; Ćurković et al., 2021). Therefore, when it is time to reevaluate the TLT, a different set of clinicians are negotiating with the patient and family about how long to continue life-sustaining treatment (C. R. Bruce et al., 2015). A physician described how no one wanted to take responsibility for calling it quits, "We kick the can down the road when there is high turnover among the team." (C. R. Bruce et al., 2015, p. 2540). Consistency and continuity are significant barriers to a successful implementation of TLT's. C. R. Bruce et al. (2015) also found that establishing achievable goals of care was challenging when implementing a TLT. As mentioned, the TLT model designed by Dr. Timothy Quill focuses on the patient's response to medical intervention and uses the TLT to measure the outcomes from these interventions (Quill & Holloway, 2011). Ideally, goals of care are owned by the patient and family. Therefore, goals of care should be created with the guidance of the leader of the TLT and health care team. These goals should be specific to the patient regarding a quality of life, including short- and long-term recovery-oriented milestones (C. R. Bruce et al., 2015). It is important to avoid numerical medical values or hemodynamic variables as outcome

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criteria. Patients and families can become fixated on numbers and fail to see the bigger picture regarding the patient's overall prognosis (Aslakson, 2015).

6.2 Value of effective communication

Communication is a critical factor in the EoL decision-making process. Effective communication enhances trust within the shared decision-making model (Cipolletta & Oprandi, 2014; Ditto et al., 2001). Research regarding challenges in communication between physicians, nurses, and patients or families is substantial (Brooks et al., 2017; Flannery et al., 2016; Hansen et al., 2009; Latour et al., 2009; Özden et al., 2013; Westphal & McKee, 2009). It is generally incumbent on the physician to deliver the message to patients and families regarding a poor prognosis or imminent death in a clear, understandable, timely, and sensitive manner, but nurses are the ones that generally have to maintain the relationship with the terminally ill patient and family (Cipolletta & Oprandi, 2014). Conversations about EoL goals of care are typically performed by attending or resident physicians, although the Joint Commission Standards for hospitals requires only a one-time discussion about advance directives by a health provider including a physician, physician's assistant, advance practice nurse, social worker, pastoral care, or nurse (Commission, 2018; Thurston, Wayne, Feinglass, & Sharma, 2014). Physicians often lack time for in-depth EoL conversations and medical training inherently leads to framing treatment in a more curative than caring approach (Gallagher et al., 2015; Yuen, Reid, & Fetters, 2011). Medical students and resident physicians often report the lack of role modeling in EoL care conversations that contributes to their lack of competence (Yuen et al., 2011).

Overwhelming research has shown that physicians face challenges in EoL transitions to palliative care including poor communication, lack of respect for patient wishes, and inconsistent

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approaches to EoL decision-making (Badger, 2005; Flannery, Peters, & Ramjan, 2020; McAndrew & Leske, 2014; Price, Strodman, Montagnini, Smith, & Ghosh, 2019).

Nurses naturally place an emphasis on the patient, as well as the family or loved ones during an EoL experience, whereas physicians typically emphasize the procedure or medical interventions necessary for survival. MacDonald et al. (2011) revealed that patients and families desire to have factual, transparent, concrete, and accurate delivery of clinical information, rather than a medical opinion. Evans et al. (2020) also found that families value relational elements of care including acknowledgment of suffering, acts of presence, and compassion despite knowing that their loved one's death was imminent. Families focus on language and remember words of empathy and honesty over medical and procedural terms (Nyborn, Olcese, Nickerson, & Mack, 2016). Patients prefer receiving information from a human source but find that physicians are often inaccessible (Neumann et al., 2011). Patients feel that nurses are easily accessible and spend more time explaining information than physicians, which contributes to better patient outcomes (Thurston et al., 2014; J. Young, Eley, Patterson, & Turner, 2016).

Nurses are the most trusted profession and offer a humanistic approach to care. Nurses feel that therapeutic and compassionate communication is an obvious and inevitable part of their role and responsibility because they typically spend the most time with patients (Ćurković et al., 2021). Nurses are uniquely privileged with the time, general rapport, trust, and skills to communicate with families about EoL care. Nurses are skillfully able to provide practical and realistic goals that patients and families are able to understand and convey to physicians (Gallagher et al., 2015). This is a skill that continues to develop as ethical comportment develops. Nurses are able to draw new understandings from clinical experiences and ethical dilemmas through thoughtfulness and reflection and can adapt their practice and grow from

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adversity (K. Ma, Wright, Vanderspank-Wright, Peterson, & Carnevale, 2020). Nurses also develop a special intuition (a gut feeling) that is strengthened with experience related to patient care, navigating organizational challenges, and a broader social-cultural content (Ćurković et al., 2021). Nurses develop “social knowledge” by spending time with patients and families and learning about the patient as a person, rather than an object or disease (Benner, 1991; Rodney et al., 2013). These are important factors for nurses as they cultivate ethical knowledge and are critical to moral action (K. Ma et al., 2020). It is important to note that not all professional nurses possess these skills (Disler et al., 2021; Griffiths, 2019). Therefore, palliative and ethics education and courses are critical for nurses to advance their expertise and confidence when communicating with patients and families about EoL goals of care (D. White & Meeker, 2019). These courses should consist of clinical knowledge and skills on patients’ cultural and health situations, therapeutic communication, and ethical and legal principles (Fliedner et al., 2021).

6.3 Nurse-led TLTs

Nurse-led initiatives offer a compassionate, patient and family-centered approach that can improve quality of life and increase patient satisfaction, in addition to providing a conduit between the patient and physician (Ora, Mannix, Morgan, & Wilkes, 2019). Nurses typically serve as intermediaries and patient advocates at the EoL (I. Fourie & Meyer, 2014). Research also suggests that nurses may even coax physicians in making decisions about withholding or withdrawing potentially inappropriate treatment (Gallagher et al., 2015). This coaxing may bring about a more realistic understanding and acquiescence from physicians to recognize the inappropriateness of curative treatment at the EoL (Gallagher et al., 2015). Nurses are ideally positioned to lead TLTs. Nurses have greater flexibility in scheduling and demonstrate a higher continuity in care than other clinicians. As a result, nurses are able to create a trusting

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relationship and rapport with families to foster communication and increase patient and family satisfaction in EoL care throughout multiple iterations of the TLT.

There is considerable research that shows the value of nurses when communicating with patients about advance care planning, such as advance directives (Chan et al., 2018; Houben et al., 2019). However, these studies generally involve nurses going out to patients' homes and communities in advance of hospital admission to discuss EoL care. While this is beneficial, patients and families need "in the moment" or "crisis" support when EoL care conflict arises in the acute care setting. Mack et al. (2012) found that EoL discussions often initially occur during acute hospital admission. Nurses are not utilized in this manner, but some nurse-led EoL communication programs have shown significant promise towards this innovative solution (Chen et al., 2021). In a recent study, nurses (who were not the primary caregivers), consulted with a critically ill patient's care team to learn about the clinical status and prognosis (Chen et al., 2021). In this nurse-led program, the nurse also assessed the family or alternate decision-maker's emotional state and experience in the ICU and provided emotional support if needed. The results of the study demonstrated that this nurse-led communication program was feasible, acceptable, and effective and demonstrated increased satisfaction rates from ADMs with this intervention (Chen et al., 2021). This nurse-led approach also reduced decision-making conflict among the health care team and improved concordance between the alternate decision-maker and clinicians (Chen et al., 2021).

Caring for patients at the EoL is an emotional and often stress-filled time for families, caregivers, and nurses. It is also important that nurses are compensated for these efforts, especially given the economic impact that they have on larger health care institutions. Nurses face tremendous demands on their time when providing EoL care. Nurses must provide physical

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symptom control for patients, emotional care for patients, as well as emotional support for families (D. White & Meeker, 2019). Researchers and nurse leaders should consider the use of advanced practice nurses to fulfill the leadership role of the TLT. Clinicians desire a leader who can take ownership of a TLT and ensure its completion, which is critical to its success. It is critical that the nurse in this role does not have multiple duties outside of their designated role as an EoL care and TLT advocate. The paucity of research that has been performed finds that nurse-led programs result in cost savings for health care organizations, especially related to a reduction in unwanted or unnecessary EoL care (Sellars et al., 2019). Palliative care interventions have also been shown to reduce ICU length of stay, therefore TLT's could also reduce cost by reducing the length of stay and aggressive medical interventions (Vink et al., 2018). Despite the lack of overwhelming evidence, it is expected that an individualized approach to EoL care preference, incorporating patient and family values will decrease conflict and provide concordant care—thus reducing the cost of inappropriate aggressive life-sustaining treatment. Research on the implementation and impact of nurse-led TLTs is warranted.

Overall, TLT can promote efficient communication, develop consensus in EoL decision-making, and set realistic boundaries for appropriate treatment based on a patient's value-laden goals of care (Chang et al., 2019). TLTs also offer families time to grieve, process, and realize that although time is often of the essence for many critically ill patients, the health care team is willing to allow the intervention time to work, which respects hope for patients and families. Nurse-led programs are an innovative approach to address EoL, and evidence suggests positive patient outcomes and positive economic impact. This approach directly addresses the challenges that families or ADMs and nurses face with time constraints and EoL decision avoidance and reluctance.

7 Conclusion

There are several recommendations to eliminate or reduce nondisclosed limited resuscitation. These include interventions that are designed to promote transparency and minimize conflict in EoL decision-making. These include tailored resuscitation orders that must be properly documented and transparently communicated. Family presence at the bedside is an immediate intervention that directly addresses the potential for nondisclosed limited resuscitation to occur. Although it is not widely accepted, policy guidelines should be implemented to help support this practice which has been shown to benefit families dealing with grief. Ethics consultation services should also be encouraged because they can contribute to increased patient and family satisfaction. Interventions such as express commitments to nondeceptive EoL practice and moral leadership that fosters an ethical environment are strategies that may interrupt the nurse's moral reasoning process from developing into moral disengagement, and therefore eliminating unethical behavior such as nondisclosed limited resuscitation. Lastly, nurse-led TLTs are another proposed intervention to minimize conflict in EoL decision-making and more research is warranted.

Chapter Seven: Conclusion

The EoL is the paramount moment when a health care professional must apply knowledge and skill to provide the most optimal care for a patient. The magnitude of decision-making is more important than any other time in the lifespan. The clinical, ethical, moral, and legal debates around EoL care are justly scrutinized because the potential outcome of death is irreversible. The purpose of this dissertation is to describe the multiple competing ethical principles that contribute to disputes in EoL care and ethically justify the moral agency that nurses experience when encountering opportunities to perform limited resuscitation. Each chapter provides a normative argument about why limited resuscitation that is disclosed to patients and families is a morally permissible approach to EoL and that nurses are morally permitted to participate in this EoL option so long as it is done transparently, and families are notified to promote shared decision-making and eliminate deception.

Chapter One outlines the history of resuscitation, including the evolution of limited resuscitation and the ethical principles that are considered by ethicists who support or oppose this practice. CPR was initially created in the 1960s with the intent to revive patients suffering from acute injury. However, CPR evolved into a life-saving practice for all patients despite the prognosis. Ethicists soon began to debate the appropriateness of life-saving efforts in patients with a terminal illness who experienced suffering and trauma only to live a short time after resuscitation efforts. Resuscitation efforts became even more complex and included traditional components of CPR, in addition to advanced medical technologies such as intubation, mechanical ventilation, and intravenous medications. Before the creation of DNAR orders, clinicians created pseudo-solutions to avoid resuscitation of terminally ill individuals, such as slow codes, or show codes where no effective action was taken, when a patient experienced a

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cardiac arrest. Finally, hospitals created DNAR policies to promote a transparent way to document EoL preferences and promote patient autonomy in decision-making. Although DNAR orders were created to alleviate some of the ethical complexity about whether to perform CPR, they were impractical to implement. A lack of clarity existed about who the ultimate decision-maker was when a DNAR was in question. Patients and families perceived a false dichotomy existed between CPR and DNAR orders, without understanding or considering the clinical efficacy of resuscitation. Clinicians also expressed confusion about when and who to resuscitate, which led to limited forms of resuscitation. Limited resuscitation initially began as a way for clinicians to deal with the ambiguity in hospital policies and laws about CPR but has been acknowledged in medical literature for over forty years. Limited resuscitation is a cardiopulmonary resuscitation (CPR) effort where full pharmacologic and mechanical intervention is not used, or the length of the resuscitative effort is shortened. Limited resuscitation efforts are often done for the benefit of the family, and clinicians do not intend for the patient to survive. Limited resuscitation efforts were typically not discussed with families and became shrouded in secrecy and deception. The veil of silence around limited resuscitation has prevented adequate research about its cause, purpose, meaning, prevalence, or consequences.

A summary of existing literature reveals five types of limited resuscitation including chemical codes, partial codes, tailored codes, show codes, and slow codes. Slow codes are the most familiar form of limited resuscitation, and ethicists have debated the moral permissibility for years. Slow codes are limited resuscitation efforts that are performed slowly and associated as a symbolic effort to “do everything” for families. Slow codes are typically associated with deception because patients and families are not made aware that this resuscitation tactic occurs. However, slow codes were not initially intended to be deceptive actions. Slow codes originated

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because clinicians lacked organizational and national guidance on addressing the clinical, legal, or ethical appropriateness of resuscitation. They were not always performed without patients or family's knowledge. Overtime, slow codes were not disclosed to patients or family members because clinicians were unsure how to respond to an increase in the demand for full resuscitation for patients with terminal illness and poor prognosis. In the 1980s, the mainstream media and public became aware of slow codes, and significant opposition resulted. Despite this exposure, very little research was conducted to better understand why slow codes occurred. Scant research reveals that nurses and physicians historically believed that nondisclosed slow codes were unethical because they did not promote a transparent understanding of EoL medicine and led families to believe that regular standards of practice were conducted to save their loved ones. This perspective has shifted over time, and recent research reveals that some clinicians believe it is ethically justifiable to perform slow codes if the patient has a poor prognosis, but that the families must be made aware that it is happening.

Nurses are squarely at the crux of the dilemma, as they are uniquely positioned and highly skilled to deliver EoL care to patients and support families. Chapter Two analyzes the nurses' role in navigating these complex EoL decisions. Nurses' development as moral agents is formed through their professional identity and ethical comportment. Becoming a nurse who has a firm grounding in moral character, skillful ethical comportment, skilled know-how as a nurse, and professional identity is important when encountering the complex ethical challenges of EoL decision-making. Ethical comportment is an expected part of being a professional nurse, and the more nurses are exposed to ethical conflict or dilemmas the more confident, skilled, and attuned they become in understanding and recognizing ethical distinctions in practice. Ethical comportment allows nurses to identify patients as a person in need of recovery with

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vulnerability, rather than as a diagnosis. This is especially critical when patients and families are reflecting on their mortality and values and preferences in the manner of dying.

Ethical comportment and moral agency are critical in the moral reasoning process because nurses are expected to carry out clinical orders directed by physicians, and often have little to no input into the EoL decision-making process. Family or ADM demands for EoL treatment often supersede the physician's recommendations. Demands for potentially inappropriate treatment may result in patients near the EoL experiencing interventions that are physically invasive and painful. Therefore, nurses must decide whether to fulfill the physician's orders for full resuscitation they perceive are aggressive, or advocate for minimizing patient harm and suffering by performing nondisclosed limited resuscitation. In these circumstances, nurses recognize that nondisclosed limited resuscitation is against the ADM's demands for inappropriate treatment. When nurses and other clinicians perform limited resuscitation, without the patient's, families, or ADM's knowledge, it is considered a deceptive act. Therefore, nurses have a choice to align their identity with their ethical behavior or comportment in practice. This behavior can reflect good or bad nursing practice and can manifest through deception or coercion. Nursing practice that is deemed deceptive, and therefore ethically unacceptable can jeopardize patient safety and trust in the nurse-patient relationship.

Deception in nursing practice is evident throughout practice settings and often occurs as a way to avoid unpleasant information or to prevent suffering. Most nurses deem that deception in nursing is unethical unless it is done in the interest of the patient, to relieve stress, or for patient safety. There is a strong societal expectation that nurses are honest and trustworthy professionals, and therefore nursing practice in opposition can threaten the nurse-patient relationship.

Deception associated with limited resuscitation occurs when families are under the impression

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that full measures were taken to keep their loved one alive— when in actuality, they were not. Nondisclosed limited resuscitation, such as nondisclosed slow codes or nondisclosed chemical codes are not likely to be documented in the medical records. Yet partial codes, and certainly tailored codes, are documented because discussion and agreement have occurred with the health care team and ADM. When nurses experience the option to demonstrate good or bad ethical behavior when an option to deceptively hide limited resuscitation occurs, they must consider whether the lie benefits or burdens the patient or family, the nurse-patient relationship and the professional integrity and moral agency of the nurse. When nurses are forced to administer aggressive EoL care that is harmful to patients but is in line with the ADM's decision and physician's orders, a conflict exists within a nurse's professional ethics. There are numerous approaches to analyzing deception. However, many of these approaches are flawed because they do not consider other factors that impact health care or the specific conflict including family and social factors that affect health. The overarching goal in the delivery of health care for nurses is to provide care that is communicated honestly and transparently and avoid hiding care that can damage the trust and integrity in the health care system. Limited resuscitation, including disclosed slow codes, that are performed with the patient's or family's knowledge, and ideally with their direction for values and preferences is not deceptive. Therefore, nurse participation in disclosed limited resuscitation is morally permissible so long as it is performed transparently, without deception.

There are numerous ways to address conflict while remaining honest and transparent. Nudging is an evidence-based communication technique that is essential in mitigating complex ethical dilemmas. Nudging targets the quick and unconscious thought by presenting what is perceived as the optimal choice in a subtle but deliberate manner to encourage an individual to

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make a specific choice. Although there are scholars that oppose nudging because it promotes an interest that may not reflect the individual's ability to think with their free will, it encourages an indirect behavior designed to influence the decision-making of an individual without coercion. Nudging can be an ideal conflict resolution strategy in EoL conflict because all ethically appropriate medical interventions are presented to patients and families. Yet, the most desired options are presented first and are described in a more appealing manner. There are no attempts to hide or deceive patients. Nudging does not restrict choice or freedom and is easy to resist. Patients and families rely on nurses to help inform their decision-making. The goal of nudging is to reach a shared decision for appropriate EoL care and minimize conflict. Nudging allows clinicians to provide families with a choice of "yes" when presenting the least harmful components of resuscitation in an appealing way, and "no" to the more harmful and vigorous interventions. Resuscitation becomes limited, but more importantly, tailored in a way that benefits the patient-family unit and avoids potentially inappropriate care. Nurses and other clinicians must be sensitive to the grief and bereavement that families are experiencing when their loved one is nearing the EoL when attempting to apply nudging to manage conflict. Nudging is an ethically defensible approach to EoL conflict that can promote choice through patients' values and preferences and minimize deceptive limited resuscitation.

EoL conflict cannot simply be evaluated from the perspective of the nurse or clinician. Chapter Three analyzes how conflict during EoL decision-making arises due to a myriad of contributing factors. Patients and their families or ADMs experience vulnerability and a lack of positioning of power in decision-making. Patients may have a poor prognosis and unlikely chance of survival, yet efforts by clinicians to provide palliative and comfort care are often resisted by families because mistrust, low health literacy, and poor communication can plague

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the decision-making process. It is critical for clinicians to consider not only the patient's values and preferences but also those of the patient's family or loved ones. The respect for patient autonomy is a foundational bioethics principle that embodies the patient's freedom and ability to make choices without controlling influences. In the U.S., respect for patient autonomy is a desired outcome for clinicians when delivering care or considering medical interventions. Patient autonomy can become complex when a patient no longer has decision-making capacity and another individual must make decisions on the patient's behalf. Designated decision-makers are often family or loved ones who know the patient's values and are responsible for making these decisions in a way the patient would have preferred. ADMs consider many factors including a patient's religious or spiritual beliefs, personality, and quality of life. The bioethical principle of patient autonomy is subject to scrutiny because of the focus solely on individual decision-making. Relational autonomy is a feminist ethics approach to decision-making that incorporates social and cultural considerations based on the notion that people are socially embedded beings and make decisions based on their relationships in which they are interdependent. Decision-making at the EoL is a highly emotional time, and people make decisions based on their emotional response, grief, and their social location. Relational autonomy allows for what may be perceived as irrational thought but promotes that acceptance of an emotional disposition that may affect a person based on life circumstances or other social determinants such as race, class, or gender. Relational autonomy also allows a person to become vulnerable and rely on another for decision-making to help inform their choices in a rich and social context.

Vulnerability is a key component in the nurse-patient relationship and a contributing factor in EoL conflict that must be acknowledged. Every person has the potential to become vulnerable and therefore is at risk of harm. Patients may be vulnerable due to illness and the need

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or reliance on care for healing or to alleviate suffering. Families are also vulnerable during this time when they feel that the EoL situation is out of their control. Families or ADMs attempt to protect their vulnerability by requesting treatment that is aggressive or clinically inappropriate as a means to regain control of the situation. Nurses are well-positioned to support a family's vulnerable state when their loved one is facing impending death. This support can serve as an antidote to the erosion of trust in the nurse-family relationship and mitigates conflict during this emotional time. The erosion of trust in health care is another contributing factor to EoL conflict that negatively affects patients who may avoid or delay seeking health care. Mistrust is common among historically disadvantaged populations and can lead to a belief that anything less than aggressive care is discriminatory.

Low health literacy is also a contributing factor that contributes to EoL conflict. Family members may not understand mortality, the disease process, or treatments, and this can impact decision-making. Nurses and other clinicians must communicate information in an effective way that is appropriate for decision-makers and reduce health literacy barriers. It is important for nurses to allow family members time and space to grieve the impending loss of their loved one. Decision-making during this crisis is often time-sensitive and family members are expected to make a life-altering decision rapidly. Family members may ask for additional time to make decisions about resuscitation options for their loved ones. When requests for additional time to make decisions are ignored or denied, families are reluctant to withdraw care or agree to a DNAR order. Nurses should help families shift the perspective of time in quantity such as in days or weeks, to time in quality reflected by values and goals of care. Respect for cultural, religious, and spiritual considerations is equally important in EoL decision-making. A lack of respect for a patient or family's beliefs can cause a breakdown in communication about the

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appropriateness of life-sustaining treatments. People have different values that are influenced by their culture or religion. Nurses have an ethical commitment to respect these values and incorporate them into the decision-making process. Patients and families are dealing with a multitude of factors that contribute to their EoL decisions, including grief associated with death and dying. When demands for life-sustaining treatments are made against medical advice, transparent, effective, and culturally sensitive communication is critical to create and maintain trust in the relationship and to mitigate conflict. Limited resuscitation, that is disclosed to patients and families in a transparent manner can be an intermediate action that allows families to express and preserve their values while respecting the expertise of clinicians to deliver appropriate EoL care. Ideally, patients and families will work with the health care team, and the ethicist, when necessary, to tailor the limited resuscitation effort in a way that meets the goals of care for the patient and the health care team by avoiding physically aggressive resuscitation efforts that are harmful to the patient and morally distressing to the clinicians. Nurse participation in disclosed limited resuscitation is morally permissible because it acknowledges a family's vulnerability and autonomy, establishes trust between nurses and families, and is a beneficent act that respects cultural humility and allows families or ADMs to have an active role in EoL decision-making.

Disclosed limited resuscitation can be an effective method to mitigate conflict between families and clinicians. Physicians may be fearful of lawsuits or legal sanctions when they accede to family demands for clinically inappropriate treatment for their loved ones at the EoL. Chapter Four analyzes the causes for legal uncertainty and confusion about EoL interventions when conflict arises. State laws and case outcomes vary, setting inconsistent legal precedent. Some courts have determined that nurses were legally liable for failing to perform CPR when the

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appropriateness of emergency medical intervention was unclear. Yet, other courts have determined that nurses were liable when they did perform CPR in similar circumstances. Courts have not yet determined the legality of limited resuscitation. Limited resuscitation is a clinical approach to care that in most circumstances would not need a determination of legality. However, because CPR does not require informed consent, yet in many states, a DNAR does require informed consent, any proposed laws could add significant confusion to an already murky landscape. Legally, disclosed limited resuscitation can provide a legal resolution for clinicians when unilateral DNAR orders are not allowed. Hospitals or health institutions implementing disclosed limited resuscitation should not require consent for participation but must provide notice of this EoL option. The development of limited resuscitation policies must include disclosure through patient and family notification, provide clinicians with education on definitions of limited resuscitation, identify safeguards to protect patients against coercion and deception, and require debriefing when limited resuscitation occurs. Although clinicians are expected to act within the law, they are not legal experts and should not be expected to keep up with the changing laws and varying court case outcomes. The variability in EoL cases and laws contributes to confusion and uncertainty about when to perform resuscitation and what forms of resuscitation are clinically, ethically, and legally appropriate. Therefore, limited resuscitation, that is disclosed to patients and families, is morally permissible because it does not defy existing laws, and in fact seeks to mitigate moral and legal uncertainty around when and if resuscitation should be performed.

Chapter Five described how factors outlined in the aforementioned chapters contribute to the nurse's moral agency and moral identity. EoL conflict over the ethical appropriateness of resuscitation for patients with a poor prognosis negatively affects nurses. Research

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overwhelmingly demonstrates that moral distress is a part of nursing practice. Nurses who have high exposure to death and dying have higher levels of moral distress, which can lead to burnout and poor retention in the profession. Nurses experience feelings of anger, resentment and they can become morally disengaged from their personal and professional morals. Moral disengagement is activated and triggered by negative emotions such as moral distress or threats to nurses' moral identity. Nurses in this stage of moral reasoning can perform nondisclosed limited resuscitation without guilt and without notifying the family or ADM. In fact, nurses feel justified in their actions even when they include deception. Moral disengagement is a protective and self-regulating psychological behavior that allows clinicians to distance themselves from the moral expectations of the clinical situation. Moral disengagement can manifest in many ways including euphemistic labeling of patients that blames them for the circumstances in which they find themselves. Moral disengagement can also be exhibited through the displacement of responsibility when nurses blame physicians or other colleagues for the failure to manage conflict at EoL, which results in the perception that there's no other option but to perform nondisclosed limited resuscitation. Even though nurses may not feel guilty performing half-hearted efforts at CPR against a patient or family's wishes, it should not be done. Limited resuscitation must be performed with the patient and family's knowledge and communicated in a transparent way. Nurse participation in disclosed limited resuscitation is morally permissible because it mitigates threats to a nurse's moral identity and ethical comportment by eliminating physically intrusive acts that cause suffering, which can contribute to moral distress, and moral disengagement. Performing CPR that is less rigorous and reduces patient harm could reduce moral distress for nurses entrenched in EoL conflict.

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Disputes in the delivery and ethical appropriateness of EoL care have existed for decades, yet limited resuscitation has never been accepted as a morally justified approach to mitigate this conflict. This reluctance to consider limited resuscitation as an option to manage EoL conflict stems from traditional misunderstandings about limited resuscitation and the deception associated with not informing patients or families when it occurred. However, research suggests that limited resuscitation is occurring in health care practice. In some organizations, it happens with medical orders and patient and family involvement, and in others, it is still done deceptively without documentation or ADM or family notice. Chapter Six highlights several approaches to eliminate or reduce nondisclosed limited resuscitation and mitigate conflict in EoL disputes. Nurses and other clinicians wishing to participate or implement limited resuscitation should do so with patient and family involvement. Patients, or ADMs when appropriate, should be given the clinically appropriate options for resuscitation and other life-sustaining interventions and provided an opportunity to select which choices would be consistent with the patients' and families' goals and values. These orders for EoL care interventions should be tailored to their needs and documented in a transparent way for the health care team. When possible, families should be an integral part of the dying process, including being present when resuscitation or limited resuscitation occurs. The presence of family members during resuscitation does not impede clinical care, increases family satisfaction, and families may be less likely to sue when they witness resuscitation efforts. Family presence during resuscitation can potentially reduce the prevalence of nondisclosed limited resuscitation because clinicians are less likely to perform acts of deception when they are observed by others. Family presence fosters relational autonomy and can also minimize conflict at the EoL because family members can witness everything that was done to save their loved one.

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Limited resuscitation efforts, regardless of if they are disclosed, arise out of a disagreement over EoL patient goals of care between the health care team and family members or ADMs. It is important for nurses and other clinicians to eliminate or minimize EoL conflict and therefore eliminate the need for limited resuscitation. Ethics consultation is an obvious, yet underutilized and under-resourced option that clinicians can use to help mitigate EoL conflict and increase family satisfaction in the patient's dying process. Most acute care hospitals have some ethics consultation mechanism that can help facilitate conflict resolution and bring a non-interested third party to help amplify the voices of all stakeholders. Not all nurses are supportive of ethics consultation and perceive consultants as being biased towards family members. Nurses who are opposed to ethics consultation must not attempt to resolve conflict alone. Higher education institutions and health organizations should provide ethics education and conflict resolution communication skills to all clinicians to support the management and reduction of ethical EoL disputes.

Nurses spend most of their clinical time at the bedside with patients and families and therefore are uniquely privileged to serve as intermediaries and advocate for patients at the EoL. Nurses can create a rapport and develop trust with patients and families to increase their satisfaction and foster communication. Nurse-led time-limited trials offer a compassionate EoL option that addresses family's requests for additional time to grieve and process the impending death of their loved one. Nurse-led time-limited trials leverage the trust that patients have in nurses and utilize the EoL communication skills that nurses possess. Time-limited trials help patients and families identify goals of care and give guidance for appropriate delineations of time to meet these goals. Time-limited trials should not be measured by laboratory values, but through patient and family member identified goals to achieve desired outcomes. Nurse-led time limited

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trials directly address the challenges that families or ADMs face with avoidance and delays in EoL decision-making. Nurse-led time limited trials support communication and reduce conflict between the family and the health care team, thus reducing the likelihood that nondisclosed limited resuscitation would occur.

Lastly, moral leadership and individual commitments to professional ethical practice are simple, yet effective ways to interrupt the nurses' moral reasoning and therefore prevent moral disengagement and deception in nondisclosed limited resuscitation from happening. Moral leadership can be exhibited through moral heroism or moral courage but can come with considerable risk to the nurse for raising or exposing an issue that is understood to be unethical but is acceptable in the work culture. Many nurses have advocated for patients within an organizational culture that did not support ethical practice. Nurses who exhibit moral heroism often face retaliation, termination, and alienation from colleagues, but remain steadfast in their personal and professional convictions. Nurses who advocate for patient's safety, dignity, and respect for autonomy, and are able to successfully protect them from aggressive and potentially inappropriate care at the EoL avoid the opportunity for limited resuscitation to occur. Nurses are able to leverage their trusted intermediary position with families or ADMs and advocate for DNAR orders, hospice, and palliative care measures. Nurses can also address the potential for deceptive nondisclosed limited resuscitation by pledging to practice honestly and transparently through an oral or written commitment to ethical and honest practice. Although this is a modest approach, it has been demonstrated to be effective in nursing and non-health professions.

Families and ADMs play a central role in their loved one's death experience, and this in itself can be challenging for the health care team. The social denial of death, which is rooted in a lack of knowledge about CPR and technological advances, poor communication about life

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expectancy, religious or cultural values, and mistrust in the health care system, results in family demands for unnecessary life-sustaining treatments. As a result, nurses have a profound obligatory feeling to perform inappropriate care, balanced with the conflicting role as a patient advocate, which leads some nurses to participate in nondisclosed limited resuscitation that may be deceptive in nature. Nurses are especially vulnerable to the erosion of moral and professional integrity due to the close proximity of care provided to patients at the EoL including repeated exposure and participation in treatment perceived as inhumane, unbeneficial, and even potentially harmful. These complex ethical issues at the EoL can lead to conflict and disagreement between families and clinicians. In circumstances when clinicians and families cannot reach a consensus over the patient's EoL care plan, ethics consultation, nurse-led time-limited trials, and other conflict resolution approaches are essential components to ensure an optimal EoL experience. These conflict resolution efforts, if successful, can eliminate or reduce the prevalence of nondisclosed limited resuscitation. However, when conflict cannot be resolved by these efforts, nurses and other clinicians sometimes perform nondisclosed limited resuscitation attempts that are deceptive and have a minimal intention for patient survival.

This dissertation offers a novel approach for nurses to address the conflict between clinicians and families over potentially inappropriate EoL goals of care. Nurses are integral to the delivery of EoL care, whether it is through compassionate comfort care or rigorous full resuscitation. The historical structure of laws and court cases have created a false dichotomy of choices at the EoL between full resuscitation and DNAR. Clinicians created an "in-between" solution with limited resuscitation that has traditionally not been disclosed to patients and families and therefore is considered deceptive. This dissertation offers to reframe limited resuscitation as a new EoL option that is transparently communicated to families in culturally

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appropriate ways to nudge family members towards the acceptance of choosing the least harmful EoL interventions that preserve dignity and avoid suffering for their loved ones. Disclosed limited resuscitation respects family's or ADM's relational autonomy, through acknowledgment and consideration of their emotional state and grief. Disclosed limited resuscitation is a beneficent act that ideally, can allow families or ADMs to have an active role and make deliberate decisions about their loved one's EoL experience. Disclosed limited resuscitation can serve as an option to meet the EoL goals of care and can be achieved through tailored codes and must not be performed deceptively. The elimination of deception can build trust, mitigate nurses' moral distress, preserve patient autonomy, and cultivate a shared acceptance of limited resuscitation as a morally permissible EoL option.

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