

Spring 1-1-2017

The Ethics of Futility Across the Age Continuum

Katherine D. McCord

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THE ETHICS OF FUTILITY
ACROSS THE AGE CONTINUUM

A Dissertation

Submitted to the McAnulty Graduate School of Liberal Arts

Duquesne University

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

By

Katherine D. McCord, MSN, RN, NEA-BC

May 2017

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2017

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ACROSS THE AGE CONTINUUM

By

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Approved March 28, 2017

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ABSTRACT

THE ETHICS OF FUTILITY ACROSS THE AGE CONTINUUM

By

Katherine D. McCord, MSN, RN, NEA-BC

May 2017

Dissertation supervised by Professor Gerard Magill

Much has been written on the topic of medical futility with reports of its existence dating back to the time of Hippocrates. However, the majority of the research on the topic has been on the adult population. Very little literature addresses the presence of medically futile treatment across the age continuum identifying issues that impact neonates, pediatrics, as well as adults.

This dissertation addresses the gap in the literature by considering the ethical problem of medical futility across the age continuum. By addressing the common thread of futility, there is an imperative for a call to action that encompasses the span of organizational ethics. This span not only includes the clinical and professional ethics, but also the business ethics.

A broad review of the literature on both medical futility and moral distress was accomplished. This yielded an integrative approach to the ethics of medical futility at the end-

of-life across the age continuum as well as its effect on the moral distress of the nurses caring for these patients.

Findings indicate that medical futility, or inappropriate medical treatments at the end-of-life, are to be found in all critical care units across the age continuum. Although there are commonalities, each age group contends with ethical dilemmas surrounding the ethics of inappropriate medical treatments that are specific to their age group. The inappropriate medical treatments are not only the number one cause of moral distress in nurses, but also create moral distress for physicians and other allied health professionals.

Increasing the conversation across the age continuum, that begins in nursing and medical schools, is needed to increase the awareness of medical futility and develop strategies to confront it. Improving communication, plus the use of advance directives and palliative care for all age groups, holds the greatest hope for the future in minimizing futile treatments at the end-of-life.

DEDICATION

“Were there none who were discontented with what they have, the world would never reach anything better.”
Florence Nightingale

I dedicate this dissertation to my loving and supportive family. First, my husband John, my toughest critic/reader, who kept me in line when my medical jargon and hyperbole got out of hand, as well as reminding me to take, “one bite at a time”. I appreciate your love and support. I can’t promise that I will cook more, but I can promise that I won’t be too busy because of school work. Second, to my children, Jennifer, Jeff, Matt and their spouses Mike, Anne, and Kate who altered plans, celebrations, and changed their lives around based on my reading, writing, and traveling to Pittsburgh. I appreciate you and your words of encouragement along the way. Finally, to my late parents who once worried I would not make it through kindergarten. I wish they were here to share my Ph.D. with me as all their efforts continue to be a work in progress. I thank them for their unconditional love and instilling in me the belief that I could do anything I set my mind to.

ACKNOWLEDGEMENT

“I can do things you cannot do, you can do things I cannot; together we can do great things.”
Mother Teresa

It is with immense gratitude that I acknowledge the following individuals who encouraged, supported and often “held my hand” as I took this Ph.D. “journey”. I never would have made it without you.

To Dr. Gerard Magill, my advisor, mentor, and dissertation director for your guidance and encouragement. I so appreciate your vast knowledge, experience, wisdom, and patience. You inspired me by pushing, when I needed that push, but also left me to forge on my own building my confidence level. Thank you for being so available when needed. To Dr. Henk ten Have, department chair and dissertation committee member. I am thankful for your dedication to medicine, research, ethics, and global health which provided information for my personal research for this dissertation topic. I appreciate your valued insights—you taught me so much. To Dr. Joris Gielen, dissertation committee member, for your keen ability to help me question the status quo and to look for the unspoken questions and answers in all my research.

To Glory Smith who not only encouraged, listened, and advised, but had a way of calming my out of control type A personality when it went into overdrive. I appreciate your vast knowledge with answers of “what do I need to do?” and “how can I fix that?” that were so often asked.

To my departed siblings—two sisters and a brother. You have taught me love, honesty, and integrity all of which I was not always willing to learn. Thank you for helping me become who I am today. I believe I would have made you proud.

To my fellow associates and Sisters of Charity who not only offered prayers on my behalf, but also shared wine with kind words of encouragement and laughter.

To my many physician colleagues and friends who cheered me on, never failing to offer words of support and reassurance. A special thank you to Jeffrey--your unending encouragement plus your enthusiasm and intellectual conversations served to spurn me on to reach the finish line.

To all my fellow classmates, especially Carrie, Chrissy, and DiAnn. We started as classmates and became friends offering words of support and friendship, as well as stimulating conversation, sharing not only our school lives, but personal lives as well. You all helped me more than you will ever know.

Finally to all my dear friends, nursing classmates, high school classmates and especially to Victoria, Bonita, and "Sam". You saw me at my worst, when self-doubt was at its highest, and personal concerns were getting in my way. I so appreciated your humor, the shared martinis, and candid conversations that always helped me see that "this too shall pass".

To all of you, and to those that I have failed to mention, I acknowledge and appreciate you for your contribution to this journey. Your faith in me kept me grounded and focused on the goal. Even though it is my name on the dissertation, it, indeed, takes a village. I am so thankful for each and every one of you.

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Chapter 1: Introduction

The benefits of medical advances and new technologies can also bring burdens to the populations across the age continuum that raise a variety of ethical dilemmas. These ethical dilemmas are most evident with regard to the debate on futile treatment, especially in critical care at the end-of-life, which affects all ages across the continuum. These dilemmas related to futile treatment have contributed to increased suffering, escalating costs, and depletion of resources, both human and material. In addition, futile treatment has been identified as one of the major contributing factors, or root causes, of moral distress in nurses. This dissertation addresses the ethics of medical futility in the critical care environment, at the end-of-life across the age continuum, in order to enhance quality patient care and diminish moral distress. Therefore, the thesis for this dissertation is as follows: medically futile treatment is not ethically justified at the end-of-life in critically ill patients along the age continuum because of its impact on quality patient care and its contribution to moral distress in nurses.

Much has been written on the topic of medically futile treatment with reports of its existence dating back to the time of Hippocrates. The majority of research on the topic of medical futility has been on the adult population with little literature addressing the imperative that is present when the totality of the issue is engaged along the age continuum. The purpose of this dissertation is to do that. This dissertation addresses this gap by considering the ethical problem of futility in the neonatal, pediatric and adult populations. By addressing the common thread of medical futility across all ages, there is an imperative for a call to action that encompasses the span of organizational ethics. This span not only includes the clinical and professional ethics, but the business ethics as well.

Much has been written about the high cost of dying, especially in the last six months of life, which is compounded if there is a stay in a critical care unit. Technology advances, healthy lifestyles, and pharmaceutical interventions have contributed to an aging population that is able to live longer lives. When this aging population needs health care, it has created conflicts as health care providers struggle to know what interventions will benefit what patients, or what will be futile treatment. In addition, there is pressure from families to do heroics at the end-of-life, when these, too, may be futile. In applying these concerns to pediatric patients, it is clear that congenital and chronic debilitating diseases, that used to claim children's lives, are now being managed so that lives go on longer. In addition, lives are being saved in the neonates at smaller weights and younger gestational ages with questionable concern or knowledge of the potential disabilities the neonates may face in later years or throughout a lifetime. These lives are lived in all stages of capacities making futile decisions for these populations more difficult than ever. No longer can the concerns regarding futile treatment at the end-of-life be focused on adults, especially the elderly, since the presence of such treatments also pertains to the neonatal and pediatric populations. This has prompted more aggressive action for improved care for all three of these populations and increased awareness of the benefit versus burden of medical treatments. In other words, more awareness of the ethics of futility across the age continuum can enhance quality patient care.

The thesis for this dissertation will be explored in a tiered fashion as the chapters develop. Chapter 1 serves as a general overview of the debate. Chapter 2 will examine the history and evolution of the ethical debate on futility across the age continuum, focusing on neonates, pediatrics, and adults. The ethical analysis will be integrated with theory as well as evidence based practice that looks at the most current issues related to futility in order to enhance quality

patient care in each age group (Chapters 3, 4, and 5). Medically futile treatments in critical care are most acutely felt by the nursing population and often are evidenced as moral distress.

Chapter 6 analyzes moral distress and considers a critical care nursing specialty where moral distress is most prevalent. Following is a summary of the analysis for this dissertation which provides an overview of the argument.

1.I. Overview of the Argument

Chapter 2 focuses on the ethical debate of medical futility beginning with its history and the establishment of a definition that could serve as a standard for all, however, the concept defies a specific, standardized definition. From focusing on the definition of futility, the evolution moves to an emphasis on organizational ethics and the utilization of policies and regulations with a concentration on the value of negotiation and communication at the bedside. There is a consensus that a different approach to the topic is needed whether that be using a different dialogue, better utilization of nurses, enhanced communication or more timely consultation with palliative care.

The neonatal population has increased its ethical debate as neonatal intensive care units (NICUs) have been established allowing for the treatment of extremely low birth weight neonates (Chapter 3). However, these NICUs have presented ethical dilemmas related to when to begin treatment or when to withhold and withdraw treatment. Debate regarding the moral status of the neonates continues, however, the best interest standard is at play when the parents or surrogate decision makers are called to make decision regarding the treatment of the neonate either in the delivery room at birth or later in the NICU.

Chapter 4 addresses the ethical debates for those between 1-18 years of age which presents

with a diverse range of illnesses and conditions. The children who died years ago from their illnesses are now living due to the advances of medical science. When death does occur, it is most often due to the withholding or withdrawing of treatment. With the broad range of development levels that occur between 1-18 years of age, the ability to consent or assent to treatments is often an issue in this age group. Although legally a child cannot consent until 18 years of age, children can often assent and express their wishes long before that age and need to be considered. End-of-life in children takes such an emotional toll, not only on the family, but on the health care providers as well, that the topic of futile treatment and end-of-life decisions are often avoided which only makes this process more painful for all involved with the child.

A major concern in the care of the adult at the end-of-life is the issue of autonomy (Chapter 5). The majority of these adults are elderly and due to age, plus the effects of the illness, they may not be competent or have capacity to make their own autonomous decisions regarding treatment. In addition, these patients may not have participated in any advance care planning that yielded an advance directive leaving the decisions up to the family, surrogates, and health care providers, as they attempt to make decisions for the patient. The prominent decisions center on withholding and withdrawing treatment in the critical care unit. Palliative care has been helpful with this population in not only managing symptoms but also providing for end-of-life care and a death with dignity.

Medical futility has a profound effect in the clinical world on the patients, families, and those who care for them. However, futile treatment has no place in the compassionate and merciful care of the patient who is dying. Medical futility is costly in terms of finances, but also in terms of its effect on the largest group of employees, the nurses. This effect is often evidenced by signs and symptoms of moral distress in nurses who provide care and futile treatment to

critically ill patients along life's continuum (Chapter 6). Although there are numerous root causes and contributing factors leading to moral distress, two top factors are the nurse/physician relationship and medical futility at the end-of-life. Moral distress is receiving more attention because of the detrimental effect to the integrity of those who experience it as well as the long term harm it does to the profession.

Action is imperative as medical futile treatments at the end-of-life are not ethically justified because of the impact on quality patient care contributing to moral distress in the caregivers. This dissertation will present the ethics of medical futility found in end-of-life treatment in the care of the critically ill neonatal, pediatric, and adult patients. An analysis of each chapter is explained in further detail in the following sections.

1.II. Detailed Analysis of Chapters

Medical futility is not a new concept as it has been around since medicine's beginning having its origin with the time of Hippocrates. It gained more attention beginning in the 1980's and 1990's sparking the ethical debate. Yet, today in the 21st century medical futility defies an accepted or standard definition with its application varying from patient to patient and situation to situation. The approach to medical futility and the many questions that result have never been more prominent in the American health care system than they are today. This prominence has been enhanced by the explosion of advanced technology and critical care procedures. The first part of Chapter 2 explores the ethical debate on futility beginning with its history to include its definition, origin, and rationale for the dilemma facing health care providers today. The second part of the chapter describes quantitative and qualitative futility taking a closer look at organizational ethics and the topic of rationing as compared to futility, ending with a discussion

on hope for the future.

From Hippocrates, the ethical debate focused on autonomy to establish the rationale that undergirds the concept of futility. The first step began with futility's definition. Defining medical futility may be elusive, yet, health care providers say they know it when they see it. For those who attempt to define it, medical futility is treatment which is characterized as useless, pointless, or having no purpose.¹ To understand the meaning of such uselessness, there needs to be confidence that this treatment is of no benefit to this particular patient.² Futility is treatment that either does not improve quality of life, does not improve the outcome, or prolongs suffering.³ A treatment that has as its sole purpose the physiological extension or prolonging of life is also considered futile.⁴

Moving into the Middle Ages, the Hippocratic view was replaced with religion and the supernatural with touches of superstition.⁵ This continued until the modern era, from the 17th to 19th centuries, when the view of modern medicine expanded with the scientific revolution and the focus on disease became something to be conquered.⁶ Progressing into the 20th century, science and religion became more integrated so that the ever-expanding technology, plus the sacredness of life, translated into doing whatever was possible to preserve life at all costs. Up to this point, the role of physicians was a paternalistic one where they made the decisions, which was accepted by the patient and family. However, this changed in the 1980's when patients/families began to demand life prolonging treatments which health care providers often saw as inappropriate. There emerged a tension between patients seeking protection from the imposition of unwanted treatment by a physician (the Quinlan case in 1976) to patients demanding futile treatments from physicians (the Wangle case in 1989).⁷ These demands were all in the name of autonomy and the debate regarding futility (that continues today) had officially

begun.⁸

The principle of autonomy is seen on the spectrum where physician overtreatment is on one end and the patient/family demand for overtreatment is on the other.⁹ The futility concept unfolded as a result of the patient/family driven demands. A contest then ensued between the patient/family autonomy and the integrity or autonomy of the physician/provider. The autonomous patient can refuse any treatment, however, this does not translate to receiving any and all treatments. There is no duty for health care professionals to provide treatment that is deemed futile.¹⁰ Physicians can easily determine treatment that has no effect which can stand up to peer review, whereas, the challenge is determining which treatment is of no benefit to the patient as this is subjective and value-laden.¹¹

The debate over who should make the decision, or have the last say in withholding or withdrawing life-sustaining treatment, has gone on for generations and continues today. There are driving forces, or rationales, that strongly influence whether the believed futile treatment is considered. One of the rationales for futile treatment continuing to be an issue is fear. Physicians as well as patients/families are fearful of approaching the subject of death.¹² Because of this fear, it can appear that “everything” is done in order to avoid the inevitable end-of-life discussion. This fear can be far-reaching and not only be regarding the patient, but it also brings one’s own mortality to the surface for both the family and physician.¹³ The physician also fears litigation if everything is not done for the patient.

A second rationale for futile treatment to continue is the focus on the physical disease which ignores the patient’s subjective experience of the disease.¹⁴ With a preoccupation on the disease, it is easy to equate survival with success, discounting the feelings the patient/family may be experiencing.

A third rationale is that providing the futile treatment is the “path of least resistance”.¹⁵ It takes less time in a busy schedule to do what has always been done and it is less controversial. Providing futile treatment is doing something, while withholding or withdrawing treatment could be perceived as doing nothing.

A final rationale is that the discontinuation of medically futile treatment is an acknowledgment that medicine is unable to master the disease process.¹⁶ To continue with the treatment is holding out hope that this might be the one case in 100 that beats the odds.¹⁷ Unfortunately, this approach gives false hope to the family as well as denies them the comfort that comes from accepting and preparing for death.

In addition to the rationales for the futile treatments at the end-of-life, there are additional reasons for continuing or initiating these treatments, which can create ethical conflicts in the providers. These reasons fall into three categories: personal, which is the largest concern, institutional obstacles, and the wishes of the patient or the family (most often the case).¹⁸

When examining the concept of futility and its historical evolution, there are further attempts to break down the concept into understandable terms. Utilizing the definitive terms of quantitative and qualitative is one such attempt to clarify the understanding, as well as establish meaning to the concept of futility. Quantitative futility is often used synonymously with physiological futility, but not with all authors. Quantitative futility is based on scientific data to determine the success of the treatment.¹⁹ This scientific data includes the physician’s experience, empirical data, expert opinion, and prognostic scoring systems that support a treatment that has been futile or unsuccessful in the last 100 attempts.²⁰ For those who differentiate physiological futility from quantitative futility, physiological futility measures the outcome that is obtained by the effect on the patient’s physiological response.²¹ An example

would be that CPR has an effect on restoring a heart rhythm. Whereas, quantitative futility relates to the remote possibility that the treatment will benefit the patient.²² The CPR may restore a heart rhythm, but the patient is still dying from metastatic liver cancer so there is no benefit to the patient's overall outcome.

Qualitative futility is any treatment that does not lead to a patient's discharge from a critical care unit along with discharge from a hospital to an independent state or at least to the state where the patient was on admission.²³ In other words, qualitative futility is when the benefit a treatment offers is extremely meager.²⁴

The debate and ethical dilemmas that arise from providing what is believed to be medically futile treatment is focused at the bedside in the world of patient care or clinical ethics. Whether it is in the realm of quantitative or qualitative is irrelevant if the physician believes the treatment to be futile. The patient's autonomous right to self-determination has limits as physicians are not obligated to perform treatment that they view as ineffective or inappropriate.²⁵ An important point is that individual physicians rarely make futility treatment decisions on their own. Instead there is an inclination to solicit support from the population of physicians, the professional organizations, or the medical standard of care, all of which compose the professional ethics.²⁶

Professional ethics is the varied roles that are filled or provided in a health care organization that work together to fulfill the organization's mission, which is the care of the patient.²⁷ Nurses, as part of the professional ethics, do the actual care at the bedside. Studies indicate that when nurses are compared with physicians in terms of qualitative futility, nurses are more frequently concerned with the patient's quality of life and are more pessimistic in terms of the outcomes of treatment.²⁸

Clinical ethics, or patient care ethics, professional ethics, and business ethics form the

concept of organizational ethics. Organizational ethics integrates these three components to communicate, apply, and evaluate its mission and values by which it is defined in the serving of the patient.²⁹ Both clinical and professional ethics play a role in medical futility. Business ethics refers to the obligations of the health care organization to its stakeholders which include employees, patients, payers, the community, society, and contractual relationships.³⁰ In confronting the ethical debates associated with futility, health care organizations need to balance the positions of opposing factions. Through this balancing, the organization's leaders are "co-fiduciaries" with the professionals in assuring that the mission and values of the organization are upheld.³¹ Approaches organizations have used to manage medical futility include giving additional authority to ethics committees, establishing policies, and supporting legislation.³² Failure to act can impact patient care, the reputation of the professionals, as well as the financial viability of the organization.

When attempting to limit treatments, rationing and futility are often used as terms to better explain their inappropriateness. Both terms, rationing and futility, have negative connotations to the general public. Steps have been taken by medical and nursing associations, both in the United States and Europe, through a policy statement to use the term "potentially inappropriate" treatment instead of futility.³³ The use of futility is saved for rare occasions when treatments are requested but cannot be fulfilled. In spite of this recommendation to change the terminology, the terms rationing and futility are often confused by both the medical profession and the general public. Part of this confusion is that the terms came into being in history at the same time and they are often found occurring at the same time with the same patient.³⁴

In considering medical futility in the care of the patient, there can be an inclination to disguise the uselessness of the treatment with rationing. This disguise can be presented as

prohibitive cost, limited number of critical care beds, or a lack of insurance coverage as a way to make treatment decisions.³⁵ To pose a futile question in a limited resource manner, or scarcity, makes it easier for the physician to discuss with the patient and family as it is less controversial, making the issue easier to comprehend than inappropriate medical treatment.³⁶

Futility looks at one patient at one point in time in a “cause and effect” relationship, while rationing looks at a problem of scarce resources, which is distributed over many patients with the same condition and situation.³⁷ Rationing implies a scarcity of health care resources that must apply to everyone without discrimination.³⁸ Futility deals with treatment that offers no benefit but can be provided, whereas rationing deals with treatment that offers a benefit but is not provided for a variety of reasons.

Just as rationing may be used to cover for futility, so can futility be used to cover for rationing. This can be seen in organizations where there is cost-containment pressures that call for withholding and withdrawing futile treatments as a financial strategy.³⁹ Regardless of how these terms get used and abused, the one known is that they are here to stay in today’s ethical debate on appropriate treatments in health care.

There are alternative approaches to the issue of medical futility. Some are helpful while others show promise. The key to all approaches or resolutions begins with honest communication and effective discourse.⁴⁰ As with health care in general, prevention is often the best treatment and this approach is true with medical futility. Prevention strategies include advance care planning, early utilization of ethics committees, and timely consultation from palliative care.⁴¹ Nurses can also serve a more prominent role in assisting with health care decisions as they are the ones who spend the most time with the patients and their families.⁴²

Medical futility knows no boundaries as it is found in all ages of the population. The medical

advances in technology and pharmacology have increased the survival rate of the extremely low birth weight neonates.⁴³ However, an improved survival rate has come at a cost by increasing the incidence of disabilities and comorbidities in the neonates.⁴⁴ The parents, or surrogate decision makers of these new members of society, are ill prepared to respond to medical futility questions without feeling guilt, confusion and intense suffering. The first part of Chapter 3 addresses the history and theoretical framework for futility in the neonate taking into account the topic of moral status and the best interest principle. The second part of Chapter 3 describes ethical dilemmas found in neonatology, the role both parents and professionals play as well as evidence based ethics applied to neonates.

During 19th century America, approximately 15-20% of all newborns died in their first year of life from infections, starvation, or hypothermia.⁴⁵ Despite this harrowing data, the beginning of NICU's is thought to have not officially started in the United States until the 1960's with the development of the infant ventilator.⁴⁶ In the United States, the first hospital to have a separate nursery to care for premature infants was in Chicago, in 1927.⁴⁷ However, through the following years progress was slow with major changes occurring in 1950-1970 with advances in technology and the introduction of antibiotics.⁴⁸

Infants in a NICU can be classified in terms of body weight or gestational weight. Those who are classified with body weight are low birthweight at less than 2500 grams (5.5 pounds); very low birthweight at less than 1500 grams (3.3 pounds); and extremely low birthweight at less than 1000 grams (2.2 pounds).⁴⁹ In determining maturity based on gestational age, an infant is considered premature if less than 37 weeks gestation, with 40 weeks considered normal or full term pregnancy.⁵⁰

The "Baby Doe" rules or regulations became a major part of neonatology's history

beginning in the 1980's. Baby Doe was born in Indiana, in 1982, with Down's syndrome and esophageal atresia with a tracheal esophageal fistula which, through a mutual agreement between the parents and physicians, was not treated.⁵¹ The infant was not fed, was given sedation, as well as pain medication, and died six days later.⁵² As a result of all the outpouring of disbelief as well as outrage in this case and others, Congress, during the Reagan administration, passed the "Baby Doe" regulations.⁵³ These were amendments to the Child Abuse Prevention and Treatment Act of 1984 which made it a violation to withhold treatment based on disability or a potential disability.⁵⁴

The act, or Baby Doe rules, allowed for treatment to be withheld if, 1) the neonate was irreversibly comatose; 2) the treatment was classified as "futile" and prolonged the dying process; and 3) the treatment would be both futile for survival and would be seen as "inhumane".⁵⁵ Much controversy has surrounded these rules/regulations. The concerns are that, although well intentioned, the rules have been misunderstood on top of misinterpreted to the point of increasing the suffering for the neonates as well as the parents and caregivers.

The theoretical framework for the end-of-life ethics in neonates begins with the moral status of neonates. Much has been written, debated, and theorized as to the moral status of the embryo, fetus and newborn. Through all this debate, there is still no one universal agreed upon determination of when moral status is conferred. In spite of that, it is at the moment of birth that the neonate is considered a member of society.⁵⁶ However, moral status reaches beyond society membership.

To have moral status requires more than the mere act of birth or coming into the world. It delves into what is required to qualify one as having moral status, protected by moral norms, with moral rights on the same level as all humans.⁵⁷ One can speculate if the moral status debate

is necessary or significant. What it comes down to and why the discussion continues is based on two points. One is based on the embryos', fetuses', or newborn's potential to become a person, and the other is as a potential person it is symbolic with life which gives it "moral value".⁵⁸

Theories that have been proposed regarding what confers moral status with no agreed upon decision. If the newborn is seen to have moral status, regardless of what theory one recognizes, then the newborn has rights which need to be acknowledged and safeguarded as an independent agent.⁵⁹ The alternative is to view neonates as having potential for moral status while being dependent on their parent's decisions under the best interest principle.⁶⁰

Prior to employing the best interest principle, the decision making regarding newborns had been the paternalistic model.⁶¹ From the delivery room to the NICU, decisions regarding whether to begin or continue resuscitative efforts are best made from the best interest viewpoint of the neonate in collaboration between the parents and physician. This can best be viewed on a continuum. On one end is evidence based criteria that the newborn would survive with resuscitation. Therefore resuscitation is done, even if the parents decide otherwise as the newborns right to life surpasses the parents decision.⁶² At the other end of the continuum is "unreasonable care" where the burdens are greater than the benefits and could be considered "abusive" if resuscitation was initiated.⁶³ The middle, where it is uncertain as to the outcome, is where the parents and the physician collaborate, assuring that the parents are aware of the facts, so informed decisions can be made in the best interests of the neonate.⁶⁴

There are many ethical dilemmas that present themselves in the care of the neonate. First, in the 1960's a baby born weighing less than 1000 grams had a 95% chance of death, today that baby has a 95% chance of survival.⁶⁵ However, 30-50% of those weighing less than 750 grams have a disability which is considered moderate to severe, such as deafness, blindness, or cerebral

palsy.⁶⁶ Of the approximately 4 million births each year, approximately 450,000, or 1 in 9, are born premature, which is defined as less than 37 weeks gestation, and 12-14% are admitted to NICUs.⁶⁷

Second, it is difficult to discern when treatment is futile. Discussion and debate occurs and varies between countries and hospitals within the United States regarding the variation in treatment of neonates born at the margin of viability and whether further treatment is futile or not. Outcomes of studies indicate that prenatal counseling and guidelines assist in the difficult decisions needed at birth.⁶⁸ The guidelines are based on the following: if a birth occurs at 22-23 weeks gestational age, then comfort care only is recommended; 24 weeks gestational age is the parents' choice; and NICU for those greater than 25 weeks gestational age.⁶⁹

Third, a great deal of speculation has been discussed and written regarding unbearable suffering of the newborn. Two identified problems come from these discussions. The first is that suffering is abstract, subjective and personal which makes it difficult to identify in the neonate.⁷⁰ The second is the concern with identifying future suffering for the neonate, which can range from chronic pain to the inability to participate in self-care.⁷¹

Fourth, care given to NICU patients that do not survive or survive with many disabilities, is often believed to add to the cost of health care. A study of 1800 neonates in over 100,000 bed days indicate that only 6% of the costs were spent on futile care.⁷² NICU care has been shown to target survivors, however, some care is still perceived as inappropriate and futile due to three major reasons. The first is the fear of litigation which is high in obstetrical medicine, so to error on the side of care is more the norm; the second is the high use of assisted reproductive technology with an effort to save neonates that are born from this intervention no matter the cost or condition; and the last is the mentality that still exists from the "Baby Doe" laws to treat

unless treatment is seen as futile.⁷³ Unfortunately, the NICU costs are only the beginning. Costs can extend for a lifetime if there are devastating disabilities with special education costs associated with low birth weight, in 2015 dollars, estimated at \$7-\$9 million annually.⁷⁴

Finally, regardless of the high cost of NICU treatment with its advanced technology, there are times when the high tech care needs to be replaced with palliative and comfort care.⁷⁵ This palliative care is appropriate after a determination of futility is based on diagnosis and prognosis as it provides compassionate care in order to minimize suffering for the patient, family and staff.

Coming to terms with futile treatment is difficult in any situation, but poses more challenges at the beginning of life. These challenges are seen as new parents serve as surrogate decision makers while recovering from the loss of the expectations of parenthood in an environment of the NICU, which is foreign and frightening. Likewise, the physicians and healthcare providers involved in the care of the newborns are challenged as they are restricted in their communication. This restriction is due to the lack of certainty in forecasting an outcome for both the short term as well as the long term survival including the probability of disabilities.⁷⁶ Evidence based practice indicates that in applying the best interest principle, it is best done through a shared decision making model which identifies the roles of the parents and professionals.⁷⁷

The parental role requires the parents to openly share their values, which may include religious and cultural views; to provide input into discussion regarding the newborn care; to communicate what they believe is the best interest of the child; and to honestly consider the recommendations of the physicians.⁷⁸ The physician role requires that information be provided to the parents regarding the medical details of the newborn; that all questions be answered; and that a recommendation be made based on experience, knowledge and expertise.⁷⁹ Parents ask of physicians in the process that they receive honest information and evidence when there is a poor

prognosis delivered in a supportive manner so an informed decision can be made.⁸⁰

Parents are often faced with life and death decisions regarding the treatment of their newborn, however, physicians are not immune from difficult decisions in the NICU setting. Physicians have indicated that the strongest influences on their decision making process does not include fear of litigation, which is often assumed. The biggest influences are the expectations they believe others have, especially the parents, of saving lives, the inability to accurately determine the gestational age, and the parents request for aggressive treatment.⁸¹

Many have believed that nurses and physicians, not only had different roles, but also were different in their ethical analysis and reasoning which could be seen at play in a NICU. On closer look, the differences were not that great with both nurses and physicians having the same moral duty to “do the right thing” and minimize suffering with both experiencing end-of-life decisions as the top ethical concern.⁸²

The environment in most NICUs is one where communication and compassion surround the the infant and parents in a team approach where conflict is rare.⁸³ However, each unit should have processes in place to recognize signs of conflict with training in conflict resolution. There is never a way to be sure of what situation or which staff, physician or parent interaction will lead to conflict, therefore, being prepared and alert for signs of impending conflict is necessary.

Evidence based ethics requires communication as the first step emphasizing its importance as the link to all ethical decisions. Communication is not just about what is said, but how it is said as well. For parents who are struggling with making life and death decisions regarding their newborn, the language used in that communication matters and affects how they respond to the information. In all communications, the health care professionals should do the following: 1) use the baby’s name when referring to the neonate; 2) provide adequate time for discussing

difficult topics; 3) tolerate silence as information is being processed; 4) ask pertinent questions such as, “what do you want to know?” or “what is your biggest fear?”; and 5) know that conversations will need to be repeated multiple times.⁸⁴

The shared decision making process surrounding the care of the premature newborn and the question of futile treatment is usually a two-step decision process. The first step is a decision on whether to treat or not and is usually made in the delivery room, whereas, the second step guides the parents through the withdrawal of treatment and the dying process.⁸⁵ Whether to treat or not requires an immediate decision with little time for discussion or questions and answers. In organizations that have established guidelines based on gestational age and birth weight, this decision is easier. However, gestational age is difficult to determine as the mother’s menstrual history is not always reliable.⁸⁶ The second step of withdrawing treatment is usually more prolonged as parents debate the process. This step is often surrounded with guilt, not only for withdrawing treatment but also for what the parents did to cause the infant’s prematurity.⁸⁷

Evidence based ethics, unlike evidence based medicine which focuses on intuition, clinical experience, and expert opinion, considers values as well as best interests and preferences of parents/surrogates in contemplating treatment decisions.⁸⁸ Three fundamental questions that need to be asked in the immediate post birth time period relate to whether to resuscitate or not, whether the best interest standard should be applicable only to the neonate, and to what extent should pain be treated in the neonate.⁸⁹

In the NICU environment, death is an all too frequent visitor. The parents’ response to the death and the associated grief is individually based. However, the caring and compassionate concern of the health care providers determines the response of the parents more than any other single element.⁹⁰ To assist parents to detach through the grieving process, they must first attach

to the infant. Attachment is done through touching, holding, bathing, picture taking, and naming the newborn.⁹¹ There is an additional opportunity to be found in neonatal palliative care programs.

Adult palliative care programs appeared in the United States in the 1980's, but fetal palliative care did not begin until the mid-2000's.⁹² An opportunity that presents itself revolves around the "uniqueness" of neonatal palliative care. Palliative care is not meant to only be about the end-of-life, but in the NICU that is when it usually happens.⁹³ Another opportunity is related to communication as well as conflict among providers, especially nurses and physicians. Physicians struggle to make the final decision that it is an end-of-life situation so they may postpone the decision while nurses see it earlier and become frustrated with the physician.⁹⁴ This can lead to a delay in getting palliative care initiated. The benefits of palliative care to the neonatal population is becoming more known and offers hope for the future in caring for neonates.

Children are not just little adults, as they were once thought to be.⁹⁵ The pediatric population, ranging from 1-18 years of age, present with diseases and conditions that make them unique. Much work has been done to eliminate childhood diseases through immunizations, disease prevention, and cancer therapies. However, this special population continues to be plagued by accidents, congenital anomalies, child abuse, AIDS, and malignancies providing immense challenges and a daunting reminder of healthcare's limitations.⁹⁶

The first part of Chapter 4 will address the historical perspective and theoretical framework for discussing futility in the pediatric population. This discussion will take into consideration the moral status of children versus adults and the influence of the family as a unit. The second part of Chapter 4 will describe the role of the consent process for children as well as discuss evidence

based practices at the end-of-life to include pain control, bereavement support for the parents, and palliative care.

The infants and children that would have died years ago, especially in developed countries, from childbirth complications, prematurity, and congenital anomalies, or birth defects, are now surviving.⁹⁷ Because of improved sanitation, vaccines, and antibiotics the childhood infections have been eliminated, in some cases, or minimized in others.⁹⁸ Another reason for the improvement in the infant age group is better education regarding sudden infant death syndrome (SIDS) which was a major contributor to mortality in the first year of life and remains so due to continued factors found in the environment. Some of these environmental factors include cigarette smoking in pregnancy and after; bed sharing for infants especially in mothers who smoke; and thermal stress that is especially evident when the infant is placed in a prone position and heat cannot be reduced from the face if exposed to heat stress.⁹⁹ Despite these improved rates, children still die with approximately 3% of the deaths in the United States each year being children.¹⁰⁰ A child's death leaves behind a life-altering experience for all who have been involved to include every member of the family as well as the health care providers.

In developed countries, the majority of children's deaths occur in a hospital and almost three quarters of these deaths occur in a critical care unit.¹⁰¹ Of those children who die in critical care units, most occur after decisions are made to either withhold or withdraw treatment.¹⁰² Therefore, these deaths are not unexpected and usually follow lengthy courses of treatment before an end-of-life decision is made regarding the initiation or continuation of treatment.¹⁰³

Many of the end-of-life decisions to withhold or withdraw care are made when further treatment is not seen as providing benefit to the child, or futile treatment, and in some cases it may actually be providing a burden or prolonging the death process. The futility challenges that

are present in the pediatric population are compounded by two distinct qualities. These are the high level of uncertainty in treating children's diseases, especially those with neurological disease or neurodevelopmental concerns, and the emotional response that ill and dying children create in the health care provider.¹⁰⁴

As with the newborns, the theoretical framework for examining futility in the pediatric population is based on the moral status of the child and the significance that holds at the various ages. The majority of the moral status of children, as well as adults, comes from the fact that they are persons or human beings which is accompanied by the rights of humans such as "life, liberty, pursuit of happiness, etc."¹⁰⁵ The remaining sources of moral status can be found in roles, such as teacher or laborer etc., reflected duties to others, and political power which can affect moral status via different levels in that power.¹⁰⁶ Of these remaining sources of moral status, children due to their lack of maturity, are unable to achieve them until adulthood.¹⁰⁷ Not only can children not achieve them, but also children at the beginning of life are unable to meet their basic needs or negotiate barriers in society to get their needs met.¹⁰⁸ Parents are responsible to feed children, bathe them, keep them safe which progresses to making them attend school, behave appropriately toward others and help them to grow up to be independent members of society.¹⁰⁹

Parental authority comes with rights and is based on the fact that the parent is the sole agent of the child.¹¹⁰ The rights of parents have been described as "stewardship rights", versus owner rights, which adds to the complexity of the moral status of parents.¹¹¹ This additional moral status of parents translates into the children's right to be sure they are protected as well as have their needs met, such as being nurtured, educated, and developed.¹¹² Along with the rights of parents, comes the duties to not violate the child's rights, to be sure no one else violates these

rights and to protect the interests of the child.¹¹³ Failure to do any of these duties can lead to a limited and eventual loss of parental rights.

While examining the moral status as the theoretical framework, it is necessary to frame the child within the context of the family unit. Unlike the newborn, where a relationship has not yet been established, there has been time for various relationships to develop within the family for the child along the age continuum. How the family functions can affect the decision making process which is key in the critically ill child.

For treatment to be initiated, withdrawn or discontinued, the consent of the patient or patient's surrogate is required. A person cannot legally consent before the age of 18. However, the American Academy of Pediatrics (AAP) has been instrumental in expressing views on the concept of informed consent in pediatric patients to ensure that the child is a part of the decision making process, whenever possible.

Prior to the establishment of the concept of informed consent, the physician made all the treatment decisions. Now it is believed that the patient surrogate has the right to make treatment decisions in collaboration with the physicians in an understandable language that includes treatment options, rights, benefits, and alternatives.¹¹⁴ In applying informed consent to pediatrics, the child's parents or surrogates/proxy decision makers are usually the ones who give the consent, or permission as one person cannot consent for another.¹¹⁵

One approach to the decision capabilities of children uses the "rules of seven" where children less than seven years are considered unable to make major decisions but can be given choices in simple matters; those 8-14 years of age are unlikely to have the ability to make major decisions, but children vary; and those older than 14 have the ability to make decisions.¹¹⁶ When children less than seven years of age are being cared for, the premise is that they cannot make

decisions and therefore, the best interest standard applies. The best interest standard is that the parent/surrogate will do what is right for the child maximizing benefits and minimizing risks.¹¹⁷

The second age group, 8-14 years, is usually able to reason, plus use logic, but may be very rule oriented and less flexible when looking at choices, however, they are usually able to assent to treatment.¹¹⁸

The adolescent group, those greater than 14 years of age, are usually able to consent. They do not pass the minimum age of consent, but can do complex reasoning, discern multiple options, anticipate outcomes, all of which is influenced by emotional maturity.¹¹⁹

The parent child relationship involves the parents' understanding of their identity as parents, the associated role expectations and obligations, plus the responsibilities to their children.¹²⁰ However, these identities, roles, as well as responsibilities get blurred and confused as their expert knowledge regarding their child is put to the test when making medical futility decisions. In making these decisions, and because of all the emotionalism associated with ill children, health care providers must focus on building relationships with both the parents and children.¹²¹ Futility decisions are best made as a collaborative effort between parents and health care providers, as well as children in some cases, depending on age.¹²²

The health care providers have the responsibility to maintain the integrity of the parent child relationship. This is done in the three following ways: 1) recognizing that parental authority does exist which may include a strong use of persuasion and at times "coercion" to get the child to respond appropriately, as long as the means are not abusive or harmful to the child; 2) observing that parents use a certain amount of discretion in performing their duties without outside interference, as long as there is no neglect or abuse; and 3) acknowledging the parents duty to advocate for their children and safeguard their rights.¹²³ It is through this parent child

relationship that the parents have not only assumed the responsibility for their child but also to the community at large to develop a member worthy of it.

Medical futility at end-of-life in pediatric patients differs from adults in two basic ways. First the psychological or emotional impact that impending death of a child can have on caregivers is so great that there is a tendency to forgo discussions regarding futile treatments.¹²⁴ A concentrated effort is needed to begin the discussions early. The second difference is in reference to the determination of brain death in children. The brain death criteria cannot be used with the same certainty in pediatric patients as it can in adults.¹²⁵ The difference is not explained by empirical data, but is thought to be due to a child's brain being more resistant to injury.¹²⁶

Problems that have been identified by parents at the end-of-life in the pediatric population include a need for improved focus on the child's symptoms and associated suffering that is commonly seen.¹²⁷ Other problems are related to communication at all levels and relationships with the health care providers.¹²⁸ The parents tend to focus on the child's pain, quality of life, and chance for improvement when making these end-of-life decisions.¹²⁹

Priorities have been identified for interventions in end-of-life care for both the parents and children. These include: 1) open, honest communication with accurate and timely information; 2) easy access to health care providers; 3) emotional support by staff; 4) maintenance of the integrity of the parent child relationship, and 5) faith support.¹³⁰

Since pain has been identified as one of the top areas of concern for parents of critically ill children, health care providers must first and foremost ensure that the children's pain needs are addressed, then their role expands to parental support in the grief process.

Pain is the most common symptom at end-of-life, as well as the most feared.¹³¹ However, there are many approaches to deal with pain which can address its prevalence, but there needs to

be adjustments to align with the various ages along the continuum of the pediatric patient. Assessment of pain in a child is different from an adult and the interventions, though similar, have unique differences in both pharmacological and non-pharmacological methods.¹³² Even though there have been advances in pediatric pain management, there remain challenges. These challenges are due to a lack of a theoretical framework specific for pediatric pain; the uncertainty in interpreting children's behavior; difficulties in measuring and applying methodologies; and biases brought to the table by both nurses' and children's past experiences, values and personal beliefs.¹³³

The care of children at the end-of-life, to include their death, does not end there. As recommended by the Institute of Medicine, the care continues through the grieving process for the parents to include bereavement support.¹³⁴ Despite all the scientific approaches to grief, the one prevailing theme that seems to make the biggest difference is the support of the clinical staff.¹³⁵ This support begins in the critical care unit and continues through the grieving process.

An area that has been identified with importance is the recognition of spiritual needs of the grieving parents.¹³⁶ The best way to address these needs is through a "caring presence", which allows the parents to be at the bedside and care for the child through the dying process, as well as help establish memories for the future.¹³⁷

The low number of children's deaths has lessened the urgency for the palliative care movement in the pediatric population resulting in a slower start than in the adult population.¹³⁸ However, palliative care's value and importance has been recognized along with its challenges and barriers. As a result there is a movement to increase the availability of palliative care and address the obstacles that are preventing its success.

Only 20% of the pediatric hospice programs have palliative programs, which is not

sufficient to meet the demands.¹³⁹ Identified challenges in establishing palliative care programs for the pediatric population including the following: 1) a lack of a definition of pediatric palliative care; 2) a lack of data to determine the needs of a palliative care program; 3) an inability to decrease the suffering while maintaining hope; 4) a need to address the health care provider's needs when caring for dying children; 5) an urgency for providing education and training programs; and 6) a commitment to include spirituality as a part of palliative care.¹⁴⁰

Adult palliative care programs can serve as a guide for pediatric palliative programs, however, pediatric programs are unique and distinct from adult programs.¹⁴¹ Both adult and pediatric programs are composed of symptom management, advance care planning, psychosocial concerns and spirituality.¹⁴² However, pediatric palliative programs must consider the developmental level of the child, as well as the needs of the parents. Advance care planning is an additional challenge as discussing children's death is still a subject that is considered "taboo" by many and against numerous cultures in developing countries.¹⁴³ Therefore, it is no surprise that the focus is on the curative versus the palliative with childhood illnesses. For those palliative programs that have grown and flourished, the results are rewarding with involvement of all staff members and the support of palliative care physicians.¹⁴⁴

More research in palliative care in the population of children is needed. However, this is not without its challenges and problems.¹⁴⁵ Even with these challenges, it is recognized that research must be attempted in order to establish a base of knowledge to further define the benefits of palliative care for children.

When referring to medical futility, the population that is most often the focus is adults. Of the adult population, it is usually the elderly that are more apt to receive futile treatment at the end-of-life. In the United States, those over 65 years of age account for over 50% of critical care

patients, however, only comprise less than 15% of the overall population, although this is growing at a rapid rate.¹⁴⁶ These elderly have a longer length of stay, higher mortality rate, and higher cost of care than those younger with the 70-79 year olds having the highest admission rate.¹⁴⁷ Chapter 5 examines futility and the adult population. The first part of the chapter addresses a theoretical framework based on competency versus capacity and the role autonomy plays not only for the patient but also for the family, health care providers, and community. The cost of end-of-life care is also examined as a problem that cannot be ignored. The second part of Chapter 5 describes evidence based practices for the adult by addressing overtreatment, contradictions in treatment, and the nuances of withholding and withdrawing treatment with the presentation of palliative care as a viable option.

The theoretical framework that embodies medical futility in adults, which ends up focusing on the elderly, is the ability to make independent and fully informed decisions about the treatments they receive or do not receive. This decision making ability puts the focus on the principle of autonomy. To fully employ the principle of autonomy, the conditions of competence or capacity must be present. Competence is defined as being able to complete a task or duty.¹⁴⁸ Only judges, or the court, can determine whether a person is competent or incompetent. Therefore, the term capacity is used in the medical arena which refers to whether the person has the capacity to understand the information and make appropriate decisions.¹⁴⁹

Determining one's competence or capacity is not simple. One can appear to have the capacity to make simple decisions, yet, not have the capacity to make life and death decisions or those that involve life-sustaining treatment.¹⁵⁰ Competence or capacity is seen as a process rather than an outcome and relates to the particular decision that has to be made.¹⁵¹ Some bioethicists see the issue of capacity needing greater evidence as the risk involved with the

decision to be made becomes greater.¹⁵²

Respect for autonomy is at the core of bioethics and is identified as one of the basic ethical principles.¹⁵³ This principle emerged partly due to the atrocities performed in Nazi concentration camps that led to the Nuremberg Code.¹⁵⁴ Furthermore, the ethical debate that surrounded both Karen Quinlan (1970's) and Nancy Cruzan (1990's) were key in establishing autonomy as the primary ethical principle in medicine.¹⁵⁵

When an individual is unable to exercise their autonomy, especially when no advance care planning has been completed, a surrogate decision maker is called upon to make treatment decisions. There are several processes that are used ranging from substituted judgment to best interest that employs past conversations, the surrogates own beliefs, as well as values, and seeking input from other family members or friends.¹⁵⁶

It has been determined that one of the major concepts that is primary in the end-of-life care of the adult patient is autonomy. This autonomy is not only for the patient but is also concerned with the autonomy of the patient's family, the health care providers and the community. Autonomy is defined as the right to determine for oneself, without undue "interference" from others, one's own decisions, objectives, and values.¹⁵⁷ In healthcare, being autonomous allows a patient to decide what treatment to receive and not to receive. The autonomy of the patient is often equated to liberty, free will, and independence with it being a characteristic that is beneficial for all to have.¹⁵⁸ An autonomous decision occurs when the individual acts with understanding and intention without undue influence from others.¹⁵⁹ The term "respect for autonomy" is used because for true autonomy to occur in healthcare there is a dual respect. This dual respect includes the patients' "right" to make their own choices and the healthcare providers "obligation" to allow the patients to make them.¹⁶⁰

The autonomy of the patient's family is complex. The family feels a responsibility to and for the patient which translates into duties and obligations to the patient who is critically ill and near the end-of-life. However, there are limitations. At the end-of-life and, especially when decisions are having to be made regarding futility, the family is burdened which takes their time, energy and can cost not only dollars, but create physical, spiritual, plus psychological trauma.¹⁶¹ If family autonomy is to be maintained in the stress producing environment that is present in critical care, two things must occur. First of all, the family must maintain some ability to control their lives.¹⁶² Secondly, healthcare providers may be torn between respecting the autonomy of the patient while supporting the family, so a high index of awareness is needed to allow for both group's needs to be addressed.¹⁶³

While healthcare providers are supporting patient and family autonomy, the subject of the providers' autonomy can be viewed as an obstacle to this support. Healthcare providers' autonomy applies to all providers, however, it is physician autonomy that gets the attention. Physician autonomy emerges when physicians refuse to provide treatment that they do not believe would be beneficial to the patient or that would be appropriate.¹⁶⁴ There are some who speculate that medical futility is used as an "ethical trump card" by physicians which is used to deny treatment and overrule choices made via patient autonomy.¹⁶⁵ In the few cases where legal action has been taken by the patient's family, after a physician refused to provide specific treatments, the courts have decided in favor of the patient/family.¹⁶⁶

Community autonomy has a role in futility as the cost of providing treatments, which are perceived to have no benefit to the patient, affects the available funds for the greater good of the health of the community.¹⁶⁷ This places the healthcare providers in the middle of balancing patient autonomy with the autonomy of the community.¹⁶⁸ In addition, there is the realization

that the professional's autonomy may impact the decision to treat or not to treat.

Whenever the end-of-life care, with the treatments that go with it is discussed, the cost problem is usually a part of this discussion. At no time does this discussion become more controversial than when cost and medical futility are discussed at the same time. The major issues focus on differentiating costs versus expenditures; the relationship of the costs to health care reform; and the ethics of cost control.¹⁶⁹ If health care is to be affordable providing the resources to patients as needed, both consumers and providers need to realize that cost control is a factor for end-of-life treatment.

A process that helps to support patient autonomy as well as lessen some of the end-of-life conflicts is for patients to participate with their providers in advance care planning with the end result being completion of an advance directive. Currently all 50 states have some type of legislation on advance directives.¹⁷⁰ Data indicates that, although more than 60% of the population want their end-of-life wishes to be observed, only approximately 25-33% actually take steps to put them in writing as an advance directive.¹⁷¹ The reason for these low numbers are threefold. These are: 1) it is difficult to discuss end-of-life issues; 2) patients change their minds often due to a lack of knowledge on medical treatments as well as their consequences; and 3) patients wait for the physician to initiate the conversation.¹⁷²

There are basically two types of advance directives. The treatment directive, or living will, and the proxy directive, or medical durable power of attorney (MDPOA). The treatment directive identifies the kind of treatment patients would want if unable to communicate their desires with some being more explicit than others.¹⁷³ Whereas, the proxy directive involves identifying a surrogate to make healthcare decisions when the patient is no longer able to do so.¹⁷⁴ Despite perceived advantages to completing advance directives, there are barriers to their

completion. These barriers include racial disparities, discomfort of physicians in talking about the subject, and the fear that the directives will not be honored.¹⁷⁵

In attempting to address medical futility, different processes have been employed. One process has been accomplished through policy and legislation, such as has been done in Texas with the Texas Advance Directive Act of 1999.¹⁷⁶ This act makes it legal for hospitals and physicians to nullify any patient or family request for treatments that are believed to be futile without fear of legal repercussion.¹⁷⁷ Other states have attempted similar policies with data from both Texas and other states being mixed as to the policy's effectiveness.¹⁷⁸

In order to confront medical futility in the adult, two major occurrences need to be considered and addressed. These are overtreatment and contradictions. The perception is that the United States has an immense problem with overtreatment which carries a negative connotation regardless of its source.¹⁷⁹ When considering medical futility, overtreatment can be viewed as physician driven overtreatment or patient driven overtreatment. Historically physicians acted in a paternalistic manner making health care decisions for patients.¹⁸⁰ The physicians were granted this decision making power because of their education, training, as well as expertise, plus the "doctor knows best" was believed to be true.¹⁸¹ This view changed when patients became more autonomous wanting a say in their own care.

A process that has helped to control physician driven overtreatment is informed consent. As informed consent was in place by the 1970's, the requirements were for patients to give consent for any treatment.¹⁸² After being informed, the patient can then decide whether to proceed with treatment or not.

Patient driven overtreatment, or family driven, is often seen in the critical care unit at the end-of-life. The concept of medical futility surfaced as a way for the physician to respond to this

patient/family overtreatment.¹⁸³ Medical futility is associated with patients at the end-of-life where new or continued treatments are not perceived by the healthcare providers as being of benefit to the patient or as providing the expected outcome.¹⁸⁴

Contradictions are defined as perspectives on an issue, such as those surrounding end-of-life, which are opposing, although one view assumes the possibility of the other such as ‘benefit versus burden’.¹⁸⁵ These contradictions, often seen in critical care, provide an opportunity for dialogue regarding decisions related to future action.

One contradiction that presents itself frequently at the end-of-life is honoring the patient’s wishes versus following the family’s wishes. At the end stage of a critical illness, the majority of patients require mechanical ventilation which limits the ability to communicate adequately or their disease, plus medications, leave them in an altered state of consciousness.¹⁸⁶ Therefore, the family, proxy, or surrogate becomes the primary decision maker for the patient. It has been reported that surrogates make up to 75% of patient’s decisions in critical care using “substituted judgment”.¹⁸⁷ This substituted judgment tends to be based on three things: 1) the surrogate’s own best interests; 2) mutual interests of the surrogate and the patient; or 3) on documents of which the surrogate has little knowledge.¹⁸⁸ Strategies to assist with this contradiction consist of including surrogates in physician/patient discussions regarding advance care planning before the healthcare crisis occurs; honoring patient’s wishes whenever they are known or are in a formal written format; and including other family members in discussions to assist the surrogates with focusing on what patients would want if they could voice their wishes.¹⁸⁹

A second contradiction is killing or allowing to die. The contradiction has been debated in the ethical world for a long time. The controversy centers on whether there is an ethical/moral difference between actions that lead to ending the patient’s life versus failing to act which leads

to the patient's death.¹⁹⁰ Two theories look at this contradiction in different ways. The utilitarian view looks at the consequences of an act as to whether it is the commission or omission of the act that brings about good or bad for the greater number.¹⁹¹ The human rights theory sees an omission as illicit if there was a right to that which was omitted.¹⁹²

Within the contradiction of killing versus allowing to die, a discussion often ensues regarding withholding versus withdrawing treatment and whether either or both fit as part of this contradiction. Beginning in the 1950's and 1960's, CPR was found to save lives, especially those who had suffered from untoward effects of medications, surgery or had a significant blood loss.¹⁹³ Soon CPR became the standard of care for all hospitalized patients if they had a cardiac or respiratory arrest. However, by the late 1970's its limitations were known and CPR had become one more option for patients on the choice continuum to overrule the paternalistic health care providers.¹⁹⁴ Today discussions occur with patients and families regarding whether they want to be resuscitated ("full code") or a DNR ("no code") as the first step in withholding further treatment or withdrawing present treatment.¹⁹⁵

Between 35-90% of the deaths in critical care are due to withholding or withdrawing treatments, with withholding being defined as a decision to not begin or expand a present treatment and withdrawing as purposefully terminating a life-sustaining treatment.¹⁹⁶ When referring to withholding and withdrawing treatments this can mean any and all treatments, such as artificial nutrition/hydration, CPR, and medications, but most often refers to mechanical ventilation.

There is a general consensus among ethicists that there is no ethical/moral difference between withholding and withdrawing treatment.¹⁹⁷ However, some patients, families, as well as providers struggle more with withdrawing than withholding treatment. This struggle is due to

the fact that it is easier to not start a treatment than to discontinue one and withdrawal is active so may invoke guilt, while withholding is passive and involves doing nothing.¹⁹⁸ Nevertheless, withdrawing has merit over withholding for the following reasons: 1) physicians take on the patient as a responsibility or duty once treatment has begun; 2) a “trial” of treatment gives the patient a better chance for improvement instead of never even trying; and 3) it is acceptable, as is withholding, by most major religions.¹⁹⁹

The topic of withholding and withdrawing treatment is not without its opportunities. One opportunity is to increase the collaboration with the nurse members of the health care team.²⁰⁰ A second opportunity is to improve communication with families.²⁰¹ A third opportunity relates to withholding and withdrawing life support in the emergency department (ED). Emergency physicians are usually faced with a lack of information on the patients they treat which leads to inappropriate intubation providing an opportunity for improved end-of-life decisions in the ED and an increased focus on palliative care.²⁰² A fourth and final opportunity is to ensure that withdrawing treatment does not equate to withdrawal of care.²⁰³ All patients deserve to be cared for, even if they are receiving futile treatment, to include providing a death with dignity.

One approach that can assist with not only symptom management, but also maximize the potential for quality of life during the remainder of time for those suffering from a life-limiting illness, is the utilization of a palliative care program.²⁰⁴ Much progress has been made in the acceptance and prevalence of these programs across the nation. However, action is still needed to enhance the benefits and address the opportunities, as well as ethical concerns that are present, such as those related to palliative sedation, euthanasia or “physician assisted dying”,²⁰⁵

Chapter 6 addresses moral distress and moral residue focusing on the nursing profession. The first part of Chapter 6 defines moral distress and its historical development plus a conceptual

framework that includes professional and personal identification. The last part of Chapter 6 focuses on the root causes of moral distress which impacts not only the nurse, but also the nursing profession, along with strategies to confront moral distress.

Much has been written about moral distress over the years, especially as it pertains to nursing, and this nursing is most often in the critical care arena.²⁰⁶ Moral distress was first defined by Jameton in the 1980's as something nurses feel, along with guilt, when they engage in treatment that they believe to be wrong but are unable to avoid.²⁰⁷ Today's current definition depicts moral distress as what occurs when a person perceives a moral problem, accepts moral responsibility, then makes a moral judgment regarding the appropriate moral action. However, because of real or perceived limitations, the individual then engages in moral "wrongdoing" by either an act of omission or commission that is seen as morally wrong.²⁰⁸

Jameton further explains moral distress as an "initial" distress leading to a "reactive" distress. This initial distress occurs after limitations and value conflicts are perceived within the organization leading to anxiety, anger, and overall dissatisfaction.²⁰⁹ Reactive distress is the negativity that results when the initial distress is not dealt with and may be caused by the individual's personal obstacles which present no recourse.²¹⁰

Moral residue, although not as widely studied as moral distress, is nevertheless, believed to exist. Moral residue is defined as that which is left when moral distress is not resolved leading to a crescendo effect.²¹¹ Other authors characterize moral residue as the leftover feelings that individual's carry with them from times when facing moral distress that the individual either severely "compromised" themselves or allowed themselves to be "compromised".²¹²

Between 33-80% of nurses state they have experienced moral distress with those who have left their jobs doing so because of moral distress 15-26% of the time.²¹³ Both critical care nurses

and physicians care for patients who are receiving treatment that they do not agree with which they find in violation of their moral conscience. This occurs in 50% of critical care nurses, 30% of attending physicians, and 70% of house physicians.²¹⁴

There has been a lack of a conceptual framework for moral distress, which is believed to have hindered further research and formulation of directed education or policies.²¹⁵ In examining the conceptual framework for moral distress, professional and personal identification are significantly integrated. To separate the professional identification, it is necessary to examine the professional and inter-professional relationships, as well as all the challenging dynamics associated with these relationships.²¹⁶ Nursing is perceived as a highly moral profession with goals that provide care to patients by protecting them from harm, preventing complications, and sustaining a healing environment.²¹⁷ When any of these goals cannot be realized, for various reasons, moral distress can result.

One of the most important inter-professional relationships that is affected by, and contributes to, moral distress is the nurse-physician relationship. Some critical care units have a history of tension between nurses and physicians that, when unresolved, can lead to moral distress.²¹⁸

Other contributing factors in the professional realm that can contribute to moral distress include shift work; staffing issues; lack of trained colleagues; leadership concerns; heavy workloads; and the emotional toll of caring.²¹⁹ Nursing, like many other professions, has a code of ethics. Nursing's code addresses both the profession's and individual's responsibility to address moral distress, taking action to prevent it, whenever possible.²²⁰

The personal identification found in moral distress in nurses starts from the beginning during the education process to become a nurse. It starts when nurses are indoctrinated with the sentiment that they have a "sacred" duty to those in their care, i.e. "the patient always comes

first”, so that there is a preconceived idea regarding the care of the sick and injured.²²¹

Two factors have been identified that affect the individual nurses and their level of moral distress. The first is moral sensitivity. This is the realization the nurse has of the moral essence that comes after the interaction with another, such as a critically ill patient who is vulnerable.²²² This sensitivity brings together moral knowledge and “moral behavior” in such a way that there is a perceived benevolent responsibility to do what is right for the patient.²²³

The second factor is the moral or ethical climate. Ethical climate is defined as the organization’s “variable” that can be altered to facilitate open dialogue regarding patient care issues and ethical concerns.²²⁴ This open dialogue leads to the organization’s culture which includes attitudes, norms, expectations, and values.²²⁵

The professional and personal identification lays the framework for moral distress. However, not all nurses suffer from moral distress, yet, work in the same environment with similar characteristics. This variance has led to many studies to determine the reasons why some nurses are affected and others are not.

Moral distress has received much attention because it is so compelling as well as detrimental to the integrity of those affected by it.²²⁶ Continued exposure to moral distress, leading to moral residue, can affect one’s core values and sense of duty which are integral to integrity.²²⁷ With a loss of integrity, in the presence of moral distress, there is a fear that it will lead to a subsequent loss of one’s personal and professional identity, which can be devastating.²²⁸

The frequency and intensity of moral distress varies between nurses in the same as well as between separate nursing units. In addition, when the United States is compared with both developed and developing countries, the United States reports a higher frequency and intensity of moral distress, especially when associated with futile treatment at end-of-life.²²⁹

The intensity studies indicate the situation when moral distress is most apt to occur. Inherent in these situations are sources or root causes of the moral distress. The top five identified root causes were identified by both nurses and physicians as indicators leading to moral distress. These include the following: 1) patient care that is affected by a lack of continuity; 2) acquiescing to the family's wishes for treatment when the patient's best interests are not considered; 3) poor communication on all levels; 4) prolonging death through "life-saving" actions; and 5) unsafe staffing conditions.²³⁰ These top five causes are similar with both the adult and the pediatric population, with the exception that following the family wishes is the number one root cause for moral distress in the neonatal/pediatric areas.²³¹ The majority of these top root causes deal with end-of-life topics and the decision making process when the patient is receiving futile treatments. Medical futility is a major contributing cause to moral distress in nurses.²³²

The nurse who experiences moral distress has usually suffered through a process of ethical decision making. This decision making has exposed moral conflicts and moral judgments on the way to moral action. An instance where over 50% of critical care nurses report experiencing conflict and moral distress is in the area of organ donation. Organ donation becomes conflicted when viewed as helping others, yet, distorting and prolonging the dying process for patient, families, and nurses before the organs can be harvested.²³³ These conflicts have increased as the source of organ donation has expanded from brain dead patients to donation after cardiac death.²³⁴

There is one contributing factor that has been identified as the underlying root cause, source, or contributing factor for the nurses' moral distress. This is the nature of the nurse and physician relationship. In the critical care environment, nurses and physicians must have a close

relationship in order to provide quality patient care. In an ideal world, this relationship would be both cooperative and collaborative where differences are confronted and openly discussed.²³⁵ However, this is not always the case and as a result, due to several factors, this lack of collaboration sets the stage for moral distress and dissatisfaction from both the nurse's and physician's perspective.²³⁶

The consequences of moral distress on the individual nurse can be profound, both in the short term and in the long term. Immediate effects are related to physical symptoms, psychological responses, feelings of a lack of support, job dissatisfaction, and attitude changes toward patients.²³⁷ As moral distress continues there is more negativity as it relates to patients, other staff, physicians, and the organization, especially where there is perceived medical futility in the treatment of the critically ill patients.²³⁸ As moral distress persists leading to moral residue long term effects become evident such as loss of self-image, the presence of more or a loss of spirituality, and health related decisions such as completing one's own advance directives or removing self from organ donor list.²³⁹ The unresolved moral distress can then proceed to burn out, early retirement, and leaving critical care and/or nursing to seek another profession.²⁴⁰

Moral distress is reported in all areas of nursing, however, it takes a major toll on neonatal nurses. The reasons for neonatal nurses experiencing more moral distress are believed to be related to uncertainty after resuscitation and whether the long term outcomes for the premature infants justify the resuscitation.²⁴¹

Moral distress can lead to nurses leaving their jobs or the profession. Historically, healthcare executives have not always given nurse turnover the attention it needs ranking it 7th in importance of top issues facing executives today.²⁴² Nursing turnover is costly at an expense of approximately \$300,000 for every 1% increase in turnover.²⁴³ However, there are other costs

associated with turnover, such as decreasing quality of care, which affects reimbursement, leading to an immense resource expenditure that often never addresses the root cause of the problem.²⁴⁴

The nursing profession has been delayed in addressing moral distress in research, education, and policy.²⁴⁵ In the past, nurses reported a lack of support from nursing management to the point of being reprimanded when seeking help or being “scapegoated”.²⁴⁶ However, all that is changing. Now moral distress has been recognized not only in the United States but internationally and the nursing profession has begun to take action. Work has begun to target nurses who work in high risk areas where the patient’s needs are uncertain with intense needs and prolonged suffering that often leads to death.²⁴⁷

Research shows that creating an ethical work environment helps to minimize moral distress and if it occurs there are processes in place for moral distress to be resolved. For an ethical environment to occur, there is a role for the organization, the unit and the individual. From the organization’s perspective, a place to begin in creating such an environment is through policy, ethics education and practices.²⁴⁸ Other efforts that come from the organization to the individual include daily ethics rounds, workshops on the topic, and an emphasis on nurse/physician collaboration that begins in schools and continues to the workplace.²⁴⁹

The leadership of critical care units is key in recognizing the moral distress and confronting it in a kind and compassionate manner. Nurse leaders can take the lead in addressing moral distress in many ways. Examples include: 1) utilize facilitators to explore symptoms and behaviors of moral distress; 2) monitor data, using root cause analysis, to help establish needed programs and monitor progress; and 3) enlist staff to develop healthy work spaces focusing on self-care renewal.²⁵⁰

The individual responsibility for the ethical work environment is to encourage open communication with colleagues, to utilize ethical principles in practice and to enhance skills in “ethical reasoning”.²⁵¹ As numerous studies support, a nurse’s ethical beliefs are influenced more by past experiences, values and religious beliefs than by the professional code of ethics.²⁵²

Ethical work environments occur when moral distress gets resolved through moral action. However, moral action does not always occur due to various constraints, whether real or perceived, that can be found within the nurse or throughout the workplace. Constraints to moral distress can be described as either internal or external. Internal constraints include such things as a lack of knowledge, skills, and abilities to understand what are the appropriate actions to take and then to take them.²⁵³ External constraints are broader and can include a lack of adequate staffing; high nurse to patient ratios; high consumer expectations for care; fiscal pressures; inadequate communication; and the influence of technology.²⁵⁴ These constraints are not unique to nursing and are experienced by all members of the health care team. The fact that nurses see them as major constraints rendering them powerless may help perpetuate the nurses’ image as “powerless victims” of the healthcare system.²⁵⁵

Another area of constraints is the lack of knowledge regarding avenues that are available for moral distress resolution. This includes ethics committees and ethics consultations.²⁵⁶ Included in this umbrella of lack of knowledge is education and training in ethics which can help individuals increase their confidence in making ethical decisions and taking moral action.²⁵⁷

A major concern in the constraints to moral action is that some nurses may have lived with moral distress for so long that they have “normalized” it.²⁵⁸ Because of this normalization and the failure to see any progress or change in the ethical environment, the nurses accept the situation and do not push for action.

Although moral distress, for the most part, has negative connotations, it can also have beneficial effects. These benefits include a call to action to better understand one's personal moral values and how that translates to professional obligations for both personal and professional growth which leads to improved compassionate care to patients.²⁵⁹

Chapter 7 provides an abbreviated conclusion to the dissertation on medical futility found in end-of-life treatment in the care of the critically ill neonatal, pediatric, and adult patients. Futility has been around since medicine's beginning and continues today for a myriad of reasons of which a major one being that death is still not accepted as a natural process of life. It is also often seen as a failure by the medical profession. In the neonatal population smaller babies are being resuscitated because of advances in technology at a price that has not been fully realized. The pediatric population is living with congenital anomalies and genetic defects that would have died years ago, which presents its own ethical dilemmas when these children require critical care. The adult population is plagued with an ever-growing elderly population that has no advance directives and when they do, too often, they want "everything" done which leads to prolonging the dying versus prolonging the living. Each of these different age populations has looked at the issue of futility within their own boundaries with little concern for those of other age groups. It is time for all health care providers from every age group to join efforts in an attempt to address the ethics of futility as a health care dilemma that crosses all boundaries. Such an approach is more apt to lead to improved strategies that places the patient first minimizing suffering and enhancing end-of-life care.

The persistence of this medical futility, along the age continuum, has gotten media attention as resources are consumed and ethical dilemmas are made visible in the social, legal, as well as ethical realms. Limited awareness has been in relation to the human effect of futility. This is

changing as there is an increasing incidence of moral conflict and moral distress along with powerlessness, and a lack of autonomy in the workplace making them vulnerable to the ravages of moral distress. This contribution to moral distress, in addition to the impact on quality patient care, has contributed to medical futility not being ethically justified at the end-of-life in critically ill patients of all ages.

However, there is hope for the future. The Centers for Medicare and Medicaid (CMS) have proposed reimbursing health care providers for having discussions with older patients regarding end-of-life issues.²⁶⁰ Hopefully this will increase advance care planning and impact the uncertainty surrounding the present end-of-life decisions. Palliative care, historically absent in the neonatal/pediatric population, is now finding its way there. Palliative care is also making an impact in the adult care arena, but there is still much room for improvement before this care can be seen to make a difference for those with a life-limiting illness.

There is no easy answer to the on-going concerns that medical futility presents at the end-of-life in critical care. The goal still needs to be to minimize medical futility treatments as they have no place in the compassionate care at the end-of-life. Removing the futile attempts to prolong life at the end, can free both caregivers and families up to focus on preparing for the patient's death in a more humane and caring manner. This is certainly what all of humanity would wish to experience at the end-of-life.

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Chapter 2: The Ethical Debate on Futility

2.I. Introduction

With the invention of mechanical ventilation in the 1960's, came the ability to save lives, rescue patients, and prolong life in ways never before imagined. At times this life saving procedure, and all the treatments associated with it, can turn into prolonging the dying process. Some patients reach a point where they have had enough with treatments that offer no perceived benefit, and prefer to die with dignity or to experience a "good death". Meanwhile, other patients are unable to respond at this critical point in life so are left in the hands of surrogate decision makers, who may or may not know the patient's end-of-life wishes and may or may not choose to follow them. All this often leaves health care providers trying to meet the patient's needs, yet, not provide treatments which the providers see as "futile" or of no benefit to the patient and, in some cases, prolonging suffering and the dying process. When all of these contending sources come together, this can place medical futility center stage in the critical care environment, producing conflict, as well as an impasse, in making decisions regarding the patient's future treatment.

Medical futility is not a new concept as it has been around since medicine's beginning, having its origin with the time of Hippocrates. It gained more attention beginning in the 1980's and 1990's sparking the ethical debate.¹ Yet, today in the 21st century, medical futility defies an accepted or standard definition with its application varying from patient to patient and situation to situation. The approach to medical futility and the many questions that result have never been more prominent in the American health care system than they are today. This prominence has been enhanced by the explosion of advanced technology and critical care procedures.

The first part of Chapter 2 explores the ethical debate on futility beginning with its history to include its definition, origin, and rationale for the dilemma facing health care providers today. The second part of the chapter describes quantitative and qualitative futility taking a closer look at organizational ethics and the topic of rationing as compared to futility ending with a discussion on hope for the future.

2.II. History of the Ethical Debate

Although the concept of medical futility has been around for a long time, dating back to Hippocrates, it was in the 1980's that it began to be a focus of attention. As it has evolved to the present day, there have been three major phases. The first phase was concerned with being able to define "medical futility", "futile treatment", "futile care" or whatever "it" was to be called.² The second phase utilized a procedural approach, such as policies, procedures, and state laws to resolve ethical dilemmas concerned with futility.³ The final phase has been more focused on communication and negotiation between health care providers, patients, and families so that the goal at end-of-life is for decisions to be made collaboratively.⁴

As these phases were evolving there were other major events occurring in health care. One that was to have a major influence on decision making processes was the shift from the paternalistic physician model to the patient/family autonomy model. This section will address medical futility from the historical perspective to include the struggle to define it and how the move to autonomy from paternalism changed the decision making process at end-of-life. Two historical cases will be presented to illustrate these changes.

2.II.A. Medical Futility---Historical Perspective

In the beginning of medicine, in ancient Greece and Rome, the role of the physician was

made clear by Hippocrates as that of assisting nature to restore health.⁵ This was to be done by relieving suffering, decreasing the force of the disease, and refusing to treat those who were “overmastered” by their disease.⁶ To attempt to do more was a sure sign of madness.⁷ Plato, likewise, echoed Hippocrates’ thoughts in that physicians should not treat those who showed no promise to benefit from the treatment, even if the patient had as much gold as “Midas”.⁸

Moving into the Middle Ages, the Hippocratic view was replaced with religion and the supernatural with touches of superstition.⁹ This continued until the modern era, from the 17th to 19th centuries, when the view of modern medicine expanded with the scientific revolution and the focus on disease became something to be conquered.¹⁰ Progressing into the 20th century, science and religion became more integrated so that the ever-expanding technology, plus the sacredness of life, translated into doing whatever was possible to preserve life at all costs. Two other factors occurred in the 1960’s that would impact the practice of medicine. These were, first, the third party payment system, especially Medicare and Medicaid, which yielded to a “nothing is impossible” mentality as insurance would pay for it.¹¹ The second factor is the revolt against authority which was never more evident than what was seen surrounding the war in Vietnam.¹² This translated in medicine to patients/families requesting the providers to do what they asked or litigation would follow. With all these activities occurring in medicine, the ability to define futility was elusive, yet, health care providers said they knew it when they saw it.

2.II.A.1. Definition---Use and Abuse of Terms

For those who attempt to define it, medical futility is treatment which is characterized as useless, pointless, or having no purpose.¹³ To understand the meaning of such uselessness, there needs to be confidence that this treatment is of no benefit to this particular patient.¹⁴ Futility is treatment that either does not improve quality of life, does not improve the outcome, or prolongs

suffering.¹⁵ A treatment that has as its sole purpose the physiological extension or prolonging of life is also considered futile.¹⁶ The following have also been used to describe futile treatments, 1) those that do not produce a physiologic effect; 2) those that produce more of a burden than benefit; 3) those treatments that are experimental with unproven results as a “last ditch” effort; 4) those treatments the physicians cannot implement for various reasons; and 5) those treatments that are likely to produce a small insignificant outcome or difference to the patient.¹⁷

Futile is derived from the Latin word *futilis*, which has meaning in both religious and Greek mythology.¹⁸ Futilis refers to an urn that is narrow at the bottom and wide at the top used only in religious and mythical ceremonies with its use in everyday life limited because it tips over when filled.¹⁹ Useless in everyday life but having a role in mythology that has been compared to futile treatments, where they appear useless or pointless to some, such as the physician, but have an almost mythical or unrealistic expectation for the family.²⁰

In Greek mythology, it is seen to represent objects that are of no value or “useless”. According to legend, the daughters of Danaus, the king of Argos, a city in Greece, killed their husbands on the night of their wedding which resulted in them being sentenced to carrying water in “leaky” (*futilis*) containers which was doomed to failure.²¹ From this word for leaky comes futile which translates to useless. Examples of medical treatments that translate to useless are giving antibiotics for a viral infection, cardiopulmonary resuscitation (CPR) for a dying patient, or organ transplants for those with terminal cancer.²²

There is no argument that the term medical futility is subjective and open to interpretation by all those involved. Some families have expressed concern that futility becomes the physicians “trump card” when they no longer wish to continue treatment.²³ However, there is agreement among the majority of health care providers on the definition of medical futility if the

following occur: 1) a mutual goal has been agreed upon by patient, family and providers; 2) a treatment plan has been agreed upon with steps to achieve the goal; and 3) there is “medical certainty” that it is impossible that the agreed upon plan will achieve the goal.²⁴ It is imperative that patient/family and provider goals are aligned so that there are not separate patient/family goals and separate medical goals. If the family wants all life sustaining treatment continued and the physician disagrees, this does not always mean the treatment is futile, but it does mean the goals are not aligned.²⁵ Therefore, open, honest communication between family and providers is essential in order to come to an agreement that meets the patient’s needs.

Using the term “futility” has been controversial. This is due to the difficulty in standardizing a definition, as well as interpreting that definition.²⁶ Some authors even believe that there is no need for a definition of futility and that the use of such terms as “useless”, “meaningless”, or “pointless” etc. are also not needed.²⁷ Instead dialogue is to occur between the health care providers and patient/family that stipulates the “conditions” and “consequences” that are present in the health care decisions to be made in the patient’s best interest.²⁸

Given the vagueness of the term “medical futility”, there is the understanding that it usually means that a successful outcome is impossible, there is a minimal chance of survival to discharge or a small probability of returning to a quality of life that is of value to the patient.²⁹ Therefore, suggested terminology includes “non-beneficial”, “medically inappropriate”, having a low probability of success, and ineffective.³⁰

While medical futility was elusive to definition and physicians were making most of the health care decisions, this gave them more control over what treatments were provided to the patient. This paternalistic model worked up until the latter part of the 20th century. Then it changed in the 1980’s when patients/families began to demand life prolonging treatments which

health care providers often saw as inappropriate. This change, from the paternalistic model to one of autonomy, made the concerns about futile treatments more onerous and challenging.

Following is a discussion on this change.

2.II.A.2. Paternalism Model to Autonomy

Paternalism is defined in the medical world, as a denial of or interference with the freedom of another.³¹ Paternalism can also be viewed as the denial of autonomy where an individual's judgment is superseded by another's judgment, as with a health care provider over a patient or family member.³²

The premise of paternalism, where the health care provider is the decision maker for the patient/family in matters of health care and further treatment, is based on the principle of beneficence.³³ It is through the principle of beneficence that the health care providers want to do what they think is best for the patient, even if it may go against the patient's/family's desires.³⁴ Patients and families were willing to acquiesce to the expertise of the physicians that is until the 20th century when patient autonomy became the predominant principle in decision making.³⁵

The word autonomy is derived from autos (self) and nomos (rule or law) meaning that persons who are autonomous make their own decisions.³⁶ In simple terms, autonomy is defined as "independent uniqueness".³⁷ This independent uniqueness allows for self-determination that is absolute and cannot be taken away by others.³⁸

Autonomy from the patient's or family's perspective gives them the right to refuse medical treatment. This medical treatment may be life-sustaining or not, which is a right to privacy and liberty that comes from the constitution as well as a common law right to be left alone.³⁹ In comparison, there are no laws, in addition to expressed or implied rights, that give the patient the authority to receive any and all treatments as desired.⁴⁰ In fact, there is a more compelling

argument for the health care provider to refuse to order treatments for patients that are deemed to be medically inappropriate, or not of any benefit to the patient.⁴¹ Without this right of refusal, it is feasible that patients/families could demand any treatment with the physician becoming a “slave” or “puppet” of the patient.⁴² Health care providers must refuse based on the standards of practice, expert opinions, clinical judgments, laws, and professional practice guidelines.⁴³

When health care providers have conversations with patients/families these can take different forms. The first is the autonomy conversation which is related to treatment options, including no treatment, the potential consequences of each option, including the likelihood of their occurrence.⁴⁴ This conversation gives the patient/family the information in a neutral manner so they can make the decision. The health care provider can give an opinion or advice, if requested.

The second conversation is the futility conversation. With the futility conversation, the health care provider acknowledges to the patient/family that even though they have made a choice or decision, the provider has a problem with that choice or decision. This problem might be because it ventures into “bad medical practice”, does not align with previously agreed upon goals, or provides no benefit to the patient.⁴⁵ The health care provider can explain in detail the reasoning behind the conversation to include getting a second opinion.

Further discussions related to the autonomy versus futility conversations have resulted in two observations. The first is that if a true autonomy conversation took place, there is questions as to whether a futility conversation would even be necessary.⁴⁶ This is resting on the premise that the patient/family would come to the conclusion, on their own, that the treatment is futile. However, such an approach would bring integrity issues to the surface. The second is that if true futility conversations occurred, that are open and honest, it could help to lessen the fear that

health care providers are doing things or not doing things without discussing them with patients/families.⁴⁷

There have been ethical medical cases that have occurred in the United States over the years. Some of these cases reflect the struggle of families exerting autonomy on behalf of patients in making end-of-life decisions. Other cases reflect health care providers exerting their autonomy in expressing what they believe is accepted medical practice in providing futile treatment for the dying patient. The next section describes two such cases.

2.II.B. Historical Cases

For over 30 years, concerns related to medical futility, have put end-of-life decisions into the hands of the legal system. For the most part, the courts have favored competent individuals making their own decisions regarding their medical care.⁴⁸ However, it has been a balancing act between giving an individual the right to make decisions versus the state's concern with the sanctity of life. This becomes complicated when the individual is unable to make their own decisions, so they are made through a surrogate decision maker. Legislation has been passed to require health care organizations to ask patients questions regarding advance directives so the conversation can begin before the end-of-life moment arrives. However, the compliance with completing such a directive is low.

The past 30 years have witnessed numerous cases that have made national headlines regarding end-of-life decisions, often resulting in court decisions. One case, Karen Quinlan, saw the family wanting to withdraw life-sustaining treatment but the provider and institution were in opposition. Another case, Helga Wanglie, was where the family wanted to continue life-sustaining treatment but the providers and institution argued for the patient's right to die.⁴⁹ A presentation and discussion of these cases follow.

2.II.B.1. Karen Ann Quinlan---1976

Karen Ann Quinlan, was 21 years old in 1975, when she consumed alcohol, combined with the benzodiazepine, Valium, which left her unconscious and not breathing when found by friends.⁵⁰ Karen had shared with many of her friends her premonition regarding an early death, as well as how she was going to “go down in history”, both of which came to be true.⁵¹ Karen was resuscitated and placed on mechanical ventilation in a critical care unit and, although she opened and closed her eyes in the beginning, that ended after a few days.⁵² She was transferred to a facility with more advanced testing capabilities where extensive brain damage was confirmed.⁵³ Karen continued to deteriorate with her weight going from 120 pounds to 70 pounds, despite being fed with a gastric feeding tube, plus her extremities became contracted into a rigid fetal-like position.⁵⁴

Karen was given a diagnosis of persistent vegetative state (PVS) by her physician. PVS cannot be confirmed by any study and is only diagnosed through prolonged observation. This observation, ranging from 3 to 12 months where the patient has permanently lost the function of their cerebral cortex, all behavioral responses, such as pain and suffering, and all voluntary reactions.⁵⁵ Others have described PVS as “eyes-opened unconsciousness” where there is separation between alertness and wakefulness.⁵⁶ The upper brain or cerebrum does not communicate with the mid brain or brain stem, however the brain stem is usually left to direct the so-called “vegetative” functions, such as heart rate and wakefulness.⁵⁷

The Quinlan’s discussed Karen’s future care with their parish priest and were reassured that the Roman Catholic doctrines did not require extraordinary treatment to continue when the treatment was of no benefit.⁵⁸ Therefore, five months after Karen Quinlan’s unfortunate incident, her parents requested that mechanical ventilation be withdrawn. Although the

physicians initially agreed, the following morning they stated their opposition to discontinuing life support and could not participate stating they believed it was equal to murder.⁵⁹ Legal proceedings were then begun by the family.

The New Jersey Superior Court denied the Quinlan's request to withdraw the ventilator for Karen so an appeal was taken to the New Jersey Supreme Court.⁶⁰ The New Jersey Supreme Court invoked Karen's right of privacy as the right to be removed from the ventilator.⁶¹ This was a landmark case in that patients or surrogates have the right to refuse life-sustaining treatment, as well as being the first state supreme court ruling on end-of-life decisions.⁶² Another significant outcome of the Quinlan case was that the judges made a statement that these cases do not belong in the court system and need to be dealt with in the institution by committees, such as today's ethics committee.⁶³ Karen was removed from the ventilator but did not stop breathing as her brain stem still functioned in the PVS. She lived 10 more years, as artificial nutrition and hydration were continued, dying in 1985 from pneumonia.⁶⁴

The Quinlan case served as a guide for other courts to address these difficult patient issues and was significant for several reasons. First, it paved the way for decisions regarding death and dying giving competent patients, or their surrogates, a wide array of decisions at end-of-life. These decisions ranged from how much one was willing to suffer, be helpless, or to endure indignity giving the option of refusing life-sustaining treatment, even if it precipitates death.⁶⁵ Second, some viewed the Quinlan case as a gain for patients' rights. However, others saw the value to the medical profession giving them the freedom from criminal liability when removing life-sustaining treatment, especially with those in a PVS.⁶⁶ Although in the Quinlan case only the mechanical ventilator was removed, there is argument that the artificial nutrition and hydration might have also been removed as extraordinary treatments.⁶⁷ Finally, the Quinlan case

set in motion the need for ethics committees, the Patient Self Determination Act with its advance directives, and brain death statutes at the state level.⁶⁸ Even though Karen was not brain dead, it brought the condition and diagnosis to light.

A second case occurred over 10 years after the Quinlan case. It is an example of a surrogate decision maker making end-of-life decisions to continue treatment while health care providers believed the treatment was futile.

2.II.B.2. Helga Wanglie---1989

In 1989, Helga Wanglie, an 86 year old woman was treated for a broken hip, discharged to a nursing home, then readmitted to the hospital due to respiratory failure.⁶⁹ Despite attempts to wean her from the ventilator, it was not possible. After five months she was transferred to a long term ventilator facility where she soon experienced a cardiopulmonary arrest with resulting severe brain damage.⁷⁰ After a period of time, Mrs. Wanglie was given a diagnosis of PVS and, although her husband agreed to a do not resuscitate (DNR) order, he wanted all other treatments to continue despite the health care providers' recommendations to withdraw treatment.⁷¹

The hospital and its physicians took its case through the legal system. There is argument as to whether the reason for the legal action was misplaced. The institution asked for the court to appoint a third party as Mrs. Wanglie's guardian versus addressing the key concern in this case, which was prolonged futile treatment.⁷² The court acted in Mr. Wanglie's favor, as there was no reason to do otherwise, since he was a competent attorney capable of representing his wife.⁷³ Helga Wanglie died three days after the court decision, on July 4, 1991, with the diagnosis of sepsis.⁷⁴

Mrs. Wanglie had no advance directive, so the health care providers relied on Mr. Wanglie who first said that she had never expressed her wishes, then changing it to how she did not want

anything done to shorten her life.⁷⁵ This was based on a strong belief that God, and not man, could only take a life.⁷⁶ Lawrence Schneiderman, physician and ethicist, has stated that at one time patients and families turned to God and their faith for miracles, then they started coming to hospitals and demanded these miracles from the health care providers.⁷⁷

The Wanglie case resembled the Quinlan case in that it concerned whether to continue life-sustaining treatment in the presence of PVS, however, Mrs. Wanglie could not sustain respirations without assisted ventilation. The difference between Helga Wanglie and Karen Quinlan was that the family's and health care provider's role were reversed. In the Quinlan case, the family wanted to discontinue treatment and the providers wanted to continue; in the Wanglie case the family wanted to continue treatment and the providers wanted to discontinue.⁷⁸

There are several lessons learned from the Wanglie case. First, it emphasized the role of patient autonomy, placing it over provider autonomy, with the physician abiding by the decision of the patient/family, which had started with the Quinlan case.⁷⁹ Second, the Wanglie case caused the medical community, as well as families, to 'embrace' the concept of medical futility, even if there was no clear definition.⁸⁰ Even if the health care providers saw continued treatment, such as mechanical ventilation, as futile for Mrs. Wanglie, the family did not, seeing it as life-saving. Third, the ethics consultant was a physician who stepped out of his role as a facilitator to organize the institution in steps to terminate treatment.⁸¹ Had the consultant stayed true to the role, there might have not been a Wanglie case as the best advice may have been supporting the family's wishes.⁸² Finally, the Wanglie case emphasized that the particular decision is less important than the "who" should be making it.⁸³ This stresses the need for patients to have written their preferences via advance directives so that they can be followed when end-of-life nears.

The debate over who should make the decision, or have the last say in withholding or withdrawing life-sustaining treatment, has gone on for generations and continues today. Some ethicists, philosophers and authors speculate that too much time and energy has been spent on attempting to define futility, claiming it defies definition.⁸⁴ There are different rationale for what keeps medical futility such a prominent issue. These rationale range from ethical obligations and include moral arguments that are for and against the debate that keeps it continuing.

2.III. Rationale for the Ethical Debate

When considering medical futility and whether to provide what, in the health care provider's best professional judgment, is considered futile treatments, there is the initial question of whether there is a duty to treat or a duty not to treat. This duty can be supported by a weak to a strong viewpoint emphasizing a range from where the treatment can be provided or not to one where it is morally and ethically wrong to do so.⁸⁵

The rationale for the continued ethical debate surrounding medical futility is complex. First, it is based on the on-going struggle between patient/family autonomy and provider autonomy. Second, it is due to individual personal reasons of patients/families and providers. Third, there are institutional and professional reasons that influence the extent treatments are offered and continued. Finally, there are religious boundaries that frame the ethical response to the debate influencing the actions or lack of actions that are taken.

All of these factors come together in the critical care environment that cares for the sickest of the population ranging from the neonates to the elderly. It is here that the patients, nurses, and physicians agree on a treatment plan to support identified goals that can be supported and worked on collaboratively. Whenever there is disagreement among nurses and physicians on

the treatment goals and plan, conflict ensues creating ethical dilemmas.

This section will address the rationale for the ethical debate of futility by describing the ethical obligation to provide futile treatments, as well as the moral arguments for and against stopping such treatment. The perspectives of the nurses and physicians will also be addressed.

2.III.A. Ethical Obligation

As the physician paternalistic model evolved into the patient autonomy model, it became accepted practice to acknowledge the patients' right to refuse treatment. The right to refuse treatment, along with the informed consent doctrine, gave the patient the ultimate decision power related to treatment.⁸⁶ In theory, when providers believed the treatment to be provided or that was being provided was ineffective, that treatment ought not to be provided. However, in many cases it had been easier to concede to treatment than to try to dissuade the patients/families differently.⁸⁷ As a result, the demand for inappropriate and ineffective treatments intensified into more inappropriate and ineffective treatments to the point that ethical principles became subordinated to the demands of patients.⁸⁸ It is not only the demands of the patients that led to the ineffective treatments continuing, but also a multiplicity of other factors that contributed to their endurance. Following is a discussion of these reasons.

2.III.A.1. Reasons for Providing Futile Treatment--Providers

When identifying reasons why futile treatments continue from the providers' perspective, the majority fall into the category of personal reasons. For the providers, first is the subject of fear. The fear relates to the subject of approaching death which is difficult not only for the providers, but also for the patient and family.⁸⁹ Because of this fear, it can appear that "everything" is done in order to avoid the inevitable end-of-life discussion. This fear can be far-reaching and not only be regarding the patient, but it also brings one's own mortality to the

surface.⁹⁰ The physician also fears litigation if everything is not done for the patient. Diseases are still viewed as enemies to be fought with death being the ultimate failure.⁹¹ Therefore, all too often “everything” is done to keep the fear of litigation at bay.

The second personal reason for providers continuing futile treatment relates to emotions such as grief, guilt, helplessness, and misplaced ego.⁹² These emotions can not only influence the decision making process but can paralyze it to the point where no discussions can occur regarding a decision. Also on the emotional level, providers have a hard time “letting go” of a patient who they may have saved from death numerous times, so to do nothing in the moment of death seems unthinkable.⁹³

The third reason for the futile treatment to continue is the focus on the physical condition which ignores the patient’s subjective experience of the disease.⁹⁴ With a preoccupation on the disease, it is easy to equate survival with success, discounting the feelings the patient/family may be experiencing. As providers have less autonomy, they tend to focus more on the technical and medical aspects of the disease process.⁹⁵ What this leads to is less trust from the patient and family with an avoidance of candid conversations related to values, goals, and relationships, which are all necessary in making end of life decisions.⁹⁶

For providers, the fourth reason for continuing futile treatments is that providing the futile treatment is the “path of least resistance”.⁹⁷ It takes less time in a busy schedule to do what has always been done and it is less controversial. In some instances, there is so much public awareness and media scrutiny that the pressure to continue futile treatment may come from outside religious, political or social sources.⁹⁸ Providing futile treatment is doing something, while withholding or withdrawing treatment could be perceived as doing nothing. In other words, it can be perceived as an avoidance of making difficult decisions when treatments

continue beyond the point of benefit.⁹⁹

A final personal reason for providers to continue futile treatment is that the discontinuation of medical futile treatment is an acknowledgment that medicine is unable to master the disease process.¹⁰⁰ To continue with the treatment is holding out hope that this might be the one case in 100 that beats the odds.¹⁰¹ Unfortunately, this approach gives false hope to the family as well as denies them the comfort that comes from accepting and preparing for death.

Other reasons that influence the providers for continuing futile treatments are institutional based and, although intended to provide assistance, they can be perceived as barriers to both providers as well as patients/families. These interventions include the following: 1) policies that provide guidance for decisions regarding medical futility; 2) integration of palliative care into all critical care units; 3) education and training of medical and nursing staff on communication skills regarding end-of-life; 4) expectations regarding frequent proactive family discussions regarding the patient's progress and plan of care; and 5) utilization of ethics consultations.¹⁰² Some institutions have established a process if a provider determines further treatment to be futile, that instead of one individual making treatment decisions, there needs to be an institutional or professional consensus.¹⁰³ This consensus can be in the form of all patients with less than a month to live will no longer receive CPR to more detailed options based on individual patients and individual situations.¹⁰⁴ For some families, this process gives the burdens to the institution relieving them of the angst and guilt that often accompanies such difficult end-of-life decisions.

Just as providers have reasons for continuing futile treatments, so do patients/families.

Following is a discussion on these reasons.

2.III.A.2. Reasons for Continuing Futile Treatments—Patients/Families

In the patient/family and provider relationship when the provider no longer believes that

ethically the treatment is benefiting the patient, yet, the family wishes to continue the treatment, the provider can refuse to continue the relationship. Under the law of abandonment, once there is a patient:provider relationship, there is an obligation to continue to provide treatment as long as that treatment is required.¹⁰⁵ However, the law of abandonment does not require that a provider continue to offer treatment that is medically inappropriate or does not meet the standard of care. The law does require that the family be given reasonable notice that the provider can no longer be responsible for offering the treatment, deemed as inappropriate, in order to find another provider and/or seek another facility, if necessary.¹⁰⁶

Even when there is an impasse in the patient/family and provider relationship in the area of futile or inappropriate treatment, a more appropriate approach is to understand the basis for the family wanting to continue or to begin futile treatment. As patients/families act under the principle of autonomy, futile treatments requested to be continued or begun are done so for various reasons. These reasons include flawed thinking, assumptions not based on reality, lack of confidence that health care providers are acting in the best interest of the patient, financial concerns, and a belief that the treatments are the patient's right or entitlement.¹⁰⁷ Additional reasons include unrealistic expectations, feelings of helplessness, belief of inaccurate diagnosis or prognosis, a fear if futile treatments are stopped, non-futile treatments would also be discontinued.¹⁰⁸ Identifying the reasons can help to address them and bring them to resolution.

The more challenging and difficult reasons families want to continue inappropriate or ineffective treatments falls into the category of deep emotional conflicts. These conflicts can be so deep that family members are unable to identify them. They may involve feelings of guilt as well as animosity; postponing the inevitability of loss; employing the use of "heroic" measures as a way to show love plus compassion; and using the futile treatments as a symbolic ritual of

a long faithful spouse.¹⁰⁹ The best response to these emotional reasons is an ethic of care which has been stronger in the nursing community than the medical community, but it is being re-emphasized so that there is increased communication skills and emotional awareness.¹¹⁰

A final area that is the reason for families to continue inappropriate or futile treatment is based on cultural and religious beliefs. From a cultural perspective, the view in Western medicine has been to be open and honest with a full disclosure of truth telling regarding prognosis at the end of life.¹¹¹ Whereas, those from the Asian and Hispanic cultural traditions have the need to have autonomy balanced with the values and traditions of the family which may not wish to be fully informed.¹¹² Still, another culture, such as on the island of Vanatinai southeast of Papua New Guinea, the people are considered dead for what the Western world considers unconscious which leads to the potential of more than one death in a lifetime.¹¹³ Therefore, the approach to futility and end of life would be varied depending if the patient was from the West, Asia, Spain, or Vanatinai Island.

Just as the cultural influence can determine the reasons futile treatments are continued, so can religious beliefs. For example, in the Islam faith, God alone determines when death occurs so everything must be done to prevent early death and save life.¹¹⁴ However, even the scholars of the Islam faith argue that this belief was not intended to be without limits and that futile treatment can be withdrawn allowing a natural death to occur.¹¹⁵

Another religion, Judaism, is strongly committed to the sacredness of life. Orthodox Jewish patients do not accept the definition of brain death and believe that the concept of autonomy has no meaning so that all treatments must be continued until the moment of death is imminent.¹¹⁶ As with the majority of the ancient religions, many of the teachings were established before modern medicine with its many advances and technologies that are present today.

A Christian religion that is often discussed when end-of-life topics are presented is the Roman Catholic religion. The Catholic religion, like Judaism, shares a commitment to the sacredness of life.¹¹⁷ The Catholic faith has as its basic premise that if a medical treatment is judged to be ordinary, that is it offers hope or benefit to the patient, then it is mandatory, but if it does not offer reasonable hope or benefit, or is a burden, then it is extraordinary and it is optional.¹¹⁸ Although suffering can be seen by members of the faith as redemptive, it is not obligatory to suffer so that seeking pain and other symptom relief is within the faith's teachings.¹¹⁹ Therefore, from a perspective of the teachings of the Catholic Church, when a treatment is determined to be futile or ineffective, there is no moral obligation for it to be initiated or continued.

At times providing what is perceived as medically futile treatments seems ethically prudent. However, this does not stop the moral arguments that often ensue before, during, and after such treatment is provided.

2.III.B. Moral Arguments

Much time and energy has been spent on the topic of medical futility starting with its definition, which has not been standardized. The latest appeals are being focused on deleting the terminology of "futile" and using "ineffective", "non-beneficial", or "medically inappropriate" with a low likelihood of success.¹²⁰ There have been arguments posed, both pros and con for the continuing debate over futility treatments. Following is a discussion on the pros and cons in the debate, as well as a look at the view from the nurses' and physicians' perspective.

2.III.B.1. Pro-Futility and Anti-Futility Arguments

The concept of futility, even though identified in theory to the time of Hippocrates, got its name and significance in the 1980's when providers attempted to limit treatments that were

demanded by patients/families.¹²¹ The pro-futility arguments went so far as to withholding or withdrawing treatments without patient approval based on three justifications. These are professional integrity, experience plus expertise, and stewardship of limited resources.¹²²

The first pro-futility argument of professional integrity stresses that providers should never be asked to act in a way that is contrary to the integrity of their professional code and values.¹²³ However, the realm of professional integrity does not give providers justification to unilaterally override patients'/families' decisions regarding inappropriate treatment.¹²⁴

The second pro-futility argument illustrates how patients and families depend on the provider's experience, as well as expertise, to assess and diagnose the patient's condition making appropriate recommendations for treatment.¹²⁵ Along with this experience and expertise comes the obligation for the providers to refrain from offering treatments that are not of benefit or are considered futile.¹²⁶ In an ideal world, futile treatments are not offered and if the patient/family requests them, they are not carried out, following an open honest dialog between patient/family and providers.

The third pro-futility argument maintains that providers have a role in the stewardship of human, financial and material resources.¹²⁷ To begin or continue to provide futile treatment can be wasteful and misuse of precious resources indicating a lack of moral responsibility.¹²⁸ Although in the United States, patients/families and providers have balked at financial reasons for limiting treatments, this is not the case in other countries. In many other countries, the principles of stewardship and justice are more explicitly applied to treatment decisions for the good of society.¹²⁹

Just as there are pro-futility arguments, there are also anti-futility arguments. These arguments relate to patient autonomy, inability to make prognostic predictions, and the lack of a

standardized consensus on the definition of futility. The first argument relates to patient autonomy. The providers are tasked with sustaining life and relieving suffering when caring for patients/families and if these two responsibilities conflict, then the patient/family has the final say.¹³⁰ The provider and institution can then decide whether they can continue to provide the treatment to the patient or whether an alternate provider/institution must be sought.

The second argument applies to the difficulty in making precise prognostic predictions. Even though there are various predictive scoring systems that can be used to help predict mortality in critically ill patients, there is still a great deal of unknowns regarding the effect futile treatments may have on death.¹³¹ The best known scoring system is the Acute Physiology and Chronic Health Evaluation (APACHE) System which is the most predictive system in critical care.¹³² This system can make assumptions representing groups of diagnoses but it is not able to benefit one patient in one situation regarding treatment that may be considered medically futile.¹³³

The final anti-futility argument illustrates the discussion of a consensus on the definition and criteria for futility. ¹³⁴ There continues to be a plethora of literature pertaining to futile treatment and medical futility which has not clarified the topic over the years. The more recent literature has demonstrated a trend that futility as a concept needs to be eliminated.

The moral argument today for eliminating the concept of futility starts with the language used. For decades, medical futility has often been called “futile care” instead of “futile treatment” which gets written in policies as “care” and discussed with patients/families in the same way.¹³⁵ Care is never futile. This must be conveyed to patients/families and all providers. Even when treatments are withdrawn, palliative care to include symptom management with preservation of dignity, will be provided.¹³⁶

Medical futility is still one of the major reasons for an ethics consult when there is a deadlock in the decision making process between patient/family and providers.¹³⁷ Even if the futile treatment was done in response to the over-arching use of life-sustaining treatment at the end-of-life, when the treatment was no longer serving the patient's goals, it does not grant providers the freedom to unilaterally decide to control the treatments.¹³⁸

As the moral arguments are exposed and more dialog plus debate occurs, the struggle between the two main patient caregivers are exposed. These are the nurses and physicians. Optimum patient care occurs when there is collaboration between these two professions, yet, on the topic of futility a lack of collaboration can be significant which affects the patient.

2.III.B.2. Nurse and Physician Perspectives

Being a patient advocate is one of the core principles of professional nursing which puts them front and center in the end-of-life discussions and decisions.¹³⁹ Nurses spend the most time at the bedside with the patient and family so they are in a good position to know their wishes in order to advocate for them, as well as support the agreed upon treatment plan. This only works if nurses are at the table when these areas are discussed between the patient/family and physician providers. It has been documented that nurses suffer a high incidence of moral distress when they are forced to provide care they see as inappropriate or futile, especially when they have no input into the decision process.¹⁴⁰ Moral distress is when the nurse knows the right thing to do but is unable to do it because of various barriers.¹⁴¹

As nurses are looked at as one of the top most trusted professions, patients and families look to them for help in making choices that are reflections of their values, yet maintain their dignity.¹⁴² Research indicates that critical care nurses are often the first to identify the shift from the curative model, with hope for recovery, to the appreciation that futile treatment would be

medically inappropriate.¹⁴³ This is often before the patient's physician comes to the same realization.¹⁴⁴ This leaves nurses often caught in the middle where they attempt to follow medical orders while advocating for the patient/family.

When physicians and nurses are compared in terms of their definition of medical futility and how it applies in practice there is often disagreement. Nurses tend to be more negative in regard to the patient's prognosis than the physicians but are more accurate in their assessment of the patients.¹⁴⁵ In determining the future quality of life for patients, both physicians and nurses were unreliable in their predictions.¹⁴⁶ One study revealed that 40% of nurses, but only 25% of physicians, believed the critical care unit frequently cared for patients who were receiving inappropriate and excessive treatment.¹⁴⁷

Nurses have a role to work with their physician colleagues in helping build better relationships. First, it starts with a self-assessment in determining whether the perceived suffering in the patient belongs to the patient or whether it is the suffering the nurse is personally experiencing.¹⁴⁸ Second, to develop collaborative relationships between nurses and physicians which can have a symbiotic effect that improves patient care in a more compassionate way. Finally, the nurse can be instrumental in bringing together an interdisciplinary team. For those patients who place value on their religious beliefs, having a religious leader as a part of the team can provide additional insight.¹⁴⁹

When examining the concept of futility beginning with its historical evolution progressing to the rationale for the continuing debate, there was an attempt to define and more accurately explain the concept using different terminology. Utilizing the definitive terms of quantitative and qualitative is one such attempt to clarify the understanding as well as establish meaning to the concept of futility.

2.IV. Quantitative and Qualitative Futility

In general terms, quantitative futility translates to the likelihood that an action or treatment will produce the desired physiological effect.¹⁵⁰ Qualitative futility refers to whether the physiological effect will be of benefit to the patient.¹⁵¹ This section takes an in-depth look at both quantitative and qualitative, as well as other categories and characteristics of medical futility. The role organization ethics plays in medical futility will also be discussed.

2.IV.A. Definition and Differentiation

In the process of defining futility, the two main categories of quantitative and qualitative have been describes as differentiators. However there are three additional categories that get described along with quantitative and qualitative, these are physiological futility, imminent demise futility, and lethal condition futility. Along with these categories are the characteristics that are present, regardless of what categories the perceived futility is placed. Following is a discussion regarding these categories and characteristics.

2.IV.A.1. Categories of Medical Futility

The first category is physiological futility. The majority of ethicists and authors equate physiologic futility with quantitative futility, but some do differentiate between the two. For those who do consider them separately, physiological futility is described as treatment which does not provide any physical or medical benefit to the patient.¹⁵² An example is when antibiotics are prescribed to treat viral infections which are not effective against viruses.¹⁵³ Although this type of futility appears easy to scrutinize in practice, it is fraught with two obstacles. The first obstacle is that the treatment can be maintaining a physiological function, yet, the patient can be in a persistent vegetative state (PVS) or imminently dying.¹⁵⁴ Second, the provider cannot always determine if a treatment is providing physiological benefit. Case law has

supported providers in that they no longer have to provide treatments that do not provide a physiologic benefit, even if the patient/family is requesting it.¹⁵⁵

The second category is quantitative futility. Quantitative futility is said to be present if a treatment has been found in the previous 100 consecutive cases to be futile, then it can be declared futile in the present case.¹⁵⁶ In other words, the treatment will not work because it has not been effective in the past 100 times, which says it has less than one chance in 100 of being any benefit.¹⁵⁷ This determination can be concluded based on empirical data, personal experience, and expert opinion.¹⁵⁸

In determining quantitative futility, a statistical approach can be used to estimate the probability of success of a particular treatment. A concern with this type of futility is that the uncertainty could lead to inertia.¹⁵⁹ Absolute certainty of the success or failure of a specific treatment is never able to be determined. Even though by definition quantitative futility states the treatment was not successful in the last 100 cases, there is data that reflect this is difficult to follow or document stressing the absurdity of the futility concept.¹⁶⁰

The third category is qualitative futility. Qualitative futility also known as evaluative futility, refers to treatment that would not benefit patients to the extent that they could leave the critical care unit or be discharged home.¹⁶¹ This type of futility is seen as the most controversial as it places a value judgment on the treatment, which the provider is not prepared to complete unilaterally.¹⁶² If the patient's condition is such that there is an inability to appreciate the benefit of the treatment, as with PVS, or if the treatment does not release the patient from being dependent on critical care, then it is considered qualitative futility.¹⁶³ Qualitative futility is also viewed from the perspective of the patients' values and goals. An example is if the mechanical ventilator is continuing until a relative arrives from a military assignment overseas, then its

continuing until that time is not futile but in line with the patient's goals.¹⁶⁴

The fourth category is imminent demise futility. This category of futility refers to the treatment that is given to a patient who is expected to die in the very near future.¹⁶⁵ An example of imminent demise futility is renal dialysis for a patient in multi-organ failure. Although the dialysis may help the kidney function on a temporary basis, the remaining organs are failing and the patient will die soon.¹⁶⁶

The final category of futility is lethal condition futility. This category is when the patient has a lethal condition, such as pancreatic cancer, and although treatment, such as CPR, will not affect that condition, the patient will die in the "not too distant future" even if the treatment is done and is successful.¹⁶⁷

Whatever the categories of futility, it is more about the "benefit" than the "effect".¹⁶⁸ It is about whether the patient benefits from the treatment. A more contemporary definition incorporates the patient's goals, the probability of prolonging life, and the ability to achieve a physiological response to the treatment.¹⁶⁹

Whatever name or category of futility is described, futile treatment has characteristics in common. Following is a presentation of these characteristics.

2.IV.A.2 Characteristics of Medical Futility

One of the characteristics employs three thoughts. These are common cause, failure and repetition.¹⁷⁰ In terms of futility, this means that there is "repeated failure" for the treatment to result in the expected or intended effect.¹⁷¹ This expected or intended effect relates back to the patient'/family's goals for the treatment. This can be that the treatment, such as the mechanical ventilator, can be futile if the goal is for the patient to breathe independently, despite end stage lung disease, yet not be futile if the use of the ventilator is just to keep living until a relative

arrives.

Another characteristic of all futile or inappropriate treatments is that they tend to be value ridden.¹⁷² These value ridden treatments and the accompanying decisions affect both the patient/family and the providers. To keep them at a minimum, providers ought not to make unilateral decisions regarding futility.¹⁷³ The concept of futility holds many uncertainties making its validity and reliability for decision making for treatment limitation unreliable.¹⁷⁴

A final characteristic of futile or inappropriate treatment is that the determination of whether a treatment is futile or not varies based on the individual's expectations. A treatment is more apt to be considered futile the higher one's expectations.¹⁷⁵ An example of this is based on a family's versus the physician's expectation of a specific treatment. The family may be content if the treatment extended the patient's life, whereas, the physician would consider the treatment futile if it did not lead to consciousness and discharge from critical care.¹⁷⁶

Whatever the category of futility or treatment that is inappropriate, which is provided in the critical care units, its effects extend beyond those walls and involves the entire organization. Likewise, the reverse is true in so much as what occurs within the organization also affects the critical care units. The next section examines how futility, or inappropriate treatment, can affect organization ethics and how ethics committees play a role in the ethics of the organization.

2.IV.B. Organization Ethics

By definition, organization ethics is a series of actions that focus on ethical issues associated with the financial, professional, clinical, and management of the healthcare organization.¹⁷⁷ Organization ethics has three basic components. These are clinical ethics, which deal with the patient care, professional ethics, which refers to those professionals who work in the organization, and business ethics, which has a focus on the management of the

organization.¹⁷⁸ Each of these three components play a role in medical futility. Ethics committees, which are a part of clinical ethics, are often used to assist when there is conflict or a dilemma involving such topics as futility.

Several end-of-life futility treatment cases have made the headlines as a result of a media frenzy focusing on patient autonomy versus provider authority, the definition of futility, and futility as a cost containment issue.¹⁷⁹ These cases have led to much debate placing clinical, professional, and business ethics under scrutiny where ethicists debate futility being in the physicians' realm, versus a more broad perspective of belonging to the community or society at large.¹⁸⁰ Following is a discussion on these arguments.

2.IV.B.1. Futility and Organization Ethics

Prior to managed care, which reached its peak in the late 1990's, the clinical side of patient care and the business side were kept separate.¹⁸¹ Providers, especially physicians, were independent practitioners who cared for patients and organizations kept the business solvent which allowed these two to be separate. However, after managed care, this changed and organizations started being seen as the business they were with many physicians being made employees of the organization so that what happened in one arena affected the other.¹⁸²

The first component of organization ethics is clinical ethics. Clinical ethics is concerned with all aspects of patient care and the ethical issues or dilemmas that ensue from that care.¹⁸³ The four ethical principles of respect for autonomy, beneficence, non-maleficence, and justice are the moral guidelines for providers in their care of patients.¹⁸⁴ Whether that care is in the realm of quantitative or qualitative futility is irrelevant if the provider believes the treatment is futile.

It is in the clinical ethics that most all concerns regarding medical futility, or inappropriate

treatment, begin and can usually be resolved. However, the ability to resolve futility debates may require both implicit as well as explicit involvement of the organization's top level leaders.¹⁸⁵ Ethical decisions, such as those surrounding medical futility, involve more than the patient and providers having a far-reaching effect into the organization's stakeholders. Therefore, it is prudent that whenever medically futile treatment is perceived and there is an impasse between patient/family and providers, that not only administrators be made aware, but also risk management, legal counsel, community relations, and internal communications.¹⁸⁶ Early involvement of the stakeholders, which include employees, patients, payers, the community and contractual relationships, allows the organization to develop a strategy in approaching the futility dispute.¹⁸⁷ A strategic plan is important because the reputation of the organization, the integrity of the providers, and the respect of the patient/family plus the community is at stake.¹⁸⁸ Strategies may include taking a case through the legal system, knowing that history has not favored providers or organizations, so they need to be prepared to lose and deal with the publicity that will follow.

When looking at clinical ethics in relation to organization ethics, there are three observations. These include: 1) the majority of clinical ethics issues have "implications" for the organization. For example: this can be a lack of staffing or policy compliance; 2) many issues in clinical ethics have corresponding issues in the organization. For example: where a possible HIV positive patient refuses to have a HIV test after a nurse is exposed to the patient's blood--- the organization has a conflict between the patient's rights and those of the employee; and 3) many clinical issues are created by the organizations. For example: policy changes made by the organization that affect the clinical areas, especially when there is no input.¹⁸⁹

The second component of organization ethics is professional ethics. This ethics focuses on

the professions of nursing and medicine, although it also applies to all professions. Nurses and physicians are trained to advocate for their patients best interest. This is difficult at times and can cause conflict when they are juggling multiple patients' needs and the organization's demands, all while attempting to have a personal life.¹⁹⁰ Both the nursing and medical professions are plagued with burnout, moral distress, and job dissatisfaction when confronted with the care of patients who are receiving futile, or inappropriate, treatments.¹⁹¹ Both professions are guided by codes of ethics and professional standards. The most current American Medical Association Code of Ethics, 2017, Chapter 5, addresses end of life, as well as medical futility by alleging that futility defies definition and that "medically ineffective treatment" is the preferred terminology.¹⁹² It is yet to be known whether having this in writing for the physicians will change behavior or not.

The third and final component of organization ethics is business ethics. Business ethics relates to the business management of the organization to include policies, compliance with rules and regulations, employees' rights plus benefits, and being innovative while maintaining financial solvency.¹⁹³ How effective the business ethics is depends on the climate and culture of the organization. The climate is defined as a composite of three things. These are: 1) shared values; 2) the mission and vision of the organization with direct expectations for staff and physicians; and 3) an environment where all individuals are free to discuss and debate ethically significant issues.¹⁹⁴ Whereas, culture is the beliefs, traditions, practices, and "ways of thinking" that is shared by members of the organization.¹⁹⁵ It is easy to change climate but culture is deep seated and takes years to change, if it is able to be changed.

In confronting the ethical debates associated with futility, health care organizations need to balance the positions of opposing factions. Through this balancing, the organization's leaders are

“co-fiduciaries” with the professionals in assuring that the mission and values of the organization are upheld.¹⁹⁶ Approaches organizations have used to manage medical futility include giving additional authority to ethics committees, establishing policies, and supporting legislation.¹⁹⁷ Failure to act can impact patient care, the reputation of the professionals, as well as the financial viability of the organization.

Futile treatment and cost have been discussed together and although they fit with business ethics, they also are a consideration in both clinical and professional ethics. Cost is an ethical issue for those who run the system (business ethics), those who work in it (professional ethics) and those who use it (clinical ethics).¹⁹⁸ The primary message regarding futile treatment is that there is not “unlimited choice” for patients regardless of where they are on the life cycle because there needs to be an equitable distribution of the benefits and costs across individuals.¹⁹⁹

Almost all health care organizations have an ethics committee as it is now a requirement if being surveyed by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO). Part of the activities of an ethics committee is to be responsive to ethics consults in the organization. Following is a discussion on ethics committees and the role they play in medical futility.

2.IV.B.2. Role of Ethics Committees

Ethics committees appeared in the 1960’s to review abortions before they were performed, then kidney dialysis triage in the 1970’s, and regulatory overview to manage compliance with Baby Doe regulations in the 1980’s.²⁰⁰ In the 1990’s, the Joint Commission developed mandatory standards for ethics committees in health care organizations to address both patient care conflicts as well as business conflicts.²⁰¹

The primary functions of an ethics committee are patient care consults, policy review as

well as development, and self-education in addition to staff and physician education.²⁰² The most common ethical issues in patient care relate to end-of-life to include withholding and withdrawing treatment, medical futility, resuscitation status, artificial nutrition and hydration, advance directives, and capacity/competency to make end-of-life decisions.²⁰³

Ethics consults, usually completed by a small team of clinical members of the full ethics committee, can be referred by patients, families, health care providers, or other interested individuals who have a question concerning patient care.²⁰⁴ The role of the consultant is most often not to make the decision. The role is to facilitate communication, explore the issues, as well as the options, and in some instances, offer advice leaving the final resolution to those closest to the ethical issue.²⁰⁵

The function of the ethics committee varies by organization and it is essential that the function be made clear, not only to the committee plus those who do consults, but also to those who request a consult. A committee, or consult, can be established in two major models. One is an optional—optional model, which is the majority of committees, where consultation is optional and following the recommendations is, likewise, an optional.²⁰⁶ The second is a mandatory---optional model where consultation is mandatory but following the recommendations is optional.²⁰⁷ This model would be used infrequently and is best utilized when there are no viable alternatives. Theoretically there could be a mandatory---mandatory model when a consult is mandatory and following the recommendations are also mandatory. An example of this would be in implementing a new policy where the ethics committee/consultant is used to monitor compliance.

An ethics consult is often contacted to help in resolving conflicts regarding medical futility. This conflict most often is when the providers believe all medical options have been explored

and it is best to withdraw treatment, but the patient's family or surrogate want all treatments to continue. This is an example of an optional---optional model where the goal of the discussion needs to focus on the common interest of all parties which is the "best interest of the patient".²⁰⁸

The Veterans Health Administration has developed an Integrated Ethics (IE) model for a comprehensive approach to ethics in all their organizations.²⁰⁹ This system is recognized by the Joint Commission as a high quality program. It is also available for all organizations to transfer to their individual systems along with all the tools and forms. One of its domains pertains to Ethical Practices on End-of-Life Care which addresses medical futility as treatment that does not benefit the patient, therefore, it needs to be withheld or withdraw.²¹⁰

In defining medical futility using quantitative and qualitative terms, it can be said that medical futility is an attempt to provide a treatment to benefit a patient (qualitative) that is in all likelihood going to fail (quantitative).²¹¹ If this is what futility is, then what it is not, is rationing. However, there is an affinity to use one for the other as a way to limit inappropriate treatments. The next section looks at rationing versus futility and how they have come to be confused terms. In conclusion a discussion will examine what can be done to address ineffective treatments as hope for the future.

2.V. Rationing versus Futility

Both terms, rationing and futility, have negative connotations and are often confused by the general public, as well as health care providers. Part of this confusion is that the terms came into being in history at the same time and they are often found occurring at the same time with the same patient.²¹² Following is a discussion on rationing and futility, to include their differences as well as similarities, plus reasons there is so much attention being paid to both of

these topics. The top categories of reasons for rationing will also be explored.

2.V.A. Differences and Similarities

In considering medical futility in the care of the patient, there can be an inclination to disguise the uselessness of the treatment with rationing. This disguise can be presented as prohibitive cost, limited number of critical care beds, or a lack of insurance coverage as a way to make treatment decisions.²¹³ To pose a futile question in a limited resource manner, or scarcity, makes it easier for the providers to discuss with the patient and family as it is less controversial, making the issue easier to comprehend than inappropriate medical treatment.²¹⁴

Futility looks at one patient, at one point in time in a “cause and effect” relationship, while rationing looks at a problem of scarce resources, which is distributed over many patients with the same condition and situation.²¹⁵ Rationing implies a scarcity of health care resources that must apply to everyone without discrimination.²¹⁶ An example proposed by Daniel Callahan uses age as a factor for rationing where some treatments would not be available after a certain age.²¹⁷ Futility deals with treatment that offers no benefit but can be provided, whereas rationing deals with treatment that offers a benefit but is not provided for a variety of reasons. In essence, futility refers to whether an individual patient will benefit from a particular treatment and rationing refers to distribution of beneficial treatments among patients.²¹⁸

Just as futility has rationale for ethical debate, so does rationing which are similar.

Following is an exploration of that rationale.

2.V.A.1. Rationale for Attention to Rationing

Rationing has been in effect in three different arenas and accepted by the population as being “the way it is”. Two of these involve resource availability. The first is organ transplantation, where the demand far exceeds the supply with patients dying daily due to the inability to receive

a transplant.²¹⁹ The second is the drug shortage, which began to get attention in 2012, with shortages occurring in first line cardiac resuscitation drugs, as well as chemotherapy agents, forcing institutions to borrow and substitute or just “make due”.²²⁰ The third rationing is in Oregon where the health system changed due to inadequate funding, in the 1980’s, limiting services based on the ability to pay.²²¹

One of the major reasons for greater attention to rationing is related to health care costs. Health care expenditures as a percent of the gross domestic product in the United States has been increasing dramatically over the past 55 years beginning in the 1960’s when it was 5.3%; in 1970 it had grown to 7.4%; and by 1985, it had escalated to 10.7%.²²² The most recent report from December 2015, for 2014, indicated it is now 17.4% or \$9,523 per person with an increase in expenses from hospital care, especially in intense services, such as critical care.²²³ Both of the political parties in the United States have yielded to the belief that eliminating treatments and services that are of no benefit would do much to curb escalating costs as the belief is that 30 % (\$800 billion) is for inappropriate treatments.²²⁴ This would be done through administrative efficiencies, coordination of care, and the elimination of inappropriate treatments.²²⁵ Although this reduction might help curb the escalating costs, it would only be sustained if there are also controls on the use of technology as well as the management of insurers, including Medicare and Medicaid.²²⁶

Rationing does occur and has occurred for cost reasons for some time. Managed care brought rationing to the forefront. When third party payers will not cover a treatment, medication, or procedure, yet, its cost is too high for the majority of the population to pay out of the pocket, then rationing has occurred.²²⁷ However, health care rationing is not like most rationing when supply, demand, and the associated pricing is at play.²²⁸ Instead, health care

rationing takes a practical perspective with a view on what circumstances and condition treatments will be allowed. The greater issue in health care rationing is who will make rationing decisions as there are many interested stakeholders including politicians, pharmaceutical representatives and vendors, physicians, hospitals, third party payers, and patient special interest groups.²²⁹

A second reason for the increased attention to rationing is the focus on high-tech medicine. Whenever a new treatment, new procedure, or new drug therapy is introduced to the general public, there is a natural rationing until its effectiveness and efficacy have been proven.²³⁰ Therefore, its use is limited in the beginning and as its use becomes more extensive, it may continue to be rationed due to cost as well as the realization that it is confined to a particular group or diagnosis.²³¹ The problem arises when new technology advances beyond its expected use and expectation by many or all patients. An example is how CPR, which was first designated to be used after acute reversible cardiac arrests, has now become an expectation for all conditions, whether reversible or not, even if imminently dying, unless specifically ordered to do not resuscitate.²³² When there have been discussions regarding CPR and how this one treatment has become a given expectation, ethicists and philosophers debate that it should be withheld if it will not benefit the patient, to the point of doing so without the patient/family consent.²³³ This illustrates the cross over and confusion surrounding rationing versus futility where rationing limits resources in treating a group of patients and futility limits resources in treating an individual patient.²³⁴

A third reason for the increased attention being given to rationing is the increased aging in America. The aging of the population has been occurring since 1800 as diseases have been eradicated, healthier lifestyles have been practiced, and medical advances have added to

longevity.²³⁵ The rate of aging has accelerated over the years with those over 85 being the fastest growing age group at 21 times greater than in 1900.²³⁶ When examining the escalating cost of health care for those receiving Medicare, it is staggering. In 2008, there were 44,831,390 Medicare recipients, or approximately 45 million, whereas, between 2010 and 2030 this is estimated to grow to 79 million at a cost increase from \$503 billion to \$937 billion.²³⁷

Dan Callahan has long been an advocate of rationing based on age partly because Medicare is headed toward a financial catastrophe.²³⁸ Other countries, such as the United Kingdom, have directly rationed the elderly end stage renal disease patients from dialysis and transplantation.²³⁹ The elderly, in all countries, are a target for both futility and rationing because of their growing numbers and the cost of health care as they age. An argument against rationing based on age, calls the fairness principle to the discussion by treating elderly as “scapegoats” for the high cost of health care stressing that many of the new advances were not available to the elderly at a younger age.²⁴⁰ The one point that Callahan does stress is that rationing needs to be accomplished by policy versus providers making these decisions at the bedside, opening the possibility for discrepancies and bias.²⁴¹

Since rationing is seen to be inevitable and occurs because of limited resources, by avoiding the “explicit” discussion, rationing may lead to “implicit” and immoral rationing.²⁴² However, the term “rationing” conjures up negativity as much as futility does. For some rationing brings back World War II coupons, for others it reflects limited organs for transplantation but it is difficult to make a negative meaning work into anything positive.²⁴³ Today’s language is more apt to include “value”, which cannot be argued, “cost effectiveness” and “comparative effectiveness research (CER).²⁴⁴ To continue to use words, such as futility and rationing, which close people’s minds, will never reach the goal of value driven quality patient care.

The last reason rationing gets so much attention is the limits on the autonomy of the patients. Autonomy once thought to be the principle to override all others, is now being challenged. Many ethicists now debate that patient autonomy does not translate to patients getting whatever they want but that choices come from those limited to ones that are “medically appropriate” for the patient.²⁴⁵ The ethical role of the providers is to balance justice in resource distribution against the responsibility of advocating for their patients’ interests.²⁴⁶

Regardless of what rationing is called, there are reasons that put the action into place in a critical care environment. Following is a discussion of these reasons.

2.V.A.2. Rationing Decisions

The main reasons for rationing decision in the critical care environment are based on three influences which include external constraints, clinical guidelines, and clinical judgment. External constraints are often based on administrative decisions or rules and regulations being imposed from an external source.²⁴⁷ These external constraints can be sufficiently forcible. Examples include drugs that are no longer available on the hospital formulary because of cost, but the provider believes the drug would benefit the patient. The provider can accept this and use a substitute drug, try to circumvent the formulary, or transfer the patient to a place where the drug is available.²⁴⁸ Another example is a laboratory test that has been outsourced for financial gain which contributed to a long turnaround time affecting patient outcome. In this instance, the patient might be transferred to another organization but not every external constraint can be resisted or bypassed.

A second rationing decision is based on clinical guidelines. Clinical guidelines have as their potential to assist with clinical decisions based on both clinical efficacy and cost effectiveness.²⁴⁹ Clinical guideline have often been referred to as “cookbook medicine” and

have focused on evidence based practice from outcomes resulting from rigorous clinical research.²⁵⁰ The addition of cost into consideration is relatively new and is not consistent in all clinical guidelines and, therefore, not followed or sanctioned by all providers. However, the time has come when effectiveness as well as cost must be associated with end-of-life treatment, especially when transpiring in an already expensive critical care unit, to include evaluating palliative care treatment.²⁵¹

The final rationing decision is based on clinical judgment. Clinical judgment is required when two conditions are present. One is when clinical guidelines do not exist for the patient's presenting condition and the other is when it is not clear how the guidelines fit a particular patient.²⁵² In either of these circumstances, the provider must make the best clinical decision for the patient and departure from the guidelines is acceptable. Other examples of rationing based on clinical judgment in critical care is based on triaging patients in critical care units when there is a shortage of available beds. A method of rationing rules out those who are too ill to benefit from the scarce resources as well as those who are not ill enough to receive this specialized care.²⁵³ Other methods to ration, besides illness severity, include age, medical diagnosis, such as multiple organ failure or terminal metastatic disease, plus chronic heart or respiratory failure.²⁵⁴

One of the ethical discussions in reference to rationing and futility involves whether disclosure to the patients is needed. If the decision is based on clinical judgment, then the patient technically does not need to consent or be informed. However, when rationing is invoked for other than what is best for the patient, then most patients/families would want to be aware, to question, or even appeal, if possible.²⁵⁵ An open, honest, transparent approach is needed by the providers to maintain the trust of patients.

Both rationing and futility, or inappropriate treatment, are factors in critical care today and

will continue to be in the future. It has been suggested that a proactive approach could be beneficial in reducing some of the debate that surrounds these topics. Following is a look at recommendations for a more proactive approach with a renewed hope for the future.

2.V.B Resolving Futility Disputes

The debate regarding futility has not been resolved with questions regarding its definition Unanswered, plus its prevalence continues to be reported. In critical care units in the United States, approximately 20% of the patients receive at least one day of what providers describe as futile treatment.²⁵⁶ Approaches to the topic that have been emerging focus on shifting from a concept of essential medical futility to “patient appropriate care” that results from collaborative decisions made by patients, families, and providers.²⁵⁷ Along with this focus to a collaborative approach, there are recommendations that can help eliminate the need for a debate to occur. There are also initiatives and programs in place that can affect the incidence of the futility treatment debate.

2.V.B.1. Recommendations

In managing, resolving, or preventing futility debates or disputes, there are suggested recommendations that can be helpful. The first recommendation focuses on communication with the inclusion of expert consultation when needed.²⁵⁸ Almost all conflicts occur as a result of poor or inadequate communication. Focused communication involves frequent, open, honest discussion with developed skills in delivering critical and difficult information in an uncertain environment.²⁵⁹ Key elements in communication at the end-of-life include increasing the amount of time spent listening to the family, reassuring the family that the patient will not be “abandoned” prior to death, supporting the family’s wishes, and discussing means to minimize patient suffering.²⁶⁰ If there is a communication breakdown, requesting expert consultation early

can be beneficial. This expert consultation can be from an ethics committee, chaplains, social workers, skilled mediators, or palliative care consultants.²⁶¹

A second recommendation is the development of policies and legislation to assist in providing guidance when a situation presents where a futile treatment is requested or continuing.²⁶² Such policies or legislation need to be detailed and specific with input from all stakeholders followed by a broad communication plan and frequent assessment, as well as evaluation on its effectiveness.²⁶³ Such policies or legislation are usually done on a local basis and differ by state.

A third recommendation stresses the need to change the terminology used from “futile” to “potentially inappropriate”. “Potentially” implies that the decision is not final and “inappropriate” is more of a clinical statement than “ineffective” which is more of a value statement.²⁶⁴ This decision regarding potentially inappropriate treatment should then be communicated to the patient/family. In the process of communication and decision making, it is recommended that the decision making authority not be given unilaterally to the family or surrogate.²⁶⁵

Even when family and surrogates follow the wishes and values of the patient, the decision making process can take an emotional toll. Critical care providers can better support families, as well as surrogate decision makers, by, 1) seeking information regarding communication needs, as well as emotional distress exhibited by family/surrogates; 2) reframing the decision from the view of respecting the patient’s wishes; 3) encouraging multiple family decision makers, even if there is only one designated medical durable power of attorney, to help share the burden; 4) soliciting the importance of religion and spirituality in the family/surrogates life. The providers can determine if this is a value and assist in placing God’s role in decisions;

and 5) acknowledging if a family/surrogate is struggling with decisions so extra time can be spent listening to their stories, as well as giving deadlines for appropriate decisions, or attempt a treatment on a time limited trial basis.²⁶⁶ If these steps do not facilitate the communication and decision making, further steps can be taken. These include seeking an expert consultation; putting the expectations in writing; obtaining a second opinion; obtaining review by an institutional committee, such as an ethics committee; offering the opportunity to transfer to another institution; and offering the family/surrogate the freedom to seek legal review.²⁶⁷

These recommendations are proposed in anticipation of minimizing futility disputes at the bedside. An even larger scope looks beyond the bedside at what is available to change the debate in a more proactive manner.

2.V.B.2. Look to the Future

As the focus is to the future, there are some safeguards that are needed. First there is the problem when the pressure to cut costs and inappropriate treatment are not kept separate.²⁶⁸ These boundaries are often blurred so safeguards include the implementation of policies and second opinions to help minimize them. A second problem is when patients/families are left out of the decision making process. The safeguards include policies, utilizing a patient advocate, plus careful documentation of the decision making process.²⁶⁹ A third problem is to take futility, or inappropriate treatment, decisions to the legal system. Safeguards include utilizing an external mediator or negotiator who can help resolve the conflict without engaging the courts, where the patient often gets overlooked.²⁷⁰ A final problem is when inappropriate decisions are based on a “clinical bias”. It is easy to focus on the medical aspect of the patient when there is an end-of-life issue in the stressful environment of the critical care. Safeguards to prevent this from becoming all-encompassing is to include psychosocial and spiritual factors as part of all

inappropriate treatment discussions.²⁷¹ These discussions need to be documented for future reference to reflect the patient's values and beliefs regarding life, as well as death.

In looking to the future, one of the areas that brings hope is advance care planning and advance directives. Discussion between patients and providers prior to end-of-life with documentation of these discussions, and frequent follow-up conversations, can serve the patient well. These discussions address values, goals, and treatment preferences so that at the time when decisions are critical, there is some direction for providers.²⁷² Even though the completion of advance directives has been encouraged since the 1990's, and the Patient Self Determination Act, there has not been much increase in completion over the years.²⁷³ An initiative by the federal government and CMS, that took effect on January 1, 2016, reimburses providers for having conversations regarding advance care planning.²⁷⁴ This action was done in hopes of encouraging the conversations by giving a financial incentive for doing so. Despite the possible benefits, there are opponents who see it as a way to commit billing fraud, a way to limit treatment that might benefit a patient, or it will lead to taxing the Medicare program.²⁷⁵ The overall success of the incentive program is yet to be determined.

Another hope for the future involves increased education to the public as well as providers on the topics of death as a normal process of living, the role of palliative care, and advance care planning. Too often the media has portrayed death as an option focusing on miracles that have occurred leaving the public to believe that these are available for them.²⁷⁶ The medical advances and boom of technology has, thereby, led consumers to believe there is nothing that should not be available to them for the asking. This leaves providers with the daunting task of balancing the interventions associated with the technology with a humanistic approach to those who are at the end-of-life.²⁷⁷

To assist with this humanistic approach, a final look to the future centers on palliative care. What was once interchangeable with hospice care has now moved more “upstream” in the progress of the disease.²⁷⁸ The current palliative care programs are no longer just about caring for cancer patients but now care for all diagnoses with a focus on symptom management.²⁷⁹ Palliative care was first offered towards the end-of-life, however, when offered earlier in the course of disease, research has found that it can improve the quality of life, as well as provide enhanced longevity, especially if offered in conjunction with curative care.²⁸⁰

2.VI. Conclusion

Medical futility is not a new concept, having been referred to since the time of Hippocrates. Futility was named and began its present discussion and heated debate beginning in the 1980’s. Today’s discussion is stressing a name change to “potentially” or “medically inappropriate” treatment because of all the negativity and emotions associated with “futility”. Regardless of what one calls it, the problem of making decisions regarding treatments that are of minimum benefit to the critically ill patient at the end-of-life is very present today. This presence can be seen across the age continuum from the neonates to the adults in the critical care units.

As the ethical debate continues, it is fueled by the aging population, medical advances and technology, plus the continued pressures from the financing of health care to attempt to control costs. Patient versus provider autonomy plays out at the bedside, with some instances of the judicial system being involved, usually in favor of the patient/family, leaving no one a winner and the patient left in the middle.

There is hope for the future with the reimbursement for having conversations regarding advance care planning and advance directives with Medicare eligible patients. These results are

yet to be seen. Palliative care has become more available and is offering symptom management and hope for patients and their families not only at the end-of-life but also earlier in life-limiting illnesses.

Futile treatments serve patients by giving a false sense of hope for continued life, albeit with suffering and life of questionable quality. Futile treatments serve families by “doing everything” and giving a limited sense of doing something as a way to show they care. Futile treatments serve health care providers by showing some sense of caring and avoidance of the tough conversations. However, futile treatments do not have a place in the humane and compassionate care for the dying patient at the end-of-life. It is time for patients, families and providers to accept death as a part of living so that a focus can be on preparing both the patient and family for this journey. This will be the best way to end the ethical debate on futility, plus the associated conflict, so that the patient’s life ends with love, compassion and minimal suffering.

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Chapter 3: Futility and Neonates

3.I. Introduction

The birth of a child is usually a time of joy and anticipation. However, this can be dramatically turned upside down when the birth is premature, when there is severe illness, or congenital anomalies in the neonate. Modern medicine has done much to improve the survival rate of newborns but the benefit of this is not always clear, plus the cost may be a compromised quality of life. New parents are often faced with a life and death decision regarding their newborn in the delivery room where they are reeling from the loss of the expectations of parenthood. Following delivery, the decisions move to the neonatal intensive care unit (NICU) where the environment is foreign, as well as frightening, plus the decisions become more complex and challenging. The life/death decisions and ethical dilemmas not only affect the parents, but also impact the professional caregivers at the bedside in the NICU. Because of medical advances, neonates are surviving at lower birth weights/ages or with illnesses and disabilities that did not survive years ago, all of which has led to increasing ethical dilemmas at the end-of-life.

Chapter 3 addresses futility in the neonatal population and the unique challenges this presents. The first part of the chapter looks at futility and the neonate from a historical perspective placing the concerns within a theoretical framework. The second part of the chapter examines the ethical dilemmas in neonatology, the influence the various roles have on the neonate's care, ending with evidence based ethics as applied to the neonates.

3.II. Historical Perspective

To more fully understand the effect of futility in the care of neonates, it is important to

grasp the evolution of neonatal care not only in the United States but in Europe as well, as it impacted care in America. Through this evolution there were influences and lessons learned that have also had significant impact to the care being delivered to this smallest of the world's population. Following is a discussion of these historical developments.

3.II.A. Evolution of Neonatal Intensive Care Units

The evolution of neonatal care was influenced by developments in Europe as well as America. As neonatal intensive care units officially came to be in the 1960's, in the United States, the need was present to be able to categorize neonates based on weight and gestational age leading to a standardized classification system. Following is an explanation of the historical influence on neonatal care, as well as the present day classification system used in NICUs.

3.II.A.1. European versus American Influence

Up through the 1800's, the birth and care of infants were done at home, assisted by female family members or midwives, with little assistance from physicians.¹ In the latter part of the 18th century and the early 19th century medical advances came about as a result of the industrial age.² With these advances, care was moved from the home to the hospital setting. Out-of-hospital births moved from 44% in 1940 to 1% in 1969 with approximately 1.4% births in 2012 being in the home, which has been rising in the past few years.³ During 19th century America, infant deaths were acceptable as a course of life with approximately 15-20% of all newborns dying in their first year of life from infections, starvation, or hypothermia.⁴ The shift of care to the hospital setting, where infection control measures and medical treatments could be employed led to a decrease in infant mortality. Even with these improvements, the beginning of NICUs is thought to have not officially started in the United States until the 1960's with the development of the infant ventilator.⁵ However, there had been a perceived need plus an effort to address the

requirements of the premature and ill neonate long before the 1960's.

Action to address the needs of the neonate began in France in the latter part of the 1800's. The impetus for action was as much a political one as humanitarian as the birth rate was down, especially when compared with the rival country of Germany.⁶ Action began in the 1880's with E. S. Tarnier, a French obstetrician, who introduced the incubator and gastric gavage decreasing infant mortality from 66% to 38% in those infants weighing 1200-2000 grams.⁷ In retrospect, it is believed that even though the emphasis was on the effect that the incubator had on mortality, in actuality it may have been the mere act of studying the infant mortality and improving the feeding with gastric gavage that made the improvement.⁸ Adolphe Pinard, picked up the cause after Tarnier, promoting more of a prevention focus than treatment, believing that if the premature infants were rescued and survived they continued to be "weaklings" the rest of their lives.⁹ Another French leader in the field was Pierre Budin who established the first premature nursery in the late 1800's but is also known for his strong message regarding the value of breast feeding, which continues to resonate today.¹⁰ With the introduction of the incubator in infant care, the incubators along with the infants were brought to world fairs, expositions, and midways as a form of "side show" to exhibit the technology, plus instill faith in medical progress.¹¹

In the United States, the first hospital to have a separate nursery to care for premature infants was located in Chicago, in 1927, in Sarah Morris Hospital.¹² However, through the following years progress was slow. The view by the majority of physicians was that saving premature babies was going against nature which was a way to expel the world of a defective child or a "weakling".¹³ The focus on neonatal care was primarily feeding, keeping warm and isolation.¹⁴ Neonatal units were shocked to realize in the 1940's that providing high levels of oxygen, which was believed to be beneficial to neonates, could lead to Retrolental Fibroplasia (RLF), or

blindness in the infants.¹⁵ This is still being monitored and studied today.

Major changes occurred from 1950-1970 as innovation and technology advances were prominent. It was also during this time that antibiotics emerged. Neonatal care would be changed forever as life threatening infections could now be treated and, in some cases, ameliorated, yet the antibiotic treatment led, in certain instances, to further devastation to the neonate.¹⁶

Neonatology officially became acknowledged as a medical specialty in the 1960's with focused care for surgical procedures, pharmaceuticals, medical treatments, and breathing problems via the ventilator.¹⁷ Along with this focused care came the belief that the premature infant should be minimally stimulated with little or no contact with the parents. This isolation theory began to change in the 1970's when research began to be done showing no greater infection rates when parents were more actively involved with their infants.¹⁸ An additional bonus was found with increased neonatal development when parents interacted with the neonate in enhanced parenting skills and bonding with the infants.

During this same time period, new procedures, medications, and technologies were devoid of research trials or exposed to any scientific process. This changed from 1970 to 2000 when research became the norm and regulatory agencies became involved with focusing on problems found in NICUs across the nation.¹⁹

As NICUs progressed and neonatology became more accepted as a specialty, there was a need to classify the neonates as well as the level of care being delivered in the various NICUs. At first NICUs were regionalized in tertiary care centers, but as the field advanced more hospitals wanted to be in the business necessitating the need to differentiate the level of NICU care being delivered. Following is a discussion of the classification of neonates and NICUs.

3.II.A.2. Neonatal Classifications

Infants in a NICU can be classified in terms of body weight. Those who are classified as low birthweight weigh in at less than 2500 grams (5.5 pounds) at birth; very low birthweight is less than 1500 grams (3.3 pounds); and extremely low birthweight is less than 1000 grams (2.2 pounds).²⁰ Another way to determine maturity of an infant examines gestational age. An infant is considered premature if less than 37 weeks gestation, with 40 weeks gestational age considered normal or full term pregnancy.²¹ Gestational age is a better indicator of development and maturation, but it is difficult to determine because of menstrual cycle variability so birth weight is , even if it is deceiving.²² A newborn is considered a “neonate” for the first 28 days of life and an “infant” from the 28th day until the end of the first year. ²³

Neonates admitted to NICU’s fall into three general categories, each with its own ethical dilemmas and considerations. The first is the full or near term neonate who has a severe illness that requires close monitoring. Ethical concerns are limited as long as diagnoses and treatments are completed appropriately with neonates usually responding rapidly or dying quickly.²⁴ The second category is for those neonates found with congenital anomalies. Ethical dilemmas relate to whether to treat or provide surgical correction to conditions when the underlying anomaly remains untreatable, yet, failing to intervene can lead to death.²⁵ Quality of life concerns are most often a focus for this category of neonate. The third, and final category, is for those neonates who are born premature. The ethical concerns include all those in the other two plus the long term uncertainty of the neonate’s progress. This uncertainty includes survival in the immediate future, as well as having mild to severe disabilities in the distant future.²⁶

Neonatal intensive care units are classified into levels by the American Academy of Pediatrics. The levels are as follows: 1) Level I cares for well newborns 35 to 37 week

gestation. Infants who become ill are stabilized and shipped to a higher level of care; 2) Level II, special care nursery, cares for neonates greater than 32 week gestation, 1500 gram weight and greater. Care in this level of nursery is for the moderately ill and is predicted to be short term. Mechanical ventilation is done for short periods; 3) Level III, or NICU care, provides for life support on a sustained basis for those less than 32 weeks gestation and 1500 grams. Access to subspecialty is available to include pediatric surgeons, pediatric ophthalmologists, pediatric anesthesiologists, neonatologists and various subspecialists. Medical treatments are advanced and can include high frequency ventilation, nitrous oxide inhalation with access to all levels of imaging; and 4) Level IV, which is a regional NICU, cares for the most critically ill and complex neonates. This level of care provides for cardiac malformation that may require cardiopulmonary bypass with or without extracorporeal membrane oxygenation (ECMO). Level IV facilities also perform research, are most often found in a university teaching facility, and usually have their own transport vehicle and team.²⁷ Even though the number of NICUs has increased over the years, studies show low mortality among the very low birth weight infants in NICUs with a higher level of care and a higher volume of these patients.²⁸

As care for neonates and the development of neonatal intensive care units have evolved over time, there have been lessons learned that have focused on providing or not providing what was seen as futile treatment. The next section addresses these lessons.

3.II.B. Significant Lessons

As neonatology became a new specialty, significant lessons were learned that are still applied today. These include the first lesson of completing an organizational assessment before any changes are made in the care of neonates, since NICUs are part of a system and adjustment in one part affects the whole.²⁹ The second lesson, before considering any new treatment, safety

should not be presumed until research has been adequately completed, as did not occur with the high flow oxygen use in neonates that led to blindness discovered in the 1950's.³⁰ The third lesson is the value of an integrated approach to perinatal care that does not separate neonatal health care from maternal care.³¹ The fourth and final lesson has been the shift from the paternalistic physician making all decisions to a focus on the "best interest" of the neonate.³²

However, the most difficult lessons center on infants with disabilities and the dilemmas that occur when further treatment seems to be futile together with the parents versus provider authority in decision making. Baby Doe and Baby K are two cases that will be examined from the ethical challenge they presented in the history of neonatology.

3.II.B.1. Origin, Influence, and Aftermath of Baby Doe Rules

The "Baby Doe" rules or regulations became a major part of neonatology's history beginning in the 1980's. Baby Doe was born in Indiana, in 1982, with Down's syndrome and an esophageal atresia with a tracheal esophageal fistula which, through a mutual agreement between the parents and physicians, was not treated.³³ Without surgical treatment, the infant would die as anatomically feeding was impossible. Surgery was denied, feedings were withheld, pain medications along with sedation were given to the infant with death occurring in six days.³⁴ In coming to this decision, there was disagreement among the physician as some believed the anomaly should be repaired while others did not, leaving the final decision to the parents. Some physicians, primarily the obstetrician, and hospital administrators went to the court system to overrule the decision, however, the county circuit court and the Indiana Supreme court both ruled in favor of the parents.³⁵ An appeal was made to the Supreme Court, but the neonate died before the case was heard.

What started out as a difficult decision regarding the fate of a disabled neonate soon became

a social and political force to be reckoned with. By this time, neonatology had been recognized as its own subspecialty; it had been 10 years since the Roe versus Wade decision which legalized abortion; 10 years since the Rehabilitation Act of 1973 which addressed the rights of the disabled; and 10 years since federal legislation required there be state agencies to ensure that children are safe from abuse and neglect.³⁶ The public, after hearing the decision regarding Baby Doe, as well as others that were similar, cried out in disbelief prompting Congress, during the Reagan administration, to enact the “Baby Doe” regulations.³⁷

There were two sets of Baby Doe rules or regulations. The first used civil rights laws, based on Section 504 of the Rehabilitation Act of 1973, which stipulates that at least one of the three criteria must exist, otherwise, to not treat was discriminatory and in violation of the neonates civil rights.³⁸ A test of these rules subsequently went to the Supreme Court where it was criticized by the Court as interfering with the parents’ rights to act in the neonate’s best interest.³⁹ The second Baby Doe rules were enacted as amendments to child abuse and neglect funding requests for states via the Child Abuse Prevention and Treatment Act of 1984, and although optional for individual states, most states had adopted them.⁴⁰ These amendments made it unlawful to withhold treatment based on a disability or potential disability. As part of these amendments a toll free “hot line” was to be established where reports could be made regarding parents, as well as physicians, who failed to provide life sustaining treatment to neonates.⁴¹ Although the “hot line” is no longer in existence, the “Baby Doe” rules continue to guide behavior as the rules are overseen by the individual states’ child protection agencies. When the “hot line” was first active (1982 to 1983), during the first 19 months, 1633 calls were received, 49 were investigated with effect on treatment in six of the 49.⁴²

The act, or “Baby Doe” rules, allowed for treatment to be withheld if, 1) the neonate was

irreversibly comatose; 2) the treatment was classified as medically futile and prolonged the dying process; and 3) the treatment would be both futile for survival as well as seen as “inhumane”.⁴³ As neonatology has evolved with increased use of neonatologist’s expertise at the bedside, there is less of a need for rules to guide decision making. The “Baby Doe” rules were often misunderstood and misinterpreted, leading to more confusion than guidance, which has given support to the best interest of the child as the ultimate guide on decisions regarding withholding and withdrawing treatment.⁴⁴

A greater ethical challenge exists when a very premature infant presents at the border of viability when disability is not yet known. With these infants it is not known if treatment is given whether they will survive. If they do survive, it is not known if there will be physical or mental deficiencies. If there are deficiencies, will they be mild or severe and will they present early or later in life. The prognosis is so uncertain it makes decision making regarding treatment for a premature neonate, as well as potentially disabled neonate, very difficult.⁴⁵

3.II.B.2. A Case for Futility---Baby K

The case of Baby K brings to light the discussion on futility and medically futile treatments. Baby K was born in Virginia in 1992 with anencephaly, a congenital defect which presents with an intact brain stem but the cerebral cortex is primitive or absent.⁴⁶ Baby K was permanently unconscious and lacked a cerebral cortex so she was believed to be unable to see, hear, talk, feel pain, or have cognitive function.⁴⁷ However, because her brain stem was intact, she could breathe, feed, to include sucking and swallowing, plus respond to stimuli by “avoidance”.⁴⁸

Although Baby K’s anencephaly was diagnosed before birth, her mother, Ms. H, opted to not terminate the pregnancy. Ms. H had a firm Christian belief that God would work miracles if that was His will and that only He could decide the moment of death.⁴⁹ At birth, Baby K was

placed on mechanical ventilation, allowing her mother to recover from the Caesarean section delivery and to fully grasp the significance of the diagnosis. With the passage of time, Ms. H did not waiver on her devotion to the sanctity-of-life principle, despite being informed of the quality of life that awaited Baby K. The futility of further treatment for Baby K was explained with the exception of supportive care in the form of nutrition, hydration, and warmth.⁵⁰ Ms. H wanted everything done for Baby K.

Baby K was weaned from mechanical ventilation, had a gastrostomy tube placed to assure adequate nutrition and hydration, and was transferred to a nursing home for continued treatment. Six months after birth she had a tracheostomy placed to assist with breathing, which was of some help, but she was to make six emergent transfers to the emergency department (ED) when she was in respiratory distress, all requiring mechanical ventilation.⁵¹

The medical providers, including the hospital, believed that each visit to the ED was futile treatment, however, the mother would not change her decision for full medical treatment. So the courts were brought into the process. Historically decisions were made between physicians and patients, or surrogates. By the 1990's, the complexity of the health care decisions now included allied health professionals, hospital administrators, third party payers, ethics committees, in addition to the patient and the patient's family, which only added to the difficulty in making any major decision.⁵²

The hospital and physicians of Virginia sought assistance from a federal district court to withhold or withdraw the ventilator as inappropriate treatment for anencephaly. In the state of Virginia, the Virginia Health Care Decision Act allows a physician to withhold "medically or ethically inappropriate" treatment.⁵³ Even with this act in place, the court used the Emergency Medical Treatment and Labor Act (EMTALA) and Americans with Disabilities Act as

justification for the treatment to continue saying that bringing Baby K to the ED meant that emergency treatment must be provided.⁵⁴ The hospital held that Baby K's reason for the ED visit was because of her anencephaly, whereas the court initially, as well as on appeal, held that it was the respiratory distress and not the anencephaly that caused the visits.⁵⁵ Baby K died on her sixth visit to the ED, in April 1995, at the age of two and a half, from cardiac arrest.⁵⁶

The take away lessons from the Baby K case are that this is an example of more than the “rights” of the parents to choose or the health care providers’ rights to not offer futile treatment. It reaches into the value of life which does not exclude death, a topic too often avoided, as it is seen as a failure or too difficult to discuss.⁵⁷ The health care providers struggled with actions that were being done “to” baby K and rarely “for” her. ⁵⁸ Dialogue must begin early continuing to place value on life, with its limits, which means facing one’s own mortality, a daunting task.

A theoretical framework is needed to establish the context from which the end-of-life ethics in neonates can originate. The next section describes such a framework beginning with the moral status of the neonate and the on-going debate around that topic. Another part of the framework examines the best interest standard which looks at what is needed for the neonate. A final point describes how balancing the values or principles is key in helping keep ethical dilemmas at a minimum.

3.III. Theoretical Framework

Theoretical frameworks serve as guides to assist in detailing the support structure for the topic being researched or explained.⁵⁹ The theoretical framework also functions, not only to build a foundation, but also as a point of reference as the research is examined.⁶⁰

3.III.A. Moral Status of Neonates versus Best Interest Standard

The theoretical framework for examining futility treatment in neonates is based on several theories and concepts. The first is the moral status of neonates. Although there has been much written about the moral status of the embryo, fetus, and newborn, there is not one final agreed upon determination as to when moral status is granted. The second looks at the best interest standard and how that plays a role as neonates are unable to make their own decisions. The final framework examines the principles and values that in the end come down to doing the right thing.

3.III.A.1. Theories of Moral Status

Although there may not be agreement on the theory of moral status, one theory that does produce agreement is that at the moment of birth the neonate is a “full-fledged” member of society bestowed with the same rights as any other citizen.⁶¹ These rights are defined legally at birth as there is no valid constitutional statute that imposes any duty on the unborn child as they are not considered persons until birth.⁶² Even with that being said, the Supreme Court has stipulated that the individual states can exercise their interest in the fetus based on its potential to “become a child” making the woman’s perceived privacy right surrounding her pregnancy not absolute.⁶³ In fact, many states have individual laws governing allowable pregnancy activities. For example 18 states view substance abuse during pregnancy as child abuse, while three states see substance abuse during pregnancy as reason for “civil commitment”.⁶⁴

Moral status does extend beyond society membership. To possess moral status involves more than the birth process. It examines what it means to have moral status, protected by moral norms with the same moral rights as other humans.⁶⁵ Another reason to examine moral status, whether it be of the embryo, fetus, or neonate, is to determine the actual or potential “moral

value” that is attached to the moral status.⁶⁶ As a potential human being, the premature neonate is a symbol of human life, no matter how small, giving it moral value which means there are moral reasons to treat it a particular way.⁶⁷

Various views have been proposed over the centuries which identify “landmarks” as to when moral significance or moral status occurs. These include when movement, or quickening, is first felt in the womb by the pregnant mother signifying that the fetus is alive; when brain waves first appear which is approximately eight weeks gestational age; when the fetus separates from the mother and can live independently at birth; when the embryo or fetus is defined as genetically human with the 23 pair of chromosomes which some say is at conception; or when the fetus looks like a human which is at 9 to 12 weeks gestational age.⁶⁸ Both religious and secular frameworks have also postulated that moral status increases with gestational age which gives rationale to the timing of abortion and research on embryos and fetuses.⁶⁹

There has been no one theory that has survived to establish moral status or personhood for neonates. A finding in a national survey indicates that when deciding to withhold life prolonging treatment from all age groups, children including infants, were given priority over adults for treatment, except if the infants were premature, in which case, they were moved to the bottom of the list.⁷⁰ This finding concluded that premature neonates are believed to have less of moral status when compared with older adults indicating an ignorance of the capabilities of this population.⁷¹

Even though no one theory prevails related to moral status, there have been five proposed theories postulated of which a combination of some form of the theories is seen as a best theory on when moral status is conferred. These five theories are as follows: 1) being a member of the human race, which implies that only humans can have moral status; 2) having cognitive abilities

such as self-awareness and information processing, which places those who have mental disabilities in a questionable state of moral status; 3) being able to make moral judgments which is not possible until later in the newborn's life; 4) experiencing sentience such as feeling pain, pleasure and suffering, which is also questionable for some disabilities; and 5) having the capacity to develop trusting and caring relationships.⁷² In any neonate, and especially in extremely low weight newborns, it is difficult to predict with any certainty whether there is or ever will be the capacity for cognition, rationality, or relationship development.⁷³ Because of this uncertainty and a lack of one universal view, the debate on moral status will continue. Whether neonates have been declared to have moral status or not, they are believed to have rights which some believe is another way of signifying moral status.⁷⁴

The rights of neonates entitle them to be acknowledged and safeguarded as individual agents.⁷⁵ Because neonates are unable to defend their own rights, they are obligated to others to do so for them. In the majority of cases, the neonates' parents are the guardians of the rights via the best interest standard.

3.III.A.2. Evolution of the Best Interest Standard

Fifty years ago, premature neonates would have died as "nature took its course, but today they survive in NICUs as a result of medical advances.⁷⁶ Decisions are now made daily by parents and health care professionals determining whether the tiniest members of society should be resuscitated, or if treatment should be withheld or withdrawn. Obviously these neonates are incompetent or lack capacities to make their own decisions. The time of the late 19th century and early 20th century was known as the "Progressive Era". During this era, there was a national focus on the health and welfare of children, which included a focus on education, child abuse, custody preferences, and child labor issues, all of which were addressed due to injustices.⁷⁷

As part of the child reform of the time period, and to lessen the premise that those who lack lack decision making capability were the property of their surrogates or guardians, the best interest standard was first introduced in the 20th century.⁷⁸ In defining the best interest of the neonate, the best interest standard, which is an accepted legal principle, centers on the morally justified decision, since it is not possible to determine the interests of the neonate.⁷⁹ The inability to determine the interests is due to the infants' limited ability to have interest in its future with a focus on the immediate interests of food, being touched, and kept warm. If a neonate is born with abnormalities it is difficult to separate the best interest of the neonate from that of the family, or surrogate decision maker. This is due to three reasons which are: 1) there are no future interests or if there are any, they cannot be known; 2) because there is no past history, no substituted judgment can be used; and 3) the neonate's life is so interwoven with the family that they cannot be separated.⁸⁰

It is a challenge to know when to invoke the best interest standard. In general, there are three ways to consider the best interests of a neonate. First, if there is any medical benefit to be gained from the treatment, then it needs to be considered in the infant's best interest.⁸¹ The second way to consider the treatment refers to the perceived quality of life. This is especially true when contemplating futile treatment that provides no long term quality of life benefit.⁸² The final way to consider best interests examines the "burden of life" for the neonate. The burden examines disabilities which will affect the neonate throughout life realizing that it is difficult to decide what a benefit versus a burden is, as this varies among individuals.⁸³

The best interest standard is not without criticism. One criticism is that by definition the "best" interest standard directs decision making to what is best which could literally translate to the top surgical team, top NICU etc. which is not always possible. The standard was designed to

give a voice to those who are incompetent refuting the previous held practice that those who are incompetent were the property of their surrogates/guardians.⁸⁴ Another criticism deals with the vagueness and subjectivity of the standard. Whenever this standard is used, there are moral and legal duties to those declared incompetent with an awareness of options that are inappropriate, which does decrease its subjectivity in actual practice.⁸⁵ A final criticism is that the best interest standard does not consider the family as an integrated system taking into consideration the interest of the neonate, without the broader interest of the family.⁸⁶

For neonatal nursing, the best interest standard is a part of the caring focus. The ethical obligations of a caring ethic includes the parents, as well as the neonate, plus the future of the neonate.⁸⁷ The attributes associated with the caring include compassion as well as empathy. Nurses spend a great deal of time with the neonates and their families. This extended care can sometimes lead to an adverse attachment but, for the most part, allows the nurse to make valued input to decisions regarding the neonate's future.⁸⁸

In the process of decision making for the neonate within a theoretical framework, the process can focus on the neonate's moral status, the best interest standard or various other ethical principles and values. What ethical principles and values that are at play is dependent on the particular situation regarding the neonate and how the principles as well as values are kept in balance.

3.III.B. Balancing the Principle and Values

Because there are numerous principles and values at play that comprise the framework for decision-making for the premature neonate, it does become a balancing act. Decisions regarding medically futile treatment often requires a balance between a physician's paternalistic role and the autonomous role of the parents. Regardless of whether physicians or parents decide,

decisions surrounding the premature neonate are often very difficult with emotions and guilt seeming at times unbearable. Whereas, the ethics of justice and the ethics of care can seem to be in conflict, they can also be complimentary. Following is a discussion of the principles and values of paternalism versus autonomy as well as the ethics of justice versus the ethics of care.

3.III.B.1. Paternalism versus Autonomy

The NICU is different from other health care situations in that the patient is a newborn who cannot make decisions leaving the parents as the surrogate decision makers. The parents have no prior relationship with this newborn, except the mother has carried it in her womb with both parents having anticipated its arrival, and now they have to make life/death decisions regarding its future. There is no such thing as “parental autonomy” as autonomy means “self-rule” and it is impossible to have “self-rule” over another, especially a child.⁸⁹ It is possible to have “parental authority”, but this does not provide as much conclusion as autonomy.⁹⁰

The first decision that most often needs to be made relates to whether to treat the newborn or not and is most often made in the delivery room.⁹¹ There are definite limitations as to what the parents could know at this point, therefore, they must be given facts from the physician to consider in order to make a moral judgment decision. Initial decisions in the delivery room are most often weight related. Babies weighing more than 750 grams with at least 25 weeks gestation have an 80% chance of survival.⁹² Whereas, those less than 400 grams and 22 to 25 weeks gestation rarely survive with those considered being in a “grey zone”.⁹³ These facts may or may not be influenced by the physician’s personal bias. Physicians may include or exclude data in order to support their recommendation.⁹⁴ Research indicates that parental desire for treatment and resuscitation will be followed more readily than the request for limited treatment, with only 10% to 13% of deaths being initiated by demands of the parents.⁹⁵

The degree of autonomous decision making by the parents varies with the urgency of the infant's condition, the physician's perception of the situation, and the parent's tolerance, as well as their ability to make decisions.⁹⁶ In any given situation, the parents can have opposite views. One being that they were glad to have had the ability to make the decisions. The other being that the physician needs to make these decisions because the parents are too stressed to do so.⁹⁷ Even if parents do not make the final decision, they still wish to be consulted, informed, heard, and included in the decision making process concerning their newborn.⁹⁸

After the decision is made to treat or not treat, the second decision involves the withdrawal of treatment. The withdrawal of treatment is most often in cases where continued treatment is concerning futility in that it prolongs suffering, as well as the process of dying, with no apparent benefit.⁹⁹ The role of "parental autonomy" in these end-of-life decisions is dependent on how much the physician permits the autonomy to exist and play a definite role in the ultimate decision.¹⁰⁰ It comes down to how the information is presented to the parents, or a "beneficent paternalism", where the physician, in order to do good, takes the responsibility for the difficult decision.¹⁰¹

In the United States, paternalism has taken on a negative connotation, which is not the case in all countries, such as France, where it is expected that physicians will make all the decisions in the NICU.¹⁰² Even in France with this paternalistic model, the parents are asked for their opinions as well as to assent to treatment decisions.¹⁰³ Physicians in the United States tend to limit parent's choices or decisions even though the model is considered one of autonomy, plus parents never have the exclusive authority to refuse treatment for their neonate.¹⁰⁴ Therefore, decision making in the NICU may not be a true autonomy model. Regardless of the decision maker, ethics is complex in that it is comprised of rules, principles, decisions, and reasoning

which depend on best judgment for the given situation.

3.III.B.2. Principles---Ethics of Justice versus Ethics of Care

At the center of all values and principles, using a personalist view, is the human dignity of the individual which supports respect for autonomy, quality of life, social justice, plus beneficence and non-maleficence.¹⁰⁵ Human dignity does not diminish with illness or disability and cannot be taken from an individual as long as they are living.¹⁰⁶ A loss of human dignity can never be a reason to withhold or withdraw treatment.

Respect for autonomy in the neonate involves decisions based on outcomes or prognosis. This is achieved through the best interest standard. Naysayers believe the best interest standard is more representative of the decision maker than the one for whom the decision is being made that is influenced by personal, religious, moral and legal domains.¹⁰⁷

A value that requires balancing and that plays a major role in decision making for the neonate is the quality of life. Often the quality of life value is used when making decisions regarding the neonate, whether that be to resuscitate or not resuscitate as well as to withhold or withdraw treatment. It is not the parents' or physicians' role to determine a third person's quality of life. However, it is in their decision making process to determine the extent of treatment, whether the treatment is futile, in that it is of no benefit to the neonate, with the burdens outweighing the benefits.¹⁰⁸

The ethical principles of beneficence and non-maleficence are ever present in health care doing good to minimize pain and suffering, which is balanced by avoiding harm. Medical futility is often present when the principles of beneficence and non-maleficence are at a juncture with the use of futility being justification for stopping treatment.¹⁰⁹ Instead of using futility, as experts agree its use is too vague and violates beneficence, statistically based

outcomes is the proposed data of choice.¹¹⁰

Justice and care are values that have been identified as alternative approaches to ethical problems.¹¹¹ When examining the ethics of justice, it can seem to conflict with the ethics of care. The ethics of justice makes reference to that which is fair and equal for all where the needs of others are considered objectively regardless of the relationships.¹¹² Whereas, ethics of care relates to empathy, and compassion by considering a particular patient in a particular situation with particular needs.¹¹³ Characteristics of the ethics of justice include objectivity, fairness, decisions based on rules, equality, autonomy, and positive rationality.¹¹⁴ The defining characteristics of the ethics of care are involvement, holistic care, harmonious relationships, and trust.¹¹⁵ Although the ethics of justice and the ethics of care can appear as opposites, they can also be complementary.¹¹⁶

Some authors have posited that justice and care cannot and should not be separated as they are always in “tandem” with each other.¹¹⁷ Others hold that they are indeed separate with significant differences and, therefore, should be kept separate. A middle ground describes a comprehensive theory that incorporates the wisdom of both ethics of justice and ethics of care keeping both of their strengths and identities, plus what they contribute to the whole.¹¹⁸ To balance the ethics of justice with the ethics of care is a major challenge in the NICU. Nowhere is the challenge felt greater than with the nurses who want to give the personal and individualized care for each infant while maintaining the equal concern for all the infants in the NICU.¹¹⁹ A struggle can also occur when treatment becomes futile for the neonate, yet, the nurse has become so attached to not only the infant, but also the family, that it becomes difficult to be objective to enable a fair (justice) and rational decision process while maintaining a relationship of trust (care). It is a balancing act that challenges all of health care.

To treat or not to treat at the end-of-life in neonates is one of the many ethical decisions that faces new parents as well as health care professionals. The next section addresses the ethical dilemma regarding end-of-life in severely premature and critically ill neonates. Suffering in the neonate will be discussed to include pain, euthanasia and the Groningen Protocol. A description of the cost concerns regarding NICU treatment will be presented followed by perspectives on medical innovations for the neonatal population.

3.IV. Ethical Dilemmas in Neonatology

Looking back at the 1960's, a neonate less than 1000 grams had a 95% risk of death, while today the same neonate at 1000 grams has a 95% chance of survival.¹²⁰ This change, some call progress, has not been without its costs, not only in dollars but also in pain, suffering and, in some cases, long term disability. These medical advances, or innovations, have also created ethical dilemmas that are often far-reaching beyond the immediate effect on the neonate.

3.IV.A. Futile Treatment and Suffering

Miracles still happen in medicine and nowhere does this seem more evident than in the NICU. Neonates are surviving at smaller weights and gestational ages with each passing moment, however, it is not always clear, or is there agreement between neonatologists and parents, when continued treatment has become futile.

A great deal of speculation has been discussed and written about unbearable suffering of the newborn. Two identified problems come from these discussions. The first is that suffering is abstract, subjective, and personal which makes it difficult to identify in the neonate, yet, it is the one greatest human opponent the health care system was developed to “combat”.¹²¹ The second is the concern with identifying future suffering for the neonate which can range from chronic

pain to the inability to participate in self-care.¹²² Because suffering in the neonate cannot be assured or predicted, does not mean that suffering does not exist. One way that suffering is assessed is through pain assessment. If pain is determined to be present, it is then treated. There are additional approaches to intractable suffering ranging from palliative sedation to euthanasia.

3.IV.A.1. Role of Pain and Its Treatment

The issue of medical futility in NICUs closely corresponds to those in adult ICUs. The one exception is that, in the past, physicians, in the NICU, often pushed for treatment of the extremely low birth weight neonate appearing impervious to pain and suffering of the neonate.¹²³ In today's NICU, with the appearance of the neonatologist as a specialized entity, there is less of the aggressive treatment at the expense of the suffering neonate.

The outcome of the neonate varies widely between NICUs and is dependent on the health of the mother along with prenatal care, the particular health needs of the newborn, medical resources available at the institution, and the skill level of the providers.¹²⁴ When providers or parents perceive that further treatment is futile offering no benefit to the neonate prolonging suffering, a collaborative discussion with a plan of action usually occurs.¹²⁵ If providers and parents are not in agreement the following can offer a hope for solution: 1) ethics committees are consulted to assist with the decision making process; 2) occasionally a legal route is taken which most often favors the parents; or 3) as the state of Texas has done, a step-by-step policy is invoked to address action to be taken.¹²⁶

When the topic concerns futile treatments, that is treatments that are not benefiting the infants and may be harming them, physicians cannot be required to provide treatment that is in conflict with their conscience.¹²⁷ However, physicians find it difficult to set standards and draw the line, especially when pressured by parents, court judges, insurance companies, or government

regulators. If physicians do not draw the line, they cannot expect others to do so for them.¹²⁸

Since pain is one of the ways to determine suffering in the neonate, a means to assess its presence is needed. Pain scales for newborns involve non-verbal cues such as facial expressions involving the brow, nose, eyelids, lips, and tongue, plus full body movements.¹²⁹ Heart rate may initially slow then increase with pain.¹³⁰ Respiratory rate changes are not consistent with some studies indicating a slowed rate after a painful stimulus and some revealing an increased rate.¹³¹ Non-verbal or vocal expression, such as crying, is not possible when the neonate is on the ventilator.

Even with basic assessment tools and an urgency to address neonates' unmet pain needs, there are several disputes that make true pain assessment a challenge. These include the following: 1) over 40 assessment tools are available with not an identified best practice; 2) premature neonates are given an average of 2 to 14 painful procedures daily; 3) the neurodevelopment of the fetus by the 20th week gestation has the ascending pathway to the brain developed to conduct pain, however, the descending pathway that helps to inhibit incoming pain does not fully develop until the third trimester (28th to 40th gestational week). This increases the premature neonates' sensitivity to pain; 4) the best indicator for pain in the premature neonate varies by gestational age; and 5) as with full term infants, but moreso with the premature infant, it is difficult to differentiate pain from distress, anxiety, agitation, or hunger.¹³² Hope for the future includes electroencephalography and neuroimaging approaches that measure somatosensory and frontal cortex activity that occurs with pain.¹³³

In the highly technological environment of the NICU, nurses report that it is common to have the intense treatment take priority over addressing the neonates' pain and discomfort.¹³⁴ The "routine" care of a NICU neonate involves such painful procedures as frequent heel sticks

for blood samples, chest tube insertions, intubation with mechanical ventilation, peripheral and central line insertion, and lumbar punctures.¹³⁵ It has been documented that premature infants show an increased sensitivity to pain when compared with full term infants, however, the significance of this has not been determined but studies are in progress.¹³⁶ Other factors related to premature newborns, indicate that since their physiological systems are underdeveloped, this may make them more susceptible to negative effects from the following: 1) long term opiates for pain control; 2) repetitive painful procedures, such as needle sticks plus routine handling; and 3) too little internal steroids, which may adversely affect blood pressure and perfusion, to too much being administered, which may disturb brain pathway development.¹³⁷

In deliberating future suffering, disabilities are the major concern. Professor John Harris, a noted bioethicist and philosopher, has taken the position that to prevent a disabled child's birth is to prevent needless suffering which is, therefore, desirable.¹³⁸ Counter positions have come back with the premise that not all disabled individuals are suffering, they may be "harmed" in some way, but can lead happy productive lives and may suffer less than the non-disabled individual.¹³⁹

3.IV.A.2. Approaches to Intractable Suffering

For neonates who are experiencing "intractable" suffering, the treatment can be taken from four approaches. These are: 1) to make no decision other than make the neonate as comfortable as possible; 2) to withhold treatment which can be hydration, nutrition and medications, such as antibiotics. This approach is supported by the American Academy of Pediatrics but is controversial and nurses, in particular, have a difficult time withholding feeding from newborns; 3) to increase sedation, often in combination with #1 and #2, as a form of "palliative or terminal sedation". This is also controversial in neonates. The goal is often ambiguous as to whether it is to reduce pain and suffering or hasten death; and 4) to deliberately administer lethal doses or

lethal types of medications which is only legal in the Netherlands.¹⁴⁰

Euthanasia became legal in the Netherlands for adults and those over 12 years of age, in 2002, but did not become legal for neonates until the Groningen Protocol was introduced in 2005.¹⁴¹ The Groningen Protocol, developed by Dr. Verhagen, came about after a personal experience with an infant who had a rare disease that involved skin sloughing causing intense pain and suffering.¹⁴² The family begged for an end to their child's suffering, but fearing legal action, Dr. Verhagen sent the child home to die with the realization he had prolonged the suffering.¹⁴³ This incentivized him to become an advocate for neonatal euthanasia and to develop the protocol.

In order to utilize this protocol, five requirements must be met. These are: 1) the diagnosis and prognosis must be accurate and hopeless; 2) the baby must be experiencing unbearable suffering despite medical efforts to relieve the suffering; 3) an individual third party physician must agree with the diagnosis and prognosis; 4) informed consent must be given by both parents; and 5) euthanasia must be accomplished via appropriate medical standards.¹⁴⁴ The deaths using this protocol are to be reported through a central reporting process. The Groningen Protocol is mostly used with a spina bifida diagnosis, which can be diagnosed in utero leading to an abortion, which is believed to explain the low numbers using the protocol of 20/year.¹⁴⁵

Even though the United States has no such protocol, medications are often given at the end-of-life, following withdrawal of treatment, in doses to manage symptoms that also hasten death, although this may not be the intent, using the principle of double effect.¹⁴⁶ To utilize the double effect principle, where there is one action with two possible effects—one good (intended) and one bad (unintended) the following parameters must be met: 1) the goal of the action must be good; 2) the intended effect is not achieved by the unintended or harmful effect; 3) the

unintended effect is only permitted, not intended; 4) there is no alternate means to achieve the good effect; 5) there is a proportionately valid reason for tolerating the unintended effect.¹⁴⁷

Analgesics and anxiolytics are frequently used for medications, but muscle relaxants are also used which lend the infant unable to breathe paralyzing the respiratory muscles.¹⁴⁸ The muscle relaxants stop the infant gasping allowing the parents to hold the infant more easily giving the appearance of a “peaceful death”. Such action is justified as relieving pain and suffering for the infant and not to end life.¹⁴⁹

The majority of deaths in a NICU occur after withholding or withdrawing life-sustaining treatment, especially mechanical ventilation.¹⁵⁰ At this time, the neonate’s best interests are key with communication and shared decision making being imperative. The approaches used and their differences are “subtle”. When mechanical ventilation is withdrawn, the palliative or terminal sedation often resembles euthanasia.¹⁵¹ Therefore, these decisions should not be taken too casually or thoughtlessly as there is a potential to cross the ethical/moral boundary.

Studies in the United States indicate that opioids are most often the type of medications used in neonates at the end-of-life. Neonates with congenital anomalies or chromosomal abnormalities, as well as those with necrotizing enterocolitis, are more apt to receive the analgesics than neonates with other diagnoses.¹⁵² A bigger factor in opioid administration in neonates is related to the physicians’ experience and attitudes regarding pain and death.¹⁵³ A study in Belgium of the neonatal deaths, over a year’s time, revealed that of the 292 deaths, 30% had been given drugs to hasten death of which most were high dose opioids with 30% also being given muscle relaxants and 18% received potassium chloride.¹⁵⁴ Even with this data, neonatal euthanasia is not legal in Belgium and many physicians denied giving medications to hasten death, yet, the high dosages indicate otherwise.¹⁵⁵

The field of neonatology has seen medical advances with technology and pharmaceuticals that have made it possible for this smallest of the human population to survive at smaller weights and younger gestational weights. The next section addresses the medical innovations asking the question as to whether they are a miracle or a curse.

3.IV.B. Medical Innovations---Miracle or Curse

From the 17th century to the mid 20th century most of the advances in neonatal care centered on nursing care. These included keeping the infant warm, feeding them sterilized formula or breast milk as the science changed, and infection control practices including isolation. It was in the 20th century, that actual medical advances came into use which led to great strides in neonatal treatment. Some see these medical innovations as true miracles saving lives that used to not be saved. Others have wondered if the innovations are more of a curse in that it has saved lives but at the same time brought misfortune to some of these lives and to their families as well. To provide intensive care to a critically ill neonate, especially for one born premature in which case that care can go on for months, is costly. This cost does not even address long term costs, if needed, for any morbidities or disabilities that may be present after the infant leaves the NICU and, in some cases, the cost burden is for the rest of the infant's life. Following is a discussion of the medical innovations and the costs of care to the critically ill neonate.

3.IV.B.1. Medical Advances and the “Grey Zone”

Since the invention of the mechanical ventilator and discovery of antibiotics, some of the major advances in neonatal treatment have been surfactant, extra corporeal membrane oxygenation (ECMO), as well as improved antenatal screening with the use of antenatal steroids.¹⁵⁶ These advances have greatly affected the mortality of premature neonates. In a study of 46 Level III NICUs, the primary causes of death were prematurity (14%), sepsis (12%),

bowel disorders (11%), under developed lungs (9.5%), intracranial hemorrhage (9.4%), respiratory distress syndrome (8%), with anomalies and genetic defects at 7.6% and 5% plus heart defects were only 3.4%.¹⁵⁷ In this same study, 86% of the deaths were of infants less than 37 weeks gestation and 36 % were less than 25 weeks gestation.¹⁵⁸

In spite of all the advances, the United States still ranks 26th among developed countries in infant mortality rates at 6.1 deaths/1000 live births.¹⁵⁹ These statistics include a higher percent of premature births than any other country, as well as more term birth deaths from SIDS, drownings, and birth defects.¹⁶⁰ Infant mortality rates are of value because they reflect the health of the nation, access to health care, as well as socio-economic conditions and public health practices.¹⁶¹

With the tools of medicine and the various advances at hand, the physician has to make difficult decisions or recommendation to parents to assist them with difficult decisions as to whether to treat or not treat premature neonates. These decisions begin in the delivery room and from there progress to the NICU. The issue has two conflicting ethical perspectives. The first holds that life is a gift from God with its own intrinsic value and anything that would hasten, expedite, or allow the neonates' death would be unethical.¹⁶² The second contemplates the "quality of life" with its benefits and burdens considering when life lacks particular qualities of human life that cannot be possible, then palliative care is the best option.¹⁶³ Some health care facilities have addressed the ambiguity related to treat or not to treat with policies that are well known by the staff and are made known to expectant parents. The policy provides care on a continuum based on gestational age. Such a policy provides comfort care at 22 to 23 weeks gestational age, parental choice at 24 weeks, and NICU treatment at greater than 25 weeks.¹⁶⁴ The 22 to 25 week gestational age range is often referred to as the "grey zone" of discretionary

resuscitation.¹⁶⁵ This “grey zone” has changed over time and can differ between facilities, physicians, and countries making it the time for the most difficult ethical dilemmas.¹⁶⁶ Spelling out the policy and the rationale behind it has demonstrated that the majority of parents select palliative care for neonates who are less than 26 weeks gestation. Having such guidelines, although not mandatory, provide frightened and stressed parents with the help they need in decision making. Parents indicate that they do not fear death as much as they do disability in their neonates and also fear that overtreatment will lead to increased disability.¹⁶⁷ When premature births are expected, prenatal consultations can help develop a trusting relationship that is conducive to decision making regarding the neonate later after delivery.¹⁶⁸

Withholding and withdrawing treatment, although ethically considered equal, are still seen as different by many parents, some religions, and even some health care providers.¹⁶⁹

Withholding treatment tends to happen in the delivery room where resuscitation and treatment is not done. Withholding is usually considered in the following instances: 1) extremely low birth weight or gestational age—less than 22 to 24 weeks gestation; 2) infants with expected shortened survival, such as anencephaly; 3) infants with trisomy 13—which have severe intellectual disabilities and physical abnormalities; or 4) infants with long term fatal prognosis, such as paralysis or intracranial hemorrhage.¹⁷⁰ As these categories are considered, so are gender, as girls fare better than boys, whether single or multiple births with single births faring better, and if the mother had had antenatal steroids, as these infants do better. ¹⁷¹

Some physician practices include an approach of intensive care for all where there is at least a trial period, unless there is a strong probability of non-survival.¹⁷² The trial period involves aggressive treatment with frequent evaluations and collaboration between health care providers and the parents. When the care only prolongs the dying, is futile not benefiting the infant, or

inhumane, or the infant is irreversibly comatose, then treatment can be withdrawn except nutrition, hydration and pain medication must continue.¹⁷³ Futility as a reason to withdraw care is very subjective. It is better framed within a goal that addresses the parents' moral structure and evidence based outcomes.¹⁷⁴

Neonatologists and Level III nurseries have done much for neonates' survival. This is not available to all areas of the nation. However, these centers not only help prevent premature births, but can impact further expenditures in treating them. Efforts can best be used to focus on the following: 1) regionalizing NICU care so there is the most efficient and effective care available for all; 2) increasing research on outcomes regarding premature births focusing on prevention; and 3) increasing the use of case management by the health care providers, neonatologists, perinatologists and neonatal nurses, utilizing palliative care as well as outpatient services that best assist those children with disabilities.¹⁷⁵

3.IV.B.2. Ethics versus Economics

Medical advances have done much in improving the survival rate of premature infants. Of the approximately four million births per year, 15% or approximately 500,000 are born premature, defined as less than 37 weeks gestational age, with 5%, or 25,000, of these weighing less than two pounds, of which 75%, or approximately 19,000, will survive.¹⁷⁶ Of those admitted to the NICU, 75% are due to prematurity with the remaining 25% due to other diseases of the newborn.¹⁷⁷

There is no question that care in the NICU is expensive. Some critics have said the care is too expensive, not only for the individual neonate, but also for society as a whole when much of the care is futile. Studies have been done to refute these critics by finding that approximately 6% of NICU costs are spent on non-survivors and when this is adjusted to money spent after

prediction of death is considered, only 4.5% is spent on what could be termed futile treatment.¹⁷⁸ Cost for the extremely low birth weight premature neonate is the most expensive and would be inexpensive if there were no NICUs as death would occur with it. The estimated cost of saving the life of a low birth weight (1500 gram) neonate is estimated between \$635,000---\$1,000,000 in 2015 dollars.¹⁷⁹ The length of stay in the NICU is usually until the infant is at least 37 weeks, provided the infant is improving, which means that for a 23 week gestational age neonate, a minimum length of stay would be 14 weeks.¹⁸⁰

Additional costs are incurred with complications. The primary complications of premature births are respiratory distress syndrome, seen in 23% of neonates with an average cost of \$65,000; intracranial hemorrhage, seen in approximately 5% but adds approximately \$76,000 and is an ominous diagnosis; and necrotizing enterocolitis only seen in approximately 23%, but is costly at an additional \$100,000 with a high mortality rate, and sepsis.¹⁸¹

Some NICUs have implemented policies regarding discretionary resuscitation which does not resuscitate those at 23 weeks or less, offers resuscitation as an option at 24 weeks and encourages it at 25 weeks.¹⁸² Discretionary resuscitation is also used when neurologic impairment is believed to be significant and if the neonates were to live with these impairments, they contribute to 5%-50% of all NICU deaths.¹⁸³ Discretionary resuscitation is not made based on gender, even though girl neonates have a better survival rate than boys, however, in some cultures there is less interest in NICU for female infants.¹⁸⁴ Discretionary resuscitation policies impact individual NICU survival statistics. They can also increase the racial disparity in preterm births as African American women have a 2-3 fold greater risk of a premature birth than white non-Hispanic women for reasons that are yet to be proven.¹⁸⁵

The question still remains as to whether the costs generated by NICUs are outweighed by the

benefits. The costs that often are not always addressed in the beginning of the neonates' life are related to the ongoing medical, social, and educational needs of the premature newborn that may continue throughout their lives. The most catastrophic disabilities that can occur are blindness, deafness, as well as cerebral palsy, while milder disabilities are attention deficit disorder, asthma, mental retardation, mild cerebral palsy, and educational needs of various degrees occurring in 40% of those less than 26 weeks gestation.¹⁸⁶ Overall NICU graduates need repeated hospitalizations and special education services nine times more than a full term infant with special education costs associated with low birth weight neonates estimated at \$700 to \$900 million per year in 2015 dollars.¹⁸⁷ Although the rate of survival has improved, the short and long term outcomes have not seen the same improvement with those neonates born less than 26 weeks gestation having a 25% chance of incurring a disability so severe that they will never function independently.¹⁸⁸

Of the total health care expenditures in the United States, NICU accounts for approximately 1 to 2% of that total, which may seem small, but is approximately \$30 billion with rapid changing technology and pharmaceuticals accounting for the majority of these costs.¹⁸⁹ Even with these monumental costs, the NICU is the most cost effective of all critical care units and has been more closely scrutinized than that of the adult critical care units. In NICU, 6% of costs relate to those who will not survive or are receiving futile treatment, while adult ICU has 40% of its costs going to the same category.¹⁹⁰ The ethical decision is whether neonatal intensive care should be limited only to those predicted to benefit, because of the high cost associated with the care, which does not seem relevant or significant. Withholding treatment to those less than 600 grams equals a savings of 3.2% and would decrease the number of survivors by approximately 575.¹⁹¹ However, if the trend continues to resuscitate smaller neonates, the financial impact

could continue to increase and have a greater impact vying for the already stretched health care dollar, as well as present ethical concerns.

In the high stress environment of the NICU, where a collaborative decision making model between health care providers and parents is the ideal, there is often a conflict among and between the various roles. In the middle is the incapacitated and incompetent newborn whose life hangs in the balance of many of the decisions being made. The next section describes the influence of the roles of the parents as well as the professionals with a focused look at the nurse and physician roles and how they are similar but different. A closer look will be taken regarding the conflict that inherently occurs among and between the roles.

3.V. Influence of Roles

There is value in paying attention to the needs of the parents, as well as the professionals, in the NICU environment, so as to facilitate ethical decision making regarding the neonate. As the care of neonates has evolved over the past century, the role of parents has become more involved and the impact on the infant's development has been significant.¹⁹² This change has been a challenge for the physicians and nurses as they have had to give up some of their control to the parents. Through all this change, it is the neonate at the center that must be the focus and the reason to collaborate and manage the conflict that inevitably results in a stressful environment, such as the NICU.

3.V.A. Major Role Differentiation

The major roles that exist in the NICU, parent, nurse, and physician, can be viewed as partners with each having a part to play and, although the roles overlap, there is still unique responsibilities performed by each of the roles. The family-centered care movement that has

become a standard of care for NICU's, not only in the United States, but also in Europe, has helped in increasing parents' confidence level in parenting, as well as staff receptivity of parents' increased involvement in their infant's care.¹⁹³

3.V.A.1. Parental/Surrogate Roles

The parental role in the care of neonates has evolved over the years. Dating back to the late 1800's, it was noted that mothers who did not participate in the care of the premature or sick newborn often abandoned them.¹⁹⁴ A "hands off" philosophy for parents with their newborns was present as care switched from home to hospital deliveries with a segregation of mothers into rooms or wards and babies into nurseries. It was also at this time when bottle feeding was encouraged over breast feeding as formula companies came into business. This all changed in the 1940's to 1950's with the advent of rooming-in where the infants stayed with their mothers in their hospital rooms yielding less infections as strict rules of separation went away encouraging parental involvement with their newborns.¹⁹⁵ Today family centered care is the preferred model where families are encouraged to be a part of the infants' care to include that in the NICU.¹⁹⁶

The role and experience in the NICU, as perceived by the mother and father, is different. The mother feels powerless with a strong need to reclaim her relationship with the newborn, while the father can experience shock at first seeing a premature or ill newborn then sees an opportunity for a beginning new connection with the newborn.¹⁹⁷ Fathers struggle with bonding more than mothers because of the infants' "fragility", plus as mothers portray stress and sadness, the fathers tend to focus on them.¹⁹⁸ The fathers are the ones who benefit the most from the clinical updates and the medical information which they use in making end-of-life decisions as the more fact finding parent in the process.¹⁹⁹ By developing supportive interventions for the fathers early in the postpartum period, the fathers' stress can be reduced and their fathering

ability can be empowered significantly.²⁰⁰

Attachment theory stresses several key factors. These are the importance of the first six months of life plus the role the first hour after birth plays; the connection between child and caregiver for emotional as well as psychological development; and that this attachment begins in pregnancy increasing during the nine months.²⁰¹ With premature or sick neonates, this attachment can be delayed or in some cases not even happen if steps are not taken to help ensure that it takes place. The staff always has to be concerned with the neonates' safety, but as soon as possible the parents should be encouraged and instructed on how to touch and hold their infant. One way to enhance touching and bonding is by placing the naked infant on the parent's bare chest, known as kangaroo mother care (KMC), which has shown to benefit both infant and parents.²⁰²

There are mixed views on the extent of involvement of parents in end-of-life decisions. This variant view is primarily based on perspective. Most all parents and health care professionals agree that decisions should be made as a collaborative effort between parents and the providers.²⁰³ However, that involvement in the decision making is perceived differently by the different parties involved. When parents are asked by physicians whether to proceed with a decision, such as to withdraw treatment including mechanical ventilation, the physicians believe the parents were part of that decision, but the parents may see this as only approval, which is not the same as making the decision.²⁰⁴ A shared decision model has the following elements: 1) both physicians and parents are participants; 2) both physicians and parents share information and are free to ask questions; and 3) both parties move toward a consensus for the decision.²⁰⁵ This may come down to more of a process than what is actually decided.

There is agreement that the withdrawal of treatment should never be one party's decision as

the guilt falls to the party making the decision and can be haunting over time.²⁰⁶ It has been shown that it is easier for parents to make end-of-life decisions in the delivery room than in the NICU after emotional bonds with the infant have been formed.²⁰⁷ Other influences that impact the parents' decision making ability regarding their infant include support from family and friends, cultural plus religious beliefs, maturity of the parents, and the relationship with health care professionals.²⁰⁸

Just as the parents fill the role of caregivers to their newborn, as well as shared decision makers, the health care professionals also have roles to fill. The nurses and physicians are the two most prominent roles that interact, not only with each other, but also with the newborn and the parents in the NICU. Following is a discussion on their roles, as well as how their roles are similar, yet different, and how they contribute to the end-of-life decisions as well as ethical dilemmas in the NICU.

3.V.A.2. Professional Roles---Nurse versus Physician

Many have believed for a long time that nurses and physicians not only had different roles, but also were different in their ethical analysis and reasoning which could be seen at play in a NICU. The nurse's role was perceived as "caring" and the physician's as "curing" where physicians made decisions, then wrote orders to be followed by the nurses, who lived with these decisions obligated to carry them out as written.²⁰⁹ On closer look, the differences were not as great as first perceived. Both nurses and physicians had the same moral duty to minimize suffering and "do the right thing" with both experiencing end-of-life decisions as the top ethical struggle.²¹⁰

In the ethical struggle at the end-of-life, both nurses and physicians experienced similar conflicts for different reasons. First in the area of values that were in conflict, the nurses were

apt to see the physicians acting on their own values versus the patient's, whereas, the physicians often saw the parents acting in their own best interest rather than the patient's. Second, in the area of limited resources, nurses felt this in staffing cutbacks or shortages while physicians saw it as triaging patients for critical care based on those most apt to survive. Finally, in the area of institutional hierarchy, nurses believed they were not being heard or having an impact on patient care decisions and physicians felt pressure to monitor resource utilization while balancing demanding parents.²¹¹

The differences in nurses and physicians can be traced to their role responsibilities; the status and authority that their individual roles give them; gender, although more males are entering nursing with more females becoming physicians, gender differentiation blending has yet to be seen; and culture differences seen in the training as well as the workplace.²¹² Other differences are that nurses often feel they are limited by physicians to speak their beliefs or act on them, while physicians did not feel this restriction from nurses. When nurses do risk speaking out, especially in the area where they believe the neonate is suffering and decisions need to be made regarding withdrawing care, it is not always well received by physicians.²¹³

Nurses and physicians in their roles are both concerned with what choice of action to take or is being taken in relation to the neonates. These concerns are especially true in the extremely low birth weight neonates where there is the "grey zone" for survival and the choice of action is never clear leading to moral conflict in the physician or moral distress in the nurse.²¹⁴ Moral distress, an issue for all of nursing, is when one knows the right thing to do but because of institutional limitations the right thing cannot be done.²¹⁵ Neonatal nurses are especially prone to moral distress in the care of the extremely low birth weight newborns because of the uncertainty with their survival, plus both the short as well as long term outcomes, leading to a poor quality of

life with numerous disabilities.²¹⁶

Both the nurse and physician perspectives are needed to assist parents in the difficult end-of-life decisions. End-of-life decision making is improved when nurses are present at family meetings and case reviews. The presence of nurses at these discussions helped bring nurses' and physicians' perspectives to the table to assist parents in making the difficult decisions.²¹⁷

The combination of the parental role along with the professional roles in a small stressful environment, such as a NICU, inevitably leads to conflict. This conflict is more apt to surface when the pressure is present to make end-of-life decisions. The conflict can get to a point where it becomes the focus versus coming to a consensus in the decision making process. Therefore, there is value in knowing how to recognize the conflict and manage it so that it serves all those it affects without being an obstacle to the task at hand.

3.V.B. Role Conflicts

The environment in most NICUs is one where communication and compassion surround the infant and parents in a team approach where conflict is rare.²¹⁸ However, each unit should have processes in place to recognize signs of conflict with training in conflict resolution.

3.V.B.1. Risk Factors—Parents versus Professionals

As NICUs have researched and developed programs and processes for resolving conflicts, some important findings have resulted. These findings are: 1) end-of-life decisions that involved withholding or withdrawing treatment were usually initiated by physicians as they saw the poor prognosis before the parents. However, nurses often saw the prognosis first as they perceived the infant's suffering; 2) conflicts between members of the health care team occurred infrequently (4% of cases) and between the parents and medical team more often (12% of cases). These conflicts were usually regarding the infant's neurologic status; and 3) that end-of-life

decisions are best put on hold until the conflicts can be resolved through increased communication, more frequent meetings and second opinions, if needed.²¹⁹

There is never a way to be sure of what situation or which staff, physician or parent interaction will lead to conflict but there are some risk factors that, when present, can give the health care providers an alert so as to begin conflict resolution strategies early. From characteristics related to the parents, conflict can be more prone to occur when there are intense religious beliefs, different cultures, low educational levels, language barriers, negative medical experiences in the past, and discord between parents.²²⁰ Whenever the parents feel a lack of trust from the providers, whether that be the physicians or nursing staff for whatever reason, conflict is most likely to occur.²²¹ Characteristics related to the health care team are such things as poor relationships with the parents; not being available to parents or too many different care givers; religious beliefs of providers that conflict with parents; or no leadership for the physicians or other health care providers.²²²

When anticipating the conflict that may occur in the NICU, especially when end-of-life decisions must be made, it is beneficial to understand the sources of the conflict so they can be addressed prospectively. Conflict arises within the family, within the health care team, or between the team and the family. Of these three areas, the one that is most common affecting the entire unit, is that which occurs between the team and the family.²²³ The top four sources of conflict between the health care team and the family are the following: 1) communication---this can be related to language barriers, inadequate or poor communication from the team, or poor comprehension of the prognosis of the neonate by the family; 2) unavailability of family---this affects the frequency and ability to keep communications open, in addition, to making timely decisions as a collaboration between the family and the health care team; 3) plan of care

disagreements---this is most often in relation to end-of-life decisions as they relate to futile treatment and withholding or withdrawing further treatment; and 4) emotional issues and poor coping on behalf of the parents---this can be expressed as anger, anxiety, depression, or general withdrawal from the scene which can be compounded if the parents are very young and part of a dysfunctional family who are unable to be supportive.²²⁴

In spite of knowing the risk factors for conflict, and taking steps to be sure all sides are heard with questions answered, conflict may still occur. Following is a discussion on how to anticipate and manage conflict.

3.V.B.2. Conflict Management

When conflict does occur in the NICU, it is almost always due to inadequate communication. This communication usually centers on whether to intensify, continue, or discontinue life-sustaining treatment for the critically ill neonate.²²⁵ A key in managing the conflict is understanding the rationale for families to insist on continuing treatment when the providers believe it to be futile and misappropriate use of resources. These rationale include: 1) the family not comprehending the poor prognosis. The solution is to maintain frequent, open communication between providers and family; 2) strong religious beliefs that hold for a miracle to occur or that only God can take measures to end life. The remedy is to present facts as well as include religious leaders into the discussions, whenever possible; 3) a belief that more can always be done, as well as a lack of confidence in the diagnosis and prognosis. The approach is to focus on gaining trust with frequent communication; 4) there is a perceived secondary gain from continuing the life-sustaining treatment, such as a mother of a critically ill neonate who fears that the father of the infant will leave her if the child dies; and 5) disagreement with the significance of the neonate's condition with its potential outcome and disabilities. The key here

is to understand from the parents' perspective, and not the providers' perspective, how the parents plan to care for this infant into childhood and possible adulthood. The parents need all facts so a realistic decision can be made.²²⁶

A means to enhance communication, plus decrease conflict, is through written information, whether via e-mail or paper, as a means to address questions, problems, and reinforce important points of information.²²⁷ Futile treatment is sometimes used in discussions with parents as when treatment given to the infant is no longer of benefit. However, futility is not an absolute term and for parents who have struggled to conceive, they do not see any treatment as futile so avoiding this term in conversations is recommended.²²⁸ Other means to try to expedite decision making with parents, when there is conflict, is a lack of trust, such as using the best interest of the patient standard, or limited resources (e.g. bed availability for another infant), are also often not useful.²²⁹ Even if it comes to a point that the parents cannot agree to withdraw life sustaining treatment that is futile, ethically and legally it can be withdrawn.²³⁰ However, before it comes to that, all steps should be taken to assist with a consensus decision.

Outside resources that can assist with resolving conflicts include other family members, second opinions of physicians, religious leaders and ethics committees. An ethics committee can assist with the uncertainty and conflict in the NICU through policy development, case consultation, educational offering, and advisory functions that assist both staff as well as parents.²³¹

It is vital that institutions support education strategies that address impending disputes regarding futility. Clinicians need practice in these crucial conversations in order to gain the necessary skills so when they are faced with a potential futility concern they are skilled in minimizing the conflict from families.²³² These educational strategies may include role playing,

fictional case reviews, and small group meetings to increase open discussion.²³³

The interplay of the various roles affect the end-of-life decision making in all health care areas, but is especially evident at the beginning of life where these ethical decisions are most difficult. The next section presents evidence based ethics by first describing the importance of communication, the link to all decisions, followed by fundamental questions in the ethics of end-of-life treatment for neonates.

3.VI. Evidence Based Ethics Applied to Neonates

Evidence based ethics requires the rigorous and discerning utilization of the best evidence in making ethical decisions regarding a particular patient in a particular situation.²³⁴ Evidence based ethics focuses on knowing the patient in great detail, understanding what evidence is in the literature regarding the patients' diagnosis, as well as prognosis, and recognizing ethical issues plus the principles at play.²³⁵

3.VI.A. Communication as the Link---Language Matters

In the process of communication, language does matter. Not only what is said, but what is not said. Therefore, it is important to communicate frequently, repeating information often, as parents with a critically ill infant are experiencing tremendous stress and have problems comprehending information.²³⁶ Following is a discussion of the parents', physicians' and nurses' view on what is valued in communication followed by the best approaches to end-of-life discussions.

3.VI.A.1. Parents', Physicians', and Nurses' View

All decisions and conflicts are based on communication, either ensuring that it is adequate or correcting poor or insufficient communication. Both health care professionals and parents

name communication as key in end-of-life decisions.²³⁷ Physicians have identified the following ethical concerns in communicating with parents: 1) what to tell---there is so much uncertainty that communicating too much negativity can take away hope which leaves parents with nothing; 2) if the communication is misinterpreted, it can compound the parents' stress; and 3) to time the information appropriately giving the parents adequate time to make end-of-life decisions.²³⁸ With all this second guessing their communication, it is no surprise that some physicians withdraw or avoid communication as a way to deal with all the concerns.

The parents, as a general rule, request several components to be met in the area of communication. First of all, the majority of parents want comprehensive, as well as evidence based information regarding their neonate, which they will most likely validate via the internet.²³⁹ These parents also request that this information be given frequently without the parents having to probe and interrogate for each answer.²⁴⁰ Parents also prefer a shared decision model between the physicians and themselves.

Second, just as physicians see the value of hope, so do the parents. They do not want those who communicate with them to be dishonest, but they do want optimism where there might be some.²⁴¹ Third, when parents are involved with end-of-life decisions, these decisions are time-consuming as well as tedious and may require repeat conversations since parents require more time to accept a poor prognosis than the health care team.²⁴² Finally, parents want to be able to express their feelings without criticism, if that cannot be done with the nurses and physicians, then have another outlet, such as spiritual care or social workers who also participate in the patients' care.²⁴³

Nursing's concern with communication is that the parents be given clear, as well as accurate information in a timely manner. Nurses expressed a strong need to be a part of decision making

discussions with parents and physicians so they could support and reinforce what has been discussed or decided. Often nurses believe physicians tend to approach parents too late or have the end-of-life discussions after the neonate, as well as the parents have been suffering longer than the nurses think necessary.²⁴⁴

Staff do not always speak up and verbally communicate their disgruntlement or distress but can send out non-verbal cues. These non-verbal cues include standing away during clinical rounds and not engaging in the process; focusing on the clinical signs of the neonate to get attention; requesting an expert or a second opinion in hopes this person will help see the situation for what it is; discussing with groups of staff their frustrations; and fixating on the parents and the lack of information they have received regarding the neonate's condition when they may not be the case.²⁴⁵

In the process of communication, language does matter. Parents should be encouraged to name their neonate and all conversations should then focus on that name versus a diagnosis or a gestational age, such as the "24 weeker".²⁴⁶ As language matters, words are, likewise, important and parents report that certain terms are more objectionable than others. Words to avoid include "doing everything", "futile", "you can have another child", "there is no hope", and "there is nothing we can do".²⁴⁷

3.VI.A.2. Approaches to End-of-Life Discussions

With the combination of stress, sleep deprivation, anxiety, and potential PTSD, it is difficult for the parents to communicate openly or to remember what they have been told. Suggestions to improve communication include: 1) having health care professionals introduce themselves repeatedly to parents; 2) hand out business cards to parents and family which state how to communicate with providers; 3) inform parents of shift rotations; and 4) inform the parents of

opportunities to e-mail or text, if available, so questions can be answered in a timely manner.²⁴⁸

Along with improved communication, an opportunity that is all too often missed in the care of the critically ill neonate is palliative care. Adult palliative care programs appeared in the United States in the 1980's but fetal palliative care did not begin until the mid-2000's.²⁴⁹ The majority of deaths in the NICU occur after withdrawal of life sustaining treatment. These deaths occur in one of two phases. The first is usually in the first 24-96 hours of life as a result of extreme prematurity, anomalies or sepsis and the second phase is 3 weeks to 3 months where intensive care technology failed as the focus changed from cure to comfort or palliative care.²⁵⁰ Palliative care is most often involved in the second phase as there is more time for involvement prior to the infant's death, however, there are opportunities to enhance this involvement.

The first opportunity revolves around the "uniqueness" of neonatal palliative care. Palliative care is not meant to only be about the end-of-life, but in the NICU, that is when it usually happens, so that palliative care becomes involved at the beginning of life which is the end-of-life for the neonate.²⁵¹ The second opportunity is related to communication as well as conflicts among providers, especially nurses and physicians. Physicians struggle to make the final decision that it is an end-of-life situation so they may postpone the decisions, while nurses see it earlier and become frustrated with the physician.²⁵² This can lead to a delay in getting palliative care involved. The final opportunity is in the area of administration. Administrative support is needed for a strong neonatal palliative care program.²⁵³ In order to get that support, clinicians need to identify the need for the program then communicate that need to administration. Finding a champion among both the nursing and medical staff can be helpful in this support.

The benefits of palliative care to the neonatal population involves both preventing as well as

relieving pain and suffering in the neonate, in addition to supporting the family during the dying process and after.²⁵⁴ Some best practices for providing that support include: 1) calling the infant by name; 2) offering sincere sympathy allowing opportunities for silence when appropriate; 3) showing emotion regarding the neonate's death; 4) providing objects for future memories such as pictures, foot prints, a lock of hair etc.; 5) providing information regarding support groups; and 6) ensuring follow-up with family after discharge to include autopsy results if one is performed.²⁵⁵ A comprehensive palliative care program is one that not only deals with the neonatal issues after birth but also begins in the perinatal period when there are life threatening diagnoses during the pregnancy, follows the mother and neonate during the birth and after the neonate's death.²⁵⁶ Although both neonatal and perinatal palliative care programs are still developing, their value has been demonstrated and offer hope for the future for those suffering the loss of a newborn.

With communication as the link to evidence based ethics and ethical decision making, the core fundamental ethical questions can be confronted in relation to end-of-life for the neonate.

3.VI.B. Fundamental Questions at End-of-Life

Evidence based ethics, unlike evidence based medicine, which focuses on intuition, clinical experience, and expert opinion, considers values as well as best interests and preferences of patients/surrogates in contemplating treatment decisions.²⁵⁷ The most basic of all questions is if continued treatment appears to be futile, is there any obligation to continue and that question gets asked with adults as with neonates. There is no one answer as it varies with each situation. Of the fundamental questions to be asked in the immediate post birth time period, two are discussed here.

3.VI.B.1. Resuscitate or Do Not Resuscitate

The first fundamental question that is presented at the moment of birth, is to resuscitate or not, which also translates to the utilization of neonatal intensive care. Birth weight and gestational age have been the benchmarks to determine, not only survival but also if the neonate will survive with severe disabilities, which may or may not be visible at birth. Use of the concept of futility in the neonate is weak and unjustified, as a strict use of quantitative futility would require 100 infants born in the one facility, with the same physical parameters, which is difficult to reach due to the low numbers.²⁵⁸ Tyson and Stoll suggest four categories on a continuum ranging from unreasonable to mandatory. Unreasonable is where intensive care should not be offered as it would provide no benefit, plus the pain and suffering could be seen as a form of child abuse, to mandatory where intensive care would be provided, even if parents object, with society having a duty to provide such care.²⁵⁹ The two categories in between are investigational, where it is unlikely that the benefits exceed the burdens, and optional where it is not clear that there will be benefit.²⁶⁰ In the United States, Canada and the Netherlands, between 69% and 93% of all neonatal deaths occur after withholding or withdrawing treatments which is done in the NICU.²⁶¹ These numbers vary greatly within the same country and within the same state, as well as city, in the United States which is being attributed to cultural differences in addition to physician differences.

Since the development of the specialty of neonatology, many advances have occurred that have saved lives of premature neonates. However, in today's world, the science has advanced faster than the ability to know when to stop its progress because the uncertainty associated with the potential mental and physical disabilities.²⁶² Parents can often be influenced by the physicians in what decisions to make concerning the life and death of their neonate. Studies indicate that the neonatologists' views regarding hastening death, as well as their personal fear of

death, strongly influences how they address resuscitation of a premature neonate.²⁶³ The greater their fear of death, the more likely they are to hasten death when there is a strong chance the neonate will have mental or physical disabilities.²⁶⁴

In considering whether to resuscitate or not, the question expands to whether the best interest of the neonate should be the only consideration or should the family as well as society also be considered. It is difficult to separate the neonates' interest from their families when considering the future in terms of caring for a disabled child.²⁶⁵ Such a decision as to whether to consider the family or not can have a major impact on the family. If the decision is to consider the family, then there is an imperative to justify ethically who else besides the patient is being considered, while this is not done in other patients of all ages.²⁶⁶

The best interest of society can also be considered. This includes considering the resources needed not only for the prolonged NICU stay, but also for the ongoing care for many of these children who have disabilities.²⁶⁷ However, interests of society as the reason to not resuscitate will not be ethically justified until it is universal and not only applicable to neonates.

3.VI.B.2. Management of Pain

The second fundamental question is related to treating pain in the neonate. Approximately 40 years ago the theory was that newborns and, especially premature neonates, lacked the anatomical and endocrine development in their nervous system to perceive pain.²⁶⁸ In fact, the risks of respiratory depression and hypotension following pain medications were believed to outweigh any potential benefits of the pain treatment.²⁶⁹

The next age of thinking occurred approximately 10 years later and as a result of research it was believed that neonates did feel pain plus under treatment could lead to greater mortality and morbidity.²⁷⁰ Furthermore, long term significance of inadequate pain management in neonates

could lead to emotional and learning disorders as well as disabilities.²⁷¹

The 21st century has brought concerns related to pain treatment in the neonate with too little having untoward consequences and too much, likewise, having untoward consequences. Not only is the amount a concern, but also the drug being used can impact the outcome. Research on such a difficult topic is done with animal subjects because of the ethical concerns of using neonates in controlled studies. This adds to the delay in timely results because the animals and human findings are not the same, as well as there is variability between critically ill neonates.²⁷² Therefore, care for the newborn premature neonate requires a pain plan from birth that minimizes painful procedures, utilizes both pharmacologic and non-pharmacologic treatment, and assesses the neonate frequently for signs of pain, along with signs of overtreatment.²⁷³

When neonatal pain studies have been performed they are usually completed retrospectively looking at what treatment the neonate had in the NICU that affected the status of the child's health in the present day. One study examined procedural pain, as evidenced by skin breaking procedures in preterm neonates of <32 weeks gestational age, and what, if any, affect this had on postnatal growth as evidence by weight and head circumference measured at birth, 32 weeks and 40 weeks.²⁷⁴ The results indicated that there was a correlation between the number of painful procedures and growth in that the more pain led to decreased body and head growth.²⁷⁵ What affect this might have on the older child is not yet known.

What these studies have revealed, as well as clinical observations, is that pain needs to be treated. Not only does pain need to be treated in the premature neonate, the choice of analgesic is vital as some can lead to further harm in the neonate.

Another study looked at the relationship of pain-related stress in neonates and its effect on

visual perceptual abilities and functional brain activity in school age children whose average age was seven. Magnetoencephalography (MEG) was used to measure the brain activity. The results showed a direct correlation in those extremely low gestational age neonates (ELGW <28 weeks) with cumulative neonatal pain-related stress, showing changes in brain oscillations that had a negative effect on visual perceptual abilities.²⁷⁶ An additional finding in this study was that morphine, as an analgesic, did not improve associations of pain with functional brain activity, an important clinical factor for not choosing morphine as an analgesic.²⁷⁷ A second finding was that the changes in the “architecture” of brain oscillations as it pertains to pain-related stress and visual perceptual abilities is seen in extremely low gestational age (ELGA {27 weeks or less}) neonates but not in very low gestational age (VLGA {28 to 32 weeks}).²⁷⁸ This is thought to be due to the differences in the brain development between the two age groups.

Associated with the treatment of pain, or the presence of opioids in the maternal population, is the neonatal abstinence syndrome. This syndrome presents as varied signs and behaviors in newborns when there is a sudden withdrawal and discontinuance of the drugs from the mother at birth.²⁷⁹ This syndrome is responsible for an increase in NICU admissions since 2004 with 4%-20% of all NICU days in 2013 being associated with this syndrome.²⁸⁰ Many of the mothers are using heroin or methadone as a treatment for opioid addiction which causes the syndrome to occur in the neonate. No specific treatment works for all neonates, however, morphine in decreasing doses is most often used to wean the neonate off the drugs.²⁸¹ Fortunately this syndrome is less severe and less prevalent in premature neonates because they are not exposed to the drugs for as long a time in utero, there is less fatty tissue for the drugs to accumulate in, there is decreased receptor sensitivity as well as development, and the transportation time across the placenta is decreased.²⁸²

Even when the fundamental ethical questions are addressed to the best of the health care providers' ability, using evidence based ethics, the best answer may be neonatal palliative care. When neonatal palliative care is engaged early in the life of the critically ill neonate, its full benefit can be realized for the infant as well as the family and health care providers.

3.VII. Conclusion

Since the beginning of neonatal intensive care units, medical futility has been an issue in the care of neonates. Long before there were ethics committees or regulations, such as “Baby Doe”, to help guide decisions regarding end-of-life, neonatologists were left to decide which treatments were indicated and which were not. With the passage of time, the medical technology and pharmaceuticals available have become more advanced making for endless choices in the way care is delivered to the tiniest members of society. To compound the situation, parental autonomy has become increasingly pronounced which has often ended up in a “tug of war” between parents and physicians when continued futile treatment is a topic of discussion and decision. An added pressure comes from hospital administration and third party payers to control expenses, or at least justify treatment costs, that do not appear to be providing a benefit. These societal, ethical and legal mandates too often have left the issue of medical futility unresolved.

The major ethical concern in caring for premature neonates at end-of-life begins at birth and focuses on whether to resuscitate the newborn, which is a decision usually needed in the delivery room from parents who are reeling from the shock of a parenthood gone awry. There is also an on-going struggle with considering the best interest standard and keeping in mind whose interest it really is—the neonate's, the parent's, the health care providers', or society's.

From the delivery room, the decisions move to the NICU where withholding and withdrawing treatment is decided when the burden seems to exceed the benefit and the question of futile treatment becomes paramount. The concern for futile treatment has become such an increasing issue filled with much controversy as premature neonates are now being saved at younger gestational ages and smaller weights making the ethical questions resound from many sources.

In between the two major decision points much work is done to prevent the neonate from becoming a victim of the treatment as well as minimizing suffering, without hastening death. As many of the premature infants are “saved” and survive, the unanswered questions and ethical concerns are related to whether this survival came at a cost that will involve a lifetime of disabilities that cannot be determined at birth.

In the care of the critically ill neonate, much work has been done to include the parents in the infant’s care from the beginning. This inclusion helps with bonding but also builds relationships that serve to make the parents participants in the care and decision making involving the infant. Even with the parents involved with decision making in the NICU, the decisions are difficult, often prolonged leading to stress, and produce suffering on the part of all involved to include the family, providers, and the infant.

There is hope for the future for futility and the neonates who are seen to be suffering from prolonged dying. Palliative care, although new to the neonatal world, is that hope for infants, parents, and health care providers. With the goal of managing symptoms and providing support, palliative care can help all those involved with the neonate to make difficult decisions that, in actuality, do consider the best interest of the patient.

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Chapter 4: Futility and Pediatrics

4.I. Introduction

Children are not just little adults, as they were once thought to be.¹ The pediatric population, ranging from 1 to 18 years of age, present with diseases and conditions that make them unique. Infants who once died from childbirth, prematurity, or congenital anomalies now survive. Children who used to succumb to an assortment of childhood illnesses, cancer, and infections now live due to immunizations, disease prevention, cancer therapies, and antibiotics. However, this special age group continues to be plagued by intentional and unintentional injuries, AIDS, congenital anomalies, and malignancies providing immense challenges, as well as a daunting reminder of health care's limitations.²

The death of a child has an overwhelming and life-altering effect on every member of the family, as well as those who provided care to the child. Although many of the deaths have been prevented, there are some that, even with the best of efforts, cannot keep death from having the last word. Because of the devastating impact a child's death can have, the issue of discussing medical futility is often avoided, which can lead to prolonged suffering for the child, the family, and all those providing care. It is not unusual for children to initiate the tough conversation concerning end-of-life when they have had enough, triggering a whole set of emotions and ethical dilemmas in the family and health care providers.

Chapter 4 will address the pediatric population and the unique challenges medical futility presents by first looking at it from a historical perspective then lay the groundwork via a theoretical framework. The second part of the chapter examines the role the consent process plays looking at evidence based practice, closing with the hope for the future in palliative care.

4.II. Historical Perspective

Pediatrics is defined as the study and care of infants, children, as well as adolescents that is concerned with, not only all organ systems to include their biological growth, but also the environment, social, and political influences on the health and welfare of each individual.³ In viewing past history, the young have been regarded as society's most vulnerable and often most disadvantaged. Because of this view, organizations and governments have intervened to take steps in the form of acts, regulations, or declarations meant to serve and protect this vulnerable population. An example is in 1959, when the United Nations issued the Declaration of the Rights of the Child, which stated the universal assumption that children have basic rights and needs that should to be protected.⁴ However, even with all the efforts to protect this population, they are often not enough to prevent illnesses and catastrophic events from happening.

Historically, there are diseases and influences that affect the childhood years. Many of these childhood illnesses and influences present ethical dilemmas that are unique and challenging, especially when they cause a pediatric patient to be critically ill. At the same time, there comes instances in caring for the critically ill pediatric patient when further treatment is futile, offering no benefit, and at times prolonging suffering. The next section explores childhood illnesses and the ethical challenge of medical futility.

4.II.A. Childhood Illnesses

Childhood illnesses were primarily infectious diseases, until the early to middle 20th century, when they were replaced by childhood chronic illnesses.⁵ This change came about as a result of disease control, immunizations, sanitation, improved living conditions, and access to medical care leading to a major improved effect on the mortality of children.⁶

4.II.A.1. Change and Its Effect

The infants and children that would have died years ago, especially in developed countries, from childbirth complications, prematurity, and congenital anomalies, or birth defects, are now surviving.⁷ Because of all the medical advances and improvements, the childhood infections in the United States have been eliminated, in some cases, or minimized in others.⁸ Despite these improved rates, children still die with approximately 3% of the deaths in the United States each year being children.⁹

Pediatric critical care is a relatively new field and evolved as the needs of the pediatric population intensified, especially related to cardiac surgery and mechanical ventilation. The first pediatric intensive care unit (PICU) was in Sweden in 1955 and in the United States, at Children's Hospital of Philadelphia, in 1967.¹⁰ PICUs spread across the United States in the 1970's, but it was not until 1987, that a certification examination was available for the specialty of pediatric critical care medicine.¹¹ The journal, *Pediatric Critical Care Medicine*, began in 2000.¹² There are approximately 337 PICUs in the United States for a total of 4000 beds, which is smaller than the estimated 67,000 adult critical care beds and 20,000 neonatal intensive care beds.¹³ Because of the small numbers, most PICUs are found in larger institutions, especially those that are associated with universities. This can present as a hardship for families, with a critically ill child, who do not live close to a university or larger institution that has a PICU.

Studies that examined the end-of-life support categories prior to death in PICUs, indicated that 46% of the time there was a withdrawal of life support; 23% were declared brain dead; 16% were a do not resuscitate; limitations of support in 3%; no limitations in 10% and no advance directives in 3%.¹⁴ Other findings were that African Americans limited treatment less frequently, institutions with no trauma centers had lower rates of limitations and that limiting

treatments were now more common in the United States than 10 to 15 years ago.¹⁵

When looking at the health of children from a global view, in 2010, there were 135 million births in the world of which 121 million, or 90%, were in developing countries, with India having the most at 27.2 million and China the second most at 16.5 million.¹⁶ Although many of the world problems between developing and developed countries are similar, as the global interconnectedness is greater than ever, there are major differences that affect the health of the pediatric population. These include the following disparities: 1) economics; 2) education, social, and cultural differences; 3) infectious agents; 4) climate and geography; 5) agricultural resources and practices; 6) gene frequencies for some diseases; 7) health and social welfare structure; and 8) political stability and forces.¹⁷

As a result of all the disparities, world leaders came together in 2000 to address them and develop goals related to child and maternal health. These goals were to be met by 2015, called the Millennium Development Goals (MDG), of which four targeted children, with MDG #4 focusing on a reduction, by two thirds, in mortality for children less than five years of age.¹⁸ The final data reflects that there has been a decrease from 90 to 48 deaths per 1000 live births in the under-five population, (a reduction from 15 to 6 in developed countries and from 99 to 53 in developing countries), with all countries reducing by one half, except the sub-Saharan Africa and South Asian countries.¹⁹ Even with the improvements, the goal of two thirds was not met.

One thing for certain that has attracted attention, whether that be in developed or developing countries, is the influence the environment can have on the health of children, not only helping to create the sickness in the first place, but continuing to contribute to it over the lifetime.

4.II.A.2. Environmental Health Hazards

Children are exposed to all types of environmental hazards beginning in the womb through

adolescence. The World Health Organization (WHO) estimates that 8,900,000 children die each year from some form of pollution and of these, 94% are in low and middle income countries.²⁰ For those under the age of five, it is estimated that environmentally related diseases are responsible for the deaths of approximately 3,000,000 children in the world every year.²¹ The “basic” risks for environmental exposures are more apt to be found in the developing countries, but are also present in many of the Southern states, as well as California.²² The “basic” risks include unsafe water, inadequate housing, substandard food preparation, faulty plumbing and waste disposal.²³ The more “modern” environmental risks are to be found everywhere and include man-made or natural materials that can be found in the water, air, soil, and food chain as well as global climate change, radiation, or electronic waste.²⁴ Although there are enough hazards in the present environment to be sufficient threats to children’s health, the past can come back to haunt the environment through contaminants in the soil from past industrial waste.²⁵

The environmental hazards that affect childhood illnesses, leading to potential critical illness and end-of-life situations are three major categories. These are asthma, childhood cancers and neurodevelopmental disorders.

The most common chronic disease found in children is asthma and between 1980-1995 its prevalence doubled in the United States.²⁶ The cause for the increase is not known and, although the disease can be inherited, the genetic features are most likely not the reason for the increase. The most likely reason can be found in the air pollution, such as being exposed to ozone combined with an outdoor exercise routine.²⁷ The outdoor pollutants increase in titers in the afternoon and when children were studied, based on the amount of time and time of day spent outdoors, there was a correlation between the air pollution and lung functional growth, such as the more pollution the less growth.²⁸ However, the disease of asthma is not only about outside

air pollution, it is also known that indoor pollutants exacerbate it as well. These include tobacco smoke, dust mites, pesticides, exposure to cockroaches, and materials added to plastics, such as polyvinyl chloride (PVC) to make them more flexible.²⁹

The second most common cause of death to children in the United States, aged 0-19, is cancer. In 2014, there were 15,780 cases of cancer for children ages 0-19 with 1,960 deaths.³⁰ Between 2003 and 2012 there was a 2% decrease in the number of children's deaths due to cancer, which was not due to a decrease in the incidence, but believed to be because of improved diagnosis and treatment.³¹ The three cancers that are the most prevalent are leukemia, central nervous system tumors, and lymphomas with etiologies greatly influenced by environmental chemicals, especially while in utero, as well as drug exposure early in life.³²

The third and final group of conditions, that are believed to be affected by the environment, are neurodevelopmental disorders which include attention deficit or hyperactive disorder, autism, dyslexia, and mental retardation.³³ Approximately 3-8% of the 4,000,000 infants born each year in the United States will be affected by one of these disorders with less than 25% of them having a known etiology.³⁴ Those with known etiologies are believed to be caused by genetic factors, chromosomal anomalies, in utero exposure to drugs of abuse, and untoward events in early life.³⁵ The etiologies for neurodevelopmental disorders are showing that environmental exposures may be responsible for the cause, include exposure to lead, ethyl alcohol, and methyl mercury.³⁶ Agricultural pesticide exposure during gestation has also shown a relationship to the incidence of neurodevelopmental disorders.³⁷ However, with these known relationships, there is still much unknown about the 80,000 chemicals registered with the United States Environmental Protection Agency (EPA) and of the more than 3000 (1,000,000 pounds) chemicals imported yearly, only 43% have had a toxicity assessment.³⁸ This leaves many potential unknowns that could be

having an impact on society's children.

Children dying was once an expected occurrence as it happened so frequently, however, with all the medical advances, this is no longer the case making a child's death an infrequent and life-altering event. Still futile treatments do occur when treatments are no longer of benefit to the child, but it is a difficult topic to discuss making the withholding and withdrawing of treatment an arduous decision for both family and health care providers.

4.II.B. Medical Futility

As in the care of the critically ill adult patient, medically futile treatment decisions must also be confronted in the pediatric patient. The difference between the adult and pediatric futility discussions are two-fold, making the dilemmas surrounding medical futility with children exceedingly more difficult than adults.³⁹ First, is the profoundly held opinion that somehow children should be different and immune from death, or at least until some hypothetical point in time or age compounding the ability to make end-of-life decisions. Second, the uncertainty that exists in pediatric illnesses and conditions that makes it difficult to predict the course of the disease or its eventual outcome.⁴⁰ Along with these differences, the patterns of death in the pediatric patient are different than the adult and the legal, as well as ethical decision making process, has nuances that are unique to this group of patients.

4.II.B.1. Patterns and Views of Death

In developed countries, the majority of children's deaths occur in a hospital and almost three quarters of these deaths occur in a critical care unit.⁴¹ Of those children who die in critical care units, most occur after decisions are made to either withhold or withdraw treatment.⁴² Therefore, these deaths are not unexpected and usually follow lengthy courses of treatment before an end-of-life decision is made regarding the initiation or continuation of treatment. The

ill and dying child elicits such an emotional response that it makes these decisions difficult for families and health care providers.⁴³

There were 2,626,418 total deaths in the United States in 2014, which is an age adjusted rate of 724.6 deaths per 100,000 population.⁴⁴ When examining the break out by age of the children's deaths in 2013, compared with 1980, there has been a significant decrease. For the infants under one year of age, where the most deaths occur, 1980 saw deaths of 1288.3/100,000 and 2013 was 594.7; ages 1-4 in 1980 was 63.9/100,000 and 25.5 in 2013; ages 5-14 was 30.6/100,000 and 13.0 in 2013; and in the 15-19 age group, which is the second highest after the infants, in 1980 was 97.9/100,000 and 44.8 in 2013.⁴⁵ Total children deaths are less than 3%, or approximately 55,000 of the total 2.6 million deaths.⁴⁶ The top causes of death for those less than five years of age, as well as those five to nine, are congenital anomalies, malignancies, unintentional injuries, intentional injuries, and influenza.⁴⁷ For those ages nine to 14 and 15 to 19, the causes are intentional as well as unintentional injuries, and malignancies.⁴⁸

In contrast, the major causes of death in developing countries, in those less than five years of age, are pneumonia, diarrhea, measles, malaria, and malnutrition.⁴⁹ Developing countries still struggle with infectious diseases and conditions that are results of environmental hazards. In the United States from age five to 18, the unintentional injuries are caused by accidents and the intentional injuries are from homicides, suicides, plus child abuse.⁵⁰ It is in adolescence that behavior begins to be linked to disease that will go into adulthood and lead to chronic diseases. These behaviors include such things as smoking, drinking, diet and exercise.

A death of a child is such a lasting sorrow that the fear and sorrow begin with the diagnosis and last a lifetime. Children also develop their understanding and beliefs regarding death from their parents and their life experiences, with those who have had a personal experience with

death usually having a better understanding of personal mortality.⁵¹ When it is the child who is dying, it calls into play those understandings and fears. There are four principal features of death understanding that are usually mastered by children between the ages of five and ten.⁵² These include the following: 1) inevitability: The acceptance that all living things, including oneself, eventually die; 2) irreversibility: Once dead there is no returning back to the living; 3) cessation of function or non-functionality: All bodily functions cease at death; and 4) causality: Death is caused by bodily function breakdown.⁵³ Studies reveal that there is no gender differences in understanding death and that once a level of understanding is reached, the fear is reduced but tends to return in adolescence.⁵⁴ This returned fear is thought to be that different factors now enter into the fear such as those from the cognitive, social and psychological world.⁵⁵

Children who are critically ill or at the end-of-life from illness, congenital anomalies, or injury often are aware of their impending death but do not always initiate any conversation regarding the death.⁵⁶ Parents vary on whether they initiate a death conversation. In a study of 430 parents, with children dying from cancer, only 27% talked with the child about death; 25% used the word “death”; 22% sensed that their child was aware of the impending death; and 46% never sensed that their child was aware of the death.⁵⁷ Secondary findings were that religious parents were more apt to have talked to their children than non-religious, with the religious beliefs giving comfort to the children, and that no one regretted talking to their child about death, but there were regrets if they had not.⁵⁸

When there comes a time in a child’s critical illness that further treatment offers no benefit, it is a time for decisions to be made. Parents and health care providers may not be in agreement as to what decisions to make. These decisions rarely go the legal route, but they do often raise ethical concerns.

4.II.B.2. Legal and Ethical Decision Making Process

The decision making process in pediatrics that distinguishes it from that in the adult realm is that there are three parties partaking in the process: the pediatric patient, the parents, and the health care providers.⁵⁹ The assumption is that the parents have the best interest of the child in mind, however it can be a struggle to know the limits of parental decision making authority and when to challenge it.

There have been times when hospitals and physicians believed the parents were not acting in the best interest of the child when medically futile treatment was being provided. At these times, it was not unusual for the legal system to be used in attempt to get assistance with medical recommendations. As a rule, the courts have not favored physicians or hospitals in using their authority to usurp parental wishes.⁶⁰ Even with continued attempts to petition the legal system, it has been made very clear in futility cases, in the United States, that it is not going to help physicians and hospitals in ending futile treatment.⁶¹ In the end, it is the parents who decide any futile treatment decisions for the child. Therefore, it is imperative that open communication between parents and health care providers be a focus.

The ethical decision making process in pediatrics calls upon ethical theory. This theory is based on the foundation of the three major players where the physician is acting on behalf of the child, the parents are acting on behalf of the child, and together the physician and parents act together as co-fiduciaries for the benefit of the child.⁶² The physician only addresses health issues, the parents address both health and non-health issues, and as the physician, together with the parents, as co-fiduciaries, there are constraints based on professional integrity.⁶³ These constraints are that the physician has an obligation to preserve the child's life when there are medical treatments which are expected to prevent loss of the child's health and life.⁶⁴ However,

the parents cannot expect the physician to act outside of medical norms or professional integrity. In an ideal situation there is on-going communication that allows for free discussion minimizing conflict so that joint decisions can be reached.

Nurses can be of benefit when they are part of the discussions between parents and physicians, as they spend the most time at the bedside with the patient and the patient's family. Studies with nurses in PICUs indicate that caring for critically ill pediatric patients, when parents wish to continue aggressive treatment that is futile, affects the nurses with feelings of anger, stress, and helplessness.⁶⁵ Not wishing to take away the last ray of hope, nurses often are quiet when they want to speak up to parents and help present realistic goals, if only to plan a good death for the patient.⁶⁶ Therefore, a team approach that includes physicians, nurses, and parents can be helpful for all players in caring for a critically ill child.

A theoretical framework provides the support for further discussion of futility in the pediatric population. The next section will first discuss moral status with a closer look at the rights of the children along with the parental rights. The second part will take an overall look at the family with an examination of the life support decisions that can be presented in the critical care unit at the end-of-life.

4.III. Theoretical Framework

As with the newborns, the framework for examining futility in pediatrics is based on the moral status of the child and the significance that holds at the various ages from 1 to 18. There is such a wide range of developmental levels in the years that are included in the pediatric population that the rights and needs of the children can have a broad variance making it difficult to have "one size fits all".

4.III.A. Determining Moral Status

The majority of the moral status of children, as well as adults, comes from recognizing the fact that they are persons or human beings which is accompanied by the rights of humans such as “life, liberty, pursuit of happiness, etc.”⁶⁷ Because of this recognition, health care providers must be committed to seeing that the children are respected as individuals with full value at each age and stage of development.⁶⁸ This is especially important in the critically ill child who because of the illness cannot always have a voice or control any of the care being delivered. The smaller the children, the more they are dependent on others, and the more they need others to be sure their rights are being protected and their needs met.⁶⁹

Other sources of moral status can be found in roles, such as teacher or laborer etc., reflected duties to others, and political power which can affect moral status via different levels in that power.⁷⁰ Of these remaining sources of moral status, children due to their lack of maturity, are unable to achieve them until adulthood.⁷¹ Not only can children not achieve them, but also children at the beginning of life are unable to meet their basic needs or negotiate barriers in society to get their needs met.⁷²

4.III.A.1. Children’s Rights

Recognizing that humans have rights is a persuasive way of saying they have moral status.⁷³ Rights have two basic functions, one being to protect the individual and the other is to place restrictions on the behavior of the moral agent of the individual.⁷⁴ Even if there is a universal belief that children have moral status based on the fact that they are human, which grants them rights, there is all too often a disconnect between theory and practice. This can be seen globally in children by the lack of education, the exploitation, the unsafe and hazardous living conditions and the abuse, as well as neglect, which millions of children endure every day.⁷⁵

There are various thoughts on the rights of children expressed by various philosophers. These include the following: 1) that children have no rights but their moral status must be protected; 2) children have the same rights as adults, although children at all ages do not have the right or ability to act on these rights, such as drive a car at a young age; 3) children have basic human rights and gain other rights as they age and mature; and 4) children have welfare rights but not liberty rights, however, adults have both.⁷⁶ Even for those who do not believe children have rights, there is an obligation on some adult's part to see that the children are cared for and protected.⁷⁷ Those that believe children do have rights also believe these rights correlate with duties from an adult or group of adults to see that the rights are preserved.⁷⁸

Those who support the children's rights theories, focus on the status of children as "being" rather than "becoming".⁷⁹ However, they distinguish the rights into three categories. The first is the right to provision, which includes the basic needs of food, shelter, and education.⁸⁰ The second set of children's rights deals with the right to protection, which includes being protected from abuse, exploitation, neglect or danger of any kind.⁸¹ The last set of rights pertain to the right to autonomy. This is looked upon as the most vital of the three and one of "being" versus "becoming" treating the child as a person with levels of autonomy commiserate with age.⁸²

With autonomy comes a level of decision making that is dependent on cognitive ability and past experiences, rather than a particular age.⁸³ Children that have lived with a long term chronic illness or disability are more apt to have a better grasp of the issues regarding treatment than those who have not.⁸⁴ This can prove beneficial for decisions regarding futile treatment as long as the child is not too ill to participate in the decision.

In 1989, 190 countries came together to develop and pass the United Nations Convention on the Rights of the Child which is one of the most ratified human rights treaties in history.⁸⁵ It also

addresses many principles to protect the rights of children to include allowing children to participate in the medical decisions, whenever possible.⁸⁶ Although the convention was signed by President Clinton in 1995, the United States is one of three countries who have not ratified it, Somalia and South Sudan are the other two.⁸⁷ The reasons for non-ratification are based on concerns that there will be legal ramifications regarding more financial support for children needs and potential governmental lawsuits.⁸⁸ A lack of ratification does not mean the United States does not support children's rights, in fact, the United States has always been committed to human rights. However, there is room for improvement in the children's rights arena in the following areas: 1) the United States is the only high income country to not grant paid maternity leave; 2) the United States is the only country in the world that a child under 18 can be sentenced to life in prison without parole and the U.N. Convention opposes this; and 3) in the United States, 21.2% of children live in poverty compared to the other member countries of the Organization for Economic Cooperation and Development (OECD) where the average is 13.3%.⁸⁹

When treatments for children have become futile, no longer providing benefit or meeting the goals for the patient, children have rights. These rights, which may include both parents and health care providers, ensure that the best medical treatments have been provided and that no further treatment is available or warranted. Even when that is the case, parents often insist on futile treatment. They insist because they feel helpless and powerless, their reasoning may be faulty, they may doubt the validity of the prognosis, they are hoping for a miracle, and they put trust in God as well as their religious beliefs.⁹⁰ In these cases, futile treatments continue to be provided and communication links need to remain open with the topic being broached at frequent intervals.

4.III.A.2. Parental Rights

Just as children have rights, so do parents, with parental authority coming with rights based on the fact that the parent is the sole agent of the child.⁹¹ Parental rights are best explained as rights with “thresholds”.⁹² A right with a threshold means the right can be overridden if one of two conditions are met. These conditions are: 1) if the right conflicts with a right that is stronger, and 2) if overridden there will be a greater benefit to another.⁹³ If parents insist on continuing futile treatments that are believed to be causing the child prolonged suffering, theoretically this could be viewed as an infringement on the parental rights. As described above, in cases of medical futility, it is difficult to take action in these cases and the court system has not been a source of assistance. However, to view parental rights with thresholds explains how these rights can exist while still granting ethical and moral scrutiny to the children.⁹⁴

The rights of parents have been described as “stewardship rights”, versus owner rights, which adds to the complexity of the moral status of parents. A steward is an agent or surrogate for another doing what is best for the child, whereas, an owner acts as if the other person is property and actions follow what is best for the owner.⁹⁵ This additional moral status of parents translates into the children’s right to be sure they are protected as well as have their needs met, such as being nurtured, educated, and developed.⁹⁶ Just as parents are responsible to feed children, bathe them, keep them safe, it also progresses to making them attend school, behave appropriately toward others and help them to grow up to be independent members of society.⁹⁷ Along with the rights of parents, comes the duties to not violate the child’s rights, to be sure no one else violates these rights and to protect the interests of the child.⁹⁸ Failure to do any of these duties can lead to a limited and eventual loss of parental rights.

When a critically ill child is at a point where medical treatment is not having a benefit and

prognosis is very poor, the parents usually have the right to determine the next steps.⁹⁹ This right is a point of discussion between the health care providers and the parents as to how further treatments are planned, as well as how ethical concerns are addressed. However, even though parents have immense responsibility in caring for a child, their authority is not absolute.¹⁰⁰ If the health care team is asked to act in a way that seems to not be in the child's best interest, then the team has a duty to not comply.¹⁰¹ Before this action is taken, it should be clear to all concerned that the requested action is not in the child's best interest and that it is harmful to the child.¹⁰² In general, in cases of continuing treatments that are termed futile, parental decisions are tolerated with a focus on reaching a point of agreement regarding withholding and withdrawing treatment.

The moral status of the child is at the center of the theoretical framework for medical futility in pediatrics with children's rights and parental rights supporting it. Another aspect of the theoretical framework is looking at the perspective of the family which examines both the views of the family and the various life support decisions.

4.III.B. Family Perspective

Studies have shown that physicians, in the pediatric intensive care unit when end-of-life decisions must be made, are reluctant to resort to unilateral decision making and do so in less than 2.7% of cases.¹⁰³ Difficult decisions are often referred to ethics committees, however, as these committees are usually composed of nurses, physicians, and hospital representatives, the parents and children do not always appear to receive fair representation. This potential for unilateral decision making and underrepresentation of parents and children in the critical care unit lead to the conclusion that, as long as reasonable, the parents' wishes need to be accommodated.¹⁰⁴

When dealing with the critically ill child within the pediatric intensive care unit, the child

cannot be separated from the family. Therefore, in essence the family unit, which includes the patient, as well as the parents, siblings, and extended family, all become the focus of care.

Following is a discussion on three views of the family.

4.III.B.1. Views of the Family

The first view of the family relates to the most basic structured view when there are parents, children, and often extended family members such as grandparents. This view is based on a blood relationship where there was a socially approved sexual relationship that produced offspring that established a residence of living together.¹⁰⁵ This was what was once referred to as the nuclear family that has now been challenged. It is seen as controversial as there are now single parents and homosexual couples who have become parents either through surrogates or adoption.¹⁰⁶ What was once the norm to have a mother who stayed at home caring for children and the home, as well as a father who was the breadwinner, as well as major decision maker, has been replaced by all variants of this “norm”. As divorce rates continue to be high, children are bounced back and forth from one family structure to another in a short lifetime. Fathers may now be the stay-at-home dad, if both parents work outside the home, blurring the lines of authority in the home which translates to the hospital and decisions to be made there.

The second view of the family refers to the family in its social being. The family is seen as a social system which focuses on the authority and needs of the family as it centers on the needs of the individual.¹⁰⁷ Within this structure, the family has moral obligations and moral responsibilities. In times of illness, especially critically ill children who are alert enough to participate in end-of-life decisions, this view opposes the role of the child in independent decision making holding the “family” as the source of decisions which equates to the parents in most cases.¹⁰⁸ This view of the family is in opposition to the U.N. Convention for the Rights of

the Child which advocates for parents to only be agents for their children's best interest encouraging the children to make independent decisions, when appropriate.

The third, and final view of the family, is a more liberal view of the liberal social-constructivist view. This view is when the family structure is created, through consent with liberty and equality for all members whose authority can change at any time per agreement.¹⁰⁹ So the view of children and decision making in critical care is that children are to participate as fully as possible as long as decisions show growth in the child's moral capacity and autonomy.¹¹⁰ The parents are still the trusted parties who are subject to oversight by the hospital and the state. This particular view of the family has been accepted by some feminists, homosexual activists, and other anti-establishment groups who wish to rescue the family from traditional patriarchal and historical norms.¹¹¹

Three views of the family have been presented with no one being superior to the other. Knowing how the family is defined and viewed for each critically ill child is vital in establishing lines of communication and for decision making regarding the children's care. Regardless of how the family is configured, viewed, or functions, there are personal roles it must fit in order to meet the needs of the child. These include: 1) love—a child needs someone to love them unconditionally throughout their childhood and adolescence; 2) physical care and homemaker who tends to all physical needs to include a clean, neat house with adequate nutritional food; 3) financial support, which may be from sources in the home, outside the home, or governmental sources; 4) moral education and teacher who teaches values to live by but also cognitive knowledge that is taught in schools, to some extent, but augmented in the home; 5) socializer as one who integrates the child into society which is a role shared by many; and 6) a gender role model which may reside inside the home or outside it, but it is necessary for role integration.¹¹²

Therefore, despite the conflicting views of the family, meeting children's needs so they can grow in autonomy and self-actualization is the goal. Even with the best intentions, it is not unusual for a critically ill child or adolescent to regress and become more dependent, both physically and psychologically, as the end-of-life approaches.¹¹³

With the family and its structure being part of the theoretical framework and the basis for decision making in collaboration with the health care team, there are many decisions that are needed to be made along the course of the illness. Three of the major types of decisions are discussed in the following section.

4.III.B.2. End-of-Life Decisions

The first category of decisions focuses on who is going to make the health care and on-going decisions regarding the child's care. As a general rule, in pediatrics, the parents make the decisions. However, because pediatrics covers the ages from 1 to 18, there are adolescents, and some young children, who can participate in the decision making process. It is encouraged, whenever possible, that children be at least a part of discussions regarding difficult decisions.¹¹⁴ Just because children partake in the discussion, does not mean they will have the final say and for years courts held that a child was a minor and was legally unable to withhold consent to treatment.¹¹⁵ There has been a change in that thinking, if the child can show signs of maturity and intelligence, via the mature minor doctrine, plus understanding the consequence of a decision to refuse or consent to a specific treatment, then the child's wishes carry significant weight.¹¹⁶ Who makes the decisions can also vary based on cultural beliefs, such as not including the child or the women in discussions or decisions. Health care providers are faced with respecting these values, even if they are not in agreement.

A second type of decisions that are often asked to be made for the critically ill patient is in

regard to medical treatment. The first of these refer to not starting versus stopping treatments. Although these have been determined to be ethically the same, families often do not perceive them as such and have more difficulty with stopping or withdrawing treatment.¹¹⁷

When clinicians work with pediatric patients and families at the end-of-life and the topic becomes continuing futile treatments or discontinuing them, the clinician can have a major influence one way or another. Clinicians, too, have their own influencers. They are greatly influenced by their personal, religious and cultural values as well as their emotional response to the child's illness and end-of-life. They can also be influenced by other factors which include: 1) a lack of knowledge or understanding of the evidence regarding the benefits and burdens of end-of-life treatments; 2) an overall lack of education in clinical ethics and the many dilemmas that present themselves; and 3) the confusion and helplessness regarding the role palliative care can play, especially when life sustaining treatments have been withheld or withdrawn.¹¹⁸

A second part of the treatment decisions concern life sustaining treatment and which will be used and which will not. Each child and the particular illness weighs heavily in these decisions. However, the ones that are first considered are most often cardiopulmonary resuscitation and mechanical ventilation. A do not resuscitate decision is more readily reached because it is about a point in the future when the child has a cardiopulmonary arrest, however, a decision to stop mechanical ventilation is more difficult and may mean imminent death for the child.¹¹⁹ Other treatment decisions include artificial nutrition and hydration, antibiotics, blood transfusions, and kidney dialysis. Of these, stopping the artificial nutrition and hydration is especially onerous in the pediatric population. This difficulty is because feeding children is such an essential task of parenting that when it ceases, it symbolizes such finality in the child's life with death soon to follow, plus the nursing staff struggle with not feeding children, especially small children.¹²⁰

The third and final type of decisions to be made regarding the child's care in critical care when further treatments appear to be futile without providing benefit to the patient, is what will be the criteria or guideposts along the way to signal that a critical decision must be made. The topic of quality of life is often discussed versus the quantity of life, and as the American Academy of Pediatrics has stated in reference to palliative care, "its focus is to add life to years and not years to life".¹²¹ However, quality of life considerations are not without ethical trepidations. Such considerations involve both objective data regarding the child's prognosis, with or without treatment, as well as subjective factors considering when is enough suffering enough so that it exceeds any benefit of the treatment.¹²²

For treatment to be initiated, withdrawn or discontinued, the consent of the patient or patient's surrogate is required. A person cannot legally consent before the age of 18. However, the American Academy of Pediatrics (AAP) has been instrumental in expressing views on the concept of informed consent in pediatric patients to ensure that the child is a part of the decision making process, whenever possible.¹²³ The next section addresses the role of assent, informed consent, and parental permission by discussing developmental and clinical considerations to include the Best Interest standard and the Harm Principle. The importance of maintaining the parent/child relationship will be examined to include the provider's role and how medical futility plays a part in that relationship.

4.IV. Role of Assent, Informed Consent, and Parental Permission

Prior to the establishment of the concept of informed consent, the physician made all the treatment decisions. Now it is believed that the patient or surrogate has the right to make treatment decisions, in collaboration with the physicians, in an understandable language that

includes treatment options, rights, benefits, and alternatives.¹²⁴ In applying informed consent to pediatrics, the child's parents or surrogates/proxy decision makers are usually the ones who give the consent, or permission, as one person cannot consent for another.¹²⁵ In giving this permission, the Best Interest standard is utilized in the decision making process.

4.IV.A. Developmental and Clinical Considerations

As the treatment options have increased using more and more of the available technology plus pharmaceuticals, the medical decision making for parents has gotten more complex. There is no longer a clear "right answer" to many of the decisions facing parents as well as health care providers. To add to the complexity, involving children in making these tough choices is encouraged as the treatment preferences come down to personal values and perceived quality of life.¹²⁶

4.IV.A.1. Decisional Capacity

One approach to the decision capabilities of children uses the "rules of seven" where children less than seven years are considered unable to make decisions; those 8-14 years of age are unlikely to have the ability to make major decisions, but children vary; and those older than 14 have the ability to make decisions.¹²⁷

When children less than seven years of age are being cared for, the premise is that they cannot make decisions and, therefore, the Best Interest standard applies. The second age group, 8-14 years, is usually able to reason, plus use logic, but may be very rule-oriented and less flexible when looking at choices, however, they are usually able to assent to treatment.¹²⁸ The AAP, in 1995, defined assent as having four components. These include, 1) assessing the patient to attain an appropriate level of awareness of condition; 2) informing the patient of expectations of the disease and treatment; 3) assessing the patient's level of understanding; and 4) obtaining

agreement by the patient for the plan of care.¹²⁹

The adolescent group, those greater than 14 years of age, are usually able to consent. They do not pass the minimum age of consent, but can do complex reasoning, discern multiple options, anticipate outcomes, all of which is influenced by emotional maturity.¹³⁰ Some adolescents may not be of legal age to consent, but by being emancipated they are able to consent before the age of 18. Emancipation includes those who are either married, in the military service, self-supporting and/or not residing at home, a parent or are pregnant, or a court has declared them emancipated.¹³¹ In some states emancipated minors can make decisions regarding any medical treatment while in other states a “mature minor” that demonstrates maturity and knowledge, similar to an adult, can make medical decisions, even if they conflict with their parent’s perspective.¹³²

The degree to which children are included in medical decision making varies with physicians. Indicators in using assent are influenced by the parent’s wishes, how the child either verbalizes agreement or exhibits non-verbal agreement, and the absence of overt disagreement, such as actively protesting through screaming, kicking or other actions.¹³³

In cases of medical futility, factors which influence the use of assent in end-of-life decisions fall into three categories. The first category is child factors which range from a lack of arousal to a high state of anxiety or depression in addition to physical discomfort especially pain, nausea, and vomiting.¹³⁴ The second category relates to family factors that are highly influenced by religious and cultural beliefs and who is allowed to participate in the decision making.¹³⁵ The last category is situational factors and can be based on the degree of difficulty with the decision in that all choices have strong negative ramifications or when a decision must be made immediately in an emergent situation, which does not allow time for any consideration.¹³⁶

Nurses spend the most time, as compared with all other care givers, with the sick child. This time commitment allows for a unique perspective on many aspects of care. Including children in decisions regarding their own care is one of these areas. The majority of nurses agree that the children's views regarding their care is a vital issue and one that shows respect for children's rights.¹³⁷ However, there is variability among and between children based on age, attitude, mental status, plus levels of well-being so that a generalized statement cannot be applied in practice but must be individualized to the child and situation.¹³⁸ For those children with a long term chronic illness, many become so well versed and knowledgeable regarding their disease or condition that some nurses are threatened by the child's knowledge, especially when they question their care.¹³⁹ This can serve to be counter-productive to having the children be full participants in their care.

When assent is used with children in medical decision making, there must always be room for dissent. A child's dissent should carry significant importance, especially if the treatment is not vital or can be postponed without serious risk.¹⁴⁰ Forcing a child to assent through bribery or manipulation is never permissible.¹⁴¹ However, when there is an impasse, plus the parents and providers believe the treatment is necessary but the child dissents, forced treatment, although morally suspect, is sometimes done after acknowledging to the child the "what" and "why" of the action.¹⁴² The example where action is taken when the child may dissent and parents do not give permission, is when emergent treatment is needed to save a child's life and is most often related to religious beliefs, such as giving blood to a Jehovah's Witness child.¹⁴³ In this instance, a court order is obtained in order to proceed with blood transfusion.

For the many times that it is not possible for the child to assent to treatment decisions, the parents are the surrogate decision makers through the Best Interest standard. However, when the

child is put in harm's way through the decision, the Harm Principle may be the more appropriate approach to use than the Best Interest standard.

4.IV.A.2. Best Interest Standard and the Harm Principle

Since children are considered incompetent to make legally binding decisions regarding their health care, providers, parents or surrogates are called upon to do this through the Best Interest standard.¹⁴⁴ The Best Interest standard implies that the parent/surrogate will do what is right for the child maximizing benefits and minimizing risks.¹⁴⁵ Although the standard was first established in 1899 to protect children from crime and incarceration, it now addresses all areas where the rights of children need to be protected.¹⁴⁶ Even children who in a healthy state may be able to express their views regarding their own health, may not be able to do so when critically ill or nearing end-of-life, therefore, the Best Interest standard becomes more applicable at these times.

Beauchamp and Childress define the Best Interest standard as when a decision maker decides, among the available options, which provides the best benefit after weighing the patient's interests against the benefits and risks.¹⁴⁷ Consequently, when the child's preferences or interests are unknown or not clear, as when critically ill, the parents or surrogates must still consider the best interest of the child. This includes making determinations that deal with suffering, preservation of life, and the quality of life.¹⁴⁸

Most health care providers and parents would agree that medical treatment should be provided in the child's best interest, however, there are critics of the best interest standard who say it does not serve the child well. The first criticism is that the Best Interest standard is not clearly defined, as well as it is often applied in an erratic manner.¹⁴⁹ In determining benefit versus harm, these are subjective and open to many interpretations between the various parents

and providers. A child's parents, as well as the health care providers, can have conflicting views regarding what is the best next steps in the course of care for the child, yet, both invoke the Best Interest standard with no one right answer.¹⁵⁰

The second criticism focuses on the Best Interest standard being too narrow and demanding when applied to specific cases.¹⁵¹ For example, if a child has a rare fatal disease and being in a university institution offers experimental treatment that might extend life, but not cure the underlying disease, this might be construed to mean moving the family closer to the institution as in the child's best interest. The best interest standard necessitates action to what is reasonable, even if this is not clearly defined.¹⁵²

A final criticism of the Best Interest standard is that it fails to respect the family as the integrated unit that it is, regardless of the structure of the unit.¹⁵³ By respecting the family and focusing on the child, decisions can still impact every member of the family. Therefore, every decision must take the totality of the family into perspective.

Even with parents making decisions via the Best Interest standard, this authority is not absolute.¹⁵⁴ When continued treatment is seen as futile or no longer providing benefit to the child and even producing prolonged suffering, health care providers may call upon the Best Interest standard as well as the parents. This can appear to be in opposition. The Best Interest standard is appropriate to use when there are alternate treatment choices to be made. However, the Harm Principle may be better suited to determine when to seek legal assistance in the decision making process.¹⁵⁵

The Harm Principle helps to identify when further action is needed. It does not just imply that the decision is not in the child's best interest, but that there might be actual harm to the child by the decision that is made, or in the process of being made.¹⁵⁶ In most court decisions, they are

lenient giving great discretion to parents to decide what is in the child's best interest, unless there is proof that the parent's action is a threat to the child's safety or health.¹⁵⁷ In the end, the use of the Harm Principle is best used as a last resort when parents' decisions are more likely to lead to death.¹⁵⁸ In the case of medical futility or treatments that are not benefiting the child and are prolonging the suffering, it is a difficult case to prove that decisions are causing harm when the child is in the process of dying from their disease.

The parent/child relationship involves the parents' understanding of their identity as parents, the associated role expectations and obligations, plus the responsibilities to their children.¹⁵⁹ However, these identities, roles, as well as responsibilities, get blurred and confused as their expert knowledge regarding their child is put to the test when making medical futility decisions.

4.IV.B. Maintaining Integrity of Parent/Child Relationship

In making difficult treatment decisions, and because of all the emotionalism associated with ill children, health care providers must focus on building relationships with both the parents and children.¹⁶⁰ Futility decisions are best made as a collaborative effort between parents and health care providers, as well as children in some cases, depending on age.¹⁶¹

In the parent/child relationship, an authority based relationship is not only tolerated, it is expected.¹⁶² This authority plays out in making treatment decisions for "gravely" ill children in that when urgent decisions are needed, the tendency is to choose life without further discussion, but when the decision is less urgent, then the quality of life is more apt to be considered.¹⁶³ As health care providers, the challenge is knowing that parents often follow a "roller coaster" emotional and decisional pattern that requires understanding, compassion, and communication by all caregivers.

4.IV.B.1. Provider's Role

The provider's role in maintaining the integrity of the parent/child relationship is critical. It starts with understanding that as providers they have a large responsibility in this relationship. This is done in the three following ways: 1) recognizing that parental authority does exist which may include a strong use of persuasion and at times "coercion" to get the child to respond appropriately, as long as the means are not abusive or harmful to the child; 2) observing that parents use a certain amount of discretion in performing their duties, without outside interference, as long as there is no neglect or abuse; and 3) acknowledging the parents duty to advocate for their children and safeguard their rights.¹⁶⁴ It is through this parent/child relationship that the parents have not only assumed the responsibility for their child but also to the community at large to develop a member worthy of it.

Parental authority is not the only ingredient in the parent/child relationship. There is also a duty that is owed to see that the rights or interests of the child are protected.¹⁶⁵ With this duty there is a fair amount of discretion on how to perform these duties without interference from outside individuals or agencies, provided actions are not neglectful or abusive.¹⁶⁶

With adolescents who are critically ill, it is the provider's role to assure that the patient's interests are being met without undermining the parental role.¹⁶⁷ This assurance includes controlling the young person's access to information while encouraging the parents to share information and not inappropriately withhold it.¹⁶⁸

Providers fill many roles when caring for the critically ill child at the end-of-life. One such role is the supporter of the family. Although this is most often performed by providers other than physicians, physicians do play a part with this focusing on the needs of the family to include emotional, environmental, informational, and spiritual needs.¹⁶⁹ A second role is that of advocating for the patient. This role requires more than support, to include medical knowledge

and helping the family navigate the clinical environment getting questions answered.¹⁷⁰ A third role is one of information giver. Based on what information that is given, the parents make decisions, often in collaboration with the physicians and other providers. The type of decisions that are made in the pediatric critical care unit at the end-of-life include whether to attempt high risk treatments with unpredictable outcomes, whether to withhold or withdraw treatment, and whether to donate organs at death.¹⁷¹ In providing this information, the ethical principles of beneficence and non-maleficence are relied upon. Beneficence implies that treatment will be centered on those which keep the child's best interest in mind and that do not harm the child (non-maleficence).¹⁷²

A fourth role for the provider is one of a decision maker. In some cases, the physician provider assumes the paternalistic role in making end-of-life decisions when the parents cannot and are willing to acquiesce this role to the physician.¹⁷³ It comes down to balancing parents' autonomy with protecting the children who are most vulnerable at the time of illness.¹⁷⁴ In other cases, there is shared decision making between the parents and physicians that involves discussing the parameters of the decision; swapping medical information plus the family values; validating the understanding of the information; deliberately considering the decision making role; and reaching consensus for the course of treatment, to include considering the values.¹⁷⁵ This approach to decision making results in greater levels of family satisfaction.¹⁷⁶

A final role for all providers is to be alert to the traumatic stress that may be exhibited by the family of a child in the pediatric critical care unit. Approximately one third of parents meet the diagnostic criteria for acute stress disorder, while the child is in the hospital, and one fifth show signs and symptoms of post-traumatic stress disorder months after the hospitalization event.¹⁷⁷ With signs and symptoms occurring after discharge or death, there is reason to develop

programs that support parents during this difficult time.

In maintaining the integrity of the parent/child relationship, as well as promote a healthy relationship between parents and providers, the topic of medical futility or treatment that no longer provides a benefit can be onerous. However, when medical treatments meet the futile description, compassionate caring, which has hopefully been occurring along the child's disease course, is definitely needed.

4.IV.B.2. Role of Medical Futility

As the terms medical futility and futile treatment have defied a standard definition over the centuries, having been around since the day of Hippocrates, there is general agreement on its meaning. In general, it refers to treatment that either does not provide a good outcome for the patient, improve the quality of life, or prolongs the suffering or dying.¹⁷⁸ Recently it has been stressed not only in the literature, but also by special interest groups and professional organizations that the use of the term "futility" or "futile" is often not understood, plus seems to imply hopelessness.¹⁷⁹ The preferred term is "disproportionate burden" when the treatment provides more burden than benefit.¹⁸⁰

Physicians can always refuse to provide treatments they believe to be futile or that provide disproportionate burden. However, when this decision is invoked unilaterally it can be controversial since it will result in a conflict with the parents if they do not agree.¹⁸¹ Also when further treatment is described in the "futile" context, it may be more about the physician's personal values than the treatment of the child.

There are ways a physician can communicate and justify the reasons to abandon continued treatment without invoking the futile terminology. The first way is when further treatment is not the patient's preference.¹⁸² In pediatrics, this is more apt to happen with adolescents but can also

occur with more mature children who can voice their preferences. The second way further treatment may be refused is when it is not serving any detectable interest of the patient.¹⁸³ An example would be a child who has leukemia that does not respond to bone marrow or stem cell transplantation with the transplant cells attacking the recipient's cells leading to kidney failure. Although it seems to be futile treatment to do kidney dialysis, it would treat the kidney failure, but it would only prolong suffering with minimum benefit to the child as the underlying disease continues to attack the cells.¹⁸⁴ A final way further treatment may be refused is based on scarce resources, whether this is due to the high cost of some treatments or their availability.¹⁸⁵

When examining the role of medical futility in the parent/child and provider relationship, the ethical principles of autonomy, beneficence, non-maleficence, and justice play a part. These principles provide the structure to uphold the fundamental ethical standards and actions within the community.¹⁸⁶ With medical futility, autonomy applies to patients, parents, and providers all having the right to self-determination in making decisions among options.¹⁸⁷ Patients and parents have the right to refuse treatments as well as the right to have access to treatments, although this does not mean any and all medical treatments. If the treatment does not benefit the patient or harms the patient, the physician must exercise beneficence in not providing it.¹⁸⁸ Legally parental autonomy supersedes the child's autonomy until they are 18 years of age, even if the child is mature, as well as knowledgeable about the treatment choices.¹⁸⁹ For the physician to deceive the patient and parents into believing the treatment offers benefits when it does not, violates the trust in the relationship. A family centered approach with honest open communication is paramount in making treatment decisions with few decisions ever being made without parental and physician consensus.¹⁹⁰

Beneficence and non-maleficence involves doing good and not doing harm. When applied

to children and medical futility, the physician must be aware of treatment that promotes the well-being of the whole person. When dealing with the stress of critically ill children, the situation may lead parents to not thinking rationally, which then leads them to not being emotionally able to make tough decisions.¹⁹¹ The principle of beneficence translates to a commitment by the physician to oversee that decisions are reasonable with the underlying family's emotional, financial and spiritual values.¹⁹²

The final principle is justice which is concerned with fair and equitable distribution of resources.¹⁹³ The concern with medical futility and justice is whether there is fair distribution of medical resources, not only in the community, but also in society at large. The debate on medical futility is focused on the debate between patient/family autonomy, physician beneficence, and distributive justice.¹⁹⁴ In so doing this, the best interest of the patient must stay as the central focus.

Evidence based practice is a practice employed by health care practitioners that utilizes the best available evidence that has been scientifically validated in order to deliver the best possible care to patients.¹⁹⁵ The next section examines selected areas of evidence based practice in pediatrics by discussing end-of-life interventions, especially when further treatments have either been withheld or withdrawn, and brain death in children.

4.V. Evidence Based Practice

Medical futility at end-of-life in pediatric patients differs from adults in two basic ways. First the psychological or emotional impact that impending death of a child can have on caregivers is so great that there is a tendency to forgo discussions regarding futile treatments.¹⁹⁶ A concentrated effort is needed to begin the discussions early. The second difference is in

reference to the determination of brain death in children. The brain death criteria cannot be used with the same certainty in pediatric patients as it can in adults.¹⁹⁷ The difference is not explained by empirical data, but is thought to be due to a child's brain being more resistant to injury.¹⁹⁸

4.V.A. End-of-Life Interventions

Problems that have been identified by parents at the end-of-life in the pediatric population include a need for improved focus on the child's symptoms and associated suffering that is commonly seen.¹⁹⁹ The parents tend to focus on the child's pain, quality of life, and chance for improvement when making these end-of-life decisions.²⁰⁰ Other problems are related to communication at all levels and relationships with the health care providers.²⁰¹

Since pain has been identified as one of the top areas of concern for parents of critically ill children, health care providers must first and foremost ensure that the children's pain needs are addressed, then their role expands to parental support in the grief process.

4.V.A.1. Pain Control

Pain is the most common symptom at end-of-life, as well as the most feared.²⁰² However, there are many approaches to deal with pain which can address its prevalence, but there needs to be adjustments to align with the various ages along the continuum of the pediatric patient. Assessment of pain in a child is different from an adult and the interventions, though similar, have unique differences in both pharmacological and non-pharmacological methods.²⁰³ The fears surrounding pain are centered on hastening the child's death by giving too large a dose of medication or too often. Research has shown that this fear is not justified and that respiratory depression is extremely rare in children under the age of two months with effective pain management showing an extended life versus that seen in those with inadequate pain relief.²⁰⁴ Even though there have been advances in pediatric pain management, there remain challenges.

These challenges are due to a lack of a theoretical framework specific for pediatric pain; the uncertainty in interpreting children's behavior; difficulties in measuring and applying methodologies; and biases brought to the table by both nurses' and children's past experiences, values and personal beliefs.²⁰⁵

Pain in children at the end-of-life can not only be due to the disease process, but also to the multiple losses, the lingering existential questions, the suffering as well as the pain may have symbolic significance indicating that death is approaching.²⁰⁶ With this approaching death can come additional emotional distress in the child, the parents, as well as the care givers. Children fear being alone or abandoned as they approach the end-of-life.²⁰⁷ Therefore, not only must the pain be managed, but so must the emotional needs be addressed.

Most often pharmacologic means are used to manage the pain at the end-of-life and these are predominately from the opioid family. Some non-pharmacologic approaches to pain that have been useful in children to reduce suffering, especially at the end-of-life, include music, imagery, hypnosis as well as massage.²⁰⁸ Of these, imagery has been especially useful when used along with pain medication and has helped express fears related to helplessness, anticipatory loss, and death.²⁰⁹ Imagery has also been shown to have sustained effects over an extended period of time making it useful for those children who are terminally ill and in the process of dying.²¹⁰

Despite the focus on the various modalities on managing pediatric pain, there have been barriers in the treatment of pain in children. The American Academy of Pediatrics (AAP) has identified some of these barriers. These include: 1) the belief that children, especially infants and small children, feel little or no pain; 2) inadequate assessment and reassessment for pain by health care providers; 3) excessive fear of pain treatment effects, such as respiratory depression

and addiction; 4) the concern that acknowledging pain in children is too labor intensive and burdensome; 5) lack of knowledge regarding pain treatment in children; and 6) a general lack of understanding on the subjective experience of pain in children and getting an adequate description of the pain from the children.²¹¹ Even with these barriers, pain in children can be addressed, managed, and, in many instances, relieved. However, research indicates that children are still dying in pain with parents reporting that 89% of children with cancer end their life suffering in pain.²¹² Pain is reported as being treated in 76% of the cases with less than 27% being successful, causing speculation that some physicians may be unaware of newer effective treatments that are available, or unaware of how to use them.²¹³ Studies reveal that when pain is adequately addressed in the child there is relief, not only for the child, but there is also less emotional distress in the parents which leads to improved decision making by the parents.²¹⁴

Managing pain in critical care at the end-of-life is most often done after withdrawing treatment. At this time sedation and pain medications are given, even if amounts needed to provide comfort may hasten death under the principle of double effect.²¹⁵ However the use of paralytic agents, although debated by some health care providers, are not to be used per standard ethical principles.²¹⁶ The reason why paralytic agents are inappropriate is that they give patients the appearance of comfort, thereby “rendering” them unable to respond to any stimuli, including pain or discomfort, while still feeling both, so they serve no purpose for the patient.²¹⁷ With intractable pain, there are few pediatric protocols compared to the adult population that has many.²¹⁸ The few pediatric protocols take uncontrolled pain as seriously as a “cardiac arrest” using protocols of strong opioid choices that are titrated per symptom control.²¹⁹

The care of children at the end-of-life, to include their death, does not end there. As recommended by the Institute of Medicine, the care continues through the grieving process for

the grieving process for the parents to include bereavement support.²²⁰

4.V.A.2. Grief and Bereavement Support

Grief is defined as the response to another's death to include the emotional, physical, spiritual, social, and psychological domains.²²¹ Studies indicate that the grief following a child's death is more intense than that experienced following a loss of a spouse or parent.²²² This loss is not only for the child, but also for a part of one's self through the parental attachment.²²³

Whereas, bereavement is defined as the "state" of having been through the experience of the loss of a significant other.²²⁴

There are several types of grief. These are anticipatory, disenfranchised, and complicated or pathological grief. Anticipatory grief occurs before the actual death and can begin at the moment of an ominous diagnosis when parents are made aware that a child has a life-limiting disease or condition.²²⁵ This grief can have ups and downs as the child seems to improve then worsen with an optimum length of time being approximately 6 to 18 months.²²⁶

A second type of grief is disenfranchised grief. This type of grief occurs with a loss that cannot be acknowledged, socially supported, or mourned in public, such as the death of a disabled child that others see as a blessing or a death from child abuse or neglect that resulted by the behavior of the parents.²²⁷

A final type of grief is complicated, or pathological grief. Although all grief is complicated, the grief associated with a loss of a child is particularly complicated. Some signs that may appear when grief has become more than the expected "normal" include: 1) active grieving that has gone on for an extended period of time; 2) subjective physical or psychological complaints such as headache, stomachache, and depression with obvious signs of weight loss or weight gain; 3) inability to function in the workplace or at home or to care for other children; and 4) risk

taking behaviors, thoughts, and talk of suicide.²²⁸ At this point, intervention is needed to assist the individuals in the grieving process.

There have been many theories postulated regarding grief. One theory relates to development. As children grow and develop, their view of death changes from one that is reversible to one that is irreversible with death happening to all living things.²²⁹ Another theory sees grief as work. Sigmund Freud was one of the first who saw grief as work and, consequently, the term of “working through one’s grief”.²³⁰ Other theories that are closely related to the work are those with stages or phases with many different ones calling the phase’s different names. The Harvard Bereavement Study uses four stages with the first accepting the loss, the second experiencing the pain of the loss, the third adjusting to the environment without the person, and the fourth relocating the deceased person back into one’s life with ways to remember them.²³¹ A final and more futuristic theory is one with continuing bonds with the deceased. This theory, once seen as pathological grief, is now seen as adaptive and is recommended so that the parents continue a relationship with the deceased child.²³² The bonding theory’s focus is “holding on while letting go” so that parents do not strive to diminish the grief but learn to keep it as it is and grow around it.²³³

The extent and severity of the grief are influenced by several factors. In general, the mother of a deceased child experiences a more intense and longer grief than the father, especially with the younger child and the adolescent.²³⁴ In addition, parents of children who die unexpectedly also have a more intense grief reaction than those who experience an expected death, as they have been grieving since the diagnosis.²³⁵ Intrinsic factors that influence grief are related to the psychological make-up of the parents, their coping abilities, and response to stressful situations.²³⁶ Extrinsic factors that have the biggest impact on grief are the support of the

hospital staff and the “adequacy” of the information that has been shared through the child’s illness, especially at the end-of life.²³⁷

Another area that has been identified with importance is the recognition of spiritual needs of the grieving parents.²³⁸ The best way to address these needs is through a “caring presence”, which allows the parents to be at the bedside and care for the child through the dying process as well as help establish memories for the future.²³⁹ Related to one’s religion or spirituality four themes emerge. These are prayer, faith, visits as well as support from hospital chaplains or one’s clergy, and belief in the divine nature of the parent/child relationship that extends beyond death.²⁴⁰ Providing an environment that supports these themes at the end-of-life is critical for the parents but also benefits children if they share the religious beliefs of their parents.

Additional priorities have been identified for interventions in end-of-life care for parents and children. These include open, honest communication with accurate and timely information; easy access to health care providers; emotional support by staff; maintenance of the integrity of the parent child relationship, and faith support.²⁴¹

Health care providers often experience profound grief following the death of a child. One approach that has been used successfully is grief debriefing sessions following a child’s death where staff who have cared for the child can share their feelings and how they are managing their grief.²⁴²

No one argues that the death of a child is traumatic for all concerned. However, there are instances where the declaration of death in a child is not always a simple task. Such an instance surrounds the topic of brain death.

4.V.B. Brain Death

The concept of brain death came to be in the 1950’s with the advent of mechanical

ventilation and the progress in organ donation.²⁴³ Today brain death is recognized in both developed and developing countries with it being made into law in some countries.²⁴⁴ In the United States the Harvard Criteria for brain death, developed in 1968, still holds true today with some state-to-state differences based on the number of required physicians needed, plus the level of expertise of the physician, and the confirmatory tests recommended.²⁴⁵ Two states, New York and New Jersey since 1987 and 1991 respectively, have religious exclusions for brain death. This religious exclusion is based on the belief of the Orthodox Jews that only the cardio-respiratory criteria is suitable for the diagnosis of death.²⁴⁶

Brain death, as defined by the American Academy of Neurology in 2010, is when there is a loss of function in the entire brain to include the brain stem.²⁴⁷ This loss of function translates to the patient being unable to have motor responses as evidenced in movement to a stimulus; loss of brain stem reflexes; or loss of respiratory drive and effort when temperature and drugs have been normalized in the patient's system.²⁴⁸ This loss of function is irreversible and is seen in both adults and children, however, it is more difficult to diagnose in children. Because of this difficulty in diagnosing, there is often controversy surrounding pediatric brain death declaration. Following is a discussion on pediatric brain death, the futility disputes that may result with a case presentation on a patient who has been declared brain dead but medical treatment has continued.

4.V.B.1. Pediatric versus Adult

Prior to the development of mechanical ventilation, death occurred when breathing ceased and the heart stopped beating, as one closely followed the other. Confusion began when mechanical ventilation could keep the patient breathing and, therefore, the heart beating. This confusion was accelerated when the concept of brain death was discovered. Although there are not two types of death, cardio-respiratory and brain, but two forms of recognition, many lay

people, and some health care professionals, do not understand the abstract way of seeing brain death.²⁴⁹ It is especially difficult when the patient is warm and the monitors reflect a beating heart with a rising chest from the mechanical ventilator. Compounding the difficulty is to place this scenario into a pediatric intensive care unit where the level of stress is high and the acceptance of death is a difficult process.

Although brain death criteria was established in the 1960's, it did not get introduced in the care of children until 1987.²⁵⁰ Brain death cannot be diagnosed in children with the same certainty as adults and as a result, extra studies such as EEG's and cerebral flow studies may be indicated to assist in diagnosis, but they are no substitute for the clinical examination.²⁵¹ The major differences between diagnosing brain death in children versus adults is that two clinical examinations are required for children (37 weeks gestation to 30 days require 24 hours between examinations and 30 days to 18 years require 12 hours between examinations), whereas, adults only require one.²⁵² The two tests are to be performed by different physicians, both of whom are knowledgeable regarding brain death criteria, with both yielding consistent results.²⁵³

When brain death has been declared, the patient is considered dead and at that point in time, it becomes the date and time of death.²⁵⁴ This point definitely ends any futility disputes. There are two other conditions that do not meet brain death criteria but which often add to the futility debate with some clinicians considering them a state of death. These are the persistent vegetative state (PVS), also referred to as the permanent vegetative state, and the minimally conscious state.²⁵⁵

PVS is considered irreversible when it has been present for more than three months after a non-traumatic event and more than 12 months after a traumatic event.²⁵⁶ PVS has been described as wakefulness without awareness and must meet the following criteria: lack of

awareness of self or environment; no language or expression, except there may be random noises, groans or shouting; no behavioral responses to stimuli; presence of sleep/wake cycles; incontinence; and hypothalamic and brainstem function to allow survival.²⁵⁷ Although some have considered this diagnosis a “death diagnosis”, the majority of clinicians do not, but with an advance directive or surrogate decision maker, life sustaining treatment has been terminated in those in a PVS. It is not just a medical, but an ethical issue, when all treatments, to include nutrition and hydration, are discontinued in a person in PVS.²⁵⁸

The minimally conscious state is often thought to be PVS but these patients may follow commands, respond to simple questions and articulate verbal responses that are intelligent but often not accurate.²⁵⁹ This condition was established because PVS was often misdiagnosed in patients who have some degree of awareness. Ethical obligations for treatment include care that meets all the patients’ needs.

As has been stated, brain death declaration signifies that the patient is dead and continued treatment is inappropriate, futile, and considered an improper use of resources. When the Harvard Brain Death criteria was established, the finality of the diagnosis was clear. However, some states, some hospitals, and some clinicians have not held to the finality of this diagnosis allowing the children to remain “alive” in an irreversible coma after being declared dead. The following section addresses the ethics of continuing treatment for those who have been declared brain dead with a case example illustrating the dilemma.

4.V.B.2. Ethics of Continued Treatment Post Brain Death

Since the development of the brain death criteria, there has been misunderstanding regarding its significance and interpretation. Brain death declaration means the patient is completely dead with no chance of recovery.²⁶⁰ Furthermore, the patient has died and any

further discussion regarding continued or new treatment is inappropriate.²⁶¹ After the Harvard criteria for brain death laid out specific conditions for brain death, many state legislatures and court systems, beginning in 1970, acknowledged brain death as a legally recognized means of establishing death.²⁶² Following in 1981, the U.S. Uniform Determination of Death Act added the brain death definition to the legal definition of death.²⁶³ In 2010, the American Academy of Neurology updated their 1995 guidelines for determining brain death in adults in hopes of improving standardization across the states and between all hospitals.²⁶⁴ However, there is still inconsistencies among states which makes it confusing for the public, especially if a person can be declared brain dead in one hospital but treated as “alive” in another. Over time, despite concern and conversation, the concept of brain death has been accepted by the Catholic Church as long as there is sufficient “medical certainty” of the diagnosis to provide the necessary “moral certainty” on the moral ethical responsibilities.²⁶⁵

After brain death has been declared, treatment is withdrawn. This withdrawal most often either occurs immediately or may be delayed if organ donation is going to occur, or if a short delay is requested to allow additional family to arrive.²⁶⁶ Requesting a delay beyond these reasons is unreasonable and may be due to a lack of understanding regarding brain death, the inability to “let go”, a state of denial, a sense of hope that is not rational, or unresolved feelings of guilt.²⁶⁷ As soon as brain death is declared, this becomes the time of death and the patient is no longer a person but is now a corpse still entitled to the utmost respect and care.

Even with the decision of brain death, there are cases when the family have requested continued medical treatment for weeks to months, and in some cases, years. This creates an ethical dilemma for these reasons: 1) to continue to provide medical treatment to a corpse may compromise the professional integrity of the health care providers; 2) it confuses the family and

public regarding the death state of the patient promoting misunderstandings; 3) it contributes to moral distress in the health care providers; 4) it raises concerns related to justice, fairness, and equality in the treatment of others and those in the future; and 5) it can create a significant struggle if the family offers to personally fund the treatments of the deceased patient.²⁶⁸

One case of continued treatment after brain death that caught national attention is that of Jahi McMath. At the time, Jahi was a 13 year old who suffered a cardio-pulmonary arrest following surgery, on December 9, 2013, to remove her tonsils, adenoids and uvula with a sub-mucous resection of the post nasal cavity.²⁶⁹ She was declared brain dead on December 12, 2013 following adherence to the pediatric brain death criteria.²⁷⁰ This adherence included two physicians (a neurologists and a pediatric intensivist) who performed a complete neurologic examination, independently, coming to the same conclusion after the apnea test with an EEG and nuclear scan showing no brain activity.²⁷¹ The family did not agree that Jahi was dead and insisted that all treatments continue. On December 15th all treatment was to be withdrawn, but with legal representation, the family met with hospital administration who agreed to continue mechanical ventilation temporarily.²⁷² The case became a media frenzy with focus on racial disparities between the patient/family and hospital administration, in addition to family statements regarding disrespect from hospital administration. The hospital spokesperson was unable to clarify any statements due to the Health Insurance Portability and Accountability Act (HIPAA) regulations.²⁷³ Legal action followed in the county superior court with several requests made by the family. These requests included a restraining order against the hospital from removing Jahi from the ventilator, that the hospital perform a tracheostomy and place a feeding tube, and that a third physician be consulted for an additional neurological exam.²⁷⁴ The family had selected a physician from Ohio, who did not support brain death, to do the

neurological evaluation. The judge granted an injunction until December 30th to give the family time to find another care facility for Jahi, he agreed to another outside reviewer but chose a physician from Stanford, and he did not agree to the tracheostomy or the feeding tube placement.²⁷⁵ The physician from Stanford was in agreement that Jahi was brain dead and confirmed it with a brain flow study.²⁷⁶ The family took responsibility for Jahi's body on January 5, 2014 moving her to a care facility where a tracheostomy and feeding tube were placed.²⁷⁷ From California, the family took Jahi to New Jersey where she can stay indefinitely on life support under the protection of religious freedom.²⁷⁸ Today, she is 16 years old and remains on a mechanical ventilator with a feeding tube responding to simple verbal commands, per her family.²⁷⁹

There are more reported cases in the literature as well as the media and there are concerns that more will follow based on the reporting related to Jahi McMath. More education and communication are needed for the public, for those who report the medical news, and for health care providers so that accurate information is given to those who have a family member declared brain dead.²⁸⁰ Hopefully this education and communication will be helpful so an occurrence, such as Jahi McMath's does not repeat itself through unnecessary coverage and a public protest during this most difficult time.

Adult palliative care has proven to be effective in symptom management in life-limiting diseases, in preparing patients and families for the end-of-life, as well as in supporting families after death. Palliative care has had a slow start in the pediatric population, but offers patients the same positive qualities as seen with the adults. The next section addresses palliative care as an opportunity to enhance end-of-life care when further aggressive treatments are futile. The history and evolution of pediatric palliative care will be discussed as well as what is in store for

the future.

4.VI. Palliative Care for Children

The low number of children's deaths has lessened the urgency for the palliative care movement in the pediatric population resulting in a slower start than in the adult population.²⁸¹ However, palliative care's value and importance have been recognized along with its challenges and barriers. As a result there is a movement to increase the availability of palliative care and address the obstacles that are preventing its success.

4.VI.A. History and Evolution

Only 20% of the pediatric hospice programs have palliative programs which is not sufficient to meet the demands.²⁸² Adult palliative care programs can serve as a guide for pediatric palliative programs, however, pediatric programs are unique and distinct from the adult programs.²⁸³ Both adult and pediatric programs are composed of symptom management, advance care planning, psychosocial concerns and spirituality.²⁸⁴ However, pediatric palliative programs must consider the developmental level of the child, as well as the needs of the parents. Historically, the focus has been on the curative versus the palliative with childhood illnesses. For those palliative programs that have grown and flourished, the results are rewarding with involvement of all staff members and the support of palliative care physicians.²⁸⁵

4.VI.A.1. Definitions and Essential Components

Pediatric palliative care, as defined by the World Health Organization (WHO), is care that has as its goal the improvement of the quality of life for those children with a "life threatening" illness, as well as their families. This is done by preventing and relieving suffering through the management of pain and other symptoms whether physical, psychosocial or spiritual.²⁸⁶ Life

threatening illness refers to those illnesses or conditions which pose a great risk of death to the patient and the treatment may yield a cure, but may also fail.²⁸⁷ Life-limiting illnesses, or life-shortening illnesses, refers to those for which there is no hope for a cure and, although palliative care may be more appropriate for these diseases, it is difficult to sort out those which may offer some hope and those which may not.²⁸⁸

In the United States, it is estimated that approximately 55,000 pediatric deaths occur annually with more than 56% of them occurring in hospitals, mainly in pediatric and neonatal intensive care units.²⁸⁹ Worldwide it is estimated that 7 million children could benefit from pediatric palliative care annually.²⁹⁰ In the United States, those children who could benefit from palliative care range from 5000 to 8600 daily.²⁹¹

The hospice movement began in London in the late 1960's, moving to the United States in the 1970's, where palliative care was developed, with children being added in hospital based programs in the 1980's.²⁹² From there, free standing facilities for pediatric palliative care began to appear in the 2000's. The movement is still a slow progressing one because both parents and health care providers focus on an aggressive curative model until the very end.²⁹³ As a result, many children and families miss the many benefits a palliative care program can offer. To know when to introduce palliative care is a challenge because the difference between palliative and curative are substantial. Palliative care is still beneficial for the child who responds to treatment by going into remission, if only to provide assistance for future illness or reoccurrences.²⁹⁴

The basic components of any pediatric palliative care program includes the following five elements. First, is the physical element which addresses all the physical symptoms with pain, dyspnea, and fatigue being the majority of physical complaints that are addressed.²⁹⁵ A second element is psychosocial. This element is concerned with fears, coping skills, communication

styles, history of substance abuse, suicidality, and future resources for bereavement support.²⁹⁶ The third element is spiritual concerns. Addressing spiritual concerns includes beliefs, practices, rituals, role of prayer, and the meaning of life for both the child and the parents.²⁹⁷ The fourth element is advance care planning. Advance care planning addresses who will be the decision makers, what to expect when end-of-life approaches, and goals of care.²⁹⁸ The final element deals with practical concerns and can include such things as financial issues, needed equipment if the child is to go home, and care of siblings.²⁹⁹

Regardless of where or when palliative care is consulted, there are concerns that can present as ethical dilemmas if they are not addressed early with communication occurring among all health care providers and the family.

4.VI.A.2. Ethical Concerns

One of the ethical concerns that often occurs in the pediatric population, when it has been determined that further treatments would be futile, is whether artificial nutrition and hydration should continue. This issue can also provide a major decision point for children in a persistent vegetative state. Optimal nutrition is beneficial in many ways and especially in children who not only need it to maintain body systems but also to foster growth, especially in infancy and adolescence when there are normal accelerated growth spurts.³⁰⁰ Forgoing, or withdrawing, artificial nutrition and hydration is especially controversial in children because they cannot speak for themselves, in most cases, and because feeding is associated with the basic care of children, yet, nourishment alone is not considered curative.³⁰¹ Many of those who object to discontinuing artificial nutrition and hydration see it as ordinary treatment versus the extraordinary treatments that are such things as mechanical ventilation and kidney dialysis.³⁰²

It is estimated that in the United States, approximately 4,000 to 10,000 children are in a

persistent vegetative state (PVS) compared with 10,000 to 25,000 adults.³⁰³ In a study of residents caring for children in a PVS whose parents wanted all treatments withdrawn, to include artificial nutrition and hydration, the residents were in agreement 100% to withhold medication and CPR; 97% to withdraw mechanical ventilation; but only 45% agreed to withdrawing artificial nutrition and hydration. These differences are thought to be due to the fact that the residents lacked experience with these situations; that artificial nutrition and hydration is ethical and medically appropriate, in most cases, as food and fluids should always be provided to those who can partake of them; and health care providers are hesitant to “give up” on pediatric patients.³⁰⁴

Despite the ethical controversy that surrounds stopping artificial nutrition and hydration in children, there are three general categories where it may be ethically permissible. The first is with total loss of neurologic function as seen in PVS or some states of anencephaly. To meet criteria for neurological loss of function there needs to be clinical certainty that the condition is irreversible with no chance that the child will regain consciousness.³⁰⁵ The second is irreversible total failure of the intestines, which is rare, and is most often seen in premature infants.³⁰⁶ Nutrition via feeding tube may not be possible, but intravenous nutrition is available, although fraught with many complications. This avenue would have to be maximized before artificial nutrition and hydration would be ethically permitted to be withdrawn, unless the child was actively dying. The last category is imminent death which translates to death within days or weeks.³⁰⁷ In this instance, artificial nutrition and hydration may be prolonging the dying process.

Withholding artificial nutrition and hydration in the final moments or days of life is not going to make death happen any quicker. However, withholding nutrition on someone who is not actively dying, and is tolerating the feeding, is an ethical concern as the intent may be to

accelerate the death process.³⁰⁸ The Catholic view, expressed in the *Ethical and Religious Directives for Health Care Services*, states that “in principle” there is an obligation to provide artificial nutrition and hydration, however, it is optional if it cannot reasonably prolong life or is a burden for the patient.³⁰⁹ To determine whether artificial nutrition and hydration are prolonging life or being a burden, the physician, other health care providers, and the patient, or in the case of a child, the parents, are responsible for determining if they are appropriate/ordinary or inappropriate/extraordinary.

Another ethical concern relates to palliative sedation, sometimes referred to as terminal sedation, however, palliative better fits the reason the sedation is administered. Palliative sedation is the administration of sedation at the end-of-life that treats anxiety, pain and agitation that is unresponsive to routine treatment.³¹⁰ The same medications are used as those routinely given to treat these symptoms but are titrated to higher doses that may lead to unconsciousness. If done appropriately and accelerated just to the point of relieving distress, this form of symptom relief should not hasten death, although this may be a concern for those who do not understand the principles and process.³¹¹

It is becoming more apparent that palliative care has a valued place in the care of children at the end-of life. There are identified challenges and barriers plus further research is needed needed before pediatric palliative care can claim its place in comprehensive pediatric care.

4.VI.B. Future of Palliative Care for Children

Palliative care for children is beginning to make a difference, however, there is more work to be done. Too often palliative and hospice care are seen as one and the same. They are different in that palliative care is symptom management for serious illnesses and conditions that can include curative approaches, while hospice care focuses on the dying patient.³¹² Since the

majority of pediatric deaths occur in critical care units, at first it would seem that intensive care and palliative care would be at odds. This difference is because intensive care focuses on prolonging life through medical advances and technology while palliative care focuses on symptom management providing compassion and support.³¹³ Still, intensive care and palliative care together contribute to solid and profound integration that meets the needs of patients and families by providing advanced technology along with supportive care.³¹⁴

Despite the symbiotic relationship between intensive and palliative care, there are challenges and barriers that keep palliative care from providing the full benefit to the pediatric population,

4.VI.B.1. Challenges and Barriers

There continues to be major challenges that are facing pediatric palliative care today. The first is defining pediatric palliative care. The answers continue to be that pediatric palliative care is for all life threatening diseases, which cast a wide net that is believed to offer the greater benefit to the greatest number of children.³¹⁵ A second challenge is to identify the needs of pediatric palliative care. The number of pediatric deaths are relatively small making it difficult to aggregate adequate data to determine what the needs are.³¹⁶ As a result chaplains, social workers, and behavioral health referrals are used to meet the child's needs leaving a wide disparity in the care provided.³¹⁷

A third challenge relates to pediatric palliative care applying cultural and spiritual values into their program. Palliative care programs promote open honest discussions including children in discussions, whenever possible, which doesn't fit into all cultures.³¹⁸ Therefore, pediatric palliative care programs must be flexible enough to adjust to various cultures. Adult palliative care programs focus on total care to patients and their families which includes the spiritual

component, however, pediatric palliative care has been slow to include spirituality as part of their program.³¹⁹ The urgency for including spirituality as part of the holistic approach has been identified and is now being included in programs across the nation.³²⁰

A fourth challenge is to see that health care professionals are educated regarding end-of-life care, as well as palliative care, so that referrals can be made appropriately. Pediatric palliative care is a specialty that uses an interdisciplinary approach which includes nurses, physicians, social workers, psychologists, chaplains, therapists and volunteers.³²¹ The training of specialty physicians, such as cardiologists, intensivists, pulmonologists etc. has historically focused on technical skills with minimum education in end-of-life communication, especially when working with children.³²² Some of that has changed with the subspecialty of hospice and palliative medicine, plus pediatricians are now being trained regarding end-of-life care and the use of palliative care programs.³²³

A final challenge is to provide support to those providers who provide day-to-day care to the children who are dying and at the end-of-life. Caring for children and families at this juncture in life can be very rewarding, but it is also stressful for the caregivers who have to learn how to grieve before moving on to caring for the next patient.³²⁴

These challenges are demanding, especially when there are barriers that get in the way of addressing them. These barriers include: 1) the uncertainty of the diagnosis and prognosis which often delays advance care planning and palliative care consultation;³²⁵ 2) limited access to pediatric palliative programs, especially in rural areas, since they tend to be located in larger cities which does not allow equal access for all patients;³²⁶ 3) communication—either lacking or inadequate between and among health care professionals as well as with the family, which is a barrier for maximizing palliative care.³²⁷ Studies indicate that the families' interactions with

staff is an important as the communication with the medical team;³²⁸ and 4) the inappropriate continuation of futile treatments, even though there is no hope for improvement.³²⁹

With all the challenges and barriers, pediatric palliative care is a hope for the future. To manage this hope, more research is needed for it is through research that practice is changed.

4.VI.B.2. Future Research

The pediatric palliative care specialty has been modeled after the adult programs but, since the pediatric population is different from adults, there has been trial and error, observation, and common sense used to design the pediatric programs. What is now needed is clinical research that can provide data from which to form standards and principles for pediatric palliative programs in order to standardize the approach that is evidence based.³³⁰

Some of the major challenges to completing research on the pediatric population for palliative care are complex. First, the diversity of ages and diagnoses extends over the continuum, unlike the adult, which tends to be in the elderly and, in most cases, is confined to cancer and cardiac diagnoses.³³¹ Second, there are a small number of cases in the pediatric population making generalizability difficult but does not rule out research as qualitative studies can be done.³³² Third, there is an ethical vulnerability with children that leads to difficulty in enrolling research subjects. This can be due to health care provider's reluctance to refer, parents feeling obligated to enroll their children or are ill informed so they adamantly refuse to enroll, and the on-going issue with the uncertainty of the diagnosis or prognosis.³³³

Even though there are challenges, research has been accomplished which has led to findings that can be beneficial to those who provide pediatric palliative care. Some of the findings reveal that the children cover a wide variety of diagnoses and age ranges with the majority having some cognitive impairment plus dependence on multiple medications and technology.³³⁴ The time

frame for the children to receive palliative care is much longer than adults and can easily extend beyond a year with two out of three patients still being alive after a year.³³⁵ Neurologic impairment leads to major signs and symptoms with palliative care being consulted early in the diagnosis, which may be in the intensive care unit. Therefore, there is a need for pediatric palliative care team members to have a familiarity and comfort with the critical care environment.³³⁶

The Institute of Medicine (IOM) as well as the National Institute of Health (NIH) have both promoted palliative care for the pediatric and adult populations. The NIH and National Institute of Nursing Research (NINR) launched a campaign in 2014 called *Palliative Care: Conversations Matter* to focus on bringing this care to patients, families, and health care providers.³³⁷ Their promotion has provided a website with brochures videos and information on the details of palliative care. This continued promotion, plus the feedback from health care providers and parents, are resulting in more pediatric palliative care programs being developed to serve this special population.

4.VII. Conclusion

Dying is a natural process of life, but when it happens in childhood it seems unnatural and, although the numbers are small, it can be devastating. With the death of a child, the hopes and dreams for the future and what might have been dies as well. Children who used to die from congenital anomalies or childhood diseases are now surviving due to medical advances. However, there are sufficient injured and chronically ill children in the pediatric critical care units across the nation that medical futility is an issue.

Because the death of a child is so traumatic, not only for the family, but also for the health care providers, approaching the topic of futile treatment is difficult and often avoided. The topic is not only avoided, but the curative approach is also the focus up to the end-of-life. Even so, if the terminology of “futility” is avoided in discussions, there are still treatments being given that are not providing benefit to children or adding quality of life, and may be prolonging suffering.

Those who care for children face a big challenge because there are many developmental changes and challenges between the ages of 1 to 18. This challenge is compounded when the child is critically ill and at the end-of-life. The health care team must develop relationships with the child, as well as the family, as they work collaboratively to determine the best treatment for the child. A treatment that respects the family structure, as well as function, taking into mind the many needs of the child.

There are ethical concerns for children who are critically ill. There is an obligation for health care providers to see that the child is as comfortable as possible with pain being managed, as well as other physical symptoms. There is also a pressing need to address the emotional needs of the child as well as the family. During the treatment of the child, there is also a role that requires the health care provider to assure that the parents are keeping the child’s best interest, first and foremost, while not extending the dying process or prolonging suffering.

Pediatric palliative care offers hope for the future as those skilled in its principles and processes work closely with the critical care team. This partnership provides technology, works on symptom management, as well as providing support and comfort at this difficult time. Palliative care is there not only through the illness at the end-of-life, but also through grief support for the family after the child’s death. Nevertheless, despite what palliative care can do, a call to action is needed to assure more programs are available with the needed research to

validate best practices. Nothing will relieve all suffering, but there has never been an imperative greater for a cause more worthy.

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Chapter 5: Futility and Adults

5.1. Introduction

It is a relatively simple task to know when someone needs to receive critical care. To help determine when that time has come, there are various types of admission criteria for critical care units that attempt to objectify a patient's deteriorating condition via physiological and clinical criteria.¹ It is a more difficult task to know who to exclude from admission to critical care. It is also more difficult to know when it is time to discontinue the treatments provided by these specialized areas, especially when the treatments no longer provide a benefit to the patient or are seen to be medically futile.

It is common in all critical care units, such as neonatal, pediatric and adult, to withhold or withdraw life-sustaining treatment when they are no longer providing a benefit to the patient, leading to most of the deaths in critical care.² In most instances, this process is uncomplicated as the patient/families and providers are in agreement. However, there are times when the issue of medical futility creates conflict between the patient/families and providers leading to what can be a struggle for the patient prolonging the dying process.

When referring to medical futility, the population that is most often the focus is adults. Of the adult population, it is usually the elderly that are more apt to receive futile treatment at the end-of-life. In the United States, those over 65 years of age account for over 50% of critical care patients, however, they comprise less than 15% of the overall population, although this is growing at a rapid rate.³ These elderly have a longer length of stay, higher mortality rate, and higher cost of care than those younger, with the 70-79 year olds having the highest admission rate.⁴ Chapter 5 examines futility and the adult population. The first part of the chapter

addresses a theoretical framework based on competency versus capacity and the role autonomy plays, not only for the patient, but also for the family, health care providers, and community. The cost of end-of-life care is also examined as a problem that cannot be ignored. The second part of Chapter 5 describes evidence based practices for the adult by addressing advance directives plus policies and legislation as potential solutions for medical futility. Overtreatment, contradictions in treatment, and the nuances of withholding and withdrawing treatment with the presentation of palliative care as a viable option will also be addressed.

5.II. Theoretical Framework

The theoretical framework that embodies medical futility in adults, which ends up focusing on the elderly, is the ability to make independent and fully informed decisions about the treatments they receive or do not receive. As the population has aged, and continues to do so, the presence of “cognitive impairment” has also increased making the assessment of decision making capacity more vital.⁵ This decision making capacity, as well as competence of these patients are complex concepts. Not only are there decisions to be made regarding routine subjects, such as driving, living alone, and finances, but also health care decisions become more prevalent and critical with some facing end-of-life choices.⁶ This decision making ability puts the focus on the principle of autonomy. To fully employ the principle of autonomy, the conditions of competence or capacity must be present.

This section examines competency and capacity from their definitions to considerations with a look at various approaches to end-of-life decisions. Substituted judgment versus best interest will be discussed as ways for surrogate decision makers to approach end-of-life decisions when the patient lacks decision making capacity.

5.II.A. Competency versus Capacity

Competence is defined as being able to complete a task or duty.⁷ Only judges, or the court, can determine whether a person is competent or incompetent. Whereas, the term capacity is used in the medical arena which refers to whether the person has the capacity to understand the information and make appropriate decisions.⁸ The terms competence and capacity, and their opposites “incompetence” and “lack of decision making capacity”, are often used interchangeably, but they were first described as being different. “Incompetence” is a term used by the court system when referring to a person who lacks competence, whereas, “lack of decision making capacity” is a term used by medical providers to describe a person who lacks the ability to make health care decisions.⁹

States vary as to their definitions of decision making capacity but the definitions usually involve the following four elements. The patients need to: 1) understand the information provided regarding the treatment; 2) acknowledge the current medical situation to include their own personal values; 3) utilize logical rationale in making a decision; and 4) communicate their final decision.¹⁰ In turn, competence has been described as patients being able to 1) communicate a choice; 2) understand the information and issue; 3) manipulate the information; and 4) appreciate the information.¹¹ During the 1990’s, many states found that the terminology for competence and decision making capacity was so similar that it was difficult to differentiate the two, therefore, many states now use the capacity terminology for both competence and capacity decisions.¹²

In determining decision making capacity of patients in critical care, first it is vital that the providers separate their beliefs, values, and opinions from those of the patients.¹³ Any physician can assess for decisional capacity, however, it is often delegated to a psychiatrist or psychologist

as they have had more experience with this assessment.¹⁴ The advantage of primary physicians doing the assessment is that they know the patient better and can therefore, see small changes that a physician who is seeing the patient for the first time might miss.¹⁵ Just as which physician is best to assess the decisional capacity of the patient, there are other considerations related to capacity. Following is a discussion of these considerations.

5.II.A.1. Considerations Related to Capacity

The process to determine decisional capacity begins with a conversation with a patient, while observing the patient's behavior, then progresses to dialogue with family, friends, and staff.¹⁶ Other means include standardized assessment tools. Several of these tools have shown a close correlation between expert assessment and scores on the tools.¹⁷ The standardized tools are easy to use and can help physicians, when psychiatrists or psychologists are not available, to assist in patient assessment for capacity.¹⁸

So many decisions hinge on the decisional capacity of the patient making it an ethical obligation for providers to, not only understand the concept, but also to advocate for the rights of the patient. There are several considerations that are paramount in the decisional capacity process. First, it is possible for a patient to be legally incompetent while still having the decisional capacity to make certain health care decisions.¹⁹ If such a situation would be present, the provider needs to seek legal counsel or request an ethics consult to assist in working through the right thing for the patient.

A second consideration focuses on the often thought premise that patients have decisional capacity as long as they agree to the medical advice or treatment and, conversely, that their decisional capacity is questionable when they go against medical advice, or refuse the treatment.²⁰ It is more about the process the patient used to arrive at the decision and not what

the final decision is that the patient made. It is not realistic to assess every patient for capacity, but when the risks of the medical treatment are high, compared to the benefits, there should be consideration given to the patient's capacity.²¹ If there are any questions, then a formal determination of capacity is needed.

A third consideration is believing that the decisional capacity is an "all or nothing" situation.²² Patients may be able to make some health care decision but not others. An example is that a patient may be able to decide regarding receiving antibiotic therapy for a cellulitis but not have the ability to decide regarding a complicated neurosurgical procedure which has many risks involved in having the procedure, as well as risks to not having the procedure.²³ In line with the "all or nothing" premise is the belief that once determined to lack decisional capacity that this is a permanent state.²⁴ Decisional capacity can fluctuate based on the patient's condition, time of day, medications received, and the presence of delirium.²⁵

A final consideration for decisional capacity is in the realm of mental illness. A mental health diagnosis, such as depression or schizophrenia, does not automatically qualify as having a lack of decisional capacity.²⁶ Even if there are thought disturbances or an involuntary commitment to a mental institution, each case must be considered separately for decisional capacity.²⁷ The two leading causes for a lack of decisional capacity are delirium and dementia, which are considered psychiatric disorders, even though they may be a result of a physiological or medical etiology.²⁸

For patients who are able to communicate, it is easy to determine decisional capacity. For those in the critical care unit it is more difficult. A discussion of approaches to use in determining decisional capacity in critical care follows.

5.II.A.2. Approaches to Determining Decisional Capacity

Determining decisional capacity in critically ill patients can be a daunting task. One can appear to have the capacity to make simple decisions, yet, not have the capacity to make life and death decisions or those that involve life-sustaining treatment.²⁹ The following concerns illustrate only part of the reasons why it is challenging to assess capacity in the critical care unit. First, there is often a mechanical ventilator preventing verbal communication, so in order to communicate, patients must be able to write, or be able to respond to yes or no questions by nodding their head, or point to letter boards to spell responses.³⁰ If the ventilator is connected to a tracheostomy tube or a tube inserted through the nose, instead of a tube in the mouth, patients can form words with their mouth provided the person communicating with the patient can “lip read”. Studies on patients who are mechanically ventilated reveal that approximately 50% can recall the ventilated experience, and that is in patients who have decisional capacity, leading to questions regarding the accuracy of assessing decisional capacity in ventilated patients.³¹

A second concern that affects the approach to determining decisional capacity in the critical care unit is the influence of medications, especially sedatives. Patients who are mechanically ventilated are often receiving continuous intravenous sedation to decrease anxiety, to prevent injuries to self, to help assure a level of comfort, and to improve the efficacy of the ventilator.³² Although there are benefits to sedating the ventilated patient, there are also repercussions which can have untoward effects on the patient. These include longer critical care lengths of stay, longer duration of mechanical ventilation, increased complications associated with the ventilator, and cognitive deficiencies, such as delirium or post-traumatic stress disorder.³³ The cognitive deficiencies from the sedation can make it impossible to accurately assess decisional capacity. As a result of these untoward effects of sedation for those who are mechanically ventilated, there

is a trend to use lighter sedation. Studies indicate that the lighter sedation may be helpful to the staff as the patient is more alert and cooperative, however, the patient's thinking is often unclear and can lead to additional stress and sleep deprivation which does not benefit the patient.³⁴

An approach that has been presented for modulating decisional capacity is a sliding scale strategy which was first endorsed by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research.³⁵ With the sliding scale strategy, the issue of capacity needs greater evidence as the risk involved with the decision to be made becomes greater.³⁶

A way to utilize the sliding scale strategy is from a three level approach. The first level considers decisions that are not dangerous as long as the patient exhibits "awareness" of the medical situation.³⁷ These decisions usually have limited alternatives and are of high benefit/low risk, such as agreeing to a blood transfusion.³⁸ The second level involves an increased level of understanding of the medical situation and its proposed treatment to include no treatment at all.³⁹ To refuse treatment involves a higher level of capacity, such as a patient newly diagnosed with lymphoma deciding to not receive chemotherapy because of the potential side effects which are offensive and frightening.⁴⁰ The third level is the most rigorous and challenging as it involves an appreciation, as well as understanding, of the medical condition and its treatment.⁴¹ This level is where dangerous decisions are made, such as amputation of a limb.

The sliding scale approach implies that an individual's capacity is contingent on the significance or outcome of the decision.⁴² There are those who have objected to the sliding scale in deciding decisional capacity. This objection is based on the belief that one's capacity does not vary with risk as stated in the sliding scale strategy.⁴³ Instead one's decisional capacity increases as the difficulty of the decision increases not as the "risk" of the outcome increases.⁴⁴

There is nothing to support that more decisional capacity is needed to make risky decisions. Other objections to the sliding scale include the premise that it supports paternalistic behavior by providers. This paternalistic behavior by providers is seen to limit the patients' discretion for self-choice, or autonomy.⁴⁵ Proponents of the sliding scale counter the objections with the belief that a sliding scale approach protects patient autonomy.⁴⁶ When comparing injury versus autonomy, if the error is on the side of autonomy or capacity, serious harm may occur, whereas, if the error is on the avoidance of injury and incapacity there may be a violation of autonomy.⁴⁷

Approaching patients at the end-of-life, or those who are receiving medically inappropriate treatments, determining decisional capacity, is the right thing to do. However, the fact remains that the majority of patients in critical care lack decisional capacity as evidenced in a study of 4250 critically ill patients where only 5% were considered to have capacity.⁴⁸ To further complicate the critical care environment, the wishes of the patient are only known in approximately 20% of cases which comes from the family.⁴⁹ It is not known whether the family speaks from a direct conversation with the patient or whether it is based on a guess or presumption.⁵⁰ Nevertheless, the providers are left to depend on the family, or a designated surrogate decision maker, to assist with health care decisions in critical care at the end-of-life. Making decisions regarding end-of-life treatment for patients who no longer have decisional capacity is one of the most ethically demanding processes.⁵¹ Following is a discussion on surrogate decision making, its standards, to include substituted judgment plus the best interests standard, as well as potential problems with surrogate decision makers.

5.II.B Surrogate Decision Making

The majority of deaths that occur in critical care units, regardless of whether that is in the neonatal, pediatric, or adult units, are due to a "conscious" decision to discontinue life-sustaining

treatment.⁵² At this point in the patient's care, patients most often cannot make decisions either due to the state of their illness or the fact that they lack decisional capacity. Therefore, a surrogate decision maker, in collaboration with the providers, is left to make these end-of-life choices. A surrogate decision maker is most often the next of kin, unless specifically stated in an advance directive. Many states have enacted legislation which does hierarchical ranking of family members based on authority position in the family, such as first the spouse, then parents, then children, then siblings, etc.⁵³ Other states, such as Colorado and Hawaii, have a proxy law where all "interested parties" meet and select a surrogate decision maker or "medical proxy".⁵⁴ If an agreement cannot be reached, then one of the group goes to court and begins the guardianship process.⁵⁵

It is estimated that surrogates make approximately 75% of medical decisions for those in critical care, which only adds to the stress of being a friend or family member of a loved one at the end-of-life.⁵⁶ The surrogate role is one that few are prepared for, likewise, providers are often not prepared to effectively work with surrogates.⁵⁷ Therefore, it becomes a learning experience on the part of both players—surrogates and providers.

In the process of decision making, there are standards that help guide the way, even though these standards are not always followed. Instead other bases are used for the surrogate decision making. Following is a discussion of these methods.

5.II.B.1. Standards for Decision Making

The first standard for surrogate decision making is substituted judgment. Substituted judgment is when a surrogate makes a decision based on the known preferences of the patient.⁵⁸ In other words, this is the decision patients would make if they were competent.⁵⁹ These preferences have usually been explicitly stated to the surrogate or the surrogate believes, based

on statements made, that this would be the patient's preference. 60

Substituted judgment is meant to be an extension of the patient's autonomy and the extent to which this occurs varies.⁶¹ Research has shown that this standard is weak, but it still remains the preferred approach to decision making for the incompetent patient, or for one lacking decisional capacity, because in most cases it supports patient autonomy.⁶² The weakness of the standard is exhibited in three ways. First, there is evidence that one's end-of-life preferences change over time and that these changes are more apt to be less if written in an advance directive.⁶³ Second, in a side-by-side study where surrogates were asked to state expected preferences of the patient and patients were asked to state their preferences, surrogates were accurate approximately 68% of the time.⁶⁴ Efforts to increase conversations and utilize educational material were of minimal benefit. Finally, research with patients has found that they do not want specific instructions to be followed if they cannot contribute to the decisions, but instead, they want input from all family members, as well as providers, in making life-sustaining decisions.⁶⁵

A second standard that is used when a surrogate does not know the patient's preferences or values is the best interests standard. This is the standard used by parents for their children who are unable to let their wishes be known. It is also used when adults are incapacitated all their life so preferences are never known. The best interests standard involves making choices or decisions based on what a "reasonable person" in a similar situation would choose.⁶⁶ Family members are usually in the best position to know values, interests, and religious views of the patient since this family relationship is based on love and intimacy not often found in other relationships.⁶⁷ However, not all family relationships are loving and caring where each wills the best for the other. There may be few family members and those who are located may have had

no meaningful interactions with the patient so there is little reason to believe they will know the patient's values. There are also many dysfunctional families so keeping the best interest of the patient in mind might not be possible.⁶⁸

The challenge of the best interests standard is to be able to assess the surrogate's perception of the patient's best interest. The surrogate does not have the same discretion in making decisions as the competent autonomous patient. The decision has to be in line with what a reasonable person would decide in the same situation otherwise the decision is rejected.⁶⁹

Besides the substituted judgment standard and the best interests standard, there are other surrogate basis for decision making. The first is based on conversations between surrogates and patients, although only 66% end up using these conversations in the decision making process and, when they do, most of it is in the standard of substituted judgment.⁷⁰ A second basis for the surrogate to use in making decisions is to rely on written documents which are most often advance directives. The evidence shows that because wishes are put in writing, the families often do not take the next step and have follow up conversations about their written wishes so questions can be asked before the directives are invoked.⁷¹ A third basis for the surrogate to use in making decisions is based on their own intuition, optimism, faith belief, and values.⁷² Even when surrogates try to separate out their own personal views, it can be difficult, especially if they are stressed and fatigued.

As surrogate decision making is commonplace in critical care, it is not without its special concerns and potential problems. Following is a discussion on some of these potential problems regarding surrogate decision making in critical care.

5.II.B.2. Potential Problems

One of the major concerns related to decision making at the end-of-life in critical care is

when the patient lacks both decision making capacity and a surrogate decision maker. It is not unusual for those without decisional capacity or a surrogate decision maker to also not have an advance directive. It has been shown that one in 20 deaths in critical care have none of the three—decisional capacity, surrogate decision maker, or advance directives.⁷³ The majority of states have no laws that provide guidance when these situations exist. Those states that do have laws, some give authority to providers to make decisions regarding life-sustaining treatment, some stipulate the appointment of a legal guardian to make the decisions, and others utilize a multi-disciplinary committee from within the institution.⁷⁴ When there is not a surrogate to speak on behalf of the patient, it has been found that decisions are less open and more apt to express judgments regarding the patient's social and individual value.⁷⁵ The volume of these patients who lack decisional capacity, surrogates, and advance directives range from 6% to 24% of the critical care volume.⁷⁶ The majority of these patients are older males, who are mentally ill or homeless, having lost contact with their families and are admitted for respiratory failure.⁷⁷

When the patient is incapacitated without a surrogate decision maker, studies that have been done illustrate several key findings. These include; 1) as many as one in six incapacitated patients in critical care do not have a surrogate decision maker for their entire stay; 2) the length of stay for these patients is longer than those with a surrogate, possibly due to the fact that their severity of illness is greater and time is taken to locate family or friends to assist with decision making; and 3) most often the primary physician for the patient collaborated with other physicians in making end-of-life decisions, versus going through the court system or contacting the ethics committee, despite state laws dictating this as action to be taken.⁷⁸

A second potential problem when working with surrogates is clarifying the identity of the surrogate. If patients have not put into writing who they wish to make their health care

decisions, then the institution is bound to comply with state laws whether that be by hierarchal rank or proxy. The key is to communicate with all family members to be sure they understand who the designated surrogate will be, to affirm that the surrogate has decisional capacity, and to address what decisions the surrogate will be making.⁷⁹ This is not a one-time communication but involves frequent communication that is a dialogue with all family members allowing for questions and answers.

A third concern when working with a surrogate decision maker is finding one who is uninvolved. This surrogate may not have close ties with the patient or be aware of values and preferences which may require legal counsel or an ethics consult.⁸⁰ Even if the surrogate does not know the patient well enough to utilize the substituted judgment standard, the best interests standard can still be applied.

A final concern relates to when there are multiple potential surrogates. This situation may arise when the designated surrogate is unwilling or incapacitated, either physically or mentally to take on the responsibility.⁸¹ It can also be a major issue when there is conflict in the family. This conflict could be evidenced when the patient has not begun divorce proceedings but is in another close relationship and the married partner insists on making all decisions. In such cases, judicial statues may help the resolution, however, it leads to a delay in making any immediate health care decisions.

Being competent or having capacity is the pivotal framework for futility in the adult and they support the basic principle of autonomy. When considering capacity and autonomy at the end-of-life, a balance is needed between self-determination and the avoidance of injury or harm.

The next section examines end-of-life care with a focus on the ethics goals, especially autonomy. The cost problem identified with end-of-life care will also be explored.

5.III. End-of-Life Care

An integral part of the “human condition”, that is never more prominent than at the end-of-life, is the innate inclination for survival.⁸² With this inclination for survival, death is not an option to the point that patients or surrogates will often choose pain and suffering in hopes of “beating the odds” by trying one more treatment or procedure versus palliative care.⁸³ Having a surgical procedure at the end-of-life has little effect on prolonging life or adding to the quality of that life with over 25% of Medicare beneficiaries reporting a surgical procedure within the last three months of life.⁸⁴ Yet, many providers continue to discuss all possible treatments for any given condition whether they are in the best interest of a particular patient or whether the provider believes they are futile or medically inappropriate.⁸⁵ This is all done to honor patient respect and autonomy illustrating a more patient-driven approach than a patient-centered one. Patient-centered would include increased communication between patient/family and providers to choose the best option for the goals of the patient.⁸⁶

Respect for autonomy is at the core of bioethics and is identified as one of the basic ethical principles.⁸⁷ This principle emerged in part due to the atrocities performed in Nazi concentration camps that led to the Nuremberg Code.⁸⁸ Furthermore, the ethical debate that surrounded both Karen Quinlan (1970’s) and Nancy Cruzan (1980’s) were key in establishing autonomy as the primary ethical principle in medicine.⁸⁹

Following is a discussion on the ethics goals with particular attention to autonomy and the role it plays for the patient, family, providers and community. An example will be presented using the case of Sam Golubchuk to illustrate the principle of autonomy.

5.III.A. Ethics Goals

The ethics goals that are the focus at the end-of-life are four fold. First is to relieve

suffering. At the end-of-life the ethical benchmarks are not only to do no harm, but to also relieve suffering.⁹⁰ This suffering is not always just in the physical sense, such as pain and other somatic symptoms. Findings indicate that one in four end-of-life cancer patients suffer “unbearably” with half of these experiencing psychological, social, and existential suffering.⁹¹ Although palliative care providers are prepared to address all types of suffering, other providers are not, and can benefit from additional education on this topic.⁹²

The second ethics goal is to assist the patient to experience living while in the process of dying. This means providing a peaceful environment, which can be a challenge in the critical care arena, and providing an opportunity to have the remaining moments be as meaningful as possible.⁹³

The third ethics goal is to respect the dignity of the patient by supplying the patient’s sense of identity to the very end-of-life.⁹⁴ There is a correlation with loss of dignity and feeling of being a burden to others.⁹⁵ With further clarification, patients conceive dignity as a sense of autonomy or freedom that tends to diminish as the end-of-life approaches.⁹⁶ Therefore, a focus needs to be on maintaining individual identity as the end-of-life nears.

The fourth and final ethics goal is the respect for persons which supports self-determination or autonomy. Terminally ill patients have identified having a sense of control at the end-of-life as a major contributor to their quality of life.⁹⁷ The patients in critical care may lack the ability to communicate their needs, but the goal should be to honor them based on advance directives or feedback from surrogates.

Autonomy has long played a part for the patient, however, there is a role that autonomy plays for the family, provider and community. Following is further discussion on how autonomy plays a role for the patient, family, provider, and community.

5.III.A.1. Autonomy: Patient, Family, and Provider

Autonomy is one of the four basic ethical principles. It is defined and explained in a far-reaching manner. Autonomy is often likened to integrity, independence, free will and individuality.⁹⁸ It is also associated with the qualities of self-assertion, awareness of one's own interests, and freedom from responsibility.⁹⁹ Autonomy can be referred to as actions, beliefs, rules, principles, and thoughts with the one common element being that autonomy is a worthwhile value to have.¹⁰⁰

Starting in the 1970's, the renewed awareness of both the Nazi medical experiments during World War II and the Tuskegee Syphilis Study, plus the civil rights movement, as well as the "second wave-feminism, led to a shift away from paternalism.¹⁰¹ This shift was to a model of autonomy for the patient where self-determination was the rule that providers were to follow.¹⁰² Not unlike futility, autonomy has also been difficult to define in a simple standard definition, but autonomy implies both the patients "right" to make their own choices, as well as others "obligation" to let them make these choices.¹⁰³

A patient who has been found to be legally competent, or to have decisional capacity to make health care decisions, may make the decision to forgo certain or all treatments.¹⁰⁴ There are certain exceptions where the patients may not refuse treatment as doing so may harm others, such as refusing treatment for certain infectious diseases. This is based on the Harm Principle where an individual's freedom can be restricted if it may harm others.¹⁰⁵ There are also religious practices that may serve to guide the patients' autonomous decisions such as donating organs, which has limitations in some religions.¹⁰⁶

Although an autonomous patient may refuse treatment, this does not equate to requesting or demanding treatment.¹⁰⁷ This scenario usually presents itself at or near the end-of-life when

further treatment is deemed medically inappropriate, or futile, by the providers and is being requested by the family or surrogate.¹⁰⁸

Beginning in the 1990's, the shift from the individual focused on more of a "relational autonomy" which emphasized the family's voice into decisions.¹⁰⁹ At the end-of-life, the family can feel a great burden as they become the decision makers. This burden is related to time spent at the bedside, energy depleted, stress from time away from family, and financial strain from time away from the job.¹¹⁰ The rights and responsibilities of family members is not always clear and it can become more confusing and stressful as patients are no longer able to speak for themselves. This confusion is compounded when there are cultural, religious, and socioeconomic factors.¹¹¹ For family members who value their autonomy, it is important for them to maintain their self-determination to manage their own lives during the time when they have a patient in critical care near the end-of-life.

The autonomy of providers most often is referring to the physician. This is usually involved when the family or surrogate demands treatment that the physicians object to because of the belief that it would not provide medical benefit.¹¹² The belief is that the original initiation of medical futility as a reason to not provide certain treatments was a resistance to patient autonomy.¹¹³ This led to a negative connotation for physician autonomy often to be equated with paternalism. However, they are different in that paternalism does not always consider the patient's best interest and physician autonomy tends to do so.¹¹⁴

The patient-physician relationship is one of "mutual obligation" so that the context of one must be balanced with the context of the other.¹¹⁵ The autonomy of the physician can be considered from three points of view: 1) as an individual; 2) as a physician who is the clinician; and 3) as a member of a profession.¹¹⁶ The physician is unable to separate the individual from

the physician with all the personal values, beliefs and religious views, however, it is the physicians' responsibility to be aware of these personal conflicts and make a conscious effort to not impose them on the patient.¹¹⁷

The physician autonomy also comes with the expectations of expert knowledge to perform the duties of the job, which the public expects.¹¹⁸ The physician must be allowed to use this knowledge, expertise, and judgment in making health care decisions in collaboration with patients/families. This does not mean physicians can be made to do anything that is beyond their personal values. It does mean that they need to inform the patient/family of choices that are within medical standards, to include transfer to another physician or facility, if the physician does not agree with the choices.¹¹⁹

The autonomy of the patient/family is often considered while the autonomy of the provider is often overlooked, however, there is another player in the form of the community which plays a role in the futility debate. Following is a discussion of the autonomy of the community followed by a case example that illustrates the role autonomy can play in concert with decisional capacity and medically inappropriate treatment.

5.III.A.2. Autonomy: Community with Case Example

Community autonomy cannot be separated from personal autonomy as any intervention that is done for the benefit of the community needs to be weighed against the effect on personal autonomy.¹²⁰ There are times when the community needs to take on a paternalistic role when there is reason to believe that an individual's autonomy is being threatened, such as from a public health danger.¹²¹ Still there is more that can be done in the community-personal autonomy relationship which is likely to change based on two causes. First, the continuing increase in respect for individual autonomy will impact the community by increasing their

awareness of how community factors impact personal health.¹²² Second, is the increased presence of communities in health care delivery, moving from an individual-centered view to a community-centered view of health, which benefits the greater good.¹²³

For patients in critical care who are at the end-of-life receiving medical treatments, there is an on-going debate and concern regarding the expanded use of resources that are needed to provide and pay for this care. An example of when the use of resources places the personal autonomy of patients and families in conflict with the community autonomy, is when the resources are supported via pressure for taxes for public insurers.¹²⁴ The end-of-life medically inappropriate treatment, not only affects the economic factor, but it also limits the availability of precious critical care beds to those who might medically benefit from them.

A case that illustrates the autonomy conflict between patient autonomy, family autonomy, and provider autonomy is the case of Sam Golubchuk (Mr. G.). Mr. G. was an 84 year old Orthodox Jew, from Manitoba Canada, who in January 2008 suffered a severe brain injury after a fall.¹²⁵ It was agreed by all caregivers that he was not brain dead nor was he in a persistent vegetative state, with speculation that he was in a minimal conscious state (MCS).¹²⁶ Those in a MCS indicate no verbal or non-verbal communication, although it is difficult to differentiate from a persistent vegetative state.¹²⁷

With the passage of a month, in February 2008, after being mechanically ventilated and fed through a gastrostomy tube, Mr. G's health continued to deteriorate and the providers wanted to withdraw life-sustaining treatment.¹²⁸ The patient's daughter and son were in opposition to this action, which they believed the patient would also be opposed to, as this was in conflict to Orthodox Jewish law.¹²⁹ As this debate was transpiring, the College of Physicians and Surgeons of Manitoba issued a guideline related to life-sustaining treatment. This guideline stated that the

minimum goal of life-sustaining treatment was for the patient to maintain or recover a degree of function so as to be aware of self and the environment in order to participate in life.¹³⁰ If the physician determines this degree of participation is not possible for the patient, then life-sustaining treatment may be withdrawn without family approval or consent.¹³¹

As steps were being taken to withdraw life sustaining treatment, the family took the case through the court system and they obtained a legal ruling against discontinuing the life-sustaining treatment.¹³² The patient died before the trial date of natural causes.

There were several key issues in this case. First, it is an insult to the principle of patient autonomy as evidenced by the guidelines from the College of Physicians and Surgeons.¹³³ The second key issue is that patient autonomy is limited in that some requests can and should be overruled based on the circumstances.¹³⁴ The third issue is that the physician's autonomy and professional autonomy were challenged as the primary physician believed further treatment was "unethical".¹³⁵ The primary physician, who had decided to withdraw life-sustaining treatment, resigned his privileges from the hospital instead of complying with the court order to treat the patient.¹³⁶ In his resignation letter, he made reference to the large skin ulcers on Mr. G. as "torture" stating that surgical intervention would be needed to "hack" away his "infected flesh" and to inflict this "assault" was not only "grotesque" but an "abomination"---"I can't do it".¹³⁷ Other providers were, likewise, resigning and refusing to care for the patient. The fourth issue is that in today's society there is a strong belief that as long as the patient is paying for it (or third party payer), then the physician should provide it, and the decision is the patient's.¹³⁸ The fifth and final issue reflects back on autonomy and how patient/family autonomy is not an absolute as providers need the authority to exert their professional autonomy by refusing to provide futile treatment.¹³⁹

Whenever the end-of-life care, with the treatments that go with it, are discussed, the barriers to end-of-life care, including the cost problem, eventually become part of the discussion. At no time does this discussion become more pointed and controversial than when medically futile treatments are added to the equation. Following is a presentation of the barriers to optimum end-of-life care including statistics to describe the cost problem and approaches that can be useful to minimize these barriers.

5.III.B. Barriers to End-of-Life Care

There are four major barriers that can get in the way of making end-of-life care an optimal experience. First, there are barriers at the patient/family level. These include the inability of patient/family to accept death as a normal process, the patient's attitude toward their care which include such things as pain management, and insufficient or lack of health insurance.¹⁴⁰

The second barrier pertains to those that come via the various providers. Although this most often relates to physicians, it can be nurses, social workers, and the various therapies such as rehab or respiratory. The biggest barrier comes back to communication between patient and providers as well as between and among providers.¹⁴¹ This communication involves having honest critical conversations with families regarding prognosis and when it is time to involve a comfort versus cure approach.¹⁴²

The third barrier relates to the health care system. Too often end-of-life care is fragmented and uncoordinated with questionable coverage by third party payers.¹⁴³ In addition, rules, regulations, and cost containment efforts put additional pressure on all health care providers.

The fourth and final barrier is a result of society, especially related to attitudes related to death and dying. The media has often portrayed death, especially cancer death, as frightening and painful leading to the movement toward physician assisted death as the end-of-life nears.¹⁴⁴

The utilization of critical care beds, with the associated high costs, has continued to escalate over the years. If health care is to be affordable providing the resources to patients as needed, both consumers and providers need to realize that cost control is a fact for end-of-life discussions. Following is a discussion on the cost problem with suggested approaches.

5.III.B.1. The Nature of the Cost Problem

Overall, health care costs continue to climb with the most current data reported in 2015 for 2014 indicating an increase of 5.3% from 2013.¹⁴⁵ This increase which equates to \$3.0 trillion, or \$9525/per person, yielding a 17.5% of the Gross Domestic Product being spent on health care in 2014, an increase from 17.3% in 2013.¹⁴⁶ Critical care has, historically, been seen as a high cost area that gets looked at when cost containment is discussed, or ways of cutting costs are needed. Although room rates vary across the nation, following are examples from the Cleveland Medical Center for “charges” per day for the following rooms as of January 1, 2016: standard semi private room \$2120; adult intensive care \$6160; pediatric intensive care \$9470; and neonatal intensive care \$8760.¹⁴⁷ These are only room charges and do not cover other charges for treatments, equipment, supplies, or pharmaceuticals.

Many have made suggestions on how to reduce the cost of health care, especially at the end of life. These include initiatives on the elderly, those receiving medically inappropriate treatments, or those whose death is imminent.¹⁴⁸ An additional explanation for limiting critical care was given by the Study to Understand Prognoses and Preferences for Outcomes and Risks for Treatment (SUPPORT). The SUPPORT study found after studying a large group of critically ill patients with less than a predictable six month life expectancy of approximately 50%, that they died at a large expense after being in a coma for at least 10 days, on a ventilator in pain, with a do not resuscitate order written two days before death.¹⁴⁹ Further work with SUPPORT

found that it is difficult to identify those who have a short life expectancy or that denying them treatment in critical care would have led to any compelling savings.¹⁵⁰ However, this did not mean palliative care did not have significant value for all patients whether there was a large cost savings or not.

Another study which looked at data from 2000 to 2010 reported in 2016, was the first to analyze the use of critical care beds based on age specific data.¹⁵¹ Some of the findings from this study include: 1) the increase in adult critical care beds corresponded to the increase in adult population but the opposite was not true for the neonatal population where the beds increased but the population decreased. The neonatal bed increase was due to increased survival of premature infants and improved prenatal care; 2) the increase in hospital bed usage reflects Roemer's Law of the 1950's that implies the more beds there are the more beds will be used; 3) proportionately there are more users of Medicaid beds than those used by Medicare patients. Medicaid patients use more critical care beds as they are often younger and in poorer health than the Medicare patients waiting to access the health care system until they are very ill.¹⁵²

Of all the expenditures in the last year of life, approximately 33% are spent in the last month.¹⁵³ The majority of these last month costs are for such things as mechanical ventilation as well as resuscitation, accounting for 78% of the costs in the last year.¹⁵⁴ What was shown to make a difference was when there were end-of-life discussions between patients and providers. This difference was shown in less life-sustaining treatments and fewer critical care admissions, with no effect on outcomes, plus there was a perceived better quality of life.¹⁵⁵ A final study with approximately 2.1 million patients was completed from 2008-2012, in ages greater than 80 (42%) and ages greater than 65 (28%) with 18% having a chronic illness that required prior hospitalization.¹⁵⁶ Of these selected patients, interventions were to include advance care

planning with palliative care. The findings were as follows: 1) depending on the effectiveness of the interventions, the range of savings is \$34,000 to \$800,000 per patient; and 2) advance care planning is more effective in reducing costs than palliative care but both are effective.¹⁵⁷ Based on the United States spending more than \$80 billion on critical care per year, results can be anticipated to be a potential savings of \$8.8 billion (11%) over the course of a year with the implementation of advance care planning plus palliative care.¹⁵⁸

The cost of end-of-life treatments in critical care and medically inappropriate treatments is something that cannot be ignored. Advance care planning and palliative care show promise not only for addressing the cost problem, but also for removing barriers to optimal end-of-life care. Following is a discussion on these and other approaches to removing barriers.

5.III.B.2. Approaches to Removing Barriers

Of all the approaches to removing barriers to end-of-life care, not only is palliative care linked with cost savings, but it also can decrease pain with symptom management, offer emotional support to patient as well as family, and increase patient/family satisfaction.¹⁵⁹ Although palliative care is becoming more prevalent in institutions, there are still barriers to its integration into critical care. These barriers include the following: 1) confusion of palliative care with hospice care by patients as well as providers; 2) concern that palliative care will “hasten” death; 3) the view that critical care and palliative care are opposing approaches rather than “complementary”; 4) inadequate preparation of providers in skills to provide high quality palliative care; and 5) excessive demands on critical care providers without appropriate compensation for palliative care excellence.¹⁶⁰

Advance care planning is another initiative for removing barriers to end-of-life care. However, when advance care planning, followed by an advance directive, is done in the acute

care setting the results are disappointing, plus they are not always followed.¹⁶¹ Whereas, when the advance care planning and advance directives are completed in the community, the results are more favorable, not only for the control of costs, but also for the benefit of the patient.¹⁶²

Inherent in all approaches to improving end-of-life care is communication. Communication skills, like any other skill, must be taught, learned, and practiced in order to be effective and accomplish its expected outcomes.¹⁶³ Strategies that have shown to improve communication include frequent formal and informal family meetings, daily team consensus discussions on the patient's progress with a plan of care, proactive ethics consultations, and proactive case findings by a palliative care team.¹⁶⁴ It is key to have the major providers involved in all family discussions such as physicians, nurses, as well as social workers and that there is open, honest dialogue in a sensitive manner utilizing knowledge of the patient's/families' values and beliefs.¹⁶⁵

Additional approaches to providing end-of-life care include enhanced communication plus four practices to optimize that care. The first practice is to enhance one's personal comfort with death. The majority of physicians have not been trained to deal with uncertainty, whether that be the uncertainty of diagnosis, prognosis, or death which can lead to "avoidance behavior".¹⁶⁶ Therefore, the place to start is for providers to deal with their own death, with its associated grief and loss, which means outside help may be needed so that the patient and family can have discussions with the providers in an honest and open manner.¹⁶⁷

The second practice is to create an environment for the crucial conversations. These conversations are important, therefore, choosing a quiet protected space away from the chaos of the critical care environment is key, along with having the right people present for the conversation.¹⁶⁸ The "right" people include key family members, as well as those providing

care to the patients, both physicians and nurses. Having a meeting with the team before the family meeting, much like a dress rehearsal, helps set the goals for the meeting and gets the team on the same page before the family is brought to the meeting.

The third practice is for providers to be willing to let go of all the control or to at least begin to do so. Whenever a family has a patient in critical care, especially adult critical care, they are besieged with rules from what to touch, when to visit, how long, etc. so they soon have no say while still dealing with an ill and often dying family member. By allowing the family more access to the patient, plus the ability to participate in the care of the patient, as well as the opportunity to see that providers do not have all the answers and can show their discomfort, can do much to help family members.¹⁶⁹

The fourth and final practice is to facilitate end-of-life decisions. When a family is already consumed with guilt, sadness, anger, and grief it is unfair to add to the pile of emotions with a decision about “pulling the plug”.¹⁷⁰ It is okay to evoke the patient’s wishes and to share thoughts of how the provider would act if they were in the family’s position. The next step is to give the family time to process the information with a follow-up meeting to answer questions and proceed with a decision.¹⁷¹

With the struggles that present themselves in end-of-life care, which range from various players seeking autonomy to the constant presence of cost control, both palliative care and advance care planning offer hope for the future. There continues to be initiatives that have been tried or are being tried from a different approach in hopes of addressing medically inappropriate treatment or medical futility. The next section focuses on medical futility and what various institutions, states, or national legislatures have implemented in hope of providing solutions to medically inappropriate treatment.

5.IV. Medical Futility and Potential Solutions

Medical futility, or medically inappropriate treatment, continues to occur in all critical care units in the world for multiple reasons. The most insurmountable reason is that futility defies any standard definition so it is a subjective concept that varies from patient to patient and situation to situation.¹⁷² Despite that roadblock, there have been attempts to develop policies, use the court system, or develop legislation to help approach and settle the conflicts that invariably arise regarding medical futility. Some of these attempted actions have had more success in accomplishing the desired goals than others. The first part of this section will address advance directives to include their historical development and types. The second part of this section discusses policies and legislation to include the Texas Advance Directive Act (TADA) as well as Physician Orders for Life Sustaining Treatment (POLST).

5.IV.A. Advance Directives

Advance directives came about as a means to help patients have a voice at the end-of-life regarding their own wishes. They are to help ensure patient autonomy when patients no longer can speak for themselves.¹⁷³ Advance directives also improve the quality of care at the end-of-life as well as reduce health care costs.¹⁷⁴ Starting in the 1970's (Karen Ann Quinlan) into the 1990's (Nancy Cruzan), these two cases brought the importance of end-of-life care planning to the attention of the public.¹⁷⁵ The use of advance directives, although well intentioned, has not been as successful as was once hoped.¹⁷⁶ Even with this limited success, advance directives are still worthy of retaining in theory, but a different approach may be needed. Following is a discussion of the historical development of advance directives, the various types of directives, and the Centers for Medicare and Medicaid (CMS) attempt to increase the completed directives via a payment system to providers.

5.IV.A.1 Historical Development

Documented back to 1914, following a malpractice case, the lower courts found in favor of the physician and institution, however, the Court of Appeals issued a ruling in favor of the plaintiff stating that humans have the right to decide what is to be done to their body.¹⁷⁷

It was in the 1960's that attempts were made to legalize tools that were called advance directives, such as the living wills, durable power of attorney and disposition of a proxy.¹⁷⁸ However, the legislation of the two laws, living will laws and durable power of attorney laws, did not occur until after two significant court decisions. The first was Karen Quinlan, which produced the first state supreme court decision regarding end-of-life and led to the living will law in 1976.¹⁷⁹ The second court decision was Nancy Cruzan, which produced the first U.S. Supreme Court decision on end-of-life, in 1990, and led to the durable power of attorney law.¹⁸⁰ In both of these cases, the parents of the young women requested they be removed from life support, after a period of time, when they did not improve following their illness. The legal system was used and eventually permission was granted, however, Karen Quinlan went on to live 10 years sustained by tube feedings and Nancy Cruzan died within the month following withdrawal of life-sustaining treatment.¹⁸¹ The parents of both Quinlan and Cruzan were in long involved conflict with, not only the legal system, but also with physicians and the hospitals who were all struggling to come to terms with the end-of-life issues.

It is believed that all the publicity regarding the Nancy Cruzan case, as well as the U.S. Supreme Court decision, helped lead to the Patient Self Determination Act (PSDA) of 1990.¹⁸² The family of Nancy Cruzan proved to be very eloquent in speaking for those who could not speak for themselves and, although work had begun on the Act long before the Supreme Court ruling, it only added to the support that something had to be done.¹⁸³ The PSDA became part of

the Omnibus Budget Reconciliation Act in 1990.¹⁸⁴ The Act requires that health care institutions, who receive funding from Medicare and Medicaid, inquire if the patient has an advance directive, if so, could they have it brought in for the medical record and if they do not have one, then information is to be offered.¹⁸⁵ The patient is to receive all this information upon admission to the facility and the caregivers are to document the discussion, plus what information was given to the patient in the medical record. The Joint Commission also requires the organizations they survey to ask patients pertinent questions regarding advance directives, offering information and education to the patient, followed by thorough documentation of this in the medical record.¹⁸⁶

The most current effort to enhance and increase advance care planning and advance directives began January 1, 2016. This was when the Centers for Medicare and Medicaid (CMS) began to pay for voluntary advance care planning under the Medicare Physician Fee Scheduling (MPFS) and the Hospital Outpatient Prospective Payment System (OPPS).¹⁸⁷ Physicians, as well as non-physician practitioners, can bill CMS each time there is a 30 minute discussion with a patient regarding advance care planning or advance directives, either when it is medically necessary or as part of an annual wellness visit (AWV).¹⁸⁸ After six months since implementation of the reimbursement for provider conversations regarding advance care planning, only 14% of providers have billed for these conversations citing they are not sure what to say and are concerned the patient will give up hope.¹⁸⁹

Research indicates that over 60% of those over 18 years of age want their end-of-life wishes observed.¹⁹⁰ However, the most current data reflects that only 18-30% of Americans have completed an advance directive.¹⁹¹ Patients state the main reasons for not completing advance directives are that they do not know what they are, or that their family knows that they want.¹⁹²

Additional reasons that completing advance directives are delayed are that it is difficult to discuss end-of-life issues, patients change their minds often, and patients wait for providers to initiate the conversation.¹⁹³ Fear is another reason to not complete advance directives. These fears include fear of substandard care or neglect if there is an advance directive, as well as fear of withdrawal of care before it is appropriate, and fear of not having the advance directive followed.¹⁹⁴ Patients who are more apt to have advance directives include those who are older, have a higher level of education, are of a higher socioeconomic status, and are of the white Caucasian race.¹⁹⁵

The presence of an advance directive is not to take the place of frequent communication between patient/family and provider to ensure that decisions previously made have not changed.¹⁹⁶ These discussions should be not only with the patient, but also with key family members, and should be directed communication focusing on meeting the patient's needs.¹⁹⁷

When an individual does decide to complete an advance directive, there are two basic types. Following is a discussion on these types.

5.IV.A.2. Types of Advance Directives

Luis Rutner, a human-rights lawyer, brought forth the first advance directive proposed by the Euthanasia Society in 1967, which was referred to as a "living will".¹⁹⁸ There are basically only two types of advance directives. The treatment directive, or living will, and the proxy directive, or medical durable power of attorney (MDPOA).¹⁹⁹

The treatment directive, or living will, by its name conveys an importance, as well as legal meaning to the document, which is often relegated to a location with all legal documents and never looked at again.²⁰⁰ The living will, completed by an individual while fully aware, details the types of treatment preferred at the end-of-life, if unable to express preferred wishes.²⁰¹

There are three factors to consider when living wills are discussed. First, the absence of a living will does not translate to meaning the patient wants “everything” done at the end-of-life.²⁰² These end-of-life treatment concerns need to be discussed whether there is a living will or not. Second, the presence of a living will does not translate into forgoing treatment at the end-of-life because living wills can differentiate what not to receive, as well as what treatment is wanted.²⁰³ Therefore, the living will must be read in collaboration with the patient/family and providers. Third, CPR needs to be addressed separately from the living will, unless it is specifically addressed in the document, because the presence of a living will does not mean do not resuscitate.²⁰⁴

The strengths of a living will are as follows: 1) it allows a patient to put choices and wishes in writing; 2) the usefulness is commensurate with the detail; and 3) it becomes a communication tool for all concerned regarding the care of the patient.²⁰⁵ The major weaknesses of a living will are: 1) it is impossible to list all possible conditions and contingencies in one document; and 2) the “laundry list” approach may leave out too many options leaving family and providers at a loss looking for clues on what to do in any given situation.²⁰⁶

The second type of advance directive is the proxy directive, or medical durable power of attorney. In this advance directive, individuals select someone to make all medical decisions when they can no longer do so.²⁰⁷ The strengths of a MDPOA are: 1) it is an advantage for providers to have a designated person to communicate with and to assist in the decision making process at the end-of-life; 2) the patient’s choose who they want to make their health care decisions rather than it being left to family members or surrogate, if there is no one designated; and 3) some patients find it unnecessary to complete a living will if they have faith in the MDPOA to follow their wishes in all circumstances.²⁰⁸ The weaknesses of the MDPOA include:

1) those named MDPOA may be reluctant to take the responsibility when the actual time arrives to do so; 2) many individuals are not able to be the “all” to anybody when the time comes, unless something spells out the patient’s wishes in writing; and 3) there may be no one to take the responsibility of a MDPOA due to the mobility of Americans and the social isolation of society, plus families are often estranged or deceased.²⁰⁹

Advance directives are one approach to help ease the burden of medically inappropriate treatment at the end-of-life. Other attempts to help provide solutions to this dilemma have been the development of policies and enactment of legislation. Following is a discussion on these approaches.

5.IV.B. Policies and Legislation

Many institutions and providers have long struggled with the concept of medical futility, or medically inappropriate treatment, and how best to approach it or to “deal” with it at the bedside. In the majority of cases, there is communication and dialogue between families and providers in critical care that eventually comes to a collaborative decision which is best for the patient that minimizes pain and suffering.²¹⁰ However, this is not always the case as these exceptions get all the attention, even when exemplary communication and superb relational skills may not resolve the conflicts that arise at the end-of-life.²¹¹

To help resolve the conflicts that occur regarding futile treatments, answers were sought by putting solutions into a written format. In the middle to late 1990’s, professional organizations, as well as policy advocates, encouraged the development of institutional policies on futility to help with the conflicts that were arising at the end-of-life.²¹² In addition, in order to give additional strength to a policy, some states such as Texas, took policies through the legislative process. Following is a discussion on the policies and legislation for addressing end-of-life

concerns.

5.IV.B.1. Policy Development

An approach that institutions have used in establishing futility policies is a multi-institutional approach. Sometimes that is a policy between hospitals in a location or region, such as Houston, Texas where three hospitals came together to develop a policy.²¹³ Other times it is a policy that is applied to institutions within a system such as the Mercy Health System which used the Houston policy as a guide.²¹⁴ Whether multiple institutions or a single institution develops the policy, the method that is most often used is a process approach. Because of the difficulty in defining futility, policies are best served by not trying to spell out a definition. The best approach is detailing what steps to take when the providers believe the patient is receiving medically futile treatment plus a conflict exists between the family and providers.²¹⁵

From the experience of various institutions who have developed futility policies, some best practices have emerged. One is when putting medically futile policies in writing, wording is always important. The Houston policy makes a conscious effort to avoid the term “futile care’ as care is never futile.²¹⁶ Another best practice is to put a role for hospital administration in the policy so the burden of any action taken is not borne only by the clinicians.²¹⁷ Most of the policies utilize the ethics committee of the institution as a mediator when conflict between families and providers occurs with many institutions finding that having this in writing in the policy makes it happen often leading to a resolution of the dispute.²¹⁸

Recommendations for inclusion in futility policies are numerous with the top three described as follows. First, a key component of the policies is to have an interdisciplinary committee develop the policy, review/revise it annually, and review each case layering it with bureaucracy to protect patients, family and providers.²¹⁹ Second, critical care must never lose

sight of its two primary goals which are to provide acute treatment that has a reasonable expectation for survival outside the unit and, if unable to do so, then to provide palliative care through the remainder of life.²²⁰ Third, the presence of futile treatment, or medically inappropriate treatment, is to be decided on a case-by-case and situation-by-situation basis avoiding the use of the term “futile”.²²¹

When the basic policy statements are included in the policy then the mere procedural aspects can be addresses such as 1) enlisting second opinions when there are potential medically inappropriate treatments in the critical care unit; 2) keep the family and surrogate informed of all actions to include ethics committee sessions so they can be present; 3) offer transfer to another physician or institution providing assistance with the process; and 4) Communicate! Communicate! Communicate!²²² Of these, the fourth which stresses communication has shown that the lack of genuine honest conversations often leads to an impasse between families and providers early in the patient’s progress.²²³ As a result, providers tend to make up their mind, share it with families who then feel disrespected, as well as mistrustful and unheard, so they “dig in their heels” even more resulting in a standstill in the care of the patient.²²⁴

Even with some prescribed standards that are best to include in a futility policy, there are still differences between the various institutional policies. The major differences include the following: 1) some policies allow for the providers to have unilateral decision making authority to the point of discontinuing futile treatment without the family’s consent, while others gave the ultimate decision making to the patient/family; and 2) many policies recommend involving the ethics committee, but rarely is it a requirement.²²⁵

Overall, for those institutions who have developed policies on medical futility the results have been positive. These positive results have been an improvement in the quality of life for

patients at the end-of-life, as well as a reduction in conflicts between families and providers at this difficult time.²²⁶ Actual data to illustrate policy effectiveness is difficult to quantify with most of the data being subjective feedback.

Despite institutional futility policies in place to help confront medically inappropriate treatment, physicians were reluctant to fully operationalize them fearing litigation, although this was rarely tested.²²⁷ One state, Texas, approached the futility debate in the form of legislation which became the Texas Advance Directives Act of 1999. Following is an examination of this act as well as a discussion on Physician Orders for Life-Sustaining Treatment (POLST).

5.IV.B.2. Texas Advance Directives Act and POLST

In 1999, the American Medical Association (AMA) Council on Ethical and Judicial Affairs issued guidelines on medical futility. These guidelines recommended a process-oriented approach to settling disputes with attempts to transfer patients and, if that failed, then the futility treatment could be discontinued.²²⁸ Shortly after the action of the AMA Council, the Texas legislature passed the Texas Advance Directives Act (TADA) of 1999.

The TADA put in place a step-by-step process to follow whenever there was debate between family and providers regarding the provision of medically inappropriate treatment that cannot be resolved through frequent conversations. The key provisions include: 1) the provider's refusal to continue or begin treatment that is seen as medically inappropriate is reviewed by an institutional appointed committee, most often an interdisciplinary ethics committee, of which the providers for the patient do not attend; 2) the family may attend the consultative committee with a 48 hour notice; 3) the committee will report the results of the meeting in writing to both the family and place a copy in the medical record; 4) if the committee is unable to resolve the dispute, the institution, working with the family, will attempt to transfer the patient to another provider and

institution; 5) if after 10 days no provider/institution has been found to accept the patient, then the treatment may be withheld or withdrawn; 6) the family or surrogate may request a continuance from the court to find another provider; and 7) if no continuance is granted by the court, the treatment may be withdrawn granting civil and criminal immunity to the provider.²²⁹

Some critics of the TADA have stated that their concerns are both political and constitutional. The political concern is that the providers, mostly physicians, are granted too much power. Physicians make the medically inappropriate decisions, they sit on the ethics committees that can help support or refute the medically inappropriate treatment decisions, and then they are immune from civil or criminal prosecution.²³⁰ The constitutional concern relates to its vagueness, which should make it void, plus its use breaches the due process for patients' rights, which is the right to be heard.²³¹

Another criticism for the TADA comes from the view of the Catholic faith. The provisions for the act are seen as "dehumanizing", which disregards patients as people with their own story and life to live.²³² The act is seen as a means to prevent patients from wasting resources adding that a 10 day window is insufficient time for the majority of families to find another physician and institution to care for the patient, which adds to the perception of the act as "unethical".²³³

Final criticism focuses on three intrinsic problems with TADA. First, there is great uncertainty on the part of providers in determining when treatment is medically futile which may vary from provider to provider in the same circumstances.²³⁴ The second problem is that most institution's ethics committees are composed of individuals from the hospital and colleagues of the physicians who are caring for the patient that the case concerns.²³⁵ The committee compositions may lead to questions regarding objectivity on the part of the committee who are now the ultimate decision makers for the outcome of the patient.²³⁶ The third problem relates to

the judges who have no jurisdiction over the decision of the institutional committees.

Those who are proponents of TADA believe that it ensures fairness and justice which are supported by the AMA. It accomplishes this by: 1) offering patients the right to address wishes with an advance directive prior to end-of-life; 2) encouraging shared decision making at the end-of-life between family and provider if the patient cannot participate; 3) having the freedom to bring in an outside consultant when desired; and 4) engaging with the institutional committee that gives the patient choice.²³⁷

With the pros and cons that have been associated with the TADA, there has been initial data but little after that. Most hospitals (86%) used ethics committees to resolve disputes and 70% of the committees agreed with the physicians.²³⁸ Additional data included: 1) of 2922 ethics consults, 974 were for futility; 2) 65 ten-day letters were issued; and 3) within the 10 days, 11 were transferred, 22 died, 27 had treatment withdrawn, and five had treatment continued.²³⁹

Another way end-of-life wishes are communicated is through Physician Orders for Life Sustaining Treatment (POLST), which is a 1-2 page check off medical order sheet, on brightly colored paper, that follows the patient across care settings.²⁴⁰ Its use is for those with a serious life limiting illness who are expected to die within a year and, although it began with hospice patients in Oregon, its use is now seen in hospitals, nursing homes and patients often keep their copy at home so it can travel with them.²⁴¹ The POLST can serve to limit interventions or to clarify what treatments are desirable. Living wills are often full of legalese that requires time to decipher, while a POLST form is a quick way to determine the patients' wishes. These wishes are in regard to resuscitation, antibiotics, treatment options of comfort measures versus aggressive treatment, plus artificial fluid and nutrition.²⁴² POLST is not an advance directive, it is an order set and does not replace a living will.²⁴³

The use of POLST has been found to be followed by health care providers more readily than advance directives and the orders more accurately reflect the patient's last wishes.²⁴⁴ The use of orders has had some push back from the Catholic leaders because some states have dropped the requirement that patients must be terminally ill (Colorado) before using the form.²⁴⁵ Another Catholic concern is that it allows patients to refuse any medical treatment for any reason removing any liability from the providers or institution and can be a form of assisted suicide.²⁴⁶

When evidence based practice in medicine attempts to align with medical futility, there are some definite problems. There is a great deal of "moral baggage" that accompanies medical futility to include a lack of definition, what policies are best to be utilized, and what treatments have the best success at end-of-life.²⁴⁷ The next section addresses evidence based practices for the adult patient receiving medically inappropriate treatments.

5.V. Evidence Based Practices

Each presenting case of patients at the end-of-life, who are receiving medically inappropriate treatment, are different making it nearly impossible to create patient guidelines to base futility confirmation.²⁴⁸ Add these concerns to the prevalent lack of trust between patients and providers at end-of-life and evidence based practice appears to be doomed.²⁴⁹

The initial lack of trust between patients/families and providers sets the stage for overtreatment as well as undertreatment with the pendulum swinging as to who is the driver of that treatment, be it the patient, most often the family, or providers. Following is an examination of over and undertreatment as it occurs at the end-of-life. Closely aligned with this over and under treatment are contradictions, defined as opposing views on an issue, which will also be discussed.

5.V.A. Avoiding Overtreatment and Undertreatment

As medical futility is confronted in the adult critically ill patient, two potential occurrences need to be monitored and addressed when appropriate. These are over and undertreatment. The United States has the perception of having an immense problem with overtreatment of patients, which carries a negative connotation.²⁵⁰ This overtreatment can be viewed as physician driven or patient driven. Historically, physicians acted in a paternalistic manner making all the decisions for patients.²⁵¹ This view changed when patients became more autonomous wanting a say in their own care. Following is a discussion of provider and patient/family overtreatment as well as undertreatment.

5.V.A.1. Provider Driven

There is a perception of overtreatment by providers in the United States. This came about as providers, especially physicians, were granted the power to do treatments that they wished because of their education and training, plus the “doctor knows best” was believed to be true by patients.²⁵² Back to the 1970’s, there were also other factors at play that led to provider overtreatment. These were: 1) the fee for service system rewarded procedures over cognitive skills; 2) fear of malpractice led to “defensive” medicine; 3) the burst of technology led to its use at a higher cost; 4) the providers intolerance of uncertainty led to increased use of treatments and tests to help attain a more certain diagnosis and prognosis; and 5) there was an oversupply of specialists who were trained to be diagnostic specific in their approach to medical care.²⁵³

The doctrine of informed consent has been helpful in controlling physician driven overtreatment. As the need for informed consent was in place by the 1970’s, the patients are now expected to give consent prior to the initiation of all treatments.²⁵⁴ A part of that consent is to inform the patient/family of what a reasonable person would want to know to

include the risks, the available options, to include doing nothing, and the consequences of doing nothing.²⁵⁵

In critical care, there are most often hospital based physicians, or intensivists, caring for the patients. Studies have shown that without prior relationship with the patients, and no advance directives to help in making end-of-life decisions, the hospital based physicians show a low level of accuracy in predicting the patient's preferences.²⁵⁶ As a result, hospital based physicians tend to make overtreatment errors.²⁵⁷ Whereas, primary care physicians, without advance directives to help in end-of-life decisions, tend to make undertreatment errors.²⁵⁸ Critical care nurses have perceived overtreatment by physicians which they credit to "fear of litigation" as well as a struggle to defy death by not "giving up" until there are no more options.²⁵⁹ There is also a push in that direction from families who want "everything" done, yet, they do not always know what "everything" means.²⁶⁰

Overtreatment, in the form of testing or procedures, is not a benign process with iatrogenic complications occurring frequently. Inappropriate hospital use has been found to occur in 20-44% of cases with inappropriate procedures being performed 14-32% of the time.²⁶¹ There is a social disparity in overtreatment with those with high income being more apt to receive treatment than those who are poorer and more often in greater need.²⁶² To withdraw treatment does not always create conflict. In a large study, it was revealed that 57% of families/surrogates agreed with the providers' recommendation to withdraw treatment, 90% agreed within five days, and only in 4% of the cases did the families/surrogates insist on the treatment continuing.²⁶³

The issue of undertreatment by physicians is difficult to identify in research, with few exceptions. One of the means undertreatment is suspected is when financial incentives are driving patient care as the providers income is directly correlated to the resources they use.²⁶⁴

This was more apt to have occurred in the 1980's with the use of health maintenance organizations (HMO's).

Another area of undertreatment is with the use of POLST. The orders on the POLST are limited and meet the needs for many as they near death, however, some patients do not believe they give an opportunity for choices or contingencies leading to undertreatment.²⁶⁵

As providers are responsible for both overtreatment and undertreatment, patients and their families can be responsible for both as well. Following is a discussion on overtreatment for the patient/family.

5.V.A.2. Patient and Family Driven

Patient driven overtreatment, which is usually family or surrogate driven, is frequently seen in critical care at the end-of-life. The concept of medical futility was introduced as a means to respond to this patient/family overtreatment.²⁶⁶ The cases that brought patient driven overtreatment to the forefront concerned dying patients or those in a PVS where continued medical treatment was not benefiting the patient and was considered futile.

Patients have a right to self-determination but as they are often incapacitated at the end-of-life, the surrogate decision maker decides on what treatment the patient is to receive. This surrogate, whether appointed by the patient in writing or granted by default to the next of kin when the patient is incapacitated, tend to make errors of overtreatment, rather than undertreatment, although both are possible.²⁶⁷

Research regarding surrogate decision making indicates that they prefer to be the decision makers in value laded decisions compared with more medical type decisions, such as what treatment to initiate or discontinue.²⁶⁸ Very few surrogates wish to give all decisional authority to providers, but greater than 90% want to know the providers' opinion regarding the

continuation of life sustaining treatment.²⁶⁹ The providers must be skilled at balancing variation in the decision preference of family surrogates as well as the different levels of authority that means for the providers.

Uncertainty is present for families and surrogates when making treatment decisions. This uncertainty leads to indecisiveness which in turn leads to continuing all treatments, or overtreatment, until a decision can be made.²⁷⁰ As a result the patient can experience a distressing and lingering death. Having frequent meetings between families/surrogates and providers has been found to be the best solution to this problem of indecisiveness. This indecisiveness is most often a result of unclear or no direction from the patient, a surrogate who is unable to articulate the patient's preference, or a mistrust of the physician.²⁷¹ Evidence suggests that surrogate decision makers are more apt to experience psychiatrist illness after a critical care experience when there is a disconnect between their actual and perceived role in decision making.²⁷² Therefore, having open communication between all parties is key to helping prevent overtreatment as well as helping lead to a collaborative decision for the patient.

At the end-of-life, there are contradictions that can add to the confusion and challenges of medical futility, or medically inappropriate treatment. Following is a discussion of these contradictions.

5.V.B. How to Manage Contradictions

Contradictions are perspectives on an issue, such as end-of-life, which are opposing, even though one view assumes the possibility of the other such as benefit versus burden, subjective versus objective, or life versus death.²⁷³ As these contradictions often occur at end-of-life, the ability to communicate becomes a focus. Communication skills, along with the ability to relate well with others at the end-of-life, is critical as it improves patient/family satisfaction and

enhances patient outcomes with fewer malpractice claims.²⁷⁴ However, this in-depth communication does not occur as often or at the level that is needed due, in part, to physicians not having the necessary skills to engage in appropriate end-of-life conversations.²⁷⁵

If families or surrogates develop a relationship with providers from the beginning that involves an opportunity to discuss the patient's wishes, plus the medical interventions and what they entail, many of the futile treatments would never occur.²⁷⁶ The barriers that seem to get in the way of providers having end-of-life conversations include: 1) discomfort with giving bad news and causing pain; 2) a knowledge deficit regarding advance directives and what they mean; 3) death is the enemy to be defeated; 4) an expectation of conflict between families and providers; 5) concern that what is said will lead to legal issues later; and 6) the conversations are uncomfortable and threatening so are avoided.²⁷⁷ Even when educational opportunities have been presented to providers as a means to improve the present end-of-life conversations, they are often "undervalued" and "underrepresented".²⁷⁸

There are many contradictions to be found in health care, two that come up more often at the end-of-life are killing versus letting die and honoring patient wishes versus following family wishes. Following is a discussion on these contradictions.

5.V.B.1. Killing versus Letting Die

At first look the distinction between killing and letting die appears to be distinct and clear. However, on closer look this is not the case. In some cases killing, or taking another's life in murder, is worse than forgoing treatment with a ventilator and letting a person die who is brain dead. Yet, some instances of letting a patient die, such as not doing surgery when it would have saved a life, may be worse than mercy killing at the patient's request, who is in unrelenting terminal cancer pain.²⁷⁹ With the passage of time, the clarity between killing and letting die has

clouded as withholding and withdrawing treatment has become more common with it being the ultimate action that leads to patients' deaths in critical care units.²⁸⁰

For most people, there is a difference between killing and letting die. Discontinuing a ventilator, either because it has become medically inappropriate or because the patient has requested it be removed, may indirectly lead to the patient's death.²⁸¹ However, the courts have historically held that death is due to the underlying disease and not the hand of the provider who turned off the ventilator.²⁸²

Killing has been described as “doing something” that causes death and letting die is seen as “doing nothing” and allowing death.²⁸³ Another view sees killing as a commission of an act that leads to death, whereas, letting die has more often been seen as an omission of action, or what was once referred to as “passive euthanasia.”²⁸⁴ This omission was not usually seen as a “killing” but this is no longer true. Omissions can kill patients either through negligence or as a malicious act, such as failing to order antibiotics for a severe infection.²⁸⁵

The concept of assisted suicide, or assisted dying, has caused much speculation as to whether this is killing or letting die. Those states with the assisted suicide statute often prohibit “causing” it but not “assisting” it.²⁸⁶ Along with these laws, is most often stipulation of a terminal illness with death expected within a year, plus various other safeguards to protect both patients and providers.²⁸⁷

Despite trying to separate the terms and all the movement to keep killing and letting die separate, families are often in a quandary when withdrawing life sustaining treatment as they are concerned that they are killing a family member.²⁸⁸ It is best to discourage the use of these terms for three reasons. First, conceptually killing and letting die do overlap with their definitions being “vague” and disputable leaving the recommendation to best avoid the terms, if possible.²⁸⁹

Second, although there is a tendency to want to place killing and letting die into a rightness or wrongness category, there are many contributing factors that apply to both that can make each right in certain instances or each wrong in other instances.²⁹⁰ The mere attachment of a label such as “killing” or “letting die” to an action or series of events in health care does not determine whether the action was “acceptable” or “unacceptable”.²⁹¹ So much more needs to be known about a particular situation before any judgment can be made such as the full circumstances, the motive of the players, what the patient desired, and the consequences of the action.²⁹² The third and final reason relates to forgoing life sustaining treatment. Whenever life sustaining treatment is withheld or withdrawn, the relevant considerations is related to the validation of the authority for the action to determine if acceptable or unacceptable, not whether it was killing or letting die.

A second contradiction that is all too common in critical care at the end-of-life is honoring patient wishes versus following family wishes.

5.V.B.2. Honoring Patient Wishes versus Following Family Wishes

Health care providers make every attempt to comply with the patient’s wishes whether that be in the form of an advance directive or verbal communication from the patient, or through a surrogate. Communication with patients at the end-of-life is difficult because most of those in critical care are unable to communicate due to either being on a ventilator or incapacitated by their illness. Even if patients are able to communicate those at the end-of-life frequently change their views.²⁹³ Moreso, if the patients had previously expressed their wishes in writing, they often express contradicting forms of these wishes as end-of-life nears.²⁹⁴

The more prevalent scenario at the end-of-life is one where family members, or designated surrogates, are left to make the decisions since less than 5% of patients in critical care have decisional capacity.²⁹⁵ The assumptions are that these decisions will be what the patient had

either put in writing or made known to family members or surrogates. If the patient's wishes were not conveyed to family members, it has been shown that family members and surrogates usually fail to express the patient's true wishes. Instead they rely on past conversations, family dynamics or their own personal values and beliefs.²⁹⁶

Whenever there is concern or conflict regarding whether to honor the patient's wishes or follow the family wishes, the most common area concerns the limiting of life support. Usually it presents where the patient wishes to limit life support but the family members preferences are to continue it.²⁹⁷ Such cases can be prolonged, especially if there is a living will with explicit instructions left by the patient, as well as a medical durable power of attorney who is left with the final say. The basic golden rule, or ethic of reciprocity, of treating others like one would want to be treated, works well in many instances, except end-of-life.²⁹⁸ At end-of-life, even with advance directives to guide the way, social, cultural and religious values get in the way of doing the right thing causing confusion and conflict with health care providers leaving the patient caught in the middle.²⁹⁹

If the contradictions occur, regarding honoring the patient wishes versus following the family wishes, it should always be first and foremost about the patient. However, it may take some time and excellent communication skills to get there. The end-of-life conversations require advance communication skills which are a challenge for the physicians who notoriously have an overall lack of communication capabilities.³⁰⁰ To be effective in end-of-life communication, there needs to be a commitment to learning the necessary skills and strategies to include decision centered and information seeking strategies, plus when best to use each when working with families at the end-of-life.³⁰¹

The presence of contradictions often are present or lead to discussions regarding the

withholding or withdrawing of treatment. There is a general consensus among ethicists that withholding and withdrawing treatment are ethically and morally the same.³⁰² However, some patients, families, as well as providers, struggle more with withdrawing than withholding treatment. The following section explores the withholding and withdrawing of treatment by first discussing what role CPR played in the limitation of life sustaining treatment. Then the role of palliative care will be described as a bridge and hope for the future when there is a struggle to limit the medically inappropriate treatments.

5.VI. Withholding versus Withdrawing Treatment

Between 35-90% of the deaths in critical care are a result of withholding or withdrawing treatment.³⁰³ Withholding treatment is the act of not initiating or increasing a life sustaining therapy and withdrawing treatment is the act of discontinuing a life sustaining therapy that the patient is presently receiving.³⁰⁴

Although the action of withholding and withdrawing treatments are equivalent from a moral, legal and ethical perspective, it is emotionally easier to withhold than withdraw treatments.³⁰⁵ Even though withholding and withdrawing are said to be equivalent, there are perceived differences for the following reasons: 1) withholding is passive while withdrawing is active and involves doing something that most frequently leads to death within 72 hours; 2) once treatment is started, providers take on the patient as a responsibility with a “duty to care” that might not have been as acute if no treatment had been started; 3) having the option to withdraw a treatment provides an opportunity to “trial” a treatment to see if it benefits a patient, versus never trying at all; and 4) there is a perceived difference between the means versus the end. Both withholding and withdrawing may have the same result but the process of getting there are

different with some religions, such as Orthodox Jews, being more apt to support withholding than withdrawing.³⁰⁶

The withholding and withdrawing of treatment involves much more than cardiopulmonary resuscitation (CPR) but over time this is often where the discussion begins. Following is a description of CPR taking a closer look at its historical development to where it is today, as well as a discussion on the recommendations that are present surrounding withholding and withdrawing treatment.

5.VI.A. More Than CPR

When providers are having conversations with families in critical care regarding end-of-life and the withholding and withdrawing of treatment, the conversation often begins with the withholding of resuscitation measures making the patient a Do Not Resuscitate, or DNR.³⁰⁷ Because the withholding of resuscitation is something that is done in the future, when a cardiopulmonary event occurs, families are often more receptive as the death is a result of a medical event versus the withdrawing of life support in the present moment.³⁰⁸ However, the media, especially television, has not portrayed CPR in a realistic light with more than 75% of those in TV dramas surviving CPR, while in reality it is closer to 16%.³⁰⁹ CPR does save lives, but was never intended to be used on the dying who end up with fractured ribs and bruised bodies, all to comply with a treatment that could be better utilized. However, CPR became part of a false belief that all deaths could and should be prevented. Following is the historical development of CPR and how it got to be a negotiating point at end-of-life.

5.VI.A.1. Historical Development of CPR

Beginning in the 1950's and 1960's, CPR was found to be valuable in saving lives, especially those in surgery and post operatively, as they suffered from the effects of the surgery,

blood loss, plus medications.³¹⁰ By 1970, the process of CPR was ingrained in all hospitals in the United States and one that every patient would experience as a cardiac arrest is the one “common pathway” for all deaths.³¹¹ During this same time into the 1980’s, ethicists were speaking out about this assault at the end-of-life while the patients’ right movement was cheering that the patient had a right to self-determination saying CPR was another choice option for patients.³¹²

From the beginning, resuscitation efforts were to be used for those in generally good health before the cardiopulmonary arrest and who would most likely survive, however, today all hospital patients will be resuscitated unless there is a specific provider order to not resuscitate.³¹³ Initially CPR was to save lives, but it has become another means of futile treatment creating a burden on resources which, if the resuscitation is successful, at best, return the patients to their dying state.³¹⁴

Even after taking the CPR concerns at the end-of-life into consideration, there are some reasons why CPR or a “full code” still continues until the moment of death for those who are actively dying. These include: 1) CPR is the one unique medical intervention where lay people are taught to perform it, yet, it takes a medical order to not do it. In some cases families have stated to providers that they will initiate CPR on their loved one if the staff do not; 2) there is a misguided public about the true benefit of CPR as miracles do not just happen when it is performed; 3) there are inappropriate demands for CPR across the socioeconomic continuum where there is often concern that, due to a “lesser status”, there is discrimination and a loved one is being denied; 4) there are few instances where the opportunity of benefit from CPR is zero, so CPR is seen as better than death; and 5) unfortunately once a patient is made a DNR or “no code”, studies indicate patients receive less care. There are less provider visits and less nursing

care given to the patient once a DNR has been ordered. ³¹⁵

It is a challenge to remove “full code” from the end-of-life scenario, but there are some recommendations that might assist in moving it in the right direction. These recommendations include: 1) removing the DNR, do not resuscitate, from the vocabulary to be replaced by “do not attempt resuscitation (DNAR) as CPR is only an attempt at resuscitation; 2) make a routine part of every admission to the hospital the discussion regarding code status, not assuming everyone is a full code until the discussion occurs at end-of-life. A follow up conversation needs to occur at frequent intervals as the patient’s condition changes; and 3) begin early open discussions with family members, so if a later discussion is needed, the stage has been set. Some states allow providers more discretion in making the final decision regarding DNAR, while other states require patient/family consent.³¹⁶

Confronting the resuscitation issue early is one way of coming to terms with withholding and withdrawing treatment. There are recommendations that can assist with managing some of the ethical debates and conflicts surrounding futility treatments at end-of-life. Following is a discussion of these recommendations.

5.VI.A.2. Recommendations

Recommendations that can be a benefit to the patient at the end-of-life is to increase the collaboration with the nurse members of the health care team. Most often physician providers are the ones who make the decisions regarding withholding and withdrawing of treatment.³¹⁷ Nurse providers rarely take part in this decision making process, even though they spend the most time with the patients and their families, which provides an opportunity to know their values and beliefs regarding dying and end-of-life.³¹⁸

Research on withholding and withdrawing treatment at end-of-life in adult critical care

indicates variant views between nurses, intensivists, and primary care physicians. A summary of some of these results indicate that 1) the reasons treatment is withheld or withdrawn is the same for all three groups which are futile treatment and patient's wishes; 2) regarding collaboration on withholding and withdrawing treatment, greater than 80% found it very or extremely satisfied with more noted in teaching hospitals. Of these, 63% were primary care physicians, 36% intensivists and 27% nurses; 3) when asked if decisions to withdraw treatment were postponed unnecessarily, nurses responded affirmatively 43%, intensivists 29% and primary care physicians 2% with the main reasons being fear of making end-of-life decisions, lack of guidelines on withdrawing treatment, and different opinions around staff; and 4) almost all nurses believe they should be involved in the decision making process, half of intensivists believe nurses should be involved and few primary care physicians believe they should be involved.³¹⁹ The final recommendation is that although nurses have no legal responsibility to be at the decision making table, these decisions should best be made from a multi-disciplinary perspective.³²⁰

Overall physicians agree on a daily assessment regarding patient outcomes but as the patients got sicker with a longer length of stay, the opinions differed.³²¹ The nurses tend to be more realistic regarding poor outcomes and were more apt to recommend withdrawing treatment earlier and more frequent than physicians.³²² Whereas, the future quality of life for the patients, as predicted by both nurses and physicians, was unreliable leading to recommended caution regarding using this metric for withholding or withdrawing treatment.³²³

Another recommendation related to withholding and withdrawing life support is in the emergency department (ED). Each year over 200,000 deaths occur in the nation's emergency departments.³²⁴ Over 80% of these patients had chronic underlying diseases and/or serious functional decline.³²⁵ The emergency department is unique in that the physicians have no

relationship with the patients or families, or knowledge regarding their state of health or wishes regarding end-of-life treatment.³²⁶ These circumstances make it difficult to intervene to withhold or withdraw treatment when the patient arrives, usually via ambulance, and decisions are needed in an emergent timeframe.

Palliative care in the emergency department has been found to be inadequate with over 35% not receiving any palliative care.³²⁷ Education and training is needed, not only for the present emergency physicians but for the future physicians, who will see an increasing population of elderly declining patients in need of end-of-life palliative care.

Just as enhanced palliative care is needed in the emergency departments, there is a need for maximizing the potential for quality of life for those suffering from a life limiting illness in the form of an integrated palliative care approach.³²⁸ Following is a discussion of the benefits and opportunities for palliative care as well as those related to euthanasia, physician assisted suicide and palliative sedation.

5.VI.B. Role of Palliative Care

Medicine has traditionally been aimed at the curative which eventually led to a preventable aspect leaving palliative medicine to emerge after both curative and preventable medicine had failed.³²⁹ Palliative care started with a focus of the patient who was dying, which confused it with hospice.³³⁰ Palliative care then evolved to care for those with a life-limiting illness, for which a cure is not possible, and the associated symptom management.³³¹ The ultimate goal of palliative care is to improve the patients' and families' quality of life.³³²

Palliative care programs are now prevalent in almost all organizations and are closely aligned with hospice programs. They are best developed for the adult populations with perceived benefits and opportunities. Following is a discussion on these benefits and

opportunities.

5.VI.B.1. Benefits and Opportunities

The benefits of palliative care are multifactorial. First, palliative care has an impact on both patient outcome and satisfaction. Studies indicate a length of stay reduction of 25% when palliative care is involved with the care of the patient.³³³ Second, palliative care has a financial impact ranging from a 77% cost reduction to a 9% cost increase with a 35% weighted overall reduction.³³⁴ A third benefit revolves around symptom management, especially pain management. Pain and the associated suffering that accompanies life-limiting illness is the number one symptom that is focused on in palliative care programs.³³⁵ Pain management through palliative care uses pharmacological and non-pharmacological methods to achieve pain relief with palliative sedation as a last option.³³⁶ A fourth benefit is the multidisciplinary approach which uses a medical, physical, psychological, spiritual, occupational, and social approach considering the whole patient.³³⁷ A fifth and final benefit of palliative care is the reduction of futile treatments. Although the data on this benefit is not as robust as researchers would prefer, it is the cost savings from its use that validates that palliative care makes a difference in reducing expenses at end of life in critical care.³³⁸ Cost savings are never the main goal of providing palliative care to patients but its impact cannot be overlooked. Palliative care programs have shown a reduced stay in both critical care, as well as the hospital, plus fewer diagnostic tests resulting in a 40% reduction in the cost of end-of-life care.³³⁹

As there are benefits with palliative care, there are also opportunities. The first opportunity is in the area of continued research in order to generate compelling empirical evidence with a focus on quality of life with early intervention.³⁴⁰ A second opportunity is to incorporate palliative care into critical care. Although this is happening more often across the nation, there is

still a need for it to occur early in the patient's illness with the bedside nurse often being the lead in getting that referral.³⁴¹ Therefore, critical care nurses and intensivists need education and training regarding the role palliative care plays in patient care and improving the quality of life for the patient, as well as family.³⁴² A third opportunity is based on limited resources that prevents some organizations from implementing a multi-disciplinary palliative care programs.³⁴³ Although more hospitals offer palliative care, approximately 25% meet the Joint Commission's staffing guidelines for palliative care programs.³⁴⁴

Although over 70% of Americans indicate they want to die at home, less than 25% do, with fewer than 60% of hospitals in any particular state offering specialized end-of-life services.³⁴⁵ The fifth and final opportunity is to continue to improve the experience of dying by sharing how patients can find meaning in life, experience love, say their farewells, and uncover remaining new avenues of hope.³⁴⁶ Death is still a frightening experience that patients and providers, especially physicians, try to avoid, as if it is an option, instead of a natural process.³⁴⁷ One of the major goals of palliative care is to provide a "good death" which honors the life of the patient, as well as ensuring the final days are a time of purpose, meaning and a legacy of a life well lived.³⁴⁸

Another goal of palliative care is the avoidance of euthanasia.³⁴⁹ Euthanasia is not legal in the United States but it gets confused with physician assisted suicide and palliative sedation.

Following is a discussion on these concepts.

5.VI.B.2. Euthanasia, Physician Assisted Suicide, and Palliative Sedation

Euthanasia involves a person, usually a physician provider, who intentionally ends another's life by a medical intervention, such as an injection of a paralytic agent.³⁵⁰ Euthanasia is not legal in any of the 50 states in America, but is legal in Belgium, the Netherlands, Luxembourg, Columbia, and Canada.³⁵¹ The goal of euthanasia is the patient's death.³⁵²

Physician assisted suicide or physician assisted dying involves the provider prescribing drugs for the patients to take to end their own life.³⁵³ In order to qualify for the assistance in dying in the six states where it is legal, the patients must have a terminal condition.³⁵⁴ The major reasons to seek assistance for death relate to pain, depression, being a burden, loss of dignity, and being dependent on others.³⁵⁵ The goal of physician assisted suicide or dying is death.³⁵⁶

Palliative sedation is an end-of-life treatment used for those who have intractable suffering, usually due to pain, but can be for other symptoms such as nausea and vomiting.³⁵⁷ The goal of palliative sedation is to relieve the suffering, which often leads to unconsciousness and the possibility of precipitous death.³⁵⁸ Since palliative sedation is closely tied to end-of-life, it has been referred to as ‘terminal sedation’ a term that has fallen out of favor. Palliative sedation is not only used for intractable symptoms, but is also used in conjunction with withdrawing mechanical ventilation when the patient is not expected to survive.³⁵⁹ The sedation prevents signs of air hunger, which increases anxiety in both family members and caregivers.

There are four factors that need to be present in order to consider a patient for palliative sedation. First, is the patient is terminally ill; the second is that the patient has intractable symptoms; third, the patient be a DNAR; and finally that death is expected to occur within hours or days.³⁶⁰

In the process of administering palliative sedation, the patient may die. The principle that serves to justify the result of the action is the principle of double effect. In order for this principle to apply four conditions must be met. These include: 1) the end action must be morally good; 2) the bad effect must not be the means of causing the good effect; 3) the bad effect is not intended and only tolerated; and 4) there must be a grave reason for the action.³⁶¹

5.VII. Conclusion

The topic of medical futility, or medically inappropriate treatment, is most often found in the adult population, especially the elderly at the end-of-life. Knowing when to withhold or withdraw these medically inappropriate treatments is a challenge as determining decisional capacity of the patient is paramount. Yet, less than 5% of the adult critical care patients have decisional capacity at the end-of-life.

Therefore, decisions regarding the continuation of treatment depends on surrogate decision making either via an advance directive, which remains limited, or through substituted judgment or the best interests standard. In most cases, an agreed upon plan is able to be determined through collaboration between families, surrogates and providers. For those small numbers that cannot reach an agreed upon decision, there is fertile ground for conflict as struggles occur between the patients', families' and providers' autonomy. This struggle can lead to both over and undertreatment.

There is hope for the future in several arenas. First, the ability to communicate cannot be over stressed. This must start with the providers who must hone their communication skills with patients, families and surrogates that begins the moment the patient enters the critical care unit then increases in frequency and intensity as end-of-life nears. Second, the ability to get reimbursed for having 30 minute conversations with Medicare patients regarding advance care planning may still have an impact on the development of advance directives so that the patients' voices can be heard. Finally, the palliative care programs across the nation are making a difference, especially those who are partnering with critical care so that interventions can begin early in the critical illness. However, more work must be done with administrative commitment to staff the programs appropriately. Dame Cicely Saunders, who is described as being

responsible for establishing the discipline and culture of palliative care, is quoted as saying, “we will do all we can, not only to help you die peacefully, but also to live until you die.”³⁶² Not only is this the belief for palliative care, but something all patients would wish for at the end-of-life.

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Chapter 6: Futility and Moral Distress

6.1. Introduction

The presence of medically inappropriate treatment, or medical futility, is in all the critical care units along the age continuum, to include neonatal intensive care, pediatric intensive care, and adult intensive care. These medically inappropriate treatments have been shown to prolong patient suffering, utilize precious resources, and at times, be a source of conflict between families, surrogates, and providers. However, there is a casualty from medical futility that often gets overlooked. This is the moral distress that is found in the nursing population who work in these critical care units.

Moral distress, a relatively new term, has been evident longer than it has been identified or given a name. Florence Nightingale, the founder of modern nursing, spoke of the moral and ethical dilemmas in nursing in her *Notes on Nursing* and recognized the dilemma when she stated “...even the most morally courageous staff may fear to speak up”.¹ This is still the case today.

Although moral distress is found in all health care professions, it is most prevalent in nursing, especially critical care nursing, and is one of the major ethical concerns affecting the nursing profession. The intensity of critical care nursing, combined with medically inappropriate treatments at the end-of-life, makes critical care an opportune environment for moral distress. This moral distress not only threatens the moral integrity of the nurses, but can also have a major impact on the quality of care delivered to the patients and their families.

Chapter 6 explores the effect of medical futility on moral distress in nursing. The first part of the chapter will describe the historical development of moral distress by defining it and

examining the conflicting terms that are often confused with it. A conceptual framework will also be discussed. The second part of the chapter describes the integrity and intensity of moral distress which details the root causes and contributing factors to include medical futility as a major cause. The impact of moral distress on the nurse and nursing profession will be described with two examples given to further the description. The final areas that will be explored relates to strategies to confront and prevent moral distress.

6.II. Historical Development

Much has been written on the topic of moral distress as it pertains to nursing.² Moral distress is seen as a concrete clinical occurrence that can be defined with definite themes. This section examines not only the first definition of moral distress by Jameton, but also extends to a new broader definition. A discussion will follow on the manifestations of moral distress and the conflicting terms that are often associated with it.

6.II.A. The Nature of Moral Distress

The role of the nurse is an ethical one that is first and foremost concerned with the essential goals of health and life of the patient.³ Since patients are usually unable to do for themselves, especially in critical care, the nurse becomes their agent acting in their best interest and as their advocate. When something interferes with this action of doing the right thing for the patient, moral distress can result. Following is a discussion on the definition of moral distress and the three types of moral problems.

6.II.A.1. Definitions: Original to Broader Definition

Moral distress was first defined by Jameton in the 1980's as something nurses feel, along with guilt, when they engage in actions and treatments that they believe to be wrong but

are unable to avoid due to constraints.⁴ These constraints can be internal, or personal, in addition to external, or institutional.⁵ Hanna further defines moral distress as recognizing, with discomfort and pain, when the good of a living thing or situation is in jeopardy through a particular act.⁶ According to Hanna, the threat to a good can be shown in several ways. One way is as shocked moral distress where there is an intense feeling followed by action such as anger, fear, or panic with activation of leaving the situation, calling for help or speaking with others involved.⁷ Another way is as muted moral distress where there is an “interior” response but the “exterior” is silent. A final way is as suppressed moral distress which is difficult to assess as “blunting” occurs so the thoughts and feelings are suppressed.⁸ This suppression can lead to chronic distress over time exhibited by symptoms ranging from fatigue to GI upsets to depression.

A more current way of describing moral distress describes what happens when a person perceives a moral problem then accepts moral responsibility by making a moral judgment regarding what is the most appropriate action.⁹ However, because of limitations, real or perceived, the person engages in moral “wrongdoing” by either an act of omission or commission that is seen as morally wrong.¹⁰ Another way to describe moral distress is to view it as what happens when a moral situation presents itself with a moral decision regarding the right action but a perceived inability to act leading to painful, negative feelings and “psychological disequilibrium”.¹¹ Webster and Baylis have proposed their definition which is that moral distress occurs when one does not do what one believes to be right due to an error in judgment, a personal weakness, or circumstances beyond one’s control, such as not enough staff. ¹²

A newer definition proposed by Campbell, Ulrich, and Grady looks at broadening the definition of moral distress. Since moral distress is seen as a “practical problem” that can affect

the welfare and retention of nurses, as well as patient outcomes, there are six types of situations where cases can emerge that present a spectrum for moral distress.¹³ These situations include: 1) moral uncertainty where the knowledge as to the right thing to do is not clear because of unclear principles, uncertainty, or lack of information; 2) mild distress which is less than the dramatic distress usually associated with moral distress and although these can have a cumulative effect, each one by themselves is mild; 3) delayed distress which indicates that moral distress may not occur at the time of the event but come later; 4) moral dilemma occurs when there is no perceived “morally” right thing to do; 5) bad moral luck where an individual performs in a morally appropriate manner, yet, the results are morally objectionable; and 6) distress by association where distress results from association with another or a group.¹⁴ The view of these six situations has then led to the definition of moral distress as self-directed negative attitudes or emotions that develop when there is involvement in an incident perceived as morally undesirable.¹⁵ This definition has been criticized as being too broad needing further research.¹⁶

Jameton not only defined moral distress but identified types of moral problems that affect nursing. Following is a discussion on these problems.

6.II.A.2. Moral Problems

The first problem is moral uncertainty. Moral uncertainty occurs when the nurse is unsure what the moral problem is, yet, has a “nagging” feeling or uncertainty that there is something wrong.¹⁷ An example can be when an elderly patient appears to be in poor health and neglected, with the problem getting minimal attention, plus the nurse is not satisfied with the treatment but is not able to identify the cause of the dissatisfaction.¹⁸

All humans, when faced with uncertainty, attempt to reduce it, even though it can either present as an exhilarating challenge or that which produces great anxiety and a sense of

powerlessness.¹⁹ Uncertainty-identity theory is based on the belief that feeling uncertain is distressing and intensely motivating.²⁰ If there are perceived resources to assist with the uncertainty, then there is powerful action behaviors, if the resources are not sufficient, then there can be a feeling of threat and “avoidant” behaviors with increased uncertainty.²¹ There are two cautions regarding the reduction of uncertainty. These are: 1) that it is possible to feel less uncertain, but not fully certain. Only those who are delusional feel fully certain; and 2) as one strives to reduce uncertainty, the process often increases the uncertainty.²² This is seen in nursing where the nurse is uncertain as to the adequacy of the care of the patient then approaches the physician with the concerns only to be belittled or criticized, often in the presence of patients/families and peers. Therefore, the original concerns are not resolved, plus there is now conflict between the nurse and the physician, that may not be resolved, adding to the building moral distress.

The second moral problem is moral dilemma. A moral dilemma occurs when two or more moral principles apply and can both be ethically justified making the decision difficult as only one course of action can be taken.²³ To give up either decision can seem daunting with a feeling of a loss being inevitable.²⁴

For critical care nurses, the occurrence of moral dilemmas most often are reported with conflicting goals between the organization and the patient.²⁵ This dilemma is often found when there is inadequate staff to accomplish the care the nurse perceives the patient deserves leaving them with a guilt-ridden conscience at the end of the shift.²⁶ Repeated shifts of this same pattern eventually take their toll leading to moral distress.

The third problem is moral distress, which is what occurs when an individual knows the appropriate action to take but because of some constraint is unable to take that action.²⁷ The

inability to take action can lead to anger, shame, agitation, and frustration.²⁸

With moral distress being discussed frequently in the literature, it is among many terms that headlines articles, book titles, and media announcements. Although there may be a fine line that differentiates the terms, there is a difference. Following is an explanation of these conflicting terms as well as a discussion on moral distress and moral residue.

6.II.B. Manifestations of Moral Distress

As moral distress is described as a layered, complex, and relational concept that threatens the individual's identity, as well as integrity, by its manifestations in moral compromise, it can be confused with other related concerns or concepts.²⁹ Moral distress is not the normal pressure or conflicts of the workplace; it is not PTSD or 'compassion fatigue' which can occur along with moral distress, but it is different and is treated differently.³⁰ Following is an explanation of two of the terms most commonly confused with moral distress.

6.II.B.1. Conflicting Terms

For moral distress to be fully understood, it is helpful to examine the terms of compassion fatigue and burnout as these are the most frequently seen terms in the literature which are used alongside moral distress or compared to it. Compassion fatigue is defined as the product of a prolonged and intensive relationship with patients and exposure to stress.³¹ The result is an expenditure of physical, social, emotional, spiritual, and intellectual resources in the individuals that exceed their "restorative processes".³² Compassion fatigue has been describes as the "cost of caring" when one is deeply entrenched in another's care and situation, as is often the case in critical care nursing.³³

Burnout is similar to compassion fatigue and is often closely associated with it as well as with moral distress, however, there are differences. While compassion fatigue occurs more

abruptly and is a result of being exposed to someone else's pain and suffering, burnout occurs more gradually when there is a feeling of powerlessness and job dissatisfaction which leads to eventual disengagement. Critical care nurses are especially vulnerable to burnout as they are routinely challenged not only by the work routines, but also by the too often lack of staff and time to adequately care for the patients.³⁴

Over time the three classical symptoms of burnout develop which are exhaustion, depersonalization or detachment, and decreased personal accomplishment.³⁵ Exhaustion, especially mental exhaustion, seen in 73% of critical care nurses, can be seen when a nurse cares for the same patient repeatedly who has no chance of recovery at the end-of life.³⁶ Depersonalization, seen in 48% of critical care nurses, is a separation from the work environment expressed by cynicism and blame where the patient is viewed as less than human.³⁷ Decreased personal accomplishment, seen in 60 % of critical care nurses, is a feeling of negative self-worth and poor self-esteem.³⁸

Risk factors for burnout include personal characteristics, organizational elements, working relationships, and end-of-life concerns.³⁹ The concerns related to end-of-life, include caring for those who are dying or participating in withdrawing life-sustaining treatment. ⁴⁰ The best treatment for burnout is prevention through self-care and creating a professional environment that focuses on teamwork and positive working relationships.⁴¹

Moral distress and burnout can overlap with one leading to the other, or occurring at the same time, which complicates the situation for both nurse and patient. Following is a description of moral distress which can lead to moral residue if it is not addressed.

6.II.B.2. Moral Distress versus Moral Residue

Moral distress can be differentiated as initial or reactive. Initial is that immediate response

when an obstacle is encountered and may be exhibited by anger, fear, anxiety, etc.⁴² Reactive distress is the negativity that results when the initial distress is not dealt with and may be caused by the individual's personal obstacles which present no recourse.⁴³ Moral residue is described as that which is carried with an individual after compromising values when faced with moral distress.⁴⁴ Moral residue is seen as a form of "betrayal" when surrendering one's values without defending them, and it correlates with Jameton's reactive distress.⁴⁵

Moral residue may be a result of the compromised integrity of moral distress where values, principles, and beliefs are either violated or dismissed.⁴⁶ With the passage of time the acute symptoms of guilt, despair, and uncertainty may have passed, but the feeling of moral compromise can last a lifetime becoming part of the moral residue.⁴⁷

Moral residue can have a positive effect when it becomes a clarifying experience for the individual as to personal values as well as identity and strengthen the commitment to do better next time.⁴⁸ Just as experiencing moral residue can bring about positive results, it can also lead to wrong thinking. This thinking most often takes three directions. These include: 1) denial—this is where the individuals persuades themselves that their personal and professional roles are separate so if the integrity in the professional role is compromised that does not mean the personal role was also compromised; 2) minimizing—the inconsistencies are minimized or trivialized so that they are really not that important; and 3) unreflective acceptance---this is where the inconsistencies between the person's values and beliefs are addressed by changing them to fit the situation.⁴⁹

An effect that has been described in the literature is called the crescendo effect. This effect is when there is an interaction between moral distress and moral residue, after repeated episodes of both, and even though the morally distressing situation may resolve, the residual distress rises

and continues to rise with a building stair step effect.⁵⁰ Because of this crescendo effect, the caregivers, or nurses, may react with enhanced intensity to repeated situations which are often taken as “over emotionalism” by nurses.⁵¹ Whereas, in reality these “over emotions” are threats to the individuals’ moral integrity. As a result, there needs to be a high alert for the building crescendo effect in the critical care units. Moral distress incidents, with the resulting residue and crescendo effects, are usually repeated yielding further implications. These implications include: 1) the realization that the issue is usually not about the patient but are deeper problems related to communication, collaboration, and powerlessness in the work environment; 2) ethics consults need to be alert to see beyond what is stated as the ethical concern because the real issue may be moral distress; and 3) moral distress is not confined to only one individual in a unit but affects all those who work there.⁵²

There has been a struggle to determine a conceptual or theoretical framework from which moral distress originates. The next section will explore some thoughts on the conceptual framework for moral distress focusing on professional and personal identification as a place to begin, concluding with the role of moral sensitivity and ethical climate.

6.III. Conceptual Framework

Since there has been a lack of a formal conceptual framework for moral distress, this is thought to have hindered further research and formulation of directed education and policies.⁵³ Historically, nursing has been viewed as a moral profession where caring for another is at its very core. The nursing profession has the expressly stated goals to keep patients safe, to prevent complications, and to provide a healing environment for both patients and their families.⁵⁴ When these goals are impeded in any way, the individual nurse along with the patient suffer. It is in

this context of the nurses' professional and personal identification that a conceptual framework is presented for moral distress.

6.III.A. Professional Identification

The professional identification and obligations of nurses cannot be separated from the nurses' personal identification and conscience.⁵⁵ Along with the goals of the nursing profession that nurses are made aware of when they enter the nursing profession, are associated values. These values are enduring, as well as being closely aligned with nurses' professional identity, allowing nurses to promote the moral integrity standards of the profession.⁵⁶ Following is a discussion of how nursing as a moral profession contributes to moral distress with the identification of four underlying themes that can be found in those who experience moral distress.

6.III.A.1. Nursing as a Moral Profession

By its very nature, nursing is a moral profession that cares for life from its beginning to end and moral concerns are bound to occur along this continuum. If these moral problems are not resolved or are resolved in ways that have a negative effect on the nurse's moral integrity, then moral distress can result.⁵⁷ This moral distress can be expressed with anger, frustration, guilt, and powerlessness to the extent that nurses withdraw from how they care for the patient, avoiding contact with the patient, or giving poor or little physical care to the patient.⁵⁸ This can then lead to burnout and the nurse leaving the nursing profession.

Moral integrity is seen to be of great value interpreted as reliable, durable, loyal, and objective in compliance with moral norms.⁵⁹ When considering integrity in the professional sense, it refers to the conduct as it occurs within the profession. A profession, like an employer, can make never-ending demands on a nurse, especially for someone new to the profession who

lacks experience. These demands can, in turn, lead to confusion, stress, and eventual withdrawal in attempts to deny the pain and suffering.⁶⁰ If these feelings are not addressed, the eventual outcome can be moral distress.

Within the professional identification of nursing are found two commitments that are formed by individual integrity. First is the commitment to intellectual excellence. This involves clinical knowledge, expertise, a commitment to lifelong learning, and clinical judgment with decision making that is evidence based.⁶¹ The intellectual excellence includes professional autonomy, in whatever role the nurse is in, plus responsibility and accountability for the quality of care provided with compliance with all regulatory requirements.⁶² Included in the intellectual commitment is advancing the profession through research, standard development and formation.⁶³

The second commitment is to moral excellence. Moral excellence refers to the commitment to the patient by practicing with compassion and respect for the fundamental dignity and worth of each individual regardless of race, gender, culture, religion, socio-economic status or nature of the disease.⁶⁴ This commitment considers conflicts of interest, as well as creating a moral environment in the workplace, plus self-care that promotes optimum personal health taking responsibility to seek guidance and intervention, when necessary.⁶⁵

To assist individuals with their professional identity and moral behavior, most professions have a code of moral ethics which serves as a reference for moral standards and behavior.⁶⁶ The Code of Ethics for Nurses was revised in 2015 with a focus on “The Year of Ethics” which incorporated more ethics terminology and introduced the term “moral distress”.⁶⁷ Moral distress, in the *Code of Ethics*, is defined in terms of a threat to one’s values and “moral integrity”.⁶⁸ However, even with the nursing profession having a strong ethical based code of ethics, findings

indicate that ethical beliefs are more determined by experience, values, and religious beliefs than from a code of ethics.⁶⁹

The original definition of moral distress by Jameton attributes a great deal to the external constraints that limit one from doing the right thing. There are other underlying considerations that reside both in the professional as well as the personal identifications. Following is a discussion on these considerations, as well as situations that give rise to moral distress in the workplace.

6.III.A.2. Underlying Considerations

There are four underlying considerations that can set the stage for moral distress. These are suffering, truth telling, role morality, and conflict. The first consideration is suffering which is accelerated when nurses are unable to serve the patient as their advocate in the way they believe is needed.⁷⁰ The suffering can be exhibited from the physical sense as a stress response from the cerebral cortex of the brain, plus the limbic system to the hypothalamus, which stimulates the Autonomic Nervous System activating all body systems.⁷¹ This response works well for the body in a “fight or flight” mode in the short term, but since moral distress can go on for a long period of time, staying in this hyper-response mode wreaks havoc on the body. This prolonged activation can over stress the body leading to many somatic complaints, such as headache, diarrhea, heart palpitations etc. Psychological and emotional suffering include anxiety, depression, fatigue, guilt, self-blame, self-doubt, hopelessness, and anger.⁷² This is especially the case at the end-of-life when pain is not being managed or when medically futile treatment is being provided to an already suffering patient.⁷³

The second consideration is truth telling. The way truth telling, or the lack of it, contributes to moral distress is when there is active deception. This deception occurs when there is a failure

to take needed action or not informing the patients regarding actions or treatments that would be in their best interest.⁷⁴ Other areas related to truth telling are whistle blowing or reporting someone who is not following policy, or is practicing inappropriately, and when administration consciously misrepresents the truth to employees.⁷⁵

The third consideration is role morality. Role morality is defined as actions nurses take to fulfill the goals of nursing.⁷⁶ A major action to meet these goals is to be the patient advocate, which most all nurses would agree that they went into nursing “for the patient”. What happens when being a patient advocate cannot be achieved, is that the nurse has choices. These choices include to act with anger, decide on a “never again approach” with future patients, withdraw by leaving the unit or nursing, all of which only lead to emotional detachment and moral distress.⁷⁷

In role morality, deciding what action to take creates a conflict of moral values. Moral distress can occur when one’s personal values and beliefs are compromised, as well as one’s professional values and beliefs.⁷⁸ While there is discussion as to whether the personal identification can be separated from the professional, failure to act as a “good” nurse can signify failure as a human being.⁷⁹ Choice is seen as the single key integrating element of nurses’ actions while other actions, such as advocacy, autonomy, and relationships, are integrated with choice.⁸⁰ If a moral situation is present and the nurse responds with shock, as well as anger, it is referred to as moral outrage.⁸¹ When nurses then act, as a result of this outrage, even if feeling fear, they are expressing moral courage.⁸² Those who have moral courage and are willing to dispute or challenge, regardless of the personal threat, are less likely to experience moral distress.⁸³

The fourth and final consideration is conflict. Ethical decision making is often based on values which act as a frame of reference when there is a morally distressing situation.⁸⁴ A

conflict in values, that cannot be resolved, causes internal discord which can then lead to moral distress. Key sources of conflict that have been identified for nurses working in critical care areas include those decisions that surround the patients and their wishes along with informed consent and confidentiality.⁸⁵ Conflict can also occur from providing treatments that are by definition futile or are concerned with limiting life-sustaining treatment.⁸⁶ Conflict can also occur in those situations that arise when working in an environment that does not support questioning regarding ethical concerns, as well as the lack of nursing being a part of the decision making for clinical resolution.⁸⁷

Just as there are considerations that set the stage for moral distress to occur, there are situations in the work environment that make it fertile ground for moral distress to appear. The first situation is when the nurses' judgments are not considered or when nurses disagree with decisions that did not put the patient first.⁸⁸

The second situation that can give rise to moral distress is in the area of professional autonomy and scope of practice. This can occur when a nurse's contribution is underrated by peers, physicians, and management making the nurse's input to patient care, as well as quality patient outcomes, appear to have no value.⁸⁹

The third and final situation that can give rise to moral distress occurs when the standard of care is not being met to include supporting the patient's autonomous rights. It is especially troubling to observe a peer or colleague not following the standards of practice, which falls below one's own professional criteria for moral integrity, as confronting the individual can produce moral distress, as well as not confronting.⁹⁰ Such a situation is amplified when patients are deceived, either by withholding information, or consciously misinforming them.

Just as the professional identity provides a framework that explains moral distress, personal

identity is also a part of that framework and cannot be separated from the professional component. Following is a further exploration of personal identification with a discussion on moral sensitivity as well as moral climate and the role they play in moral distress.

6.III.B. Personal Identification

The personal identification found in moral distress in nurses starts from the beginning during the education process to become a nurse. It begins when the nurses are indoctrinated with the sentiment that they have a “sacred” duty to those in their care, in that the “patient always comes first”.⁹¹ This preconceived idea regarding the care of the sick and injured stays with nurses throughout their practice.

Nurses are formed morally, not only by the professional requirements, but also by the requirements of personal identity. The source of personal identity can be found in one’s genetic background, environmental influences, and religious beliefs.⁹² A significant finding has been that those with religious or spiritual beliefs have fewer incidences of moral distress, which is believed to be due to seeing end-of-life issues differently with more hope than non-believers.⁹³

As nursing is a moral endeavor, the theory of moral distress depicts a chain of events that occurs from the external work environment that induces an internal or individual response when the nurse is unable to advocate for the patient.⁹⁴ This theory is based not only on the belief that nursing is a moral profession, but also that nurses are moral agents. Whenever moral agency cannot be engaged, moral distress is more apt to occur and the presence of moral competency can help keep that from happening so that moral action is the result.⁹⁵

Another key in personal identity has to do with empowerment and the belief that one can succeed in a particular situation. This empowerment is based on learnings that include a belief that places value on one’s work, a belief that one is skilled to accomplish the action of the work,

a belief that one has control over one's autonomy, and a belief that one's work makes a difference.⁹⁶ Moral distress is reported less often in those who express that they feel empowered.⁹⁷

Recent studies indicate that the severity of moral distress varies according to two influences. These are moral sensitivity and moral or ethical climate. Following is a discussion regarding these influences.

6.III.B.1. Moral Sensitivity

Moral sensitivity is a skill that individuals can develop which can augment personal identity. Moral sensitivity is defined as a "process" through which a person senses that there is an ethical issue or problem, then defines the issue or problem, and decides what the best options are.⁹⁸ Having moral sensitivity compels nurses to be able to interpret behaviors from patients, both verbal and non-verbal.⁹⁹ The concept of having a "moral sense" dates back to the 17th century with British philosophers who proposed that making moral decisions, or moral and ethical differentiation, was as much a feeling as it was a mental judgment.¹⁰⁰ Moral sensitivity is also influenced by the nurses' culture, sexual preference, gender, age, education, religion and values.¹⁰¹

As moral or ethical problems are identified, one of two directions may be taken. One direction involves moral uncertainty where moral sensitivity is not fully developed so the problem is not confronted and no position is taken.¹⁰² The second direction involves moral deliberation where information is gathered, reviewed, with action taken as appropriate.¹⁰³ If there is an obstruction that occurs in the moral deliberation process, a "chain of moral distress" can occur which can also re-stimulate the deliberation and if obstruction continues a sense of powerlessness can result.¹⁰⁴

Moral sensitivity is also seen as an intuitive skill that allows one to identify the moral conflicts while visualizing the proposed consequences of actions taken. There are four generalizations that can be made that show the relation of moral sensitivity to moral distress. These are: 1) nurses with a keen moral sensitivity tend to have less moral distress as they are more committed to patients with an advanced moral competency; 2) nurses who have moral sensitivity, but lack moral competency, are more apt to have moral distress; 3) nurses with moral sensitivity that employ various problem solving strategies to solve ethical dilemmas are more apt to have moral competency with less moral distress; and 4) gender, education, and experience all may have an effect on moral distress that varies between individuals.¹⁰⁵

Moral sensitivity is more apt to develop in a moral or ethical climate. Ethical climate is defined as the perception of the organization, by the individuals who work there, that affects their behaviors and attitudes.¹⁰⁶ Following is a discussion on ethical climate and its role in moral distress.

6.III.B.2. Ethical Climate

The ethical climate within an organization fosters ethical inquiry and discussion, along with differing opinions, while valuing the individuals in a trusting relationship.¹⁰⁷ The trusting relationship for the nurse extends to patients, peers, physician colleagues, managers, and administrators with evidence indicating that a positive ethical climate is necessary to support professional nursing practice.¹⁰⁸

The ethical climate of an organization can help mitigate the effects of moral distress in an individual.¹⁰⁹ The ethical climate can also be modified to improve the work environment which is done through interactions, policies, role clarity, and the overall culture to include ethical behaviors that are accepted, as well as those that are not.¹¹⁰

The ethical climate does not get as much attention as moral distress, yet, focusing on the symptoms, and not the cause, will not lead to any permanent resolution. Critical care nurses have expressed that major concerns in the work environment are the lack of involvement in ethical discussions, inadequate support of their practice from administration, and inconsistent practice policies.¹¹¹ Further concerns are differentiated patient care ethics, where nurses wanted a voice, and organizational ethics, where nurses often did not see organizational values being followed, with more focus on the bottom line than on patient care.¹¹²

When the nurses' concerns are present in a poor ethical climate, even if there is a high level of moral sensitivity, there is a "psychological disequilibrium" that occurs.¹¹³ This leads to moral distress when the decision is made but the correct moral behavior cannot be accomplished as a result of the constraints of the climate. Nurses will respond to the type of climate they work in. Therefore, a positive, strong, ethical climate will not only recruit nurses who respond in an ethical manner, but will also tend to retain them longer.¹¹⁴ The opposite is also true as nurses will tend to not respond in an ethical manner in a negative ethical climate. Moral agency serves to link the concepts of moral sensitivity and ethical climate with moral agency being seen as a moral recognition of moral problems and the associated duty to others.¹¹⁵

Studies have been done examining ethical climate and its effect on various professions. Regardless of the profession, perceptions of a higher ethical climate led to lower moral distress.¹¹⁶ Even in the same ethical climate, physicians, overall, scored lower levels of moral distress than nurses and other allied professionals.¹¹⁷

Moral distress has received much attention because it is so compelling, as well as detrimental to the integrity of those affected by it. The intensity of moral distress can vary between nurses in the same unit and between separate nursing units. The next section examines

the integrity and intensity of moral distress by exploring its root causes and contributing factors identifying the nurse-physician relationship as a major factor. Medical futility will be discussed as the number one reason for moral distress in nurses, as it is for physicians and other allied health professionals.

6.IV. Integrity and Intensity of Moral Distress

Continued exposure to moral distress, which can lead to moral residue, can affect one's core values and sense of duty which are integral to integrity.¹¹⁸ Integrity is defined as the feeling of "wholeness" and self-worth that is a result of congruency between one's values and actions.¹¹⁹ With a loss of integrity, in the presence of moral distress, there is a fear that it will lead to a subsequent loss of one's personal and professional identity which would be devastating.¹²⁰ Based on the situation and the individual nurse, the intensity of the moral distress can vary from low to high. In order to address the integrity and intensity of moral distress, getting to the root causes, plus the contributing factors, is the best approach to minimizing its presence. Following is a discussion of the root causes and contributing factors of moral distress with an in-depth explanation on medical futility, the number one reason for moral distress in critical care nurses.

6.IV.A. Root Causes and Contributing Factors

Common root causes and contributing factors have been identified for moral distress through nursing research, however, not every nurse who is exposed to these situations will experience moral distress.¹²¹ Even if moral distress is experienced when these causes or contributing factors are present, the intensity of that moral distress may also vary depending on the nurse and the situation.

The root causes for moral distress have changed little over the past 10-12 years. The top

seven root causes, or sources, in rank order, of moral distress found in critical care nurses include: 1) lack of continuity of care which contributes to suffering for the patient; 2) adhering to family wishes for life-sustaining treatment when it is not in the best interest of the patient; 3) poor communication which affects care; 4) prolonging death with life-sustaining treatment; 5) staffing levels which are deemed “unsafe”; 6) feeling obligated to follow orders seen as “unnecessary”; and 7) focusing on cost reduction which affects optimal care.¹²² Of these seven root causes, all can be present as a source or result of futile treatments leading to moral distress.¹²³ Other root causes that have been identified include working with nurses or physicians who do not measure up to competency standards, giving false hope to both patients and families, and failure to provide adequate pain management out of fear of hastening death.¹²⁴ The major root causes for moral distress are similar with both adult and neonatal/pediatric critical nurses with the exception of following the family wishes being the number one root cause for the distress in the neonatal/pediatric population.¹²⁵

The contributing factors for moral distress can be viewed from three perspectives, the individual, institution specific and external factors. An additional contributing factor that is a main source of moral distress in the nurse-physician relationship. Following is a discussion on these contributing factors.

6.IV.A.1. Individual, Institution Specific and External Factors

The contributing factor related to the individual, includes personal character traits, or who they are, and their comprehension of the incident, especially related to autonomy and taking authority.¹²⁶ It can also include a worldly view of expectations, moral sensitivity, and the perspective of one’s values.¹²⁷ The role of the nurse, the nurse’s confidence, along with the nurse’s knowledge and skill all shape the experience of the moral distress event.¹²⁸

Another area that rests with the individual is the value of experience. Some studies indicate the more experience the nurse has, the less moral distress, which may be a factor of more exposure, increased ability to resolve issues, or a dulling of one's "psyche" from the prolonged exposure to stressful situations.¹²⁹ Other studies show the more experience, the more moral distress due to the increased exposure to situations.¹³⁰

For individual nurses to avoid moral distress, they must be able to communicate the ethical dilemmas in language that is both understandable to medical staff and administration.¹³¹ It is then necessary to have authority and capability to be able to take the necessary action required as a result of this dilemma.¹³² The courage and risk needed to take moral action may be the "greatest challenge" in avoiding moral distress for nurses.¹³³

The second source of contributing factors to moral distress is institution specific, however, many of the same issues are found in multiple institutions. In addressing institutional specific factors, it comes down to limited resources. The two limited resources that are prominent include time and money. These are operationalized into cost reduction initiatives, reimbursement concerns, or being unable to complete the tasks necessary to care for patients adequately.¹³⁴ However, the one institutional factor that gets named most frequently in both the United States and other countries is related to staffing. Staffing contributes to moral distress when there are insufficient numbers to adequately care for the patients, or if the staff training has been inadequate to care for the patients or to manage new equipment and procedures.¹³⁵

Another institutional specific factor relates to a lack of beds with the constant triaging of patients to be able to care for the most immediately critically ill, which can mean transferring patients out of critical care who may still need a great deal of care.¹³⁶ Added to this daily "musical beds" routine is the inadequate or insufficient palliative care services to meet the

patient needs, especially in the neonatal and pediatric population.¹³⁷ Other work related sources of contributing factors include such things as organizational structure, poor management, inferior communication, inadequate policies, lack of support from management or administration, and insufficient recognition.¹³⁸

A third and final contributing factor source for moral distress can be found in external factors. These sources are broad, but are found in the health care of today and include the professional responsibilities, the regulatory requirements, and compliance expectations.¹³⁹ Overall, the patient focused concerns are major sources of moral distress for nurses. These include actions to the patient that produce pain and suffering; prolonging the dying process without informing the patient or family about treatment options, such as palliative care/hospice; and the treatment of patients as “objects” for personal or organizational reasons.¹⁴⁰ In addition, the factors can include restrictive policies and procedures, legal constraints, and third party expectations.¹⁴¹

In the critical care environment, nurses and physicians must have a close collegial relationship in order to provide quality patient care. This does not always happen in every instance and the relationships that exist between nurses and physicians have been identified as an underlying root cause or contributing factor for nurses’ moral distress. Following is an exploration of this relationship as a cause of moral distress.

6.IV.A.2. Nurse-Physician Relationships

In an ideal world, the nurse-physician relationship would be both cooperative and collaborative where differences are confronted and openly discussed.¹⁴² However, this is not always the case because of various factors. One factor is the difference in the responsibilities of the two roles---the nurses focus on the “care” and the physicians focus more on the “cure” of the

patient.¹⁴³ A second factor is the disparity in status and authority between the two positions.¹⁴⁴ A third factor is the gender differences between the nurse and physician. Even with more men entering nursing and women becoming physicians, there are still male-female concerns.¹⁴⁵ The final factor is the enculturation of each profession through the training and education process that perpetuates the “physician gives orders” to the nurse and the “nurse follows them” hierarchical culture.¹⁴⁶

When addressing nurse-physician relationships, nurse autonomy and its connection between job satisfaction and moral distress are well known. Nurse autonomy is referred to frequently in the literature. This connection can be to professional or personal identity and integrity or to the nurses’ professional code and the ability to make autonomous decisions as one of the criteria to be a profession.¹⁴⁷

As nurse-physician relationships can be a major source of moral distress, so can “incivility” among and between all health care professionals.¹⁴⁸ This incivility is often demonstrated by bullying, refusing to assist co-workers or provide needed information, humiliating co-workers in public, and circulating gossip.¹⁴⁹

Critical care nurses make an average care decision every three seconds with a total of 18 clinical decisions every two hours.¹⁵⁰ These clinical decisions are further subdivided into intervention decisions, communication decisions and evaluation decisions, with not all requiring communication with the physician.¹⁵¹ For those that do require physician communication, when there is a collaborative approach between the nurse and physician, there is an enhanced level of autonomy, job satisfaction, and less moral distress.¹⁵²

In being the patient advocate, when the nurse believes the patient is receiving inappropriate medical treatment, there are several paths the nurse can take. Which path is taken and which one

will produce positive results is dependent on the nurse-physician relationship with variance noted between individual nurses and individual physicians. The first path is to do nothing which results in no confrontation with the physician and, therefore, no risk of retaliation, however, the nurse can be left with feelings of not being the patient advocate leading to moral distress.¹⁵³ A second path is more underhanded involving communication strategies that may be through others so as to achieve the goal without using the direct approach, reinforcing the “doctor-nurse games”.¹⁵⁴ The last approach, and the one that would confront the issues, is to talk with the physician directly. For many nurses this approach has not been successful resulting in intimidation, anger, and fear with poor results for the patients, as well as the nurses, ranging from discipline to blame, leading to moral distress.¹⁵⁵ Disruptive physician behavior continues to be a problem in health care and can intimidate the nurse leading to moral distress with impaired communication between the physician and nurse eventually putting the patient at risk.¹⁵⁶

The issue of moral distress in the nurse-physician relationship is not just about nurses, even though nurses tend to experience moral distress differently than physicians due to their lack of authority in making decisions along with the stress of daily patient care.¹⁵⁷ Physicians also experience moral distress. For both key professionals, moral distress can permanently threaten moral integrity.¹⁵⁸ It is time to not only re-think the culture that nurses and physicians practice in, but to also change the longstanding hierarchical way of life that has led to the present moral climate.¹⁵⁹

Several studies indicate that medical futility is the most common source of moral distress, not only for nurses, but also for physicians and respiratory therapists.¹⁶⁰ Following is a discussion of how medical futility, or medically inappropriate treatment, contributes to the moral distress in critical care nurses.

6.IV.B. Medical Futility at End-of-Life

There are many definitions to be found on medical futility. It is an act or treatment where the predetermined goals cannot be achieved and the possibility of success is practically impossible.¹⁶¹ In other words, medical futility at the end-of-life is the treatments or interventions that are not likely to lead to a successful outcome.¹⁶² Each individual clinical situation must be examined individually for medical futility as no one definition fits all situations. Reasons found for treatments to be seen as futile include those in which the patient would not survive beyond the stay in critical care, the patient was permanently comatose, the patient's goals were not achievable, and the patient's death was imminent.¹⁶³

Critical care nurses have reported moral distress surrounding medical futility at the end-of-life, especially when their thoughts regarding the end-of-life decisions are not sought or valued.¹⁶⁴ Furthermore, there is some question regarding whether nurses' concerns with some of the end-of-life decisions are appropriately within the nurses' domain, which leads to the feeling of helplessness and powerlessness.¹⁶⁵

Studies have not only shown medical futility to be the most common source of moral distress, but also that futile treatment situations lead to the highest levels of moral distress.¹⁶⁶ Following is a discussion on the situations surrounding futility that lead to moral distress.

6.IV.B.1. Futility Situations Leading to Moral Distress

Research has linked futile treatments to moral distress, as well as job satisfaction and nurse turnover, with futile treatments being experienced by 66-89% of the nurses in critical care.¹⁶⁷ Other studies examined the frequency of futile treatment. Over 30% of nurses provided futile treatment once a month and approximately 17% provided futile treatment daily with 78.3% being provided on the physician's order, 47.1% based on family's demand, and 33.3% was because of

hospital administration's request to do so.¹⁶⁸

Futile treatment situations that can lead to moral distress include unnecessary end-of-life treatments; the prolonging of death by performing extensive life-saving treatments; failing to determine patient/family wishes regarding life-saving treatments; and general failure to communicate by the physicians to the patient/family as well as the health care team.¹⁶⁹

Moral distress has been found to be associated with two perceptions frequently felt at the end-of-life. The first is a feeling of being "distrusted" by the family, especially if the nurses have expressed an openness regarding the patient suffering with continued futile treatment.¹⁷⁰ The second is the perception that the patient is being "abused" during the dying process by the infliction of additional treatment procedures.¹⁷¹

Additional situations that have been identified under the umbrella of futile treatment include those which are perceived to induce suffering in patients with "complex life threatening" diseases.¹⁷² Nurse specific situations include: 1) following physician orders for unnecessary tests and treatments when death is imminent; 2) caring for a patient who is sustained on a ventilator and no one will make a decision to withdraw the machine; 3) giving intravenous life-sustaining medication during cardiopulmonary resuscitation without doing the necessary circulatory support as in a "meds only code"; 4) lacking communication between nurses and physicians that would lead to shared decisions on what is the best care for the patient; and 5) continuing to follow the family's wishes when they are not in the best interest of the patient.¹⁷³

Critical care nurses experience pain and suffering when they care for patients for weeks or months who are burdened by the excessive treatment that the nurses see as being of no benefit or futile.¹⁷⁴ Just as the patients are suffering, they are being cared for by nurses who are, likewise, suffering. Although critical care nurses and physicians have similar definitions for futile

treatment, physician assessments are more closely aligned to patient mortality, plus they also control the treatment withdrawal.¹⁷⁵ When nurses assessed patients to be receiving futile treatment, the patients died in the hospital 58% of the time and within six months 68% of the time raising the questions as to whether nurses focus more on suffering than survival.¹⁷⁶ When the assessments were done by physicians and nurses collaboratively, the predictions were improved, which not only stresses the value of collaboration, but also opens up the opportunity for earlier palliative care referral.¹⁷⁷ Other studies indicate that both critical care nurses and physicians care for patients who are receiving treatment that they do not agree with which they find in violation of their moral conscience. This occurs in 50% of critical care nurses, 30% of attending physicians, and 70% of house physicians.¹⁷⁸

Further futile situations that can lead to moral distress include being unable to relieve or treat the perceived physical suffering, especially the pain.¹⁷⁹ Inadequate pain management is a result of either patient/family preference so patients are more alert for their dying moments or the providers fear of overmedicating the patient leading to a hastened death.¹⁸⁰ In either situation, it is the patients who suffer.

In many instances, the moral distress related to futility has been focused with strategies being developed to address preventing and treating this moral distress. However, this approach has not been sustaining for the long term. Therefore, it has been recommended that in confronting the moral distress associated with futility, the best recourse is to focus on mitigating the presence of futile treatment, instead of preventing moral distress and its effects, which will lessen if futility is addressed.¹⁸¹

Nurses play varied roles in the cycle of futility and moral distress. Following is a discussion of these roles.

6.IV.B.2. Nursing's Role

In critical care, when patients are perceived as receiving medically inappropriate treatment, or futile treatment, it is nurses who are more often the first to challenge the effectiveness of continued treatment, as well as to encourage communication and decision making.¹⁸² However, often the nurses' input does not extend beyond the first alert to a more collaborative role in the final decision making regarding withdrawing life sustaining treatment.

Three areas of concern have been identified regarding the decision making process for futile treatment for nurses, all of which contribute to the environment that leads to moral distress. These include: 1) nurses input is marginalized and often not seen as being of value; 2) varying opinions with resulting orders between and among the different physician consults that may also confuse the family where one gives hope and another takes it away; and 3) when the final life and death decision is made by only one individual versus a collaborative team effort.¹⁸³ To lessen these concerns, it requires nurses to become sufficiently trained in order to be active participants seeking to offer input to decision making, whenever it is in the best interest of the patient.¹⁸⁴

Nurses function in several roles and these roles are especially needed at the end-of-life when medically inappropriate treatments are a point of concern. The nurses' major role at the bedside is to be the patient advocate, the "go between" for not only the patient/family to the providers, but also for the providers to the patient/family with the goal of addressing the patient's needs.¹⁸⁵ As being an advocate or voice for the patient is the nurses major function, there are other roles the nurse fills that become more prominent in critical care at the end-of-life. These roles include the following: 1) mediator—in this role the nurse brings the family and providers together to discuss concerns as well as proceed with end-of-life decision making when the time is right; 2)

educator—the nurse explains as well as interprets information and procedures to the families who are under prolonged stress which makes processing information difficult; 3) facilitator—the nurse can help facilitate the time of death due to treatment withdrawal so that the appropriate family member can have their “good-byes” or be present, if desired; and 4) comforter—the nurses uses knowledge of grief and loss in providing comfort to family members, as well as providers, who also experience loss when a patient dies.¹⁸⁶ Whenever nurses are performing these various roles in critical care units surrounding the end-of-life and medical futility, it has been found that when their role is seen as valuable, collaborative, and consultative there is less evidence of moral distress.¹⁸⁷

If there is an absence of palliative care at the end-of-life in critical care, the burden of providing quality end-of-life care or a “good death” falls to the critical care nurse. There are four major domains for this end-of-life care which most critical care nurses are involved with on a routine basis. These involve providing adequate symptom management which includes pain as the number one concern, but also includes breathlessness, nausea and vomiting; avoiding the prolongation of the dying process with better communication between patients, families and providers; helping the patient have a sense of control at the end, even if they are no longer conscious, in which case the proxy decision maker takes over and also has the need for a say in seeing that the patient’s wishes are followed; and strengthening relationships with loved ones as dying offers opportunities for reconciliation and closure.¹⁸⁸

The various root causes and contributing factors that can lead to moral distress take their toll not only on the individual nurse, but also on the entire nursing profession. The next section illustrates the impact moral distress has on the critical care nurses as well as the nursing profession with organ donation seen as a subject critical care nurses often struggle with which

causes moral distress. Neonatal intensive care nursing will be presented as an area with a high incidence of moral distress.

6.V. Impact on Nurse and Nursing Profession

The impact of moral distress on the individual nurse can be profound in the short term and in the long term, not only personally, but also professionally. The immediate impact most often starts with physical symptoms, psychological responses, attitude changes toward patients, job dissatisfaction, and feeling a lack of support.¹⁸⁹ As moral distress continues, there is more negativity as it relates to patients, other staff, physicians, and the organization, especially where there is perceived medical futility in the treatment of the critically ill patient.¹⁹⁰ Following is a discussion on the consequences that moral distress has on the outcomes of the nurse and the profession of nursing.

6.V.A. Consequences

The consequences or impact that moral distress brings to nurses and the nursing profession are multi-faceted. Not only are they multi-faceted, but they are also unfavorable to both nurses, as well as the patients and families the nurses care for in the critical care unit. Although nurses are first and foremost obligated to their patients, they have a responsibility to address their own suffering. It is only through addressing their own suffering that they will be able to be present for the patients and families in their time of need. Following is an examination of the impact of moral distress on the nurse.

6.V.A.1. Nurse Impact

The consequences of moral distress can impact many areas. The first impact causes a range of physical, emotional, behavioral, and spiritual responses with the resulting problems often

lasting for years.¹⁹¹ These responses include: 1) physical responses which include headaches, insomnia, heart rhythm disturbances, gastro-intestinal abnormalities, unplanned weight loss or gain, and a range of ailments from any of the body's systems; 2) emotional responses to include depression, anxiety, fear, guilt, powerlessness, and grief, all of which may lead to emotion exhaustion and burnout; 3) behavioral responses such as addiction to drugs or alcohol, anger, agitation, violence, avoidance, and forgetfulness; and 4) spiritual responses which include a "crisis of faith", a separation from work or family, loss of self-worth, and a loss of purpose.¹⁹² If moral distress goes unresolved with a failure to act, the nurses' personal integrity may be jeopardized. When integrity is compromised, the person is altered causing a detachment from others.¹⁹³

The second impact concerns the detachment from others with these others, in one case, being patients so that care suffers. Nurses who experience this impact may ignore the patient's needs or only meet the basic physical needs leaving the patient with untreated pain, unforeseen complications, longer hospital stays, and untoward outcomes.¹⁹⁴ These nurses may end up in disciplinary action or leave a position, or the profession, for a different occupation.¹⁹⁵ In other cases, moral distress can cause nurses to detach from personal relationships to include family and friends, with some reporting they have substituted other substances, such as drugs and alcohol.¹⁹⁶

The third impact of moral distress relates to the accountability of nurses in a hospital environment. In the presence of moral distress, the power imbalances in the workplace can seem to be exaggerated.¹⁹⁷ This exaggeration comes from the triad of accountability that nurses are held to which is the accountability to the patients/families, the bureaucratic health care system in which they are employed, and the physicians who care for the patients.¹⁹⁸ Even as leadership opportunities present themselves in a health care institution, moral distress may prevent nurses

from actively seeking them.¹⁹⁹

A fourth and final impact that moral distress has on nurses is that it causes them to leave the critical care unit, the institution, or the profession.²⁰⁰ Three different studies indicated that because of moral distress 46.2%, 45%, and 10% of the nurses left or considered leaving a job.²⁰¹ Other studies indicate that between 15-43% of nurses leave their jobs due to moral distress.²⁰² Whether the nurse is struggling with the decision to leave or planning on leaving, this contributes to the moral distress of the nurse and adds to the overall stress of the critical care unit.

Moral distress, usually seen in a negative light, can have some positive benefits. Moral distress can help open communication, re-channel the image of the passive powerless nurse, employ acts of courage plus advocacy, and educate on how to confront barriers.²⁰³ The presence of moral distress has been shown to lead to both personal and professional growth which, in turn, leads to more compassionate care to patients.²⁰⁴ The experience of moral distress can also teach better self-care with an increased awareness on one's own beliefs, values, and ideals for the betterment of the patient.

When moral distress takes its toll on individual nurses, this eventually has consequences for the nursing profession. From the beginning of nursing with Florence Nightingale there have been ethical dilemmas as there are challenges found in "caring work", such as nursing.²⁰⁵ This caring work is magnified when placed in a stress filled critical care environment making it a difficult place to recruit and retain nurses. When moral distress enters the scene, it can add to the already stressful environment of critical care which eventually impacts the nursing profession. Following is a discussion of the effect moral distress has on the nursing profession.

6.V.A.2. Nursing Profession Impact

The *2013 Critical Care Nurse Work Environment Survey* revealed data that had worsened

since the previous survey done in 2008. This survey was from 84,444 nurses across the nation and identified the following results: 1) those very satisfied with their present position decreased from 32% to 25.5% in five years; 2) those who would recommend nursing as a career was 54.7% in 2008 and 50.6% in 2013; 3) of those nurses dissatisfied with their present position, 35.7% are willing to stay and assist with changes, 32.3% plan to leave the organization and 16% plan to leave the unit but stay in the organization; and 4) the incidence of moral distress increased from 2008 with it now being that 23.3% of the nurses say they experience it frequently and 9.4% experience it very frequently.²⁰⁶ With these results, there is an imperative for change if improvements are to be seen. Other findings indicate that both health care organizations and nurse leaders fail to recognize the needs of the nurses, to support them adequately, or to provide the necessary education and training for their growth and collaboration.²⁰⁷

Historically, health care executives have not always given nurse turnover the attention it needs ranking it seventh in importance when compared with such things as reimbursement concerns, regulatory issues, quality of patient care, and physician matters.²⁰⁸ Nursing turnover is expensive at a cost of approximately \$300,000 for every 1% increase in turnover.²⁰⁹ It has been estimated to cost between \$92,000 and \$145,000 to replace a nurse, depending on specialty, with a higher cost to replace a critical care nurse.²¹⁰ However, turnover creates costs in many ways as it affects quality of care to patients, which affects reimbursement, leading to an immense resource expenditure to correct concerns that often do not address the root cause of the problem.²¹¹

In the present cycle of nursing shortage which plagues the nursing profession throughout history, the health care system cannot afford or tolerate loss of valuable critically skilled nurses. Therefore, leaders and administrators of health care systems must assure that their environments

are designed, as well as managed, so that each health care professional's "moral agency" is strengthened and not weakened.²¹² A way to assist in maintaining moral agency and minimize moral distress in the professional work environment is to encourage nurses to have a voice, develop structured debriefings, foster problem solving, and support relationship building.²¹³

The profession of nursing, although originally created by men over 2000 years ago, is today predominantly female.²¹⁴ Of the approximately 3.5 million nurses, only 9.6% are male compared to 2.7% in 1970.²¹⁵ Studies indicate that moral distress is statistically significantly higher in female nurses than males.²¹⁶ The reason for this gender difference is not clear, but it is speculated to be similar to the differences between the male and female psychology with the females showing more sensitivity than males, as well as females scoring higher on moral sensitivity than males.²¹⁷ Future studies on the gender differences, as they relate to moral distress, are needed with hopes of gaining knowledge that can benefit both genders.

Moral distress has consequences for the nurse, the profession, and the organization with action needed by all three for change to occur. When taking a closer look at moral distress, there are situations and areas that can lead to a higher incidence of moral distress. Following is a discussion on examples when and where moral distress has a tendency to be high.

6.V.B. Moral Distress Examples

There is one medical procedure that takes place in critical care units that over half of the critical care nurses have reported moral distress when caring for these patients, which is the process of organ donation.²¹⁸ A critical care nursing unit where moral distress is high is in the neonatal intensive care unit (NICU) in caring for the extremely low birthweight neonates.²¹⁹ Organ donation and NICU nursing will now be discussed as two examples where moral distress is seen frequently.

6.V.B.1. Organ Donations: Universal Problem

The majority of clinical situations that create moral distress are associated with end-of-life experiences.²²⁰ One such experience is organ donation. The demand for organs far exceeds the supply. Approximately 30 parts of the human body can be transplanted either by regenerative cells, such as blood, or non-regenerative cells found in organs such as the heart, lungs, liver, pancreas and kidneys.²²¹ For organs to be harvested, they need blood perfusion as close to the recovery as possible which means that almost all patients are sent from a critical care unit to the operating room for organ recovery. Therefore, critical care nurses are key in getting the donation process started, yet, with over half of critical care nurses reporting distress from the organ donation process, the distress might serve as a barrier to the donations that are so desperately needed.

When organ donation occurs after brain death, the critical care nurse can no longer focus on quality end-of-life care or a “good death”. The focus is now on keeping the organs perfused until they are ready for retrieval.²²² The pathophysiology of brain stem death sets off a chain reaction in many of the body’s systems that must be managed as these patients are prone to physiological instability.²²³ This management takes the most highly skilled critical care nurse who may have been focusing on end-of-life care with this patient and family up until the moment of brain death declaration. This shift in focus is what leads to the moral distress as well as not allowing for a “good death” that allows the machines to be discontinued with the family at the bedside, all of which allow for the final farewell process for family and staff.²²⁴

Although organ donation is voluntary, it is required as a condition for Medicare reimbursement that all health care institutions have “request” policies regarding organ donation.²²⁵ The donor’s decision, which is usually made by the family or surrogate decision

maker, must be free from coercion, it must align with the doctrine of informed consent, and it must be obtained without financial incentives.²²⁶

The majority of organ donations occur after the patient has been declared brain dead but remains connected to life-sustaining treatment in order to keep the organs perfused. The contributing factor to moral distress has two components. The first is setting the stage with the family for organ donation, early in the patient's care, even though the nurse does not seek consent, as this is done by the organ procurement organization.²²⁷ The nurse can be very convincing by either supporting organ donation or not and can influence the family by their verbal or non-verbal support, or lack of support, of the process. This pressure places the nurse in the middle where they can feel the need to protect the family from "overzealous" transplant coordinators.²²⁸ First and foremost, the nurses' responsibility is to advocate for the patient under their care and not be pressured or influenced by another patient who is awaiting the organs in order to continue living.²²⁹

The second component that adds to the moral distress is the initiation and continuation of active treatment to preserve the organs as well as the need for invasive procedures, such as heart catheterization, which can seem to prolong the dying and suffering.²³⁰ When all the pre-donation work has been completed, along with recipients found for the various organs, the patient is moved to the operating room for organ retrieval.

The addition of donation after cardiac death (DCD) or the non-heart-beating donor, has added to the moral distress. Some of this distress is due to a lack of knowledge with only 11% of nurses reporting being confident in their knowledge of DCD, 20% could accurately describe the process, but 29% were in error regarding their understanding of the process.²³¹ Another part of the distress is the fear that death will be promoted in order to obtain viable organs for waiting

recipients.²³² To provide quality end-of-life care and provide a “good death” when treatments are being withdrawn, as happens in the non-heart-beating organ donor, is still the highest priority and the organ donation process should not interfere with this.²³³

Organ donation is a procedure that causes moral distress in all of the critical care areas to include neonatal, pediatric and adult. However, there is one critical care arena where moral distress is higher than any of the others. This is the neonatal intensive care unit (NICU) where nurses care for the extremely low birthweight neonates.²³⁴ Following is a discussion on the moral distress that is unique to the NICU.

6.V.B.2. Neonatal Intensive Care Nursing

There have been many technological advances and pharmaceuticals in the care of neonates making it possible for smaller, plus earlier gestational age neonates, to survive. Although the changes of survival for premature neonates is improving, to survive without some disability or complication is exceptional.²³⁵ What makes it even more challenging is that the disability may not be evidenced at birth or show until the child is six years of age or older.²³⁶

To predict neonatal mortality, the birthweight and/or gestational age have been used. Gestational age is a more accurate indicator of mortality, even though it is not always easy to determine as it is based on the menstrual cycle which can be unpredictable. Survival rates are predicted at 15% for 23 week gestational age infants; 56% at 24 weeks, and 79% at 25 weeks.²³⁷ Lung maturity is also a factor for survival with the Apgar score being a quick reference at birth to determine how the baby is doing. A neonate at <24 week gestation, weighing <750 grams, with an Apgar score of <3 has a 30% chance of survival.²³⁸

Even though the survival rates are low for neonates less than 23 weeks gestation, parents and physicians still agree, in many instances, to attempt a trial resuscitation to see how the

neonate will respond. Neonatal intensive care nurses describe these infants as a very special group of patients who are not only very tiny, but also vulnerable needing their protection.²³⁹ As a result, these nurses consider themselves the infants' protector and become very attached to them so that inflicting pain to the infant causes the nurses to experience great moral pain.²⁴⁰ Therefore, when death occurs, it is often accompanied with guilt for nurses who see death as a release from the suffering and depression due to the repeated deaths and unresolved grief.²⁴¹

It is no surprise that moral distress is common in NICU nurses given the circumstances under which nurses caring for the extremely low birth weight neonates work. The major concerns that contribute to moral distress in the NICU include: 1) uncertainty related to whether to resuscitate a premature neonate and when to withdraw treatment; 2) the best interest of the patient and whether the parents are emotionally able to decide what that is; 3) varying perspectives between physicians, parents, and nurses. Nurses are often not involved in any of the decision-making but are left to deal with the decisions that have been made which causes conflict and moral distress; 4) pain and suffering—the nurses often relate that the neonate is suffering and wonder when will it be stopped as nurses are the ones spending the most time with the neonate; and 5) supporting the family and the constant need to “be there” for the family through the many ups and downs, supporting them, providing them with accurate information, while trying to keep an emotional distance for self-preservation.²⁴² As premature neonates require more surgeries or experience more complications, the NICU nurses' moral distress is more apt to increase as they question the appropriateness of the aggressive treatment.²⁴³

One hope for moral distress in the NICU is for palliative care to find its place. It has had a slow start compared to the adult. With the large number of critical care nurses, in all of the various critical care units, reporting moral distress which has impacted job satisfaction, turnover,

and ultimately patient care, steps must be taken to resolve the previous moral distress as well as prevent it from reoccurring. The next section discusses strategies to confront moral distress which includes the call to moral action that is needed now as well as the constraints that prevent that moral action from occurring.

6.VI. Strategies to Confront Moral Distress

When health care providers, which includes nurses as well as physicians and all other allied professionals, recognize ethical concerns that they can do nothing about, an open discussion among all parties is a first approach. If this were to be the approach by all parties, with each dilemma, moral distress could be minimized. As simple as this may sound, it does not always happen. With open discussions as one approach, there are other calls to moral action that are needed, including the 4 A's proposed by the American Association of Critical Care Nurses (AACN). However, there are also constraints to action that are at play which are making it a challenge to act. Following is a discussion on both the call to moral action and the constraints to that action.

6.VI.A. Call to Moral Action

With the incidence and prevalence of moral distress being recognized in critical care nurses, there has been a moral imperative identified for a call to action. This call to action goes beyond nurses to the physicians and other allied health professionals who are, likewise, suffering from moral distress.²⁴⁴ This call to action also goes beyond the individual nurse and beyond the individual unit, affecting the entire organization.

In responding to moral distress, there are situational concerns that must be addressed before strategies or action plans can be implemented. The first is to acknowledge that moral distress is

a dilemma for health care organizations at all levels and must be challenged.²⁴⁵ The second is to understand that, although moral distress affects nursing, especially in critical care, it also affects all members of the health care organization.²⁴⁶ The third concern is that response is needed in an organized manner acknowledging the moral hardship that it causes for those who work in a morally demanding environment.²⁴⁷ In other words, support is needed for those who are experiencing moral distress.

Since the call to action is not about a one way approach, there are roles for the organization, the patient care unit, the individual and the profession. Following is a discussion on these roles in confronting moral distress.

6.VI.A.1. Role for Organization and Patient Care Unit

For action to have impact on moral distress, there are roles for the organization and the patient care unit. First of all, the organization must implement interdisciplinary strategies to not only recognize as well as name moral distress, but also establish forums where patient care goals and diverse opinions can be freely expressed.²⁴⁸ Second, the organization must establish mechanisms to determine what situations lead to moral distress with a systematic process to review, as well as analyze these situations so corrective action can take place with a plan to address futile treatments.²⁴⁹

A third role for the organization is to develop educational programs for staff, as well as physicians, which includes topics such as communication skills, self-inquiry, conflict management, negotiation, and ethics training.²⁵⁰ Fourth, the organization must develop policies which addresses ethical dilemmas with representation of staff on ethics committees, as well as a culture of zero tolerance for disrespectful behavior in the workplace.²⁵¹ Finally, the organization needs to assure that support systems are in place that include employee assistance

programs, critical stress debriefing, grief counseling, policies regarding end-of-life care, and access to palliative care.²⁵²

It is up to the organization to create the culture that is needed to address moral distress through policy, ethics education and practices.²⁵³ Other efforts that come from the organization to the individual include daily ethics rounds, workshops on the topics, and an emphasis on nurse-physician collaboration that begins in schools and continues in the workplace.²⁵⁴

The leaders of critical care units are key in recognizing moral distress and confronting it in a kind and compassionate manner. Nurse leaders can take the lead in addressing moral distress in these ways: 1) enlist interdisciplinary colleagues to help create an ethical environment; 2) utilize facilitators to explore symptoms and behaviors of moral distress; 3) establish focus for the unit, such as care conferences, unit meetings, etc.; 4) monitor data regarding moral distress to help establish needed programs and monitor progress; 5) utilize root cause analysis to monitor trends; 6) use support systems appropriately, such as ethics consults, employee assistance, bereavement support etc.; 7) enlist staff to develop health work space focusing on self-renewal; and 8) develop policies and interventions as needed.²⁵⁵

Just as the organization and the leadership of the patient care unit have roles in moral distress, so do the individual and the nursing profession. Following is a discussion on these roles.

6.VI.A.2. Role for Individual and Profession

The role of the individual in moral distress is multi-faceted. For those individuals who are experiencing moral distress, it is difficult to take on a proactive role as many are actively suffering. Studies indicate that individuals experiencing moral distress respond in one of three ways. They may withdraw from situations that are ethically challenging; they may change their

views, which may compromise them morally; or they may let their voices be heard by raising objections and concerns when situations are ethically challenged.²⁵⁶

For those who can respond in a more proactive manner in relation to moral distress, there is a role for these individuals. First, nurses need to recognize, as well as promote discourse in an organized and appropriate manner about the moral problems at all levels of the organization.²⁵⁷ The conditions associated with moral distress cannot go unchallenged if they are to change for the future.

A second role for individual nurses is that they must seek the necessary education so they are informed and prepared to address the ethical challenges awaiting in the workplace.²⁵⁸ One study found that only 57% of nurses had any ethics education in their basic or advanced nursing programs and that 23% of the nurses reported having no education at all to include in-service or continuing education.²⁵⁹ Those who have had ethics education found that it influenced both the ability to make ethical decisions and take moral action.²⁶⁰

A third and final role for the individual nurse is to support other nurse peers and health care colleagues.²⁶¹ This support may take the form of debriefing following difficult cases or deaths, creating a safe place for experiencing grief or moral distress, or seeking outside support, such as ethics consultation or spiritual care.²⁶² The individual responsibility for the ethical work environment is to encourage open communication with colleagues, to utilize ethical principles in daily practice, and to enhance skills in ethical reasoning.²⁶³

The nursing profession has been delayed in addressing moral distress in research, education, and policy.²⁶⁴ In the past, nurses too often reported a lack of support from nursing management to the point of being reprimanded when seeking help or being “scapegoated”, both of which discourages the request for assistance.²⁶⁵ However, all that is changing now as moral distress has

been recognized, not only in the United States, but also internationally, and the nursing profession has begun to take action. Work has begun to target nurses who work in high risk areas where the patient's outcomes are uncertain with intense needs and prolonged suffering that often leads to death, since these often contribute to moral distress.²⁶⁶ AACN has developed a model to be used to address ethical dilemmas and to support nurses through moral courage when confronting ethical conflicts.²⁶⁷ This model, called the *4 A's to Rise Above Moral Distress* uses Ask, Affirm, Assess, and Act as a process to assist in combating moral distress.²⁶⁸

Ask, as the first of the 4 A's, begins with ascertaining if the nurse is experiencing moral distress or if it is the stress of the work or other conflicts.²⁶⁹ With this first step, questions are asked to also determine if the individual's personal or professional integrity are being compromised. Affirm, as the second of the 4 A's, looks at the nurse's feelings realizing that these must first be addressed before the nurse can acknowledge the suffering of others.²⁷⁰ It is associated with a commitment to address the feelings. Assess, the third of the 4 A's, begins to put issues and facts together with a thorough self-assessment to determine if one has the skills and ability to facilitate change.²⁷¹ It is during this phase that it is determined whether the situation is urgent or severe enough to necessitate immediate action. Act is the final of the 4 A's. This is where an action plan is completed and implemented with built in pitfalls which are apt to occur.²⁷² A process must be associated with the action so as the change can be maintained.

In the process of confronting moral distress, moral actions are often met with constraints. Many of these constraints to moral action are thought to be some of the same factors that lead to moral distress. Following is a discussion of some of these constraints as well as strategies and best practices to counteract them.

6.VI.B. Constraints to Moral Action and Strategies to Overcome

A constraint is seen as that which limits or prevents resolution of a moral conflict in agreement with one's moral judgment.²⁷³ Constraints to moral action can be described as internal or external with both often occurring at the same time. Following is a discussion on the constraints to moral action in moral distress.

6.VI.B.1. Internal and External Constraints

Internal constraints include such things as the inability to take moral action, as well as make moral judgments, and are usually due to a lack of moral awareness, skills, knowledge, and perspective.²⁷⁴ It is another way of saying that the nurse lacks "moral competency" or knowing what the appropriate actions are to take and then to take them which, therefore, limits moral action.²⁷⁵ Other internal constraints relate to one's self image and abilities to act in a situation such as assertiveness and the feeling of powerlessness.²⁷⁶ With internal constraints, it is not easy to know what the right thing to do is with all the multiple possibilities that can be conflicting leading to confusion as to what is a true moral dilemma versus moral distress.²⁷⁷

External constraints are clearer than internal constraints in that the nurses usually know the right thing to do but are unable to do it because of the constraints. Examples of external constraints, which seem beyond the nurses' control, include a lack of adequate staffing, time constraints, poor leadership, a lack of resources, obstructive medical structure, and organizational policies.²⁷⁸ Other external constraints that have been identified and are relevant in today's health care are the impact of technology, cost containment pressures, and consumer demands plus expectations on how health care should be delivered.²⁷⁹ These latter constraints are not unique to nursing as they are experienced by all members of the health care team. The fact that nurses see them as major constraints, leaving them powerless, may help perpetuate the

perception of nurses as “powerless victims” instead of experienced professionals who can challenge and change the situation as well as the system.²⁸⁰

Other ways nurses have described constraints for moral action have been in terms of barriers. These barriers are categorized as human barriers, communication barriers, emotional barriers, and cultural barriers. Of these barriers, the ones that were cited most often related to human barriers and were the disparity between the physician and the family regarding expectations of the nurses related to the patient’s goals.²⁸¹ Nurses often see the physicians’ goals being to keep the patients alive at all costs, whereas, the nurses see their own goals as realizing that everyone eventually dies so they attempt to make each death be a “death with dignity”.²⁸²

The second barrier that is most commonly related to is related to communication. These communication barriers include ineffective nurse-patient/family communication, physician communication to patient/family that is incomplete, inaccurate, or deceptive, and inadequate communication between nurse-physician that could also be demeaning and threatening.²⁸³

One of the internal constraints that bears more discussion relates to knowledge via ethics education. This knowledge can be in the form of education and training in both content as well as context that varies from a theoretical approach to a case-based approach. Those who receive education, plus continuing education, are more apt to ask for help and use the available resources, such as ethics committees along with ethics consultations.²⁸⁴ Too often ethics committees or consultations are used as a last resort and not as the resource they are in helping with moral decisions early in the process.

Inadequate nursing staff has been identified as a major root cause or contributing factor to moral distress, but it is also a major constraint to moral action. The real or perceived problem of insufficient staff, whether in adequate numbers or insufficient skills, has been identified as a

concern for years in critical care units resulting in nationwide and international recruitment and retention efforts.²⁸⁵ Staffing as a cause of moral distress, as well as a constraint to action, can set off a cascade of events that influence one another. This cascade begins with inadequate staffing which leads to decreased communication and collaboration which leads to poor patient outcomes, more errors and complications, leading to nurse turnover with the resulting staff shortages and inexperienced staff with the process repeating itself.²⁸⁶

A final, yet, major concern in the constraints to moral action is that some nurses may have lived with and experienced moral distress for such a lengthy period that they have “normalized” it.²⁸⁷ This normalization has made moral distress the accepted and expected norm.

Despite the many constraints to moral action, there are three additional strategies and best practices that are worthy of further discussion related to moral distress. Following is a discussion on these three strategies and best practices.

6.VI.B.2. Strategies and Best Practices to Overcome Moral Distress

One of the strategies and best practices that has not been fully stressed in the workplace, is based on studies that implicate that moral distress leading to burnout can be seen as contagious in a critical care unit. This study stressed that critical care nurses needed to support each other and not “tear each other down”, which is too often the environment of a critical care unit.²⁸⁸

Included in this support of each other is living a healthy lifestyle, which includes caring for oneself outside work such as taking vacations, limiting alcohol, nicotine as well as caffeine, eating healthy, exercising, and getting sufficient rest.²⁸⁹ It also involves caring for oneself inside the workplace and includes such things as taking breaks, asking for help, and saying “no” when unable to take on one more task.²⁹⁰

A second strategy or best practice that has not been fully recognized revolves around further

research on the topic of moral distress. A lack of research and the resulting data explains why education and policies regarding moral distress have been so slow in coming so that change can occur in nursing practice.²⁹¹ Further research is needed on the impact moral distress has on patient outcomes in all areas of critical care, but especially in the neonatal intensive care unit where the incidence of moral distress is so high.²⁹² There are many articles written in regards to moral distress with many focusing on its incidence, sources, and consequences but more work is needed on its prevention plus the long term effects on nurses, patients, as well as families.²⁹³

A third and final strategy, or best practice, is the employment of a clinical or nurse ethicist. The specific role of the nurse ethicist, or clinical ethicist, as both titles are used, is fairly new in the United States. The clinical ethicist's primary role is to work from an interdisciplinary approach with the sole purpose of providing the highest quality patient care possible.²⁹⁴ This includes communication and collaboration with all members of the health care team, as well as patients/families so there is sound and effective decision making.²⁹⁵ A clinical ethicist usually has an advanced degree and/or experience in clinical ethics who participates in ethics consultations, education, research, policy development, and is instrumental in addressing futility in critical care.²⁹⁶

Evidence is beginning to indicate that the role that the clinical ethicist fills, where communication and conversations are increasing related to ethically challenging situations, is decreasing the incidence of moral distress.²⁹⁷ An additional benefit of clinical ethicists is creating a more positive ethical climate which is also associated with a reduction in moral distress.²⁹⁸

6.VII. Conclusion

The literature is bountiful on the topic of moral distress, especially in critical care nurses. What is known is that moral distress is one of the major ethical concerns affecting nursing and that the nurses are suffering. This suffering, in turn, has led to turnover from positions as well as from the nursing profession. The suffering and turnover have led to an ethical crisis in the care of critically ill patients who are in desperate need of qualified and compassionate care givers committed to their care. Unfortunately, the patients often reap the results of moral distress in the form of errors, complications, untoward outcomes, pain, and unnecessary suffering.

Moral distress in nurses also takes its toll affecting their physical, psychological, spiritual, and behavioral beings. Because moral distress is so powerful as well as destructive, prolonged and unresolved moral distress can negatively affect one's integrity and moral agency.

Although the literature on moral distress is abundant, the recommended actions to solve the problem of moral distress, or resolve its presence, are not as ample. When the focus is only on the nurse, the results will only be short term. These short term results will be because the problem encompasses all players in the health care organization—the patients, the families, peers, physician colleagues, leaders, and administrators. The nursing profession is now paying attention to moral distress and taking action to help prevent it, but more is needed.

The actions must focus on the root causes. This focus will take an organized effort that needs to begin in nursing, as well as medical schools, and continue throughout all health care organizations addressing all providers of health care. Two of the major contributors to moral distress in critical care nurses need special attention. These are nurse-physician relationships and medical futility at the end-of-life as these have been identified as common threads in all critical care units.

A quote from Martin Luther King says that, "Our lives begin to end the day we become

silent about things that matter”.²⁹⁹ The first step is giving moral distress a voice---this has been done and it is beginning to be heard. The tough work now begins with discussions on the difficult ethical decisions and dilemmas all care givers are facing that need to be done with a commitment to find common ground through mutual respect. There is no room for silence.

Notes

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Chapter 7: Conclusion

This dissertation has presented the ethics of medical futility found in end-of-life treatment in the care of the critically ill neonatal, pediatric, and adult patients. Futility has been around since medicine's beginning and continues today for a myriad of reasons. The first part of this chapter will summarize the findings as to the presence of futility across the age continuum identifying the nuances that are particular to the different age groups. The last part of the chapter summarizes the findings related to moral distress and futility with a look to what is most hopeful for the future.

7.I. Ethics of Futility

Medical futility at the end-of-life, whether that be in the neonatal, pediatric, or adult critical care unit, is not ethically justified. Yet, it continues. The first reason is because there continues to be no standard, accepted definition of medical futility. It has been called medical futility, futile treatment, futile care, or the new accepted term, inappropriate medical treatment. Even though there is no one definition, there is acceptance that it relates to treatment that does not produce a physiologic effect, treatment which produces a burden instead of a benefit, or treatment that is useless when applied to a specific patient. However, when applied to patients, it has been found that futile treatment varies from patient to patient and situation to situation with providers saying they know it when they see it.

A second reason futility continues is because death is not accepted as a natural process of life. It is also often seen as a failure by the medical profession and is associated with fear of the unknown as well as concerns with one's own mortality.

A third reason that inappropriate medical treatment continues relates to the aging

population and the switch from a paternalistic physician decision making model to a patient or surrogate autonomous decision making model. This change has, too often, resulted in the demands to have “everything” done for the patient. This “everything” demand for inappropriate and ineffective treatment intensifies into a continuance of more of the same until ethical principles become subordinated to demands of the patient and a surrogate decision maker.¹

A fourth reason that inappropriate medical treatment continues is due to personal reasons of the provider and patient/family. Providers may continue treatment because of conflict avoidance, fear of confronting death, a need to feel that they are doing “something”, the path of “least resistance”, the inability to confront personal emotions, or the failure of medicine to master disease.² Whereas, patients/families continue treatment because of lack of knowledge regarding end-of-life, poor communication with providers, emotional conflict that deals with guilt as well as loss surrounding the patient relationship, and cultural/religious beliefs.³

A final reason inappropriate medical treatment continues focuses on the organizational ethics where the clinical, professional, and business ethics are in conflict. This can occur when the patient care decision of whether to continue or withdraw treatment collides with the administration’s recommendation to continue or withdraw treatment which is based on financial, legal or social concerns. Although these conflicts can usually be resolved with the passage of time and negotiation, they do present an impasse in the care of the patient.

With all these varied reasons that play out at the bedside in critical care, the key player is and will always be the patient. By the time patients reach the end-of-life, they are usually unable to communicate so decisions are left to both the providers as well as the families. Their role is to focus and frequently re-focus their purpose on whether their actions are prolonging the living or prolonging the dying by creating unnecessary suffering.

The ethics of futility and the reasons inappropriate medical treatments continue today applying to all ages across the continuum. However, there are nuances that are peculiar to each age group in the neonatal, pediatric, and adult population that present their own challenges.

7.II. Futility in Neonates, Pediatrics, and Adults

Medical technological advances, plus pharmaceutical availability, have made for numerous choices in the way care is delivered to the smallest members of society. As a result, neonates are “surviving” at smaller weights and younger gestational ages than ever before, but not without a cost. This cost is in the form of blindness, deafness, cerebral palsy, and various other disabilities that can occur in the neonate as well as develop later in life with various degrees of disabilities occurring in 40% of those less than 26 weeks gestation.⁴

The major ethical decisions regarding medical futility at end-of-life for neonates occurs at two points. One is at the time of birth and the other is later in the neonatal intensive care unit (NICU) when treatment is withheld or withdrawn. The decision at the time of birth relates to whether to resuscitate or not to resuscitate. The decision making struggle calls into play the best interest standard in making decisions for the neonate, keeping in mind whose best interest it is—the neonate’s, the parent’s, the provider’s or society’s. Although it is most often a collaborative decision between parents and providers, the new parents are often unable to grasp the magnitude of the decision while blinded from the shock of parenthood gone wrong. Therefore, the decision falls to the provider who may recommend a resuscitation trial to see how the neonate responds to aggressive treatment. As gestational age is used to help determine what decision is made, 22-25 weeks gestational age is considered a “grey zone” for discretionary resuscitation, greater than 25 weeks is a trial resuscitation and less than 22 weeks is to not attempt a resuscitation, except in

rare circumstances.⁵ These “rare circumstances” are now becoming more commonplace in some medical centers with the survival of 19-21 week gestational age neonates.

From the delivery room, the decisions move to the NICU where withholding and withdrawing treatment is decided when the burden seems to exceed the benefit of continued treatment. Here the concerns of futile treatment are a main consideration and an increasing issue with neonates as they are being resuscitated at earlier gestational ages, leaving much uncertainty for what difficulties the infant may face in the future.

Between the two decisional points of the delivery room and the NICU, work is focused on keeping the neonate from becoming a victim of the treatment by minimizing suffering, without hastening death. The questions that remain unanswered producing ethical concerns relate to the price of survival and if it has led to a path of suffering that cannot be determined at birth.

The pediatric population, ranging from 1-18 years of age, present with diseases and conditions that make them unique. Infants who once died from childbirth, prematurity, or congenital anomalies now survive. Children who used to perish from a variety of childhood illnesses, cancer and infections now live due to immunizations, disease prevention, cancer therapies, and antibiotics. However, this age group continues to be afflicted by intentional and unintentional injuries, AIDS, congenital anomalies, and malignancies which provide immense challenges.

The death of a child has a lasting effect on the family as well as caregivers. Although many of the deaths have been prevented, death still continues to have the last word. Because death is so difficult in a child, the topic of medical futility is often avoided which can lead to prolonged suffering in the child, family and health care providers. Death is compounded in the pediatric patient in that the patterns of death are different than for the adult making the need for end-of-life

discussions more difficult to predict.

The biggest challenge in the pediatric populations at the time of end-of-life and the decisions that are needed when further treatment becomes futile, is focused on the rights of the child and the rights of the parents. Parents, as the decision makers for the children, utilize the best interest standard. By legal definition, children do not have the right to consent until the age of 18. However, children younger than 18, but usually not less than 7, are able to assent to treatment and should be encouraged to be part of the decision making process, whenever possible, after all factors are considered.⁶ This also includes the right to dissent to treatment which can be a source of conflict for parents and the health care providers.

When caring for pediatric patients, all care givers must realize that there are two patients--- the child and the child's family. Therefore, the care, communications, decisions, and emotional needs must be directed to both realizing that these may be different for the two patients.

When referring to the adult population, it is the elderly who are most apt to be receiving the inappropriate medical treatments at the end-of-life. The elderly is an ever-growing population that often have no advance directives and either they, or their surrogates, want "everything" done which may seem to prolong the dying versus prolong the living. This elderly population has a longer length of stay, higher mortality rate, and a higher cost of care than those younger.⁷

A challenge that is found in the adult population is determining whether they have decisional capacity. This decisional capacity can be determined by health care providers, however, the majority of patients are on mechanical ventilation when in critical care at the end-of-life so communication is difficult. In addition, studies have shown that only 5% of the patients have capacity at the end-of-life in critical care.⁸ This leaves the decisions to be made with the family or surrogates and the providers.

The decisions that are made for the adult patient are based on substituted judgment or the best interest standard. Substituted judgment is based on the known preferences of the patients and the best interest standard is used when the preferences are not known and choices are based on what a “reasonable person” in a similar situation would choose.⁹ In this decision making process the autonomy of the patient, the autonomy of the family, the autonomy of the provider and the autonomy of the community are subject to review as who is best served by the decision.

Despite there being much written and discussed on the topic of medical futility, or inappropriate medical treatments at the end-of-life for adults, no one best solution has been found. Attempts have been made to minimize the concerns that have taken the form of improved advance care planning and advance directives with the Centers for Medicare and Medicaid (CMS) having instituted a payment for voluntary 30 minute discussions with Medicare patients on end-of-life planning. Policies and practice guidelines have been written with minimal effect. Legislation has been passed with Texas enacting the Texas Advance Directive Act of 1999 which has had mixed results. All of this is occurring in an environment where more and more states are passing legislation legalizing physician assisted dying of which its effects are yet to be fully known.

Each of these three age populations has looked at the issue of futility within their own boundaries with little concern for those of other age groups. It is time for all health care providers from every age group to join efforts in an attempt to address the ethics of medically inappropriate treatments as a health care dilemma that crosses all boundaries. Such an approach is more apt to lead to improved strategies that places the patient first minimizing suffering and enhancing end-of-life care.

The persistence of the medical futility, or medically inappropriate treatments, along the age

continuum, has gotten media attention as resources are consumed and ethical dilemmas are made visible in the social, legal, as well as ethical realms. Limited awareness has been in relation to the human effect of these inappropriate medical treatments on those who care for the patients, especially the nurses. This is changing as more and more is written about the incidence of moral conflict as well as moral distress in the workplace. Moral distress also has a relationship with medical futility which makes it imperative that strategies be implemented to address futility because in doing so, moral distress is, likewise, addressed.

7.III. Futility and Moral Distress

Although the term of moral distress is relatively new, having originated in the 1980's, the suffering of moral distress has been around since the time of Florence Nightingale. Nightingale attended soldiers in the Crimean War working in horrifying conditions, with incompetent physicians who wanted her and her nurses to go home.¹⁰ Just as medical futility is found across the age continuum, so is moral distress. Moral distress is particularly prevalent in nursing, especially critical care nursing, but is found in all members of the health care profession. The impact of moral distress is that it not only threatens the moral integrity of nurses, but can also have a major effect on the quality of care delivered to the patients and their families.

The facts that are known regarding moral distress are that nurses are suffering, they are leaving their jobs as well as leaving nursing. Patients are suffering in the form of errors, complications, and unmet needs. All of this is creating a crisis in the care of the critically ill where the need for skilled, knowledgeable, and compassionate care is the highest. In addition, the cost of turnover is great in both dollars and human suffering.

Although moral distress is found in all critical care units across the age continuum, it

especially affects those nurses who care for the extremely low birthweight neonates. The high prevalence found in caring for the neonates is due to the uncertainty related to whether to resuscitate a premature neonate, as well as when to withdraw treatment; the best interest of the patient and whether the new parents are emotionally able to determine what that is; the varying views that are found between the family, the providers, and the nurses who are, too often, not valued for their opinions; the pain and suffering the nurses see the neonates enduring; and the never-ending responsibility to be there for the parents, not only to serve as a source of information, but also as support in times of grief and anxiety.¹¹ All of this takes its toll on the nurses leaving them with physical, psychological, behavioral as well as spiritual signs and symptoms.

In addition to futility as a root cause of moral distress, the nurse-physician relationship is a major factor. This relationship can be a factor when it becomes negative to the point of bullying, intimidating, ignoring, humiliating and reinforcing the “doctor-nurse” games that have been around for centuries.

The strategies and actions for moral distress must focus on the root causes of which the top two are medical futility and nurse-physician relationships. This needs an organized effort that begins in both the nursing as well as medical schools and continues into the clinical environment with support from the professional organizations and the administration of the organizations.

There is no easy answer to the ethical concerns of medical futility, or inappropriate medical treatment. However, there is hope for the future in the form of strategies and initiatives that are believed to be making an impact.

7.IV. Hope for the Future

Medical futility at the end-of-life in critical care is not ethically justified whether that be for neonates, pediatrics, or adults. However, it continues and will undoubtedly continue for a variety of reasons. Therefore, the best strategies are those that focus on a proactive approach to prevent or at least minimize medical futility before it presents as an ethical dilemma or leads to conflict between and among all players.

First and foremost, the strategy that cannot be overemphasized is communication. Since almost all misunderstandings and conflicts are a result of poor or inadequate communication, it is vital that providers are available, approachable and compassionate providing frequent, honest communication that can help counteract these problems. Decisions are best made when they are collaborative efforts between the patient/family and providers plus a solid communication framework can help facilitate that happening. Included in this communication is avoidance of the term “futility” utilizing potentially inappropriate medical treatment as an alternate.

A second strategy utilizes policies and procedures regarding inappropriate medical treatment. Even though the policies and procedures have not always been effective, especially when attempting to define what constitutes medically inappropriate treatment, they can have merit when defining an approach for action when there is inappropriate treatment.

A third strategy that offers hope for the future of medical futility is to include nurses in the discussions and decision process with patients/families and physicians. Nurses spend more time with patients than other providers and can be influential and helpful by their advocacy for the needs of the patients as well as families.

A fourth hope for the future is to continue to advocate for advance care planning with the completion of an advance directive. It has been over a year since the implementation of

reimbursement for providers having end-of-life discussions with Medicare eligible patients. The initial data reports that the utilization of this reimbursement code has not been as widely used as was hoped for with this additional reimbursement. However, it is still too soon to tell if there will be any impact over time as providers are encouraged to promote end-of-life planning.

The fifth and final hope for the future is one that is believed to be already making a difference, this is the utilization of palliative care programs. The palliative care programs are especially beneficial when they are begun in the critical care unit and when critical care with its curative focus is partnered with palliative care with its caring focus, as well as symptom management. Adult palliative care programs have been established in the United States for approximately 40 years. Palliative care programs for neonates and children have been slow to develop and are just now beginning to gain favor across the country. Despite perceived barriers against developing neonatal/pediatric palliative care, there are benefits that make it a worthwhile endeavor for this special population.

Health care providers enter their particular professions in order to provide care that benefits as well as improves the patients' quality of life, whether that be in living or in dying. The call to action for each provider stems from Hippocrates, "to cure sometimes, to relieve often, to comfort always".¹² For it is in the environment of the critical care unit of all ages that the concerns of medical futility will be on-going, but the take away message is that even if curing seems to be futile, caring will never be futile.¹³

Notes

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