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Improving Medical Decision Making for Technologically Dependent Infants in State Custody –
Avoiding Medically Ineffective Treatment

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Master of Arts

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An abstract of
A thesis submitted to the Faculty of the
James T. Laney School of Graduate Studies of Emory University
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Abstract

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By Helen O. Williams

The question of "futility" in neonatal intensive care has been extensively discussed in the bioethics literature. The modern neonatologist employs various technologies to compensate for the dysfunction of vital organs, thereby sustaining babies who might otherwise succumb to their illnesses. Most of these therapies are designed for temporary use, allowing time for the patient's damaged organs to rest and recover. However, when a patient is technology dependent in the long-term, we become concerned that these treatments have become medically ineffective.

Technology dependent infants in state custody present a unique challenge for healthcare providers. In Georgia, the Department of Family and Children Services (DFCS) is responsible for overseeing the care of these babies. Like many other state child-welfare departments, Georgia DFCS will not consent to the withholding or withdrawal of life sustaining treatments. This position holds, irrespective of the patient's prognosis, degree of pain and suffering, or quality of life. Without a voice to speak directly for their best interests, medically fragile infants in state custody are some of the most vulnerable patients in the NICU.

For this thesis we will consider the example of a neurologically devastated, ventilator dependent infant. Severe hypoxic ischemic encephalopathy (HIE) is a condition that can lead to this degree of brain injury and disability. In infants with HIE, a lack of oxygen delivery to the brain *in utero*, or during labor and delivery, leads to cell death as evidenced by seizure and altered consciousness. Long-term survivors may develop severe cognitive disability, cerebral palsy, and in some cases, the inability to effectively breathe without a ventilator. For these severely affected patients, withdrawal of intensive care to allow for natural death, is considered an ethically valid option.

This thesis will address the importance of end-of-life alternatives for critically ill infants in state custody. By mandating indefinite intensive care, the state has allowed foster children to be regarded differently than other patients with similar conditions. We will refute the presumption that continuing intensive care is always protective of the child's best interests by discussing the ethicality of treatment withdrawal, quality of life concerns, and the responsibilities of surrogate decision makers. We will conclude by presenting a novel tool to assist in the process of medical decision making – the PREFER model.

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Introduction

Child protective services, in the form that we currently recognize, developed in response to the 1962 Social Security Act amendments. (Myers, 2008) Prior to that time, a disjointed system of well-meaning private organizations carried the mantle for protecting children from abuse and neglect. However, large segments of the population went unserved by these nongovernmental organizations, leaving many children vulnerable to continued maltreatment. (Myers, 2008) Therefore, a provision in the Public Welfare Amendments of 1962 held that each state establish a child welfare program, with responsibilities that included "preventing or remedying, or assisting in the solution of problems which may result in the neglect, abuse, exploitation, or delinquency of children". (Cohen 1962) The law also specifies that, "The staff, to the extent feasible, is to be composed of trained child welfare personnel," and federal funds were designated to facilitate this instruction. (Cohen 1962)

The Division of Family and Children Services (DFCS) provides for child welfare in the state of Georgia. In recent data published by Georgia DFCS, 13,516 children were in state custody as of December 2017. Of these children, 3,629 entered into custody because of caregiver neglect and 670 for caregiver abandonment. (DHS 2017) Approximately eleven hundred Georgia children in protective custody are below 1 year of age. Overall, a disproportionate number of foster children have complex medical needs; approximately 10% compared with 1% in the general population. (Seltzer, Dodge, and Boss 2018). Furthermore, the majority of children who enter into medical foster care do so in their infancy (Seltzer, Henderson, and Boss 2016).

The process of medical decision-making is not always clear for children in foster care. For a child in state custody, these decisions may involve the biological parents, the foster parents, the child-welfare agency and its representatives, or the courts. (Strassburger 2016) In general, when ‘the state’ is referenced, we are denoting the governmental child-welfare agency. Although they may share the responsibility for decision-making with other parties, the state can independently provide consent for routine medical care in all jurisdictions (Strassburger 2016) Of concern, medical decisions are inevitably less informed (and arguably less valid), when they are made by individuals who are not physically present with the child, or involved in their daily care. (Seltzer, Dodge, and Boss 2018) This paradigm is especially ironic when we consider that lack of parental involvement is often the reason for the initial referral of the family to social services. (DHS 2017) The foster parent is responsible for seeking medical care when circumstances dictate. Nevertheless, their ability to consent for treatments is limited in most states and is typically not inclusive of authorization for surgery or initiation of select medications. (Strassburger 2016)

As representatives of the state, caseworkers may be called upon to make medical decisions for the foster children they oversee. (Strassburger 2016) However, there are several reasons why they are under-equipped to make these often complex and important decisions. The caseworker may be responsible for a large number of children. In Georgia, the goal is to reduce caseloads to 15 per worker, but in 2017, the average assignment remained at 19. Furthermore, Georgia DFCS reports an annual rate of turnover of 29% among child welfare employees. (DHS 2017) This is similar to other states where rates vary between 20 and 40%. (Strassburger 2016) High employee turnover disrupts the therapeutic relationship between the worker and the child/ foster family. It also challenges new caseworkers to quickly acquaint themselves with the often-lengthy medical history of the child. However, high caseloads may preclude such an in-depth review. This task is particularly challenging because caseworkers rarely have medical training. Furthermore, studies show that the majority of child-welfare workers are not formally trained in social work with either a bachelor’s or master’s degree. Although the vast majority of caseworkers are college graduates, their degrees are more often in a field unrelated to child protection. (Barth et al. 2008, Staudt et al. 2015)

The objective of DFCS (and other child welfare organizations) is child protection, with efforts towards reunification, placement permanency and safety. (Seltzer, Dodge, and Boss 2018) To that end, welfare agencies tend to regard life-sustaining interventions to be consistent with their goal of child protection. The corollary is that treatment withdrawal is generally perceived negatively. Therefore, the state will often consent to treatments that prolong life, while they are unwilling to allow withholding or withdrawal of these same treatments. (Seltzer, Henderson, and Boss 2016) On the other hand, medicine is outcome focused, and treatments perceived as ineffective in improving health, are often viewed as harmful and excessive.

We contend that continuing life-sustaining intervention is not always consistent with the goal of protecting a child’s best interests. In some cases, the state’s refusal to consider treatment limitation, inappropriately excludes ethically valid, or even preferred, options for care. For this thesis, we will focus on the newborn patient with severe neurocognitive injury. We will discuss the concepts of medically ineffective care and present arguments for treatment discontinuation in these cases. We will conclude by presenting a tool, designed to aid patient surrogates tasked with complex medical decisions.

Case Presentation

The following case is based on an actual clinical scenario. Names and some details have been changed to protect patient confidentiality.

Baby Eric Bridge was born at term to a 38-year-old mother of three other children. Ms. Bridge suffered with schizophrenia and cocaine abuse. She did not have custody of her other children and struggled with homelessness. These children were in kinship care with their aunt, Mrs. Wilson.

Ms. Bridge presented to the labor and delivery unit with vaginal bleeding and was quickly diagnosed with a placental abruption (a condition where the placenta tears from the uterine lining leading to oxygen deprivation in the fetus). Consequently, an emergent Caesarian section was performed. At the time of birth, Eric had no heart rate, respiratory effort or muscle tone (i.e. he was stillborn). The neonatal team performed a full resuscitation including intubation and mechanical ventilation, chest compressions, and intravenous epinephrine administration. As a result of these efforts, Eric's first heart rate was detected 12 minutes after the time of his birth. The umbilical cord blood gas indicated that his body had been deprived of oxygen for quite some time before birth.

The attending neonatologist evaluated Eric and determined he had severe hypoxia ischemic encephalopathy. As such, he was treated with therapeutic hypothermia, the standard of care treatment for infants with this condition. He also had multi-system organ failure requiring careful management of his breathing, blood pressure, fluids, and electrolytes. Although his kidneys, heart and lungs eventually recovered, Eric continued to suffer from severe brain damage. His electroencephalogram (EEG) showed abnormal brain waves and his magnetic resonance scan of the brain was consistent with profound neurologic injury. Sadly, Eric remained in an unconscious state, requiring mechanical ventilation and intravenous nutrition. He had no spontaneous movements and he could not swallow, cough or gag. A brain death evaluation was performed but Eric began to gasp after a minute of apnea testing. Although he was not brain dead, he was thought to be in a state of permanent unconsciousness and he was expected to be dependent on mechanical ventilation for the rest of his life. The medical team made a recommendation to remove Eric's breathing tube and allow natural death. The cause of death would be his severe brain injury.

The Division of Family and Children's Services (DFCS) took custody of Eric. By policy, they refused to allow consideration of treatment withdrawal, or even non-resuscitation in the event of cardiopulmonary arrest. Eric's Aunt, who was already the caregiver for his three siblings, strongly believed that withdrawal of intensive care was in his best interests. However, even if she were allowed to foster him, DFCS would retain medical decision-making authority and thus mandate the continuation of intensive care.

Three months later, Eric remained on the ventilator in the NICU. His condition had not improved and he had suffered several bouts of infection. His arms and legs became stiff at the joints because of disuse. He received no visitors and was rarely held. The medical team had consulted the hospital bioethics committee who agreed that withdrawal of life-sustaining support was in his best interest. However, because DFCS was unwilling to consider this, the medical team was arranging to transfer Eric to the children's hospital for tracheostomy and gastrostomy tube placement. A medically fragile foster home for Eric had not been identified and there are no long-term care facilities for tracheostomy dependent children in the state of Georgia. The Children's

Hospital required that a caregiver be identified prior to surgery so that they could begin the teaching of post-discharge care.

Chapter 1 – “Futility”

The issue of medically ineffective treatment or “futility” has received significant attention in the bioethics literature. Despite this vast commentary, there remains a conspicuous lack of consensus among bioethicists. Indeed, there may be only two points on which most scholars concur. The first being that conditions exists where continuing medical treatment appears futile. The second is that futility is difficult, or even impossible, to define. This would suggest that futile care only exists in the ‘eye of the beholder’. It also questions whether the study of futility is in itself a futile endeavor (Brody and Halevy 1995).

It would be understandable to wonder why ethicists continue to perseverate on this issue when a consensus seems so unlikely. Nevertheless we persist, because so many ethical questions pivot on this point (Anderson-Shaw et al. 2005). Furthermore, an abandonment of the word “futility” does not detract from the reality that sometimes medical treatments no longer serve the good of the patient (Pellegrino 2005). In this chapter, we will discuss the concept of medically ineffective treatment or “futility”. First, we will review the landmark court cases that established the patient’s right of self-determination. We will then turn to some of the arguments made against the provision of medically ineffective treatment. Finally, we will address the question of definition and summarize some of the key literature in the debate.

Ethical and Legal Background

In the United States, patient or surrogate autonomy is considered of foremost importance in medical decision-making. Autonomy, derived from the Greek words ‘*auto’* and ‘*nomos’*, literally means the right to self-rule (Beauchamp and Childress 2001). In a medical context, this is the right to self-determination, which may encompass the right to refuse treatment. The contrasting principle is paternalism, which describes when physicians direct medical care based on what they believe to be in the patient’s best interests (Beauchamp and Childress 2001). Paternalism prevailed in medicine until several court cases changed the culture of American healthcare.

The 1905 case of *Mohr v. Williams* brought one of the first judicial rulings that acknowledged the patient’s right to self-determination (Rich 2001). In this case, Dr. Cornelius Williams had received the permission of Anna Mohr to operate on her right ear. Once under anesthesia, Dr. Williams determined that her left ear was more severely diseased than the right and he proceeded to operate on that ear instead. Ms. Mohr claimed that Dr. Williams’ decision to operate on the left ear constituted assault and battery since she had not given him permission to do so. The ruling that follows describes the concept that we now refer to as patient autonomy:

> “The free citizen’s first and greatest right, which underlies all others – the right to himself – is the subject of universal acquiescence, and this right necessarily forbids a physician or surgeon… to violate without permission the bodily integrity of his patient by a major of capital operation… without his consent of knowledge.” *104 N.W 12 (1905)* as quoted in (Rich 2001).

Many years later, the 1969 case of *Canterbury v. Spence* helped to define the essential elements of informed consent (Menikoff 2001). Dr. Spence, a neurosurgeon, chose to withhold some of the risks of a medical procedure from his patient Mr. Canterbury, determining that these risks were insignificant and their disclosure may have undue negative effects on the patient. Consequently, Mr. Canterbury agreed to spinal surgery with incomplete knowledge of all the relevant risks. Then, perhaps as a result of this surgery, Mr. Canterbury was left paralyzed. When he brought suit against Dr. Spence, the presiding judge determined that:

> “Every human being of adult years and sound mind has a right to determine what shall be done with his own body. True consent to what happens to one's self is the informed

> exercise of a choice, and that entails an opportunity to evaluate knowledgeably the options available and the risks attendant upon each". *464 F.2d 772 (D.C. 1969)* as quoted in (Menikoff 2001)

Karen Quinlan's case in 1976 brought into focus the rights of patients and their surrogates to refuse medical treatment, even when these treatments are life sustaining (Menikoff 2001). Ms. Quinlan had suffered a cardiorespiratory arrest, which left her in a persistent vegetative state (PVS). In time, her family requested that the ventilator be withdrawn. The 14th amendment to the United States Constitution states: "…Nor should any State deprive any person of life, liberty or property, without due process of the law; nor deny to any person within its jurisdiction equal protection under the law". Citing the 14th amendment and its liberty principle, the court ruled that patients have the right to refuse life-sustaining treatment and this right could extend to their surrogate decision maker.

The case of Nancy Cruzan further delineated the scope of a patient's right to refuse medical intervention. A serious motor vehicle accident left Ms. Cruzan in a PVS. Unlike Karen Quinlan who remained on a ventilator at the time of her case, Nancy Cruzan required only tube feedings to subsist. Although the lower courts decided against removal of the feeding tube, the United States Supreme Court ruled in favor of the family after they presented evidence that removal of the feeding tube was consistent with Nancy's previously expressed wishes. This court ruling was significant because it allowed a patient or her surrogate to refuse an ordinary, relatively inexpensive treatment like tube feeding. (Menikoff 2001)

In each of these sentinel cases, the common theme is physicians engaging in over-treatment and the patient's right to decline these therapies (Brody and Halevy 1995). The futility debate encompasses the opposite scenario. In contrast, it is the patient or their surrogate who are driving the perceived ‘over-treatment’, while the physician is recommending forgoing medical interventions. Physicians see this over-treatment as harmful to the patient, even though death will result if these technologies are withdrawn. Families insist on the continuation of life-sustaining therapies since biological life itself is in the best interest of the patient. When the physician and the family disagree, the rights of the legal medical decision maker to continue life-sustaining treatment usually supersedes all other interests. It follows that the debate over medically ineffective treatment is a logical progression of the patient’s rights movement.

The arguments against “futile” treatment fall into the following categories (Clark 2002):

1. Futile treatment is burdensome for the patient
2. Futile treatment is burdensome for society
3. Futile treatment is burdensome for healthcare providers

At the heart of the argument against futile treatment is the belief that there exists some patient states that are so harmful that they might be considered worse than death. Put another way, there is a certain minimum quality of life necessary to justify the continuation of medical interventions. When the burdens of treatment overwhelm the benefits such that no net good is afforded to the patient, treatment becomes futile (Pellegrino 2005). A patient with severe, irreversible brain injury who is unable to be weaned from intensive care technologies could exemplify such a futile case. This patient has profoundly impaired or absent cognition, perception and interaction, which arguably are essential components of meaningful human existence (Brody 1998). Without these abilities, life is reduced to the preservation of homeostasis. For this patient, medically ineffective treatment may cause physical pain, and lead to objectification and diminution of legacy, as they linger in a state close to death. I use the term ‘diminution of legacy’ to reference the effect that prolonged unconsciousness may have on how the patient is remembered by their loved ones and by society. Although, this concept has not been studied, it is encapsulated in the phrase “I don’t want to remember her like this,” spoken in response to a formally vital individual who becomes persistently unconscious.

Some counter that withdrawal of these life-sustaining treatments constitutes ‘playing God’ on the part of the physicians, since the hour of one’s death should be determined solely by the divine. However, since medicine always interferes with the natural order, by altering the course of disease, all therapeutic interventions could be similarly viewed as ‘playing God’ (Singh, Lantos, and Meadow 2004).

Despite these concerns, it is recognized that some patients may actually be beyond the point of harm (Mendola 2015). These individuals are so impaired that they are unlikely to have any perception of pain and therefore minimal burden associated with continued treatment. This concept is exemplified by the case of Baby K (Schneiderman and Manning 1997). Baby K had anencephaly, a condition where the cerebral cortex and midbrain did not develop *in utero*. Since these infants have an intact brain stem they are capable of some autonomic physiologic processes, however pain perception is absent because of the lack of cerebral cortex. Baby K’s mother insisted that all efforts be made to keep her alive. Baby K’s physicians petitioned the court to allow them to forego resuscitative efforts, including mechanical ventilation, on the grounds that such treatment was “futile”. However, the courts ruled that the requested aid must be rendered based on the Emergency Medical Treatment and Active Labor Act (EMTALA) and that the decision to withhold treatment belonged to Baby K’s mother. Although the physicians saw no benefit to resuscitating her, it could be argued that there were also no real harms for the patient from continued intensive care due to lack of pain perception. In these ‘beyond harm’ cases, other arguments are needed to support withholding or withdrawing life-sustaining therapy. (Schneiderman and Manning 1997)

Medically ineffective treatment is blamed for draining much needed resources from other areas in the healthcare sector (Silverman 2003). There is significant financial cost associated with most life sustaining measures, and the intensive care bed occupied by the patient with perceived futile treatment, could potentially be better used for another patient whose recovery is more likely (Fortune 2006). Countering this argument is the familiar admonishment that one should not put a price tag on human life. Clark points out the inherent contradiction in this statement (Clark 2002). In the American healthcare system, there are those that are uninsured and thus unable to access needed healthcare. In a fee-for-service medical system there is inevitably a price on human life, especially for those that are unable to pay (Clark 2002). Regardless, decisions about the allocation of resources are best made by universally applied societal policies and not at the bedside of individual patients (Fortune 2006).

Another concern is that medically ineffective treatment erodes on the professional integrity of the healthcare provider and is a violation of their personal autonomy (Wreen 2004). Physicians and other healthcare providers have a duty to do no harm. When medical interventions are perceived to be harmful, caregivers may feel in violation of this duty. As we will discuss in a later chapter, this may lead to moral distress, which may in turn result in diminished job satisfaction and burnout. Physicians and other providers also have their right to autonomy, which we see exercised in cases of conscientious objection to performing certain procedures, for example abortion. Provider autonomy is rarely asserted but it becomes relevant when physicians feel forced into rendering care with which they disagree. Nevertheless, the possibility of facing litigation compels most clinicians to set aside their objections, which in turn amplifies their discontent (Clark 2002).

We will now turn to the question of definition. As Dr. Andersen and colleagues highlighted in the article ‘The Fiction of Futility’ the definition of futility is challenging because the term is both descriptive and prescriptive (Anderson-Shaw et al. 2005). Therefore, once the label of “futility” is applied we are left with a singular mandate, to discontinue the intervention in question. However, data shows that physicians and other healthcare providers often prognosticate incorrectly (Meadow et al. 2012). Consequently, the futility judgement must be held to the highest level of scrutiny, since it will lead to an irreversible consequence, the death of the patient. No other medical label carries such great weight.

Baruch Brody describes four major kinds of futility (Brody and Halevy 1995). These are: 1) physiologic futility also known as quantitative futility, 2) imminent demise, 3) lethal condition, and 4) qualitative futility. Of these, physiologic futility is the easiest to conceptualize. As the title would suggest, physiologic futility describes a treatment that is incapable of mechanistically yielding the desired effect. It would be physiologically futile for an antibiotic to cure a viral infection. It would be physiologically futile for vitamins to reverse brain injury. Physiologically futile therapies should be withheld based on an absence of the desired medical effect and require no judgements about quality of life.

Imminent demise futility refers to the circumstance when the patient is rapidly deteriorating to the point of death and this decline is irreversible. A patient who does not respond to cardiopulmonary resuscitation is in a state of imminent demise where further treatments become futile. Therefore, although the law mandates that cardiopulmonary resuscitation be attempted, it leaves to the discretion of the physician the measures employed and the duration of these efforts.

Lethal condition futility lengthens the timeframe in which death is expected. In these cases, the underlying condition will lead to the patient's death and any procedures performed will not change the course of disease. Metastatic cancer is an example of lethal condition futility. In pediatrics, there are certain mitochondrial disorders for which no cure exists. Any therapies that are attempted may provide temporary relief of symptoms but they will not affect the underlying condition.

Brody's final category, qualitative futility, is the most subjective. In these cases, the therapy in question will have the desired physiological effect. However, that effect does not significantly alter the patient's quality of life, which is determined to be poor. In the case of neonatal hypoxic ischemic encephalopathy, a tracheostomy is often viewed as qualitatively futile. The tracheostomy will not change the patient's degree of brain damage but it would allow for continued mechanical ventilation through a stable airway and thus discharge from the hospital. Physicians may regard a treatment as qualitatively futile in circumstances where parents consider treatment worthwhile. Both parties lay claim to acting in the best interest of the child (Greenstein 1987). This difference of opinion gives rise to the most difficult futility dilemmas. As such, it is for these qualitative futility questions that clinicians most seek clarification and guidelines.

The Royal College of Pediatrics and Child Health (RCPCH) offers a framework for decisions involving the withholding or withdrawing life sustaining treatment in children (RCPCH 2004). To provide context, the RCPCH lists five situations where it may be ethical and legal to consider the withdrawal of life sustaining therapy. In many ways, these conditions echo Brody's categories of futility. Specifically, the RCPCH describes the “No purpose” situation stating that, “Although the patient may be able to survive with treatment, the degree of physical or mental impairment will be so great that it is unreasonable to expect them to bear it”. The term ‘no purpose’ is laden with value judgment and is itself inherently negative. The Royal College further states:

> “The duty of care is not an absolute duty to preserve life by all means. There is no obligation to provide life-sustaining treatment if:
>
> - its use is inconsistent with the aims and objectives of an appropriate treatment plan
> - the benefits of that treatment no longer outweigh the burden to the patient.”

The Royal College suggests that a ‘responsible body of professional opinion’ should concur that withdrawal of treatment is in the best interest of the child. This ‘Bolam test’ is traditionally used to define malpractice by establishing the standard of care and what constitutes a deviation from that standard. However, in this instance it is applied to the judgement of medical futility. In other words, futility is what most physicians would consider futile. Understandably, this definition is very unpopular with those who champion the patient’s right to decide.

In the UK, there is precedent for the courts ruling that withdrawal of life-sustaining therapy is acceptable in cases deemed futile by physicians. The recent case of Charlie Gard received significant attention from the United States lay press and bioethical community (Caplan and Folkers 2017, Lantos 2017, Spiezio 2017). Charlie Gard was born with a rare and fatal disease called mitochondrial depletion DNA syndrome. There were no proven treatment strategies but an experimental therapy was available at Columbia University Medical Center in the United States. His parents requested that he be transferred for evaluation. Charlie’s treating physicians in the UK believed that any further treatment would cause him continued pain and suffering without a proportional degree of benefit. The court agreed with them stating:

> "It would be lawful for the hospital to withdraw life sustaining treatment because it was likely that Charlie would suffer significant harm if his present suffering was prolonged without any realistic prospect of improvement, and the experimental therapy would be of no effective benefit." European Court of Human Rights as quoted in (Caplan and Folkers 2017)

In this case, the parents of Charlie and his medical caregivers disagreed on which course of treatment would be in his best interest. The physicians argued that Charlie's life was unbearable for him on grounds of pain and suffering. However, even on this point, there was no scientific consensus (Lantos 2017). Ironically, the 'patient's rights community' and the 'right-to-life' movement has found common ground with their opposition to the Charlie Gard decision.
As a result of the court ruling, Charlie was removed from the ventilator and he died at 11 months of age.

As Lantos described, the 1982 Baby Doe controversy is also relevant to the futility discussion (Lantos 2006). In this case, the parents of an infant with Down syndrome and esophageal atresia refused to allow surgeons to operate, resulting in the baby's death. The 1984 Child Abuse and Treatment act was the congressional response to this case. It defined circumstances where parents could lawfully decline treatment. Although the act aimed to provide clarity, it actually furthered the ambiguity by using the term futility without forwarding a definition. Parents could decline futile treatments but the law did not identify which therapies are thus classified. Although the debate has shifted to parents demanding treatments that physicians judge to be futile, we are still no closer to a clear definition of futility.

John Lantos suggests two essential elements to the futility determination. First, the goals of care are identified. Since these goals are value based, they appropriately lie within the purview of the parent. The role of the clinician is to use their expertise to determine the likelihood of treatments meeting these goals (Lantos 2006). For example, if a parent’s goal is to take home a living child, tracheostomy placement might facilitate this aim. However, if a parent’s goal is to take home a child without lung disease, tracheostomy will be ineffective in furthering this goal and therefore situationally futile.

The approach described by bioethicist Edmund Pellegrino also focuses on the goals of treatment. To determine futility, the intervention in question is evaluated for its efficacy, benefits and burdens, in the context of a specific end. Efficacy is the more objective measure, which lies within the domain of the physician, determined by the best medical evidence. Benefit is both subjective and objective, and is ascribed by the patient or surrogate based on their unique value system. Finally, the calculation of burden lies within the purview of both the physician and the patient. The role of the physician is to inform the patient of the potential negative consequences of treatment. The patient then uses this information to decide whether the balance of benefits and burdens favors proceeding with the intervention in question. Pellegrino’s approach emphasizes shared decision making by focusing on the “proper partitioning of expertise”. (Pellegrino 2005)

According to Lawrence Schneiderman, the distinction between efficacy and benefit is central to understanding futility. He regards efficacy as limited to a part of the patient’s body whereas benefit is an improvement for the person as a whole. Furthermore, in his construct, a treatment should be considered futile if it was unsuccessful in the last 100 instances where it was attempted. Physicians can use their own experience or published studies to make this calculation of probability. Consequently, this definition of futility is purported to be more objective because of its reliance on empirical data. If it is ‘highly improbable’ for a treatment to achieve the goal of care, it should be considered a futile intervention. (Schneiderman, Jecker, and Jonsen 1990)

Policy Considerations

To close this chapter on medically ineffective treatment, we will now turn to the concept of the futility policy. Born in part out of frustration, the futility policy intends to provide an avenue to empower physicians to override the demand for treatments that they consider medically inappropriate (Lantos 2006). Recently, many professional societies, including the American Medical Association, have endorsed futility policies (AMA , Bosslet et al. 2015). The Texas Advanced Directives Act (TADA) is an example of such a process that was cauterized into law (Rubin and Courtwright 2013).

These policies attempt to diffuse the responsibility for the futility determination by requiring the concurrence of an independent third party, often the institutional ethics committee (Rosoff 2013). The intention is to instill fairness into the process of decision making by transparently adhering to a series of predefined steps. Thus, the vulnerable patient is protected from any potential bias on the part of their physician. Although the number of steps vary, typically somewhere between seven and eleven, there are three common elements found in all policies (Pellegrino 2005, Rubin and Courtwright 2013). To initiate the process, the physician who perceives futile treatment must refer their patient for adjudication. Secondly, the independent committee or third party makes a determination of whether the treatment is indeed futile. Finally, there is a consequence if life-sustaining therapies are deemed futile by the third party. At that point, the policy could require the parent to find another hospital willing to accept their child for care. Typically once all avenues are exhausted, the physician is permitted to withdraw life-sustaining therapy which, in the vast majority of cases, will lead to the death of the patient (Rubin and Courtwright 2013). The futility policy does not hinge on any definition but instead applies a form of procedural justice (Rosoff 2013).

Philip Rosoff authored a thorough critique of futility policies in the *HealthCare Ethics Committee Forum* (Rosoff 2013). He highlighted several flaws in each step, beginning with the initiation of the procedure. Since individual attending physicians activate the process, there is the possibility for bias in the identification of futility cases; in other words, the selection of patients is relatively arbitrary. This raises concern for differential treatment of patients based on their socioeconomic status, race or ethnicity. The ethical principle of justice requires that patients with similar medical conditions be afforded similar treatment. However, it may be less likely that futility procedures will be invoked on the child of a prominent politician or on a patient whose family threatens involvement of the media. Conversely, a patient with 'difficult' family members may be more likely to be referred.

Rosoff also notes the potential for conflicts of interest within the committee. Given that most ethics committees are largely comprised of medical personnel and those individuals are employees of the hospital, it is possible that they too are subject to outside influences. As Pellegrino stated we 'might simply substitute group bias for a clinician's bias' (Pellegrino 2005). Rosoff contends that futility policies are ultimately designed to be coercive. That is to say, parents are given the difficult and intimidating task of finding another physician and hospital that will assume the care of their child. Resource limited families may be compelled to 'give up' at this point and acquiesce to the removal of life-sustaining therapy.

Summary

This chapter reviewed the still unresolved issue of medically ineffective or futile treatment. The debate will no doubt continue to be relevant as medical technologies advance and the expectations for medicine's curative powers increases. Although futility is a recognized problem, identification of a remedy is stymied by the lack of a clear definition. Procedural approaches to the futility determination raise concerns for inequitable application and potential conflicts of interest.

For children in state custody, these futility questions are particularly challenging. In such cases, it can be difficult to identify the appropriate medical decision-maker, or to ascertain the scope of that person's decision-making authority. Once the patient surrogate is identified, it may still be challenging to engage them in a meaningful discourse about the infant's care, because of their lack of physical presence at the bedside, and limited understanding of the medical complexities. Hospital caregivers may believe they are better equipped to speak to the child's best interests than a caseworker whose contact with the patient has been limited. The reluctance of the state to consider treatment withdrawal is particularly difficult to reconcile with their lack of meaningful involvement in the child's care. We have discussed in this chapter the importance of communication in addressing concerns about medically ineffective treatment. For foster children, there is often a lack of communication between the medical staff and decision-makers, which only reinforces the belief that the child has no one to effectively represent their best interests. (Seltzer, Dodge, and Boss 2018)

Chapter 2 – Neonatal Hypoxic Ischemic Encephalopathy

In this chapter, we will overview hypoxic ischemic encephalopathy (HIE) and the long-term implications for affected neonates. We will also review disorders of consciousness and address neonatal brain death criteria.

Hypoxic ischemic encephalopathy (HIE) is the term used to describe the injury that results from inadequate oxygen delivery (hypoxia) and insufficient blood flow (ischemia) to the fetal brain. This condition may be caused by events prior to, during, or shortly after birth, respectively termed antepartum, intrapartum and postpartum and known collectively as peripartum. HIE is sometimes referred to as birth asphyxia but the latter term has lost favor because of its litigious connotation. The incidence of HIE is approximately 1 to 2 per 1000 live births in developed countries. Therefore, HIE is a major cause of brain injury in the term newborn. (Martin, Fanaroff, and Walsh 2015)

With the advent of therapeutic hypothermia, progress has been made in the treatment of some affected newborns. However, infants with severe HIE remain at high risk for lifelong neurologic abnormalities including cerebral palsy, developmental delay, seizures and blindness. The most profoundly affected children have altered levels of consciousness and are incapable of some basic autonomic reflexes, e.g. sustained breathing, blinking, coughing, and swallowing. The majority of the brain injury caused by hypoxia and ischemia occurs after the precipitating event has ended. Therefore, therapies implemented after birth may limit injury caused by hypoxia prior to birth. (Douglas-Escobar and Weiss 2015, Volpe and Volpe 2018)

Oxygen delivery to the fetus is a function of the placenta. Therefore, any factor that interferes with normal placental physiology has the potential to cause HIE. Since the placenta is the interface between the fetal and maternal circulations, the health of the pregnant woman directly influences the health of her fetus. Maternal conditions that cause low oxygen or abnormal blood pressure may impair the delivery of needed oxygen to the fetus. For example, a mother who is experiencing an exacerbation of her asthma may be unable to adequately breathe in air. In turn, her fetus is also oxygen deprived. Certainly, if the placenta becomes detached from the uterus, a condition known as placental abruption, the fetus is at risk for severe compromise. In addition to lack of oxygen delivery, placental abruption is also the cause of significant blood loss from both mother and baby, which further compounds the potential for injury. (Martin, Fanaroff, and Walsh 2015)

Oxygen rich blood from the placenta returns to the fetus through the umbilical vein, which along with two umbilical arteries, comprises the umbilical cord. If blood flow through the umbilical cord is impeded, the fetus is also at risk for HIE. Such obstruction can result from knotting of the cord or its compression around the neck or body of the fetus. Similarly, if an infant were to be ‘stuck’ in the birth canal, a common problem for bigger or post-term babies, the cord may become compressed. This complication is technically termed shoulder dystocia as the head can be delivered, but the infant’s body is proportionally too large to follow. Other maternal conditions that can increase the risk for HIE include diabetes, excessive blood clotting, hypothyroidism and autoimmune disease. (Martinez-Biarge et al. 2013)

Once fetal distress is detected, the infant is delivered as quickly as possible, which often entails an emergency cesarean section. If cardiopulmonary resuscitation (CPR) is needed, neonatal providers follow guidelines published by the American Heart Association and American

Academy of Pediatrics, in the Neonatal Resuscitation Program (NRP)(Weiner et al. 2016). This protocol primarily involves assisted ventilation, but the addition of chest compressions and epinephrine is warranted if the infant does not positively respond. The NRP suggests that providers can stop resuscitative efforts if the infant does not regain a spontaneous heart rate following 10 minutes of well-performed resuscitation.

McGrath, Wilkinson and colleagues addressed the question of when resuscitation at birth should cease and suggested that, in most cases, CPR should continue for at least 20 minutes. (McGrath, Roehr, and Wilkinson 2016, Wilkinson and Stenson 2015). The decision to stop resuscitation is complicated and requires careful consideration of the patient's best interests. In this regard, a shorter resuscitation will result in more deaths while decreasing the chance of survival with disability. A longer resuscitation may salvage more babies but at the cost of increased potential for impairment among survivors. The authors argue that erring on the side of treatment allows more time to evaluate the infant. Since withholding and withdrawing treatment are ethically equivalent, withdrawal of intensive care could still occur later in the NICU, if the infant's prognosis is expected to be poor. They also note that "while it is important for parents to be informed about ongoing resuscitation it is not necessary and would be arguably wrong to seek their consent to cease resuscitation once those providing resuscitation have determined that it would be medically inappropriate to continue" (McGrath, Roehr, and Wilkinson 2016).

Part of the difficulty in advocating for longer resuscitations is the potential shift in decision making from physician to parent. Cessation of ineffective resuscitation after birth is an example of imminent demise futility (Brody and Halevy 1995) and as such, physicians are able to make this decision unilaterally in keeping with the standard of care. Once the infant is in the NICU, parents may be reluctant to redirect care and, as we discussed in Chapter 1, there is limited recourse if treatment seems qualitatively futile. The resuscitating physician may feel moral distress since the infant, who was born dead, is now subject to a life of pain and suffering. The challenge of most resuscitations is to restore life; in the case of the neonatologist, there is arguably the added burden of creating life, and perhaps a life that is complicated by severe disability.

After the stabilization of breathing and circulation, the neurologic exam of the baby guides further therapy. Most neonatologists use the staging system developed by neurologists Harvey and Margaret Sarnat (Sarnat and Sarnat 1976). Based on their symptomatology, infants are classified into three clinical states, with stage one being the most favorable and stage three reflecting severe disease. In their landmark article, they describe these stages as follows:

> "Stage 1 lasted less than 24 hours and was characterized by hyperalertness, uninhibited Moro and stretch reflexes, sympathetic effects, and a normal electroencephalogram. Stage 2 was marked by obtundation, hypotonia, strong distal flexion, and multifocal seizures... Infants in stage 3 were stuporous, flaccid, and brainstem and autonomic functions were suppressed." (Sarnat and Sarnat 1976)

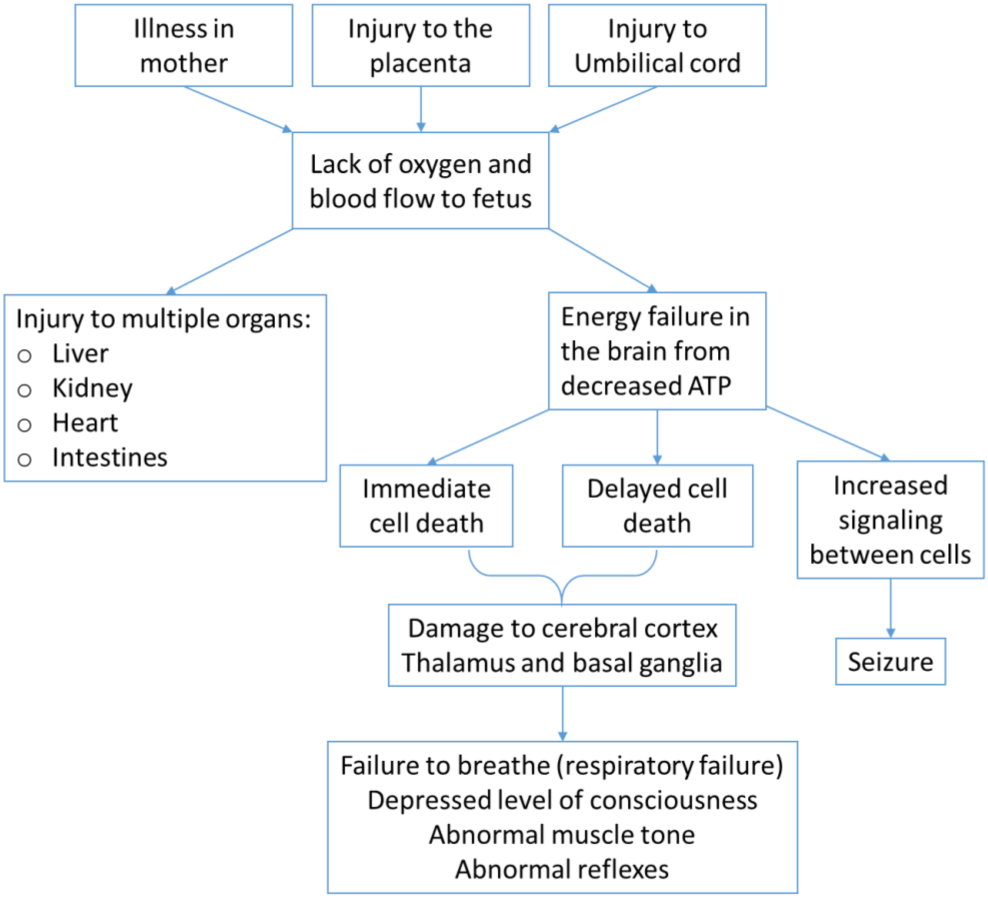
Since this initial publication, further research has shown prognostic value in the Sarnat staging. Infants with stage one symptomatology generally experience full recovery without any long-term sequelae. Conversely, those babies classified as stage three are at great risk for death or lifelong neurologic impairment. The moderately effected, stage two infants, have a less clear prognosis and as such remain the focus of much of the research into neuroprotection – the term used to describe the mitigation of brain injury after a period of oxygen deprivation. This group of infants has also derived the most benefit from therapeutic hypothermia or whole body cooling (Shankaran et al. 2016).

The pathophysiology of HIE is complex and beyond the scope of this thesis. To summarize briefly, lack of oxygen in the fetus leads to inadequate production of adenosine triphosphate (ATP) which is the ‘currency’ of cellular energy. This absence of ATP disrupts many intracellular metabolic processes leading to cell death or, in the case of some neurons, ‘over-signaling’. As a result of this over-signaling, a surge of electrical activity may occur in an affected brain part, which is clinically manifested as seizure. Additionally, the blood supply to many areas of the brain has some redundancy, which allows for continued perfusion even when a degree of ischemia occurs. However, other parts of the brain have a more tenuous blood supply. These areas are termed ‘watershed’ because they lie at the furthest tributary of an artery and are most vulnerable to injury when blood flow is compromised. Specifically, in hypoxic ischemic encephalopathy, the areas of the brain known as the cerebral cortex, basal ganglia and thalamus are particularly prone to injury. Loss of neurons in these regions correlates with the symptoms of HIE that we see in the neonatal period and in the long-term. (Volpe and Volpe 2018)

Therapeutic hypothermia (whole-body cooling) reduces rates of death and disability in newborns with moderate and severe hypoxic ischemic encephalopathy (Shankaran et al. 2016). This therapy is considered standard of care for any infant deemed to be in Sarnat stage two or three encephalopathy. In order to be most effective, cooling must be initiated within six hours of birth. The mechanism of neuroprotection provided by hypothermia remains incompletely understood. However, we do know that the metabolic activity of the infant decreases with their lower body temperature. This allows for less energy expenditure and interrupts the cascade of events that results in cell death. The patient remains hypothermic for a period of seventy-two hours. (Volpe and Volpe 2018, Douglas-Escobar and Weiss 2015)

Lack of fetal oxygen potentially damages all of the organs in the newborn. However, unlike the brain, these other organs have the capacity for regeneration. Infants with moderate or severe HIE require significant supportive treatment during the acute phase of their illness. These supportive therapies substitute for, or augment the baby's impaired physiologic processes. For example, a shocked heart may not pump adequately resulting in a lower blood pressure and inadequate blood flow to the brain. In these cases, medications to increase blood pressure may be indicated. When the liver is damaged, the baby may develop jaundice and delayed blood clotting. Kidney injury can lead to disturbances in electrolytes, and inadequate urine production. Medical management of these other conditions is essential to limit ongoing brain injury. In this regard, infants with HIE require highly specialized neonatal intensive care. (Douglas-Escobar and Weiss 2015)

The figure below 2.1 – summarizes the pathophysiology of Hypoxic Ischemic Encephalopathy



The majority of infants who die with HIE do so in the first 48 hours of life. Furthermore, most of these deaths occur after withdrawal of life-sustaining technologies (Garcia-Alix et al. 2013). In these circumstances, it is especially important that physicians accurately counsel parents regarding their baby's prognosis (Brecht and Wilkinson 2015). Nevertheless, in some cases, there is concern for establishing a self-fulfilling prophecy (Wilkinson 2010). A self-fulfilling prophecy occurs when a prediction becomes true because actions are taken that will inevitably result in that outcome. When life-sustaining support is withdrawn on an infant with HIE, a physician can claim their prediction of poor prognosis was made accurately. However, it is unknown if continued intensive care would have resulted in a more positive outcome. Clinical trials on HIE usually have a composite adverse outcome of death or severe disability. However, when withdrawal of life-sustaining technologies occurs, the extent or the infant's future disability, or lack thereof, will never be known.

Clinicians may perform a number of studies to aid in prognostication for the HIE baby. These include cranial ultrasound, computed tomography (CT), electroencephalogram (EEG) and magnetic resonance imaging (MRI) (Volpe and Volpe 2018). Cranial ultrasound has the advantage of being portable, and as such, it can be used on the most critical infants who would otherwise be too unstable for transport. However, this tool has limited utility for diagnosing hypoxic-ischemic brain injury. Cranial ultrasound is most useful for seeing large brain malformations, cysts, hydrocephalus or hemorrhage. The findings of HIE are often too subtle to be reliably detected with ultrasound.

The electroencephalogram records multiple brain wave frequencies, which a neurologist can interpret. It is primarily used as a tool for seizure detection but is also helpful in cases of severe HIE. A classic pattern, known as 'burst suppression', is sometimes seen in infants with severe

HIE and is associated with a poor prognosis. An isoelectric or flat EEG tracing portends a dismal prognosis as it reflects minimal brain activity. It is important to note that EEG patterns are altered if the baby is undergoing therapeutic hypothermia. Sedatives and anti-seizure medications may also depress the activity of brain waves. Therefore, the EEG must be interpreted in the context of the infant's clinical condition. (Volpe and Volpe 2018)

Magnetic resonance imaging (MRI) is preferred over CT since the former does not expose the infant to ionizing radiation. (Excessive ionizing radiation is implicated in the development of some cancers.) MRI scans show both anatomical and functional abnormalities in the brain. Consequently, they are considered the best imaging study for evaluating infants with HIE. These abnormalities are most accurately visualized after 3 days of life. The appearance and location of injuries detected by MRI are useful in predicting a patient's long-term neurodevelopmental outcome (Wilkinson 2010). However, these correlations are not always definitive. Wilkinson's meta-analysis showed that in the first week of life, MRI has a 71% sensitivity and an 84% specificity for detection of severe adverse outcomes. Therefore, some cases of severe adverse outcomes are missed because of falsely reassuring MRIs and some grossly abnormal studies belong to patients who will do better than predicted. In this regard, MRI findings alone are insufficient to identify infants who will have the worst outcomes and they should not be the only consideration in end-of-life decision making (Rasmussen, Bell, and Racine 2016).

Much of the difficulty assessing the neurological status of newborns stems from their typical developmental limitations. A healthy neonate would not be expected to roll over, sit, stand, purposely vocalize or respond to their name. An older pediatric patient or adult, who typically has these abilities, can be assessed for their loss. However, neonatal providers are asked to predict whether these developmental milestones will be reached. Likewise, a normal newborn is expected to sleep eighteen hours a day. Therefore, diminished states of consciousness, easily discerned in older patients, are harder to perceive in neonates.

Abnormal states of consciousness are well described in the adult population. These are: minimally conscious state, persistent vegetative state and permanent vegetative state. Death by neurologic criteria or brain death is also discussed in this setting as it represents the most extreme state of altered consciousness, its irreversible absence, along with complete cessation of both cortical and brainstem functioning. We will now address these terms individually.

The persistent vegetative state (PVS), also termed "unresponsiveness wakefulness syndrome," is a condition where the patient has no awareness of environment, or self, and no evidence of purposeful behavior. They may demonstrate awake and sleep cycles, however, when their eyes are open, they are unable to track or fixate upon an object. They may also have random, involuntary movements of the limbs and trunk. Since brainstem function is preserved, these individuals are usually able to breathe spontaneously without difficulty (Daroff and Bradley 2016). It is estimated that between 4000 and 10,000 children in the United States are in a vegetative state. Of these, approximately 18% are due to perinatal insults (Swaiman 2018).

A patient can be said to have entered into a permanent vegetative state when there is a "high degree of clinical certainty that the clinical state is irreversible and the chance of regaining consciousness is exceedingly unlikely" (Daroff and Bradley 2016). According to the Multi-Society Task force on PVS, adults with hypoxic-ischemic brain injury are very unlikely to recover consciousness after a period of 3 months and the prognosis for children with non-traumatic brain injury (of which HIE is an example) appears to be similar (Multi-Societal_task_force 1994).

The minimally conscious state (MCS) has a better prognosis for recovery than the PVS. In the MCS, patients may have partial awareness of their environment and are able to perform some simple purposeful behaviors. The presence of limited conscious awareness distinguishes the MCS from the vegetative state. However, it is important to note that disorders of consciousness are a continuum running the gamut from brain death to normal awareness. The boundaries of the intermediary conditions have relatively arbitrary definitions. (Daroff and Bradley 2016)

A brain-dead patient has an irreversible absence of all brain functions, including those controlled by the brainstem. For the first time, the 2011 *Revised Pediatric Brain-Death Guidelines*, established criteria for brain-death declaration in term infants of 37 weeks gestation or greater (Nakagawa et al. 2011). Prior to these guidelines, there were no established standards for determination of death by neurologic criteria in the newborn patient. Hypoxic ischemic encephalopathy is the most common cause of brain-death in babies less than 1 month of age (Swaiman 2018). There are still no agreed upon criteria for brain death in preterm infants under 1 week of age.

Prior to testing for brain death, patients must have a normalized core temperature and blood pressure. Additionally, any metabolic or pharmaceutic causes of coma should be excluded. On physical examination, the patient should have no response to external stimuli and absent brainstem reflexes. If this is the case, the next step is to perform an apnea test. The apnea test requires that a patient does not develop spontaneous breathing when carbon dioxide is allowed to accumulate in their blood (≥20mmHg above their baseline). If these criteria are met, the exam should then be repeated 24 hours later. If the exam remains consistent, brain death is declared. The major difference in determining brain death in the infant under 30 days is the requirement for a longer period between examinations. In older patients, assessments are 12 hours apart. (Silverman 2003). Despite its apparent simplicity, death by neurologic criteria remains controversial. For this reason, New York and New Jersey have clauses to allow for continued intensive care treatment for those who have religious or personal convictions against the concept (Drake, Bernard, and Hessel 2017).

The infant with HIE presents a clinical and ethical challenge for the neonatal provider. With the advent of therapeutic hypothermia, more infants are surviving HIE without disability. However, some babies continue to have profound neurologic impairment and are perceived as having a poor quality of life. The inability of clinicians to prognosticate accurately for these neonates raises questions about the ethicality of withholding and withdrawing life-sustaining treatment. In this regard, the ethical variable of time may be helpful to allow the baby to ‘declare themselves’. Infants who remain in a persistent vegetative state after 3 months are unlikely to recover consciousness and represent a patient population where intensive care may be considered qualitatively futile. In conclusion, this discussion brings to mind a quote from ethicist Nancy King. She states that:

> “Dealing with uncertainty is unquestionably the most difficult task of medicine; yet it too is a task that is best shared with those for whom the decision matters most.” (King 1992)

As neonatal providers counsel parents, it is important to include prognostic information, but this should be balanced with an acknowledgement of the limitations of our ability to predict outcomes. Although an overused cliché, it remains true that physicians do not have the proverbial ‘crystal ball’.

Chapter 3 – Home Care and Foster Care of Infants with Complex Medical Conditions

Following a protracted intensive care hospitalization, the next challenge for the neonatal patient is making the transition to home. In this regard, the vast majority of NICU graduates have discharge needs comparable to those of a healthy term baby. However, a subset of infants require continued medical interventions at home, including oxygen, mechanical ventilation, tube feeding, and administration of multiple medications. This group of NICU graduates comprise one third of the population of technology dependent children (Toly et al. 2016). Sadly, they are more likely to be victims of child abuse and neglect than healthier newborns (Nandyal et al. 2013). It follows that there is a disproportionate number of medically complex children in the foster care system (Seltzer, Johnson, and Minkovitz 2017b, Seltzer, Henderson, and Boss 2016). Indeed, the majority of children who enter into medical foster care do so in their infancy (Seltzer, Henderson, and Boss 2016).

In this chapter, we will overview the home care required for the medically complex infant. This discussion will highlight the considerable challenges that occur when medically ineffective treatment continues in the home setting. Complex home-care regimens, coupled with an under-resourced foster system, result in significant medical and social burdens for the child. (Seltzer, Henderson, and Boss 2016) When DFCS prohibits withdrawal of life-sustaining treatment, medical foster care is often the only practical alternative to continued intensive care hospitalization. The question then becomes, whether continuing life sustaining-treatment is ethically appropriate, when the provisions for the child’s future needs are so inadequate and the prognosis is poor.

Various terms are used to reference the child with significant long-term medical conditions; these infants are sometimes referred to as `medically fragile' or 'technology–dependent'. However, recently the term 'children with medical complexity' (CMC) is preferred, because it emphasizes the child primarily and the medical condition secondarily (Seltzer, Henderson, and Boss 2016, Cohen et al. 2011). In 1998, the Maternal and Child Health Bureau offered the following definition for Children with special health care needs:

> "Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally." (McPherson et al. 1998)

To expand on this definition, Cohen and colleagues described four domains that are especially pertinent for the child with medical complexity. These are:

1. Increased health care service needs. E.g. need for multiple specialists
2. The presence of one or more chronic medical conditions.
3. Functional limitations E.g. need for a feeding tube or a wheelchair
4. High utilization of healthcare resources. E.g. prolonged hospitalizations, multiple surgeries. (Cohen et al. 2011)

To exemplify these domains, we will return to the case of Eric Bridge. This baby has severe hypoxic ischemic encephalopathy; he is in a non-cognitive state, ventilator dependent and tube fed. For the first domain, he will require the care of multiple sub-specialists. At a minimum, this would entail:

- A pulmonologist - to manage his ventilator
- An otorhinolaryngologist/ ear, nose & throat surgeon – To monitor his tracheostomy

- A gastroenterologist to manage his tube feeds
- A pediatric surgeon to monitor his gastrostomy tube site
- A neurologist to follow his cerebral palsy and monitor for seizures.

Additionally, he will need an excellent general pediatrician to synthesize his care plan and serve as the ‘medical home’. The American Academy of Pediatrics recommends that all children have a medical home where they can receive continuous, comprehensive and coordinated primary care that is family centered and culturally informed (Medical Home Initiatives for Children With Special Needs Project Advisory Committee. American Academy of 2002). Eric will also need access to allied health services. Since he is unable to move spontaneously, he requires physical therapy to maintain the range of motion in his joints and prevent the development of contractures. A contracture occurs when the soft tissues of a joint develop fibrosis (scarring) because of disuse. This results in increased resistance to stretch with the fixing of the joint in a flexed position (Herring and Texas Scottish Rite Hospital for Children 2014). In turn, this can make positioning of the child difficult, which may present an additional challenge for caregivers.

In the second domain, Eric has chronic respiratory failure and hypoxic brain injury. Both conditions will be lifelong. His need for tracheostomy and mechanical ventilation also increases his risk for acute complications such as tracheitis (infection of the trachea) and pneumonia. Furthermore, children with neurologic injury are unlikely to outgrow their need for a tracheostomy (McPherson et al. 2017). His severe HIE will result in cerebral palsy (CP) and profound cognitive impairment. Cerebral palsy can develop after fetal or neonatal brain injury and involves abnormalities in muscle control and posture. In infants with HIE, the most common form of CP is spastic quadriplegia – increased stiffness in the muscles of all four extremities (arms and legs). In its most severe form, this precludes any voluntary, coordinated movements of the arms and legs, rendering the child immobile and unable to perform common activities of daily living. (Kliegman et al. 2016)

Eric has multiple functional impairments. He will need a ventilator to breathe, a feeding tube for nourishment, a wheelchair for movement and potentially additional assistive devices as he becomes older. Indeed, when neonatologists discuss severe HIE with parents, a commonly used analogy is that the child will ‘remain a baby forever’, effectively growing in size but not gaining any abilities or reaching developmental milestones. In this regard, Eric would need to be diapered, carried and fed for his entire life, and although he will gain weight and height, his care needs will not decrease. Understandably, caring for a child of one hundred or even fifty pounds is significantly more physically taxing than caring for a smaller infant.

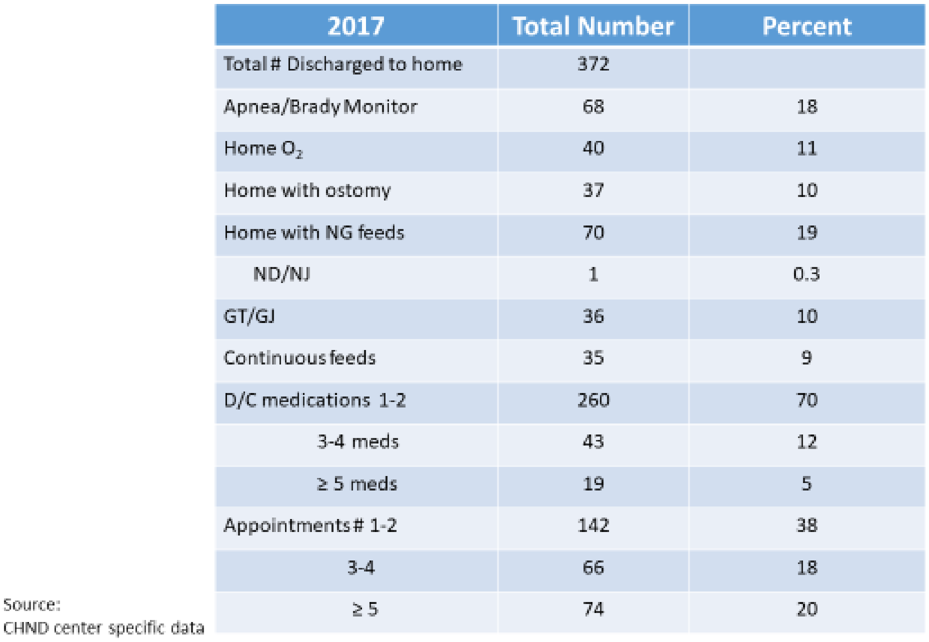
We would also expect that Eric would require significant healthcare resources throughout his lifespan. With any hospitalizations, he will need admission to an intensive care unit. He has already undergone two major surgeries – tracheostomy and gastrostomy placement. These devices will need to be reevaluated and upsized as he grows. Additionally, he is at risk for pressure ulcers due to immobility. In light of his CP, he may need joint surgeries or medications like botulinum toxin (Botox) injections, to improve his joint flexibility. It follows that these complex care requirements will come at a significant financial cost. (Lemmon et al. 2017)

Indeed, care for children with medical complexity constitutes approximately 30% of total pediatric healthcare expenditures in the United States (Murphy and Clark 2016). This is particularly noteworthy since less than 1% of children (approximately 600,000) are classified as CMC (Toly et al. 2016). This portion of medical spending is estimated to be between $50-$110 billon per year (Murphy and Clark 2016). The majority of children with complex medical conditions are covered by Medicaid, and they account for about a third of Medicaid's pediatric outlay (Murphy and Clark 2016). Furthermore, hospitalizations of children with neurologic impairment constitute one third of total pediatric hospital charges. In this regard, there has been a shift observed in the patient population cared for at children's hospitals, away from the acute care of the previously healthy child, to the longer-term management of children with medical complexity (Davies, Hartfield, and Wren 2014). As Murphy notes, the children who are the highest utilizers of healthcare resources have the potential to accrue massive expenses throughout their lifetime (Murphy and Clark 2016). Nevertheless, it is important to recognize that the vast preponderance of healthcare dollars are still spent on adults in the final months of their lives (Wilfond 2014).

To appreciate the care needs of children with medical complexity, it is necessary to overview some of the treatments and technologies that can be utilized in the home setting. For this thesis, we will limit our discussion to those treatment modalities used in infants under one year of age. In 1987, the U.S. Congress, Office of Technology published the memorandum, *Technology Dependent Children: Hospital Vs. Home Care* (Wagner et al. 1987). Therein they identified four groups of children that were characterized as technology dependent. This schema is still very relevant today. These groups are:

- Children dependent on mechanical ventilators
- Children requiring prolonged intravenous administration of nutrition or medicines
- Children who are dependent on tracheostomy tubes or tube feeding
- Children with prolonged dependence on other medical devices such as dialysis, urine catheters or ostomy bags. (Wagner et al. 1987)

Among newborn infants, respiratory support and nutritional support are the most frequently required technologies after hospital discharge (American Academy of Pediatrics Committee on and Newborn 2008). At our level 4 nursery at Children's Healthcare of Atlanta, Egleston, we care for a population of newborns that typically require surgery. As such, these infants have very complex discharge needs. The continued medical needs of these patients at discharge is shown in the table below.



2017	Total Number	Percent
Total # Discharged to home	372	
Apnea/Brady Monitor	68	18
Home O_2	40	11
Home with ostomy	37	10
Home with NG feeds	70	19
ND/NJ	1	0.3
GT/GJ	36	10
Continuous feeds	35	9
D/C medications 1-2	260	70
3-4 meds	43	12
≥ 5 meds	19	5
Appointments # 1-2	142	38
3-4	66	18
≥ 5	74	20

Source:
CHND center specific data

Table 3.1 – Discharge Needs for Neonates with medical Complexity – Children's Healthcare of Atlanta, Egleston (Piazza 2018)

Neonates may require continued supplemental oxygen at the time of discharge. For these infants, the nasal cannula is the simplest form of home oxygen delivery. Although blended oxygen (between 21% and 100%) is utilized in the hospital, infants are usually discharged to home on 100% oxygen, which is contained in large canisters that must travel with the baby at all times. Infants discharged on oxygen are typically monitored with a pulse oximeter. This device detects the oxygen saturation of the infant and alarms if its value is outside of the programmed parameters, thereby prompting the caregiver to intervene or seek outside help.

Figure 3.1 - Infant mannequin with tracheostomy

Children with lung disease, airway obstruction or impaired control of breathing (e.g. brain injury), may require a tracheostomy (colloquially ‘trach’) for discharge (Amin and Fitton 2003). A tracheostomy is a surgically created opening in the airway/windpipe, made through the neck, below the voice box (see figure 3.1 above). A tube inserted through this opening, maintains its patency and allows for the connection of equipment. In medical parlance, the word ‘trach’ represents both the surgical opening, and the tube placed therein. Tracheostomy ties, which surround the infant’s neck, hold this tube in place. As part of the home care regimen, the tracheostomy tube must be exchanged each week and the ties should be replaced daily. The caregiver will also need to suction the tracheostomy regularly to prevent mucus accumulation, which can clog the tube and cause suffocation. Therefore, a machine for suctioning must also be available at all times. A tracheostomy dependent infant requires at least two trained caregivers. Furthermore, in the event of an emergency, there should ideally be two individuals in the home; one person to activate emergency services and a second to attend to the infant. (Srivastava, Stone, and Murphy 2005)

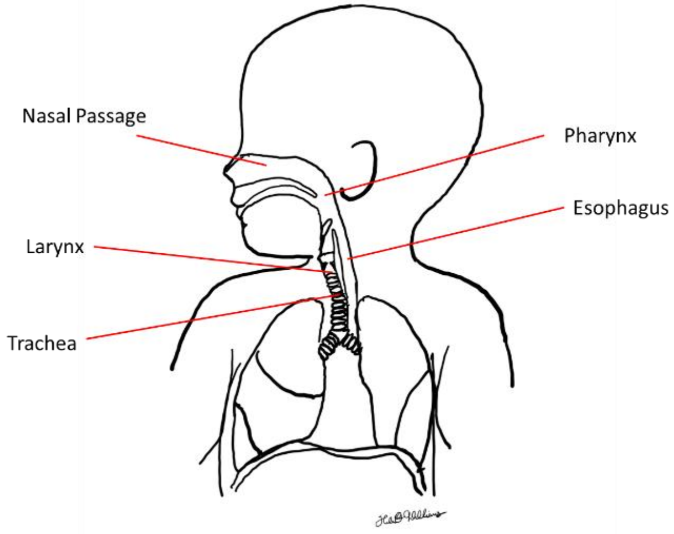


Figure 3.2 – Simplified diagram of neonatal airway.

The upper airways (nose, mouth and pharynx) are responsible for warming and humidifying inspired air. Figure 3.2 above reviews upper airway anatomy. These physiological processes are circumvented in the patient with a tracheostomy. Consequently, infants must receive oxygen through their tracheostomy that is already warmed and humidified. This can be accomplished through a tracheostomy mask, which functions similarly to an oxygen facemask, except covering the tracheostomy instead of the nose and mouth. Infants with more moderate lung disease and those with upper airway obstruction may be discharged on a tracheotomy mask rather than a ventilator. (Lesperance and Flint 2015)

The majority of infants with tracheostomies require a ventilator for breathing support. The ventilator delivers breaths to the infant at a defined pressure and rate to meet their needs for oxygen intake and carbon dioxide removal. Home ventilators must cycle continuously and require a battery back up in the event of a power-outage. The need to run the ventilator continuously consumes significant electricity thus increasing the utility bills in the home.

In their review of pediatric tracheostomy and home ventilation, authors Amin and Fitton inventory the required equipment for the ventilated patient. This includes:

- Primary ventilator
- Oxygen source
- Remote alarm
- Back-up ventilator
- System humidifier
- Ventilator Circuits
- Suction apparatus
- Suction equipment
- Spare tracheostomy tube
- Battery charger (Amin and Fitton 2003)

As we noted earlier, the infant with a tracheostomy is at increased risk for a number of complications. In a recent study by Mahida and colleagues, 24% of children under the age of two who underwent a tracheostomy, experienced a major complication within 30 days of surgery. These complications included surgical site infections, pneumonia, postoperative sepsis, cardiac arrest and, in 5.8% of patients, death. (Mahida et al. 2016).

In the longer term, the tracheostomy dependent infant is at risk for a number of other serious complications (DeMauro, Wei, and Lin 2016, Srivastava, Stone, and Murphy 2005). They are more likely to develop bacterial or viral tracheitis and pneumonia. Obstruction to air flow may result from mucus accumulation. Furthermore, repeated suctioning could cause bleeding in or around the tracheostomy. In turn, this trauma and inflammation leads to the growth of granulation tissue. As part of the physiologic response to injury, new tissue rich in collagen and blood vessels develops at the site of a wound and this occurs even when the opening is surgically created. This growth of granulation tissue occurs both inside the trachea and around the tracheostomy site. Since granulation tissue is highly vascular, it easily bleeds, even with a minor disturbance. The cycle of injury followed by attempts at wound healing leads to the proliferation of aberrant, granulation tissue. Intra-tracheal granulation tissue may eventually grow to the point of occluding the trachea and blocking airflow. In this event, the patient requires further surgery with its attendant risks of bleeding and airway compromise.

There is a constant concern for accidental dislodgment of the tracheostomy tube. Additionally, with reinsertion, there is the possibility of creating a false passage, whereby the trach tube lies within the soft-tissues of the neck rather than inside the trachea. These complications along with the patient's underlying illness combine to increase the risk of death with tracheostomy. A recent study by Edwards and colleagues reports 5-year survival with tracheostomy at 80%, which is consistent with previous estimates. (Edwards, Kun, and Keens 2010, McPherson et al. 2017)

The parents of the child with medical complexity are expected to perform this medical care in the home setting. Although they receive significant training before hospital discharge, they are not typically from a medical background (Srivastava, Stone, and Murphy 2005). Indeed, when Thomson studied the demographics of these parent caregivers they noted that 5% of parents did not graduate high school and 24% of parents did not have any formal education beyond their high school diploma or GED. Only twenty two percent of parents had any postgraduate education (Thomson et al. 2016). Moreover, the family home must be easily accessible and suitably sized to house the equipment the child needs. Parents may be compelled to cease working outside the home in order to devote themselves to the around-the-clock care of their child with medical complexity. This loss of income creates additional strain on the family finances and is frequently cited by caregivers as a cause of stress (Murphy and Clark 2016, Montagnino and Mauricio

2004). In addition to medical expenses, the costs of utilities, transportation and childcare for siblings, add to the financial burden of caring for the CMC.

Studies have shown that providing care to the medically complex child has a profound effect on the caregiver (Carnevale et al. 2006, Lemmon et al. 2017). In this regard, when compared with other parents, caregivers of children with medical complexity experience more social isolation, sleep deprivation, anxiety, and depression (Srivastava, Stone, and Murphy 2005, Carnevale et al. 2006, Hopkins et al. 2009). There is also data to suggest that caring for a child with medical complexity adversely effects other relationships. Indeed, when Carnevale interviewed parents of ventilator dependent patients, some expressed guilt about not having enough time to devote to their other children (Hopkins et al. 2009). Other studies suggest increased rates of divorce in these families.

To further compound these difficulties, there are many unmet home healthcare needs for this vulnerable population (Hefner and Tsai 2013). In Hefner's study of unmet needs for ventilated children, it was noted that 25% of parents provided 16 hours per day of direct patient care. Seventy-one percent of families had regularly unfilled nursing hours and thirty-seven percent could not find home healthcare nurses with pediatric qualifications. Indeed, it is worth noting that when an infant with a tracheostomy is hospitalized, a registered intensive care nurse and respiratory therapist work together to provide their care. These professionals have time-limited shifts, usually not exceeding twelve hours a day and forty hours a week. However, in the home setting, parents must provide continuous care, and they are challenged to find home-health nurses with adequate training to allow for any respite time. Worry about the health of their child and concerns about their abilities to render the needed care combine to cause considerable anxiety for these parents (Montagnino and Mauricio 2004). Nevertheless, in spite of these difficulties, many parents report tremendous satisfaction in caring for their medically complex child (Carnevale et al. 2006). Furthermore, parents often perceive a good quality of life for their technology dependent infant (Goldsmith et al. 2017).

At the time of discharge, an infant may also require tube feedings. This includes feeds via nasogastric tube (NG), gastrostomy tube (G-tube), or gastrojejunostomy tube (GJ). Indications for these medical feedings include dysphagia (abnormal swallowing), intestinal malabsorption, intestinal blockages and the need to supplement with additional calories to facilitate growth (Srivastava, Stone, and Murphy 2005). Infants with tracheostomies also require tube feeding, though they may acquire oral feeding skills later in life. Among pediatric patients, the most frequently encountered indication for home tube feedings is neurologic impairment (Srivastava, Stone, and Murphy 2005). Gastrostomy tubes are surgically placed through the skin into the stomach. GJ tubes have a second internal tube that terminates in the small intestine (jejunum).

Prior to discharge from the nursery, an infant may undergo surgical gastrostomy tube placement. However, if the infant is expected to outgrow their need for tube feedings, or if there are concerns about general anesthesia, a nasogastric tube can also be used at home. Discharging infants with tube feeding reduces the length of hospital stays, which results in decreased healthcare costs (Khalil et al. 2017). Parents receive extensive instruction on placement of the nasogastric tube, and how to verify correct positioning. Dr. Khalil and colleagues studied the rates of tube-related complications in infants discharged with g-tubes and nasogastric tubes. The authors concluded that “short-term home NG feeding in infants does not appear to have any higher risk for tube-related complications requiring medical attention than home G-tube feeding” (Khalil et al. 2017).

As with any medical procedure, both the nasogastric tube and the gastrostomy tube are associated with specific complications. For the nasogastric tube, there is a small probability of inserting the tube into the airway instead of the esophagus. If this incorrectly situated tube is used for feedings, severe respiratory compromise will result as milk would be administered directly to the lungs. The NG tube is also prone to inadvertent removal and misplacement within the gastrointestinal tract. If the tube is too high in the esophagus at the time of feeding, severe refluxing of milk will occur, which could lead to choking or aspiration. Insertion of the tube causes physical discomfort and irritability in the infant. Likewise, in this author's experience, the caretaker may find their baby's reflexive crying and withdrawing during tube insertion to be stressful and incongruent with their role as a parent. However, in Khalil's study, most of the infants with NG tubes were able to achieve full oral feedings by 6 months of age. This would suggest that a trial of NG feeding has value in preventing the need for surgery and general anesthesia.

For the gastrostomy tube, a number of complications can occur at the site of insertion. There can be leakage of milk or acidic gastric secretions on the skin surrounding the stoma, which leads to skin irritation and potentially infection (cellulitis)(Srivastava, Stone, and Murphy 2005). The inevitable movement of the g-tube may cause bleeding, enlargement of the stoma site, and the development of granulation tissue. The g-tube may be inadvertently removed and reinsertion requires expertise and confirmation of correct placement by radiograph. Other severe complications include gastrointestinal bleeding, peritonitis, bowel perforation and the development of gastrocutaneous fistulae (Srivastava, Stone, and Murphy 2005).

Finally, a small group of infants require continued parenteral (intravenous) nutrition at the time of discharge. These are infants with severe intestinal malabsorption and growth failure. In such cases, a central venous line (CVL) is required. There are a number of serious complications associated with long-term need for intravenous access. Most notably, there is an increased risk of blood stream infections and the potential for the formation of clots (thromboses). (Srivastava, Stone, and Murphy 2005)

In cases where the medical needs of the child overwhelm the resources and abilities of the parents, medical foster care may be required. This is the case for ~10% of the foster care population (Seltzer, Henderson, and Boss 2016). As the child's medical complexity increases, there is a greater likelihood of neglect and abuse (Seltzer, Johnson, and Minkovitz 2017a). Foster parents are reimbursed for the medically complex child at two to three times the basic rate. Since it is difficult for these foster parents to continue employment outside the home, they are incentivized to accept several CMC simultaneously. Caring for multiple medically complex children, each with competing needs, can overwhelm the capability of even the most experienced caregivers (Seltzer, Henderson, and Boss 2016). Children with medical complexity are less likely to have placement stability and permanency, and there is a direct correlation between length of need for foster care and the degree of medical complexity (Seltzer, Johnson, and Minkovitz 2017a).

The training required for medical foster parents also varies considerably, with marked differences from state to state. For example, in New York City, the Children's Aid Society requires the following from their foster parents:

- Participate in orientation and training
- Complete home study evaluation
- Successfully complete background check
- Have physical examination
- Identify one parent to stay at home

- Appoint a back-up person (respite provider) for emergency situations (Diaz et al. 2004)

Often identification of the medical foster parent occurs relatively late in the child's hospitalization. Consequently, the newly assigned caregiver has limited time to learn the necessary skills required to care for the child, or to become familiar with the details of their complex medical history. Indeed, the foster parent might only be identified when the child is medically ready for discharge. This practice extends the hospital stay and results in increased pressure to expedite discharge teaching.

While foster parents are entrusted to determine when the infant needs medical care, the authority to consent for treatment often remains with the biological parent or with the child welfare agency. In this regard, parents may request burdensome treatments without seeing the consequences of these interventions on their child. Similarly, the state will often consent to any recommended interventions as long as they are life sustaining. However, they are reluctant to consider withholding or withdrawing of treatments, thereby limiting options for children in their care. (Seltzer, Henderson, and Boss 2016)

This discussion raises the question of what society owes to the child with medical complexity. The current system of healthcare and home-care is both fragmented and under-resourced. Parent and Foster caregivers are expected to learn medical procedures and provide continuous care for their medically complex child. These caregivers have few options for respite and are prone to feelings of isolation and depression. In turn, CMC are more likely to be in foster care because of medical neglect. This paradox is particularly striking in the neonatal intensive care unit where considerable resources are spent, over the course of many weeks or months, on life-saving efforts to bring the infant to the point of discharge. Once at home, support for their outpatient care is then minimal resulting in recurrent and potentially preventable rehospitalizations. Is it ethically appropriate to discharge infants with tracheostomies when the system is so ill equipped to support them in the long term? The justification for parental surrogate decision-making is in part predicated on the fact that they will bear the consequences of the choices made for their child. Therefore, is it reasonable that their decision to pursue tracheostomy and mechanical ventilation requires such a life-altering, personal commitment? However, this reasoning cannot apply when the parent does not provide direct care for the child and the state is left to make accommodations.

We contend that medically inappropriate care inevitably leads to poor outcomes. The current child-welfare policies that mandate indefinite life-sustaining treatment are an example of death deferred, but that deferment comes with significant cost. This is particularly true for the foster child whose social situation is unstable and care needs complex. In these cases, society has made an incomplete commitment to care for the child, which may be more damaging than making no commitment at all. Despite the allocation of significant resources, the outcome for these children is predictably severe chronic illness, hospital readmissions and death at an early age.

Chapter 4 – Moral Distress and Moral Resilience

Moral distress and the interrelated concept of moral resilience are relative newcomers to our bioethical vocabulary. The rise in popularity of these constructs runs parallel to the increased use of technology in medicine, especially those therapies classified as life sustaining (Prentice et al. 2016). First described in 1984, Andrew Jameton defined moral distress as “The experience of knowing the right thing to do while being in a situation in which it is nearly impossible to do it” (Jameton 1984, Jameton 2017). It is noteworthy that Jameton coined the term after discussions with his nursing students, many of whom cited the NICU as an area of moral concern. Subsequent studies have shown that moral distress is most prevalent in the intensive care setting (Larson et al. 2017). Although the idea of moral distress originated in the nursing literature, additional studies have affirmed its relevance to other members of the patient care team (Trotochaud et al. 2015, Larson et al. 2017). Moral resilience describes the attributes, which allow a provider to resist or tolerate moral distress without diminishing the quality of their care. There is great interest in strategies to cultivate this ability among healthcare providers in hopes of mitigating the deleterious effects of moral distress. In this chapter, we will discuss moral distress and moral resilience in the context of technology dependent NICU patients.

To illustrate elements of moral distress, we will once again consider the case of Eric Bridge during his primary NICU stay. First, we will reflect on the concerns of Eric’s nurse, who we will call ‘Marie’. We will then explore moral distress from the perspective of Eric’s resident physician ‘Dr. Green,’ and his attending neonatologist ‘Dr. Grey’.

Moral Distress has become a problem for Marie and many of her coworkers. She spent her last two shifts, each 12 hours in duration, taking care of Eric. She is very worried about his pain and suffering and his poor quality of life. Marie feels her care is hurting Eric more than helping him, and she questions her role as his nurse.

Marie must suction his mouth and breathing tube frequently to clear his secretions. Every three hours she begins his nasogastric feedings. She also performs the stretches prescribed by his physical therapist, but his joints are stiff and she is worried she might be causing him pain. Marie really does not know what Eric feels because he has no intentional movements or facial expressions. (Hauer and Houtrow 2017) Family never visit him and he is rarely held. Although Marie would like to hold him, she has two other patients who also need her time. To prevent pressure sores, she and a colleague work together to turn him every 6 hours, alternatively positioning him prone, supine or on his side. These brief times of repositioning are often the only instances when Eric is out of his bed.

During this shift, Marie notes that Eric’s endotracheal secretions have become yellow and thick compared with the previous day. When she reports this to the resident, he orders lab tests and x-rays to evaluate for pneumonia. She has to prick Eric’s heel to obtain the blood gas and complete blood count. His heels are scarred from numerous capillary blood draws over the course of his short life. In order to obtain the necessary amount of blood, she had to vigorously squeeze his heel. Despite this, the first sample clotted and she had to redraw the labs. Although everything looked reassuring from the standpoint of infection, Eric was noted to be quite anemic with a hematocrit of 24 percent. The resident ordered a blood transfusion for which Marie had to start an IV line. Eric’s veins are tortuous and fibrosed because of his need for many previous venipunctures. She works with the charge nurse and after six attempts, they are able to place an IV in Eric’s scalp. As Marie hangs the blood, she wonders what the donor would think about her patient. Indeed, she is unsure why he requires this transfusion since it will do nothing to change his overall prognosis or improve his quality of life. In Marie's opinion, the pain associated with starting the IV outweighs any benefits of transfusion. Marie speaks with her charge nurse about changing her patient assignment for her next shift.

Dr. Andrew Green is the pediatric resident assigned to Eric Bridge. Andrew considered a fellowship in critical care before his NICU rotation. Now he feels that too many resources are spent on the 'futile' care of terminal patients like Eric. He is discouraged that they are 'forced' to continue ventilating him despite his vegetative condition. When the nurse reported the change in his secretions, he ordered labs and an x-ray but he did not examine the patient (which would be his usual practice). In his opinion, pneumonia might be a blessing for Eric because it may cause his death and prevent further suffering. Andrew is counting down the days until the end of his NICU rotation when he can go back to taking care of patients that 'actually have a chance'.

Dr. Grey is the attending physician in the NICU. She has practiced neonatology for 35 years and is nearing retirement. Dr. Grey is wistful for the 'old-days' when infants were not discharged home on ventilators, and a baby like Eric would be considered terminal. In the past, no one would question removal of his ventilator and allowing Eric to die naturally, because there were no other options for his care. Now children leave the hospital on ventilators but many of them eventually just die at home. She questions what kind of life Eric will have in the foster care system. At least once every day she is asked "why are we continuing to do this?" by a resident or another staff member. Indeed, she has tired of this question and her answers have become more and more abrupt. It is difficult for Dr. Grey because the staff thinks she is not making the appropriate efforts to advocate for Eric, but the truth is her hands are tied.

She is also worried because the unit has been running a census near capacity and a patient who has no hope of recovery occupies one of her beds. Over the course of her career, she has seen many good nurses burnout and leave the NICU. However, she admits the rate of attrition seems greater in recent years and the nursery seems frequently under-staffed. Taking care of a baby like Eric is challenging even when a loving family is involved. However, Eric seems abandoned in her nursery with no one to speak for him. Dr. Grey is very frustrated with DFCS and their inability to consider what is in Eric’s best interests.

In this example, all three providers experience moral distress. However, the immediate cause of that distress is variable, along with the way in which it is experienced e.g. avoidance, powerlessness, guilt etc. The common theme is a recognition that Eric has a devastating neurologic condition and a poor quality of life. Nevertheless, there is an inability for the provider to alter the treatment plan, as they deem appropriate, because of external constraints. This quandary is familiar in intensive care settings.

Prentice et al. recently conducted a comprehensive review of thirteen empirical studies on moral distress in neonatal and pediatric ICUs (Prentice et al. 2016). As we observed with our futility discussion in Chapter 1, overly aggressive treatment and the disproportionate use of technology are often the precipitant for moral distress. In this regard, the medical team perceives that a therapy is excessively burdensome for the patient and therefore not in their best interests. Typically, the distress arises when the opinion of the medical decision maker runs counter to the views of the healthcare providers. The result is competing ethical principles; typically respecting the autonomy of the parent conflicting with the desire to do good (beneficence) and avoid harm (non-maleficence) in the physician or nurse. Such ethical conflicts often arise in ‘grey zones’ or areas of prognostic uncertainty, and result from value differences among the parties (Prentice et al. 2018). The authors also note that it is rare for under treatment (i.e. treatment refusal) to engender these same feelings of distress and disempowerment in providers.

Moral distress is not limited to the intensive care setting or end of life decision making. However, we will continue to focus on these areas for the purpose of this thesis. Jameton notes that organizational problems may also contribute to moral distress (Jameton 2017). These concerns include inadequate staffing, resource challenges, poor communication, power structures and institutional policies (Rushton, Caldwell, and Kurtz 2016).

In our example, inadequate staffing contributes to Marie's moral distress. Her patient assignment does not allow time for her to hold Eric, which Marie believes will be most beneficial for him. Since her work is mostly task oriented, she feels that she is doing things to Eric but not necessarily for him. Marie feels as though she is compromising on his care.

Limited bed-space availability compounds the distress experienced by Dr. Grey. Bioethical doctrine dictates that resource allocation is a societal debate and not appropriate to guide medical decision making for individual patients. Consequently, distributive justice concerns often go unspoken in the intensive care unit. However, it is important to acknowledge that limitation of resources can be a key driver for moral distress and a potential area of focus when seeking solutions. For example, if Dr. Grey had an acceptable plan for handling the high patient census, the distress she feels in Eric's case might be partially assuaged.

Poor communication and disagreements among providers also contribute to feelings of moral distress. Marie did not share with Dr. Green her views on transfusing Eric. This contributed to her belief that she was actually harming Eric by inserting the IV. If she shared her concerns with Dr.

Green, he would have an opportunity to explain his rationale for proceeding with the transfusion and she would have a chance to advocate for her patient. Furthermore, since Dr. Green is a resident in training, he might not have known about the IV access issues when he made the decision to order the transfusion and Marie is best suited to bring this to his attention. In hierarchal organizations, some staff members feel disempowered to voice their concerns and this silence may form the basis of moral distress.

In turn, Dr. Grey's lack of communication may have contributed to the moral distress of her colleagues. By abruptly ending discussions about Eric's care plan, she misses the opportunity to empathize with her nurses and clarify her own moral stance. This often leads to divisions in the care team, an "us versus them" mentality and a culture of blaming (Rushton, Caldwell, and Kurtz 2016). Indeed, Dr. Grey believes that the staff are dissatisfied with her efforts and as such, she feels isolated. Cynda Rushton, a renowned nurse ethicist, has written extensively on moral distress and moral resilience. She notes that intrateam conflicts are often a trigger for moral distress. Many such conflicts have their roots in poor communication between team members.

The resident physician, Dr. Green is also concerned about the allocation of resources although he conflates this with the child's pain and suffering. He demonstrates two concerning sequelae of moral distress. Dr. Green has altered his career plans based in part on the morally distressing experience of taking care of Eric. This is akin to burnout in an established NICU provider. Furthermore, he is providing Eric with a lower level of care than he would any other patient. He avoids examining Eric and actually finds himself wishing him harm, in the form of pneumonia, because his teleological ethic suggests that the ends would justify the means. In another context, we can expect that Dr. Green is a virtuous and moral physician. However, his distress in this situation has eroded on his ability to provide compassionate care. Similarly, in response to her moral distress, Marie requests not to take care of Eric during her next shift. Although this seems like a better method of coping with moral distress, it is not a tenable solution if the entire nursing staff have the same request.

How individuals react to moral distress can vary significantly, but often includes a number of emotional, physical, spiritual and behavioral changes (Jameton 2017, Rushton, Caldwell, and Kurtz 2016). These disparate manifestations can make moral distress difficult to recognize and therefore challenging to address. Moral distress evokes the body's autonomic stress response, known also as fight or flight, which causes many of the physical symptoms that caregivers describe. These include heart palpitations, insomnia, hyperactivity and gastrointestinal disturbances (Rushton, Caldwell, and Kurtz 2016, Rushton 2017). As exemplified in the case study, emotional changes like depression, anxiety, dismay, loss or personal integrity, burnout and feelings of powerlessness also occur. In response to these emotions, there can be a number of maladaptive behavioral changes such as avoidance, blaming, disengagement and defensiveness. Dr. Rushton summarizes these responses to moral distress in a Venn diagram, which is included in appendix A to this thesis.

Expectedly, these behavioral changes have negative impacts in both the professional and personal spheres. Authors document a correlation between moral distress and diminished job satisfaction leading to burnout (Larson et al. 2017). Maintaining skilled ICU nurses is an important focus for healthcare management. The cost of nursing turnover according to Robert Wood Johnson Foundation ranges from approximately $64,000 to $88,000 per nurse (Kozub et al. 2015). Furthermore, it can be argued that in the ICU setting there is no substitute for experience, making the loss of a seasoned nurse impossible to quantify in monetary terms.

Moral distress may negatively affect patient care in a number of other ways. The individual provider may deliver a lower quality of care because of burnout, cynicism, and decreased job satisfaction. Fractured team dynamics may distract from the needs of the patient and potentiate lapses in communication and medical errors. Staff turnover and absenteeism influence both patient care and hospital finances. (Rushton 2017)

The recognition of the breadth and depth of the moral distress problem has inspired a large body of literature on the concept of moral resilience (Gillespie, Chaboyer, and Wallis 2007). Again, much of this work has been driven by nurses, but is potentially beneficial for any member of the patient care team. Moral resilience describes a number of adaptive skills that allow an individual to cope with moral distress (Prentice et al. 2018, Rushton 2016). The term first gained popularity with the seminal paper of Gillespie et al in 2007 (Gillespie, Chaboyer, and Wallis 2007). Dr. Rushton has written extensively on this topic and notes that it is a ‘concept under construction’ (Rushton 2016). That is to say, we are still learning about strategies that will mitigate moral distress while preserving the personal integrity of the provider. Nevertheless, several themes have emerged in the literature, which we will discuss below. (Jameton 2017, Larson et al. 2017, Prentice et al. 2016, Prentice et al. 2018, Rushton 2016, Rushton, Caldwell, and Kurtz 2016, Trotochaud et al. 2015)

The first theme is recognizing that moral distress is in part the result of moral sensitivity, and therefore not entirely unwelcome. In the absence of a personal and professional ethic, providers will not experience moral distress. Moral sensitivity describes this ability to recognize ethical tensions that arise in the care of patients. It is grounded in empathy for the suffering of others and a sense of professional duty on the part of the healthcare provider. Although moral sensitivity can lead to moral distress, it can also be directed towards seeking solutions and an openness to hearing the perspectives of others. (Rushton 2016)

This brings us to the second theme: moral subjectivity. Moral subjectivity involves a more complex assessment of an ethical dilemma. While an individual will likely hold to their principled beliefs, there should also be a degree of humility that allows an appreciation for other points of view. An awareness of moral subjectivity can be enhanced with formal ethics education in both moral theory and the four major principles. Since many instances of moral distress relate to end of life care, it is important for providers to recognize that individuals hold different views about the meaning of life and the nature of suffering. Moral subjectivity begins with an acknowledgement of common goals (e.g. the good of the patient). It then requires an understanding that others may find a particular aspect of that goal to be most important (e.g. length of life versus quality of life). They may also see a different pathway to achieve the goals of care. (Rushton, Caldwell, and Kurtz 2016)

The third theme encourages open discourse among members of the healthcare team. These conversations should occur horizontally across disciplines, and vertically within a hierarchical structure. A change in organizational culture may be needed to empower individuals to speak up about their concerns. Likewise, providers must also be willing to listen to the views of others without being dismissive or defensive. Efforts should be made to have a complete understanding of the situation at hand, free from innuendo and unsubstantiated facts. It is not helpful to villainize any one individual or victimize another. E.g., “This is Dr. White’s fault. If Dr. Brown was on-service this would never have happened.” Constructive communication prevents misunderstandings and creates an opportunity to seek solutions. (Rushton 2016)

Self-care is the next theme. Moral resilience increases when caregivers care for themselves. This includes time for self-reflection (meditation), seeking the support of colleagues and, if necessary, stepping away from the morally distressing situation. There may be a point when a provider feels they must consciously object to continued participation in the care of a patient. Part of self-care also involves taking a stand and holding to one's convictions when personal integrity is at stake. (Young and Rushton 2017)

As we explored these themes, we noted that many of the key terms, related to moral resilience, began with the letter S. As a life-long student and a fan of memory-aids, this author offers the following figurative summary for consideration.

FROM MORAL DISTRESS TO MORAL RESILIENCE

When you face an ethical dilemma or conflict:

STOP

Recognize the **SIGNS** and **SYMPTOMS** of moral distress

Know the complete **STORY** and the details of the **SITUATION**

Appreciate moral **SENSITIVITY**
It is a good thing to care about ethical issues

Acknowledge moral **SUBJECTIVITY**
Try to see the dilemma from a different point of view

SPEAK-UP appropriately and then listen **SILENTLY**

Care for **SELF** and make time for **SELF-REFLECTION**

Seek **SOLUTIONS**

Ask for **SUPPORT**

If needed **STEP AWAY** and **STAND** for what you believe in

Figure 4.1

In this chapter, we have introduced the topics of moral distress and moral resilience. With this background, we will now move on to the ethical analysis of Eric’s case.

Chapter 5 – Ethical Analysis and Recommendations

In the preceding chapters, we have referenced the case of Eric Bridge, a three-month-old boy with severe hypoxic ischemic encephalopathy, who is in a non-cognitive state and ventilator dependent. Since Eric is in state custody, there is a mandate that he remain on life-sustaining support, even though the medical team and his only involved relative, his aunt Mrs. Wilson, believe withdrawal of intensive care is in his best interests. A similarly affected infant, in the custody of their parents, would have the options of withholding or withdrawing life-sustaining treatment. On the surface, it would appear that this policy is consistent with the state's duty to protect life. However, continuing intensive care could also be viewed as prolonging the infant's pain, suffering, and ultimately his death. Arguably, the latter seems more consistent with punishment than protection. In cases such as this, the expectation is for the medical decision maker to carefully consider the benefits and burdens of treatment before choosing a therapeutic course. By offering a singular answer to end of life questions, the state is failing in their duty to stand *in loco parentis*. Eric's quality of life is not factored into decision-making and his dignity as a person is undermined.

Eric's case is certainly not unique. As we discussed in Chapter 3, there are many children with medical complexity in the foster care system. Before we begin our ethical analysis, it would be helpful for us to consider another case of a child in state custody. Again, the names are fictitious but the narrative is based on a true clinical scenario.

Baby Owen Carter was a four-month-old infant hospitalized in the pediatric intensive care unit (PICU). Previously, he was a healthy baby boy. However, a month ago, his mother brought him to the emergency department, reporting that he "rolled off the bed and hit the floor". At the time of his initial evaluation, Owen was unconscious and he required CPR to reestablish a regular heartbeat. After stabilization, he was transferred to the PICU on the ventilator, where he has remained unresponsive due to severe, traumatic brain injury. Further investigations raised significant doubt regarding his mother's explanation of the antecedent event. It appeared that Owen was in fact the victim of non-accidental trauma (NAT), commonly known as shaken baby syndrome. Owen's parents were questioned by the police and both were arrested on charges of child abuse. In turn, Owen was taken into state custody under the Division of Family and Children's services (DFCS).

Owen remained unconscious, breathing minimally over the ventilator. Although he was not brain dead, he was unable to open his eyes, move spontaneously or respond to touch. He was considered to be in a permanent vegetative state. He would need a tracheostomy and gastrostomy to allow for discharge to foster care. Consequently, the treating clinicians in the PICU strongly believed that continuing intensive care was not in his best interests. They recommended withdrawal of the ventilator to allow him to die from his severe brain injury (it seems inaccurate to say 'natural death' in this case, as these injuries were intentionally inflicted and certainly unnatural). There was considerable moral distress among the staff, many of whom believed that intensive care only served to perpetuate the abuse that Owen had already suffered.

In this case, DFCS took a slightly different tact. Although they provided all medical consents for Owen, they deferred end of life decisions to his parents, who both remained incarcerated. In this regard, the parents were adamant that intensive care for Owen should continue. The PICU team requested an ethics consult because they believed his parents were not acting in his best interests. Indeed, were he to die of his injuries, the parents' charges could be upgraded from child abuse to murder. The latter carried the potential for a life sentence. It is difficult to reconcile the paradox of DFCS protecting the child by removing custody, yet allowing the same parents, who injured the child (thus clearly failing to act in his best interests), to make the decisions about his life and death. As we noted in Chapter 3, parental decision making is ethically validated by the presumption that parents will make choices in the best interests of their child, and in their role as parental caregivers, they (after the child) are most affected by their choices. Arguably, Owen's parents are primarily concerned with their own interests, related to their criminal charges.

We present these cases to bring attention to the inadequacy of state medical decision-making for critically ill infants. The state's current model endorses the initiation of invasive, life-sustaining interventions but provides no accessible pathway for the discontinuation of these same treatments. Indeed, the ethical challenge exists precisely because our legal 'decision-maker' is unable (or unwilling) to actually make any medical decisions. Moreover, the state's lack of medical knowledge and limited participation in the child's daily care, calls into question their qualification to exercise decision-making authority. Indeed, if the state cannot or will not make informed decisions, we propose that a different medical surrogate is needed for these critically-ill infants. This chapter addresses the inherent problems of state decision-making authority and discusses possible alternatives.

State decision-makers

As noted previously, the state holds the legal responsibility for child welfare and protection. This duty is defined as:

> "Public social services which supplement, or substitute for, parental care and supervision for the purpose of (1) preventing or remedying, or assisting in the solution of problems which may result in the neglect, abuse, exploitation, or delinquency of children, (2) protecting and caring for homeless, dependent, or neglected children, (3) protecting and

> promoting the welfare of children of working mothers, and (4) otherwise protecting and promoting the welfare of children, including the strengthening of their own homes where possible or, where needed, the provision of adequate care of children away from their homes in foster-family homes or day-care or other child-care facilities.". (Cohen 1962)

The statement of purpose above, emphasizes the state's duty to "*substitute* for parental care and supervision" in cases of neglect and abuse. This is the doctrine of *parent patriae*, which grants to the state the authority to protect citizens who are unable to protect themselves. (Strassburger 2016) The state's obligation includes more than just the provision of nourishment and shelter. It encompasses other 'ideals' including the provision of security, safety, healthcare and education. The expectation is that the state will do a better job protecting the child's interests than their biological parents. However, simply providing better childcare than the birth family is insufficient. After all, these parents were deemed unfit and should not be used to set any standard for attainment. Likewise, the foster home need not be luxurious or excessively accommodating. The state should aim for a care environment where the child's best interests are prioritized and protected. This child-centric position may seem intuitive, but for children with medical complexity, other factors may compete with their best interests when treatment decisions are made. For example, the state's mandate to work towards family reunification may lead to compromises in the level of care that is acceptable for the child.

In neonatology, a surrogate medical decision maker is required, since infants obviously lack the capacity to make decisions on their own behalf. The vast majority of parents excel in this role, despite never having a formal bioethics education. Indeed, choosing the treatment that will be most beneficial and least harmful, is a natural extension of a parent's love and concern for their child's well-being. However, when an infant is in state custody, these important medical decisions appear to lack the appropriate degree of scrutinization. This concern exists both for questions of treatment initiation and treatment withdrawal.

The Georgia DFCS policy manual contains a section on “coordination of care with hospitals”. (DHS 2018) This document details the responsibilities of the caseworker when a child in state custody is hospitalized. As the title would suggest, the policy emphasizes the need for communication and collaboration between social services and medical providers. Indeed, it states that the caseworker should “Work continually and closely with the hospital or treatment facility during admission, treatment, and discharge to ensure full engagement and coordination throughout the child’s stay”. To meet this obligation, workers are expected to “Advocate for the child in treatment team meetings”. However, the reality is quite different from what this policy prescribes. In actuality, the contact of a foster child with their caseworker is often extremely limited, sometimes as little as 10 minutes a month. (Bass, Shields, and Behrman 2004) (Greiner et al. 2015)

In Georgia, workers average an assignment of 19 cases, which is above the department’s stated goal of 15. (DHS 2017) Across the country, caseloads of 10 to greater than 100 per worker have been documented. (Bass, Shields, and Behrman 2004) Furthermore, high employee turnover has been a long-standing problem for child-welfare departments. Georgia DFCS reports an annual rate of turnover of 29% among their employees, which is consistent with the rates reported in other states. (DHS 2017, Bass, Shields, and Behrman 2004) This high employee turnover leads to discontinuous care and contributes to the agency’s lack of longitudinal perspective on the child’s illness. (Barnett 2018)

Of added concern, studies show that the majority of child-welfare workers lack formal training in social work, although they are usually college educated in another field. (Barth et al. 2008, Staudt et al. 2015) Nevertheless, caseworkers holding either a bachelor's or master's degree in social work, attain better job performance, and demonstrate higher rates of job retention than their colleagues. (Bass, Shields, and Behrman 2004) When modern child protective services were established in the 1962 social security amendments, the law stated that "The staff, to the extent feasible, is to be composed of trained child welfare personnel". (Cohen 1962) However, many child welfare departments continue to have difficulty attracting and retaining experienced social workers. (Bass, Shields, and Behrman 2004)

As caseworkers struggle with higher caseloads, the nature of their work has also become more complex. This is in part attributable to increased documentation requirements. However, it is also the result of the increasingly diverse population of children that DFCS serves. As we noted previously, a disproportionate number of children in state custody are medically fragile. The caseworker, who usually has no background in healthcare, is then challenged to find suitable foster placements where their disparate medical needs can me met. Even the most experienced social workers may have difficulty understanding the clinical details of a case, and even more difficulty using this information to make medical decisions. Indeed, it has been noted that the child welfare system was never intended to deal with prognostic uncertainty or the value-based judgements that modern medicine demands. (Seltzer 2018)

Concern has been raised that a conflict of interest may exist in child welfare departments. Caseworkers may be motivated to decrease their workload by placing medically complex children with foster parents who lack the necessary skills to care for them. (Greiner et al. 2015, Barnett et al. 2018) They may also be poorly motivated to expedite hospital discharges since a child in the hospital is presumed to be safe from abuse and receiving optimal care. (Seltzer, Henderson, and Boss 2016) Indeed, Georgia DFCS will not identify a foster parent for a newborn until a discharge date has been specified. This practice works to the detriment of both the newborn and the foster parent. Such delay leaves less time available for parent teaching and restricts the opportunities for caregivers to familiarize themselves with the medical history of the child. Additionally, the infant may spend much of their hospitalization without nurturing visitation, since they lack a consistent, dedicated parental presence.

Despite these difficulties, child welfare workers, as representatives of the state, are called upon to provide medical consents for hospitalized newborns in state custody. As noted in the Georgia policy handbook, the worker should, “Be immediately available to provide or facilitate authorization of *necessary paperwork* (e.g. admissions documents, consent forms, discharge documents, etc.)” (DHS 2018). The term “necessary paperwork” implies that informed consent is distilled down to a perfunctory signature. Indeed, the process of “obtaining DFCS consent” may be more aptly described as obtaining DFCS assent. That is to say, if a physician determines that a treatment is appropriate, their expertise is usually not questioned, and the proposed treatment is allowed to proceed. In my experience, these important informed consent conversations are reduced to sending a form to the caseworker by email or facsimile, which is eventually signed and returned. Indeed, clinicians have minimal face-to-face interaction with the DFCS worker. Ironically, when a parent is persistently absent from the bedside, a clinician may become concerned for medical neglect. However, for newborns in DFCS custody, this lack of visitation or engagement in treatment decisions is often the norm. (Greiner et al. 2015, Bass, Shields, and Behrman 2004) Here we see an example of the state failing to meet the minimal level of care expected from a parent.

Beauchamp and Childress describe seven essential elements of the informed consent process. The first two criteria apply to the person making medical decisions and are considered preconditions; in other words, valid informed consent cannot happen if the decision maker lacks these characteristics. The first prerequisite is competence to understand and make decisions. The second aspect is a voluntariness to decide. (Beauchamp and Childress 2001)

It is appropriate to evaluate the degree to which the state meets these criteria: competence and voluntariness. In order to have an adequate understanding of the decision at hand, a representative of the state would need to visit the child regularly, participate in care-conferences and spend some time independently researching the child’s condition. In order to make decisions voluntarily, there should be no conflict of interest or *a-priori* limitation of medically and ethically acceptable options. DFCS may be influenced by several factors which are not directly related to the child’s welfare including public image and budgetary limitations. (Strassburger 2016) To the extent that the state does not meet these conditions, they should be disqualified from making medical decisions for children in their custody.

End of life decisions are an area in which child welfare agencies typically choose to remain silent. (Seltzer, Henderson, and Boss 2016) In the state of Georgia, this is not specifically addressed in the written policies, but it has been the consistent practice of DFCS to deny physician requests for non-resuscitation or treatment withdrawal. In some other states, the policy is stated clearly and unequivocally. For example, in the Tennessee, “Administration policies and procedures” it is stated that “The Department of Children’s Services (DCS) has no authority to consent to or make decisions regarding the end of life of a child in its care” (DFC, TN 2010). In South Carolina, when parental rights have been terminated, only the State Director is able to make decisions on end-of-life care. (DSS, SC 2003) In Texas, the caseworker is referred to the courts if authorization for treatment limitation is requested. In Minnesota, end-of-life decisions can only be made by the state commissioner of the Minnesota Department of Human services (DHS, MN 2017). The New Jersey DNR policy specifies:

> "As the state child protection agency, CP&P [Child Protection and Permanency] is statutorily mandated to care for children, with an implicit goal of preserving life. Therefore, in order to avoid possible conflicts of interests, CP&P is not permitted to sign a consent form for a DNR order." (DCF, NJ 2013)

Finally, the Indiana policy states:

> "The Indiana Department of Child Services will involve the court when a physician or hospital contacts any DCS staff member regarding the removal of life support or the issuance of a Do Not Resuscitate (DNR) Order for a child under the care and placement of DCS". (DCS, IN 2009)

The consistent theme in all of these state policies is deference of end of life decisions to administrators and/or the courts. Again, this is an example of someone very removed from the child, being the only person with any authority to make these decisions. It is understandable that the tendency of those unfamiliar with the case is to err on the side of life, by ruling that treatment should continue.

We contend that these policies result in unequal treatment for infants in state custody when compared with other infants. Additionally, since state welfare departments have received negative press for children dying under their supervision, it is possible that they are legally averse to making end-of-life decisions, even in cases where the child derives no benefit from continued medical interventions (Strassburger 2016, Bass, Shields, and Behrman 2004)

Equal treatment

The equal treatment we describe here is equality of opportunity. Let us stipulate for now that both withdrawal of life-sustaining treatment and continued intensive care are morally acceptable choices. Since parents will make decisions according to their values, some will opt to withdraw therapy while others will continue to pursue intensive care. Therefore, although this group of patients have similar degrees of brain injury, they are treated differently, from a medical standpoint.

If it is mandatory to continue life-sustaining treatment for babies like Eric and Owen, they will receive the same treatment as some infants who share their diagnosis. However, the inequity comes because in their case, there is no active consideration of choices. To limit the options of one baby, but not another, is to treat that child differently. Therefore, it is no more just to mandate life than it is to mandate death. It is this absence of informed choice that sets our babies apart from others with similar conditions.

This is only compounded when we consider the challenges of foster care described in Chapter 3. One could infer that if a parent decides to take their infant home on a ventilator, they have made an informed choice with full knowledge of the required commitment. However, for our babies in foster care, there are the additional challenges of placement and permanency, which accompany their technology dependent lives. As such, these children are disadvantaged by both an under resourced system and a lack of parental commitment to their continued existence. Studies have affirmed the relationship between neonatal outcomes and the family who care for the newborn after discharge. Accordingly, it is clear that these babies are not receiving equitable treatment in the foster care system.

As John Rawls states in his theory of “Justice of Fairness”, all persons should have equal access to healthcare and inequity is only acceptable if there is a preference for the poor (Littleton 2010). However, in our cases, the care options of the disadvantaged (those in state custody) appear to be limited to continued technology dependence. If intensive care was clearly the best option, we can argue that this policy protects these patients. Conversely, if one contends that palliative care rather than intensive care is the better course, these already disadvantaged babies are unfairly committed to the less desirable treatment plan.

The Medical Providers as Decision Makers

For the hospitalized newborn, it is indeed likely that the intensive care staff are most familiar with their history and medical needs. Perhaps this could be used to forward an argument that physicians and nurses are best suited for the role of surrogate decision maker when newborn patients are in state custody. However, there are also serious ethical concerns with this relapse into paternalism. Again, healthcare is an outcomes-based endeavor. As such, physicians are more likely to perceive a low quality of life for disabled infants. (Wilfond 2014) This reflects a more functionalist view on personhood, which we will discuss below. With this decidedly ableist bent, it is probable that medical professionals are more likely to recommend treatment limitation in infants with neurologic injury. As we discussed in chapter 2, the difficulties in prognosticating for newborns, calls into question the basis for these value judgments.

Personhood

The question of what it means to be a human person seems elementary on the surface. Nevertheless, philosophers have grappled with this subject for centuries. A popular contention is that you are a person simply by dint of being born human. Indeed, this seems to reflect the state's position. This definition seems acceptable, but many scholars argue that birth is an arbitrary time-point at which to confer personhood. Much of the commentary in this area relates to the abortion debate (Timmons 2013). By choosing birth as the point at which a human being becomes a person, the prenatal period is morally devalued or even discounted. Is a forty-week (full-term) fetus not a person until they are born? This fetus is most likely capable of survival outside of the pregnant woman, having developed the physiologic capacity to breathe, eat, eliminate etc. Both the fetus and the baby are largely dependent on the care of another. They possess the same physical attributes and capabilities both before and after birth. However, they are not a person until they are born, at which point the main difference is their ability to breathe independently. Would a baby who is unable to spontaneously take their first breath, not be conferred with personhood? Those of us who participate in neonatal resuscitation, recognize that apnea (not breathing) is a common problem, and one that is often easily surmountable with a few moments of assisted ventilation. Therefore, independent breathing, the primary physiologic change that occurs at the time of birth, is not a prerequisite for personhood.

We can also consider a preterm infant born at a previable gestation, 21 weeks for example. Is this 21-week baby a person? Even though this gestation is incompatible with life, one would still strive to treat this baby humanely. I think the majority of us would recoil at the idea of putting this baby in a trashcan, simply because she is incapable of long-term extrauterine survival. If the baby has a heartbeat, she receives a birth certificate and ultimately a death certificate. Her prematurity is incompatible with survival but she is live-born, and therefore a person by the birth definition. However, is she more of a person than the 40-week fetus on the day before he was born? I would suggest that the answer is no.

Consideration of biology alone seems inadequate for the personhood definition. This leads us to the functionalism debate (Cox 2011, Timmons 2013). In this school of thought, various human capabilities give rise to personhood; for example, cognition, socialization, self-awareness, autonomy and rationality. Of these, rationality is purported to be exclusive to human persons. I can argue that my cat possesses many of these other traits but he is certainly not rational. The philosopher, Immanuel Kant, believed that moral requirements apply to all rational agents (Timmons 2013, Walker and Lovat 2015). For Kant, rationality was an ‘end in itself’; an ultimate good that forms the basis for human dignity and personhood. Autonomy, according to Kantian theory, is the application of rationality through freedom of choice. A similar rendering of this concept is the popularly quoted, “I think therefore I am’’ from French philosopher Rene Descartes.

Likewise, for the utilitarian, personhood pivots on the idea of self-awareness (Cox 2011). In order to ascribe personhood, there must be some recognition of one’s own desires, most importantly, the conscious desire for continued existence. Indeed, an infant lacks both self-awareness and cognizance of their place in the continuity of time (Wilkinson 2006). According to philosopher Michael Tooley, since newborn infants cannot envisage their future, they can have no interest in preserving that future (Sklansky 2001) quoting (Tooley 1983). Moreover, they are not wronged when that future is taken away.

Disability advocates strongly refute the functionalist position, as it excludes many with cognitive differences. By applying this definition, individuals with intellectual limitations or severe psychiatric diseases may not meet the criteria for personhood. Additionally, newborns, young children and anyone with impaired consciousness (e.g. PVS) also fall short of the rationality or self-awareness requirement. Meanwhile, IBM’s Watson, an artificial intelligence system programmed for decision-making, could be considered rational and thus a person.

If one were to hold to this functionalist perspective, the moral standing of Eric and Owen would be negated. Consequently, it would be easy to surmise the correct course of action, since ventilator withdrawal from a non-person would be incontrovertible. Indeed, there would be no mandate to provide medical care to any newborn including those that we expect to restore to complete health. As a neonatologist who is also an ethicist, functionality alone seems to be an incomplete definition.

Quality of life Considerations

Quality of life is especially difficult to assess in the newborn patient. Perhaps these considerations do not even apply to those who are yet to be self-aware (Wilkinson 2006). Furthermore, Wilkinson contends that without prior knowledge of some human pleasures, one really cannot suffer in their absence. It is certainly easier to be content in the economy cabin when one has never experienced the pleasures of first-class. In the case of our babies, they have never spoken, eaten by mouth, walked, played outside etc. so their inability to do these things should not negatively affect their quality of life. For this reason, he contends that it is difficult for an able-bodied, cognitively intact adult to appraise the future life of a disabled infant. We would see their disability through a lens of loss, which would be significantly more distressing than having never possessed these same capabilities.

However, in the case of our babies, their quality of life is solely impacted by the experience of pain because they lack the cognitive capacity for happiness. (Hauer and Houtrow 2017) In chapter 2, we discussed disorders of consciousness and brain death. Eric and Owen were both evaluated for brain death but did not meet criteria because of some residual brain stem functioning. The question here relates to the moral difference between our babies and those who are brain dead. We pose this question from the standpoint of evaluating quality of 'life' rather than for purposes of organ procurement. In these severely brain damaged infants, most higher cortical function is lost, but some elementary brain stem functions continue. The brain stem is responsible for autonomic (subconscious) physiologic processes, such as swallowing, breathing, blinking, coughing etc. All voluntary actions and the thoughts that underlie these actions are controlled by the cerebral cortex. Therefore, our severely impaired newborns are able to maintain homeostasis but lack the ability to command their own bodies or even comprehend their present-moment existence. As such, the neurologic state of these infants closely resembles brain death, with one subtle but significant difference: Eric and Owen's relative physiologic stability may allow them to subsist in this manner indefinitely. We contend that it is morally reproachable to allow a person to linger interminably in a state of 'near-death', especially when that condition is maintained exclusively through medical technology.

Limitation of Resources

Bioethicists recognize that limited resources, coupled with a relatively boundless demand for medical services, necessitates the rationing of treatment. As Wilkinson surmised, it is not a question of whether we ration but how we ration (Wilkinson 2013). Currently, in the United

States, rationing (although often not recognized as such) occurs mostly along geographical and socioeconomic lines. Health outcomes are consistently poorer among inner-city and rural residents. For example, entire counties in the state of Georgia lack the availability of an obstetrical or midwifery provider. In American medicine, the well-insured have access to state-of-the-art care while the uninsured rely on an overtaxed system of safety-net hospitals and clinics. This uncalculated method of apportioning care does not consider treatment outcomes, cost effectiveness or medical need. As such, our healthcare system is criticized for its injudicious use of scarce resources, which results in substandard population outcomes despite extraordinarily high *per capita* spending. Since much of this spending takes place towards the end of life, the various branches of intensive care have been challenged to justify their worth to society.

Predictably, the NICU is an area where the value of healthcare dollars is questioned. Research by Janvier and others indicates that newborns are seen as a lesser priority for treatment resources than older patients (Janvier, Dupont-Thibodeau). This likely reflects views on the personhood of infants, discussed earlier in this chapter. However, studies by Lantos and Meadows demonstrate that only 7% of total NICU expenses are spent on non-survivors (Meadow 2011, Bucch 2007). As such, neonatal care is extraordinarily cost effective. When life years saved are added to the calculus, neonatal intensive care is unrivaled in its successes. An octogenarian, who survives a medical ICU stay, may look forward to a year or two of continued health. In contrast, a NICU graduate can be expected to have a full and productive life beyond the newborn nursery. Of course, the reverse is also true. An infant with severe neurologic injury will continue to consume a disproportionate share of healthcare resources over the course of their life. This leads us to question whether scarcity of resources should be a consideration when determining which infants should receive intensive care.

The utilitarian moral theorist would vehemently oppose continued intensive care for babies like Eric and Owen. The primary concern in this philosophy is to provide the greatest good for the greatest number of people. In this regard, costly intensive care cannot be justified when a patient derives no tangible benefits i.e. fails to regain any degree of normal functioning. The finances expended to maintain Eric in his unconscious state, would be better spent on other healthcare endeavors that positively impact the population at large. Also, the hospital bed which he occupies, should be allocated to a patient who experiences greater benefit from intensive care. In other words, utilitarian doctrine requires that resources are not expended on "futile" treatment. Again, since "futility" is hard to define, the threshold of benefit required to justify allocation of resources, remains an issue for debate.

Summary

For a critically-ill newborn without a parental presence, only two parties consistently have any knowledge of their medical complexities – these are Social Services, typically through the caseworker, and the medical team (physicians, nurses etc). We have described reasons why both groups should be excluded as ethically appropriate surrogate decision makers. Consequently, in order to allow for thoughtful and deliberate medical decision-making, each child is entitled to have an independent 'medical guardian'. This role may be served by a court appointed special advocate, a guardian *ad litem* or another volunteer. These are proposed criteria for this medical guardian role.

1. This is a volunteer, lay position. In other words, no medical expertise is expected. Medical staff can only participate if they have no clinical involvement with the baby. For example, an adult dialysis nurse would be able to serve as a medical guardian. However, an NICU nurse who works in the same nursery where the child is hospitalized would be excluded.

2. The medical guardian should regularly visit the infant and receive frequent updates from the physicians and nurses about the infant's condition. They should be included in any care conferences with respect to the patient. A minimum of ten hours commitment is expected each week.
3. The medical guardian should advise the social services case worker about any proposed surgeries or procedures. If the guardian determines the intervention to be in the best interest of the patient, medical consent should be provided.
4. The medical guardian should be approached by the medical team for any questions concerning treatment limitation. The medical guardian will then meet with the hospital ethics committee, treating physicians and involved family members to discuss the proposed treatment course for the infant. The medical guardian should submit a recommendation which carries equal weight to the opinion of the ethics committee. Both must agree that non-resuscitation or treatment withdrawal is in the best interests of the infant for this care plan to be exacted.
5. It is recommended that the medical guardian use the PREFER model (discussed below) to evaluate the morally relevant aspects of the child's case.

The Prefer Model

To facilitate healthcare decisions, it is important to provide a framework for evaluating possible treatments. This author proposes the PREFER model as a method to incorporate morally relevant information in the formulation of medical decisions. In parentheses, we reference the primary ethical principle applicable to each element.

P – Prevent patient pain and suffering (nonmaleficence)
R – Recommendation of primary physician (beneficence/ nonmaleficence)
E – Evidence for efficacy of treatment (beneficence) – Experimental treatment
F – Family preference/ foster parent preference (autonomy)
E – Economics of care (justice)
R – Rarity of resource (justice)

These six elements receive a score of 1 (favorable) or 0 (unfavorable). The PREFER model addresses ethical variables that are particularly germane to children in foster care. However, the tool can be used to aid in decision making for many treatment questions. Generally, a therapy with a score of 4 or greater should be implemented. Alternatively, three or more unfavorable elements suggests that the treatment should be foregone.

The PREFER model attempts to create objectivity from a subjective matter by answering specific binary questions. However, each element of PREFER is itself subjective to a degree. For example, who is the arbiter of what is expensive? Nevertheless, we theorize that PREFER curtails individual bias by requiring careful consideration of each of the six factors. By incorporating all elements into the larger decision at hand, there is clarity of reasoning, and transparency in the choices that are made.

A criticism of the model is its bias towards the will of the medical team (which may reflect the bias of the author). Indeed, parental autonomy is relegated to only one of six concerns. It should be emphasized that the primary use of this model is for children in foster care, whose legal medical decision maker is the state.

Another point of contention is the dual considerations of R (recommendation) and E (efficacy). The presumption is that the patient's primary physician (i.e. the provider most familiar with the details of their condition) will choose a course of therapy perceived to be in the child's best interest. This treatment plan may involve the implementation of some therapies and the withholding or withdrawal of others. Efficacy is a more objective standard, assessing whether a therapy can accomplish the stated goal. Herein, experimental therapies directed towards the condition in question, also receive consideration.

There are two elements related to utilization of resources: rarity and economics. This addresses the fact that some very expensive therapies are widely available (e.g. neonatal intensive care). The rarity of the resource is an independent concern and not always correlated with expense e.g. an antibiotic, chemotherapeutic agent or vaccine in short supply. Neither point is prohibitive when other factors are favorable.

We will conclude this chapter with some examples of the PREFER analysis. First, we will return to Eric and Owen.

In Eric's case we will evaluate continuation of mechanical ventilation.

P – Pain and suffering is present – thus a score of 0 applies

R – The physicians do not recommend treatment – a score of 0 applies

E – Efficacy of treatment – 1 could be scored here since the ventilator successfully maintains respiratory homeostasis

F – Eric's aunt disagrees with continuation of treatment, hence a 0 applies here

E – Economics of care – ICU care is resource intensive and therefore a score of 0 applies

R – The ICU resources are relatively unlimited so 1 point can be allocated

Eric's total score is 2 which would suggest that treatment should be discontinued.

In Owen's case, there are many similarities. However, his parents are in favor of continued treatment. This brings Owen's score up to 3, which still supports discontinuation of treatment.

Let us consider what the PREFER model suggests in the case of Baby Doe, the infant with Down syndrome and esophageal atresia. We will evaluate the esophageal repair surgery:

P – Post-operative pain will be present – 0. However, it is possible that the pain and suffering associated with non-treatment will be greater, in which case one point could be allocated. In this case, regardless of the assigned score, the analysis yields the same result.

R – Physicians recommend treatment - 1

E – Evidence shows this treatment is efficacious – 1

F – Family refuse treatment – 0

E – Treatment is economical – 1

R – Treatment is widely available – 1

In this case the PREFER score is 4 (or 5) which indicates that surgery should be pursued.

We can also consider a homeopathic treatment forwarded by a patient's parents, which has no proven medical benefit. Since the treatment is not recommended by the primary physician or proven efficacious, these elements will score 0 points. However, if the treatment does not cause the patient pain, is economical and readily available, the family's preference should prevail. The PREFER score here is 4 which favors treatment. The ethical rationale is that the treatment does not cause pain or suffering but it may have benefit. It is also economical and readily available. However, if this treatment is only available in Switzerland, the point given for rarity (and probably also economics), should be subtracted. This brings the score down to 2 or 3, and so the treatment is no longer favored.

The PREFER tool is designed for application by an independent third-party, such as a Court appointed special advocate, guardian *ad litem* or judge. It requires a clear understanding of the relevant facts of the case. Each element may spark further discussion resulting in a more comprehensive analysis of the issue. In this regard, the individual scores must be defensible in order for the overall score to be valid. The PREFER analysis can also be summarized in terms of conflicting ethical principles. For example, in the Baby Doe case, we can say that beneficence (Recommendation and Efficacy), nonmaleficence (Pain prevention) and justice (Economics and Rarity) conflict with parental autonomy (Family preference).

This model is designed for ease of application, as it employs a single acronym to prompt consideration of the six elements. It is probable that this simplicity excludes other factors important to a particular ethical dilemma. Therefore, PREFER is intended as an aid in decision-making and not the sole mechanism for determining the appropriate course of treatment. For some dilemmas, PREFER may stimulate a thorough ethical analysis leading to a clear recommendation. In other cases, our tool may only form the basis for a more in-depth discussion. Regardless, the aim is to prompt recognition of the important ethical dimensions of a case and to make these concepts accessible to individuals of different backgrounds with different skills in bioethics.

Conclusions

The provision of medically ineffective treatment in the neonatal intensive care setting has a number of unfortunate consequences. Primarily, we are concerned with the pain and suffering of the patient who is entirely dependent on medical technology for their cardiorespiratory functioning. Furthermore, the provision of “futile” treatment results in moral distress among some medical providers, which may ultimately diminish the quality of care given to all patients. Technological advances in medicine continue to allow for sustained physiologic support of patients who incur the failure of various organs. Nevertheless, circumstances arise where these treatments serve solely to stall death, rather than restore any degree of wellbeing to the patient. It is difficult to justify the allocation of scare or costly medical resources in this fashion.

In chapter one we reviewed the challenge of defining futility. Despite the lack of a clear definition, healthcare providers continue to identify instances of perceived “futile” treatment. We presented two cases of severely and irreversibly brain damaged infants who are ventilator dependent, the first with hypoxic ischemic encephalopathy and the second with non-accidental trauma. We contend that the medical decision making process is unacceptably abbreviated, and at times completely omitted, for some critically ill infants in state custody. Since neither social services, or the medical team are well equipped to speak for the infant, we propose each child have a designated medical guardian.

Finally, we present the PREFER model as a tool to facilitate complex medical decision-making for medical guardians. This simple acronym reminds the patient surrogate of the essential elements of a benefit and burden assessment. With the application of the PREFER model, we hope to encourage thorough scrutiny of treatment decisions for children in foster care. Ideally, this will allow foster children to receive the same consideration as their peers who have parental decision-makers. We speculate that a more structured approach to medical decision-making will decrease demands for medically ineffective treatment, thus curtailing the pain and suffering of these technology dependent patients.

In the current paradigm, children in foster-care must continue to receive life-sustaining treatment, regardless of their quality of life or expected prognosis. We contend that any treatment decision arbitrarily made, without consideration of a patient's unique circumstances, infers a disregard for the individual interests of that patient. If we mandate intensive care for infants in foster care, the end-of-life treatment options for these patients are unfairly restricted. In turn, this may only add to the pain and suffering of our most vulnerable patients who we are charged to protect.

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Appendix A

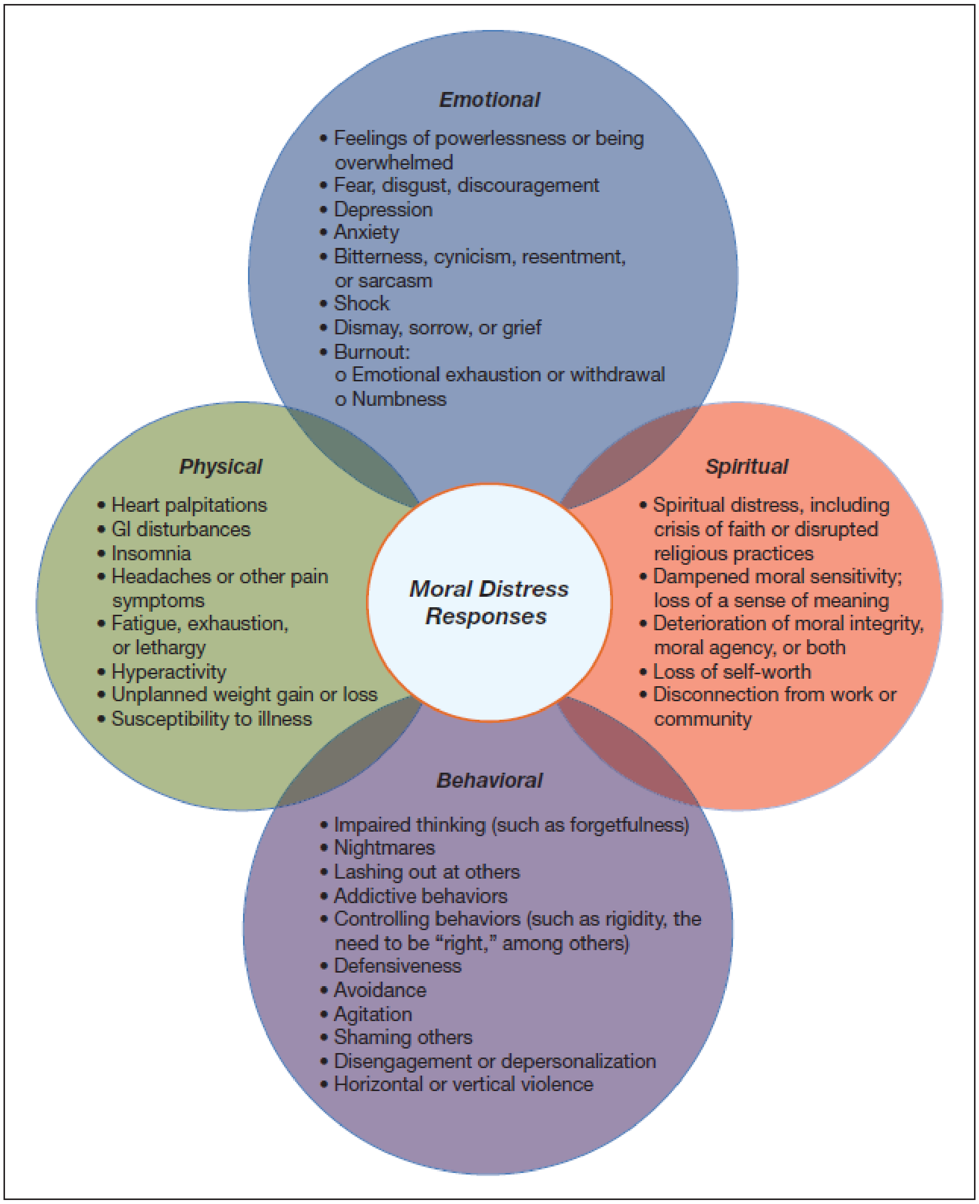

Figure 1. Selected Individual-Level Responses to Moral Distress[6, 9, 12, 20-24]

Moral Distress Responses

Emotional

- Feelings of powerlessness or being overwhelmed
- Fear, disgust, discouragement
- Depression
- Anxiety
- Bitterness, cynicism, resentment, or sarcasm
- Shock
- Dismay, sorrow, or grief
- Burnout:
  - o Emotional exhaustion or withdrawal
  - o Numbness

Physical

- Heart palpitations
- GI disturbances
- Insomnia
- Headaches or other pain symptoms
- Fatigue, exhaustion, or lethargy
- Hyperactivity
- Unplanned weight gain or loss
- Susceptibility to illness

Spiritual

- Spiritual distress, including crisis of faith or disrupted religious practices
- Dampened moral sensitivity; loss of a sense of meaning
- Deterioration of moral integrity, moral agency, or both
- Loss of self-worth
- Disconnection from work or community

Behavioral

- Impaired thinking (such as forgetfulness)
- Nightmares
- Lashing out at others
- Addictive behaviors
- Controlling behaviors (such as rigidity, the need to be “right,” among others)
- Defensiveness
- Avoidance
- Agitation
- Shaming others
- Disengagement or depersonalization
- Horizontal or vertical violence

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