

Intractable Conflict in Pediatric Critical Care:  
A Case Examination and Analysis of Futility

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First and foremost, I would like to acknowledge all of the caregivers involved in the care of the child who is the center of the case used for this paper, as well as the parents. These voices often go unheard in academic literature but are the ones who inspire and are affected by the work that is produced. These voices deserve to be heard. Nothing exists in a vacuum, and for this reason I acknowledge everyone in my life who I have interacted with and has influenced the objects of my curiosity and focus. I would also like to acknowledge my committee who have each contributed to constructing the complex view of a complex topic. My advisor Joan Liaschenko, and committee members Cynthia-Peden-McAlpine, Dan Pesut, Hans De-Ruiter, and Naomi Scheman. I would like to thank the Center for Bioethics, Deb DeBruin, Don Brunnquell, Thaddeus Pope, and countless other colleagues who have listened to me talk about this case, helped shape this work and its implications for improving interactions between parents and caregivers. This study received funding from the Minnesota Nurses Association Foundation through a research grant.

Dedicated to the families who have had to make difficult decisions, the children, and  
the caregivers.

To Emily, Mary, and Cate

The focus and reliance on a concept can often blind us from the real things that exist that cause a concept to come into being. Futility as a concept has been painstakingly debated in the literature. This study takes a different approach and seeks to discover complexity and dynamics of what happens during the course of the care of a child that leads to intractable conflicts. A single case study method is used. Participant interviews, chart review, and policy review were the sources of data explored. Transcriptions of interviews were inductively and deductively analyzed using Walker's expressive-collaborative model of morality. The roles, relations, objects, and concepts were critically analyzed through systems theory and critical realism. The results of this study suggest reframing discussions away from definitions of futility and movement towards conceptualizations and dialogues that include the moral community, and relationships between and among clinical and organizational ethics. The study advocates a moral and ethical need for early identification of futility dynamics, continuity in communication, and a perspective about managing polarities and problems versus solving them.

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## Chapter 1: Introduction to the Study

The purpose of this study is to investigate and critically analyze the social structure around a case that evolves into an intractable conflict and evokes the concept of futility. This will help to construct the pieces of the system that make it possible for futility, or perceptions of futility to exist. The results from this study will help shape future methods of ethical inquiry around patient, provider, and hospital interactions as well as a method to investigate ethical issues that result from structural flaws in other areas of healthcare such as disparities and deficiencies.

The concept of futility has been the subject of much debate since the advancement of several life-sustaining technologies (LST). There have been many attempts to define futility and there is still no consensus as will be described below. This has resulted in decades of discussion, policies, statements, and articles. The recent “consensus” around this term is that we should abandon its use in non-literal applications (Bosslet et al., 2015). In this reorientation, futility is anchored back towards definitional clarity: futility as having no use in the current context such as CPR on a body in rigor mortis. However, clarifying futility and shifting the conversation towards using terms such as “potentially inappropriate” and “non-beneficial” simply replaces the value-laden and subjective connotation of futility with another. There has been no attempt to analyze futility as an unintended consequence of a system or to examine what it is about the structures of healthcare where futility conflicts can exist? Healthcare providers operate within a social structure as a part of a system. Futility, or intractable conflict, provides a unique vantage point with which to investigate social structural causation that supports futility dynamics within healthcare.

The concept of futility seems specific to many clinicians but applying it objectively can be difficult and is the impetus for many conflicts (Bosslet et al., 2015; Brody & Halevy, 1995). Intractable conflict related to disputes over the conception of futility in pediatric critical care are normally considered individual dilemmas in decision-making between parent and provider. The focus is aimed at mitigating the conflict and coming to an amenable decision. Futility, however, is a social phenomenon and concept that is dependent upon a particular context. Futility is necessarily dependent upon a particular viewpoint within a particular context of society's ability to provide the care deemed futile as well as competing viewpoints, yet the bulk of the futility literature in the past few decades has focused on defining it as an objective measure. For example, if we didn't have a sophisticated electrical-power grid, many of the treatments referenced in futility debates would not be practically feasible.

The concept of futility has become viewed as imprecise, ambiguous, and even subjective (Bonanno, 1995). Additionally, the goals of a treatment can be ambiguous enough to make it difficult to apply true futility. Nevertheless, it has been the focus of much discussion and has led to the initiation of "futility" policies in health care institutions (Frankel, Goldworth, Rorty, & Silverman, 2005).

Academic discourse on futility coincides with the implementation and innovation of the mechanical ventilator, as well as the dialysis machine (Kaufman, 2015). The earliest published literature on futility appear as early as 1988, which seems to be when an initiative to define futility began (Carnevale, 1998). The concept of futility, however, is much older. Hippocrates discussed it saying that to "...attempt futile treatment is to display an ignorance that is allied to madness (Schneiderman, 2011, p.124)." Using this history as a starting point, Schneiderman argues that futility has

both a quantitative and qualitative component (Schneiderman, 2011; Schneiderman, Jecker, & Jonsen, 1990). Schneiderman, Jecker, & Jonsen argue in 1990 that there is a common sense, though not objective and value free, definition of quantitative futility where if the treatment has not worked in 100 cases it will not work again (1990). Schneiderman (2011) sought a “reasonable consensus” approach as opposed to an absolute knowledge. In contrast, qualitative futility is defined as a situation where the effect of a treatment cannot be appreciated as a benefit to the patient (Schneiderman, 2011). The definitions of medical futility have also included concepts such as patient’s goals, prolonging life, and physiologic effect on the body (Schneiderman, 2011).

Truog, Brett, & Frader (1992) discuss the addition of “futility” to the bioethical lexicon in a *New England Journal of Medicine* editorial titled “The Problem with Futility.” The authors discuss several limitations in how the concept of futility is being utilized. They find three paradigms of futility: cases involving persistent vegetative states, cardiopulmonary resuscitation (CPR), and organ-replacement technology (R D Truog, Brett, & Frader, 1992). They find that the use of futility in these paradigms seems to be an obscuring concept and that the ambiguities and assumptions that are obscured can be grouped into problems of subjective values and probability of treatment success (R D Truog et al., 1992, pp. 1560–1561). Problems with value are the most apparent test to physiologic futility as it requires some set goal that seems to shift depending on how or what a person values quality of life.

Probability, as explained by Schneiderman (2011), is problematic too because it doesn’t seem to articulate issues of variance in patient factors such as comorbidities, ability to sustain treatment, etc. Resource allocation is also mentioned here by the authors as problematic because futility arguments conceal “...many statistical and value-laden assumptions, whereas strategies based on resource allocation force these

assumptions to be stated explicitly (R D Truog et al., 1992, p. 1562).” They also 4  
contend that futility will simply have no impact on making resource allocation  
arguments because they will have little impact as these cases are relatively sparse.

Truog, Brett, & Frader conclude with a discussion of social consensus and report  
the professional societies the Hastings Center, the Society of Critical Care Medicine  
(SCCM), and the President’s Commission positions (at the time) on keeping patients  
who are in a persistent vegetative state alive as being a misuse of resources and  
should be removed from life support (R D Truog et al., 1992). Their analysis leads  
them to conclude that the concept of futility “...generally fails to provide an ethically  
coherent ground for limiting life-sustaining treatment...” except for very narrow cases  
of physiologic futility (R D Truog et al., 1992, p. 1563). Finally, they argue for a  
removal of futility from the professional language of bioethics because it is  
undermined by clinical variability and differing values (ibid, 1992). In addition, the  
focus or response around futility in resource allocation arguments conceal real issues  
and arguments that may have a more important place in the debate over proper use of  
resources.

Brody & Halevy (1995) are the first to question the validity of the concept of  
futility itself. The authors develop a framework of eight types of futility definitions  
and then analyze these definitions. They also analyze statements from three  
professional medical organizations, The American Medical Association (AMA), The  
American College of Physicians (ACP), and the American Heart Association  
(AHA)(Brody & Halevy, 1995). Essentially, the definitions of futility they find are  
physiologic-not physiologically feasible, imminent demise-person will die, lethal  
condition-condition will not change with treatment requested, and qualitative-  
subjective quality of life (Brody & Halevy, 1995, p. 128). They conclude their  
thorough analysis by arguing that while there may certainly be “...patients whose

condition is so poor that life prolonging interventions are qualitatively futile...” bāt that:

...Advocates of the various conceptions of futility have not given enough thought to the conditions that must be satisfied by any adequate conception of futility that could be used as the basis for a unilateral limiting of life prolonging interventions (Brody & Halevy, 1995, p. 142).

In addition to this problem, Brody & Halevy also put forth that much of the discussion around futility appears to be motivated by concerns of resource allocation and that these discussions would be better focused on the resource itself rather than futility (1995, p. 142).

More recently the debate around futility has taken a new course in a multi-societal policy statement from the American Thoracic Society (ATS), American Association of Critical-care Nurses (AACN), American College of Chest Physicians (ACCP), European Society of Intensive Care Medicine (ESICM), and SCCM (colloquially known as the “ATS” statement) (Bosslet et al., 2015). This was followed up with a society specific statement from SCCM (Kon et al., 2016). The multi-society statement listed four recommendations with two of those dealing with the concept of futility. The authors of the statement argue for the use of the term “potentially inappropriate” rather than “futile” when there is at least some chance of an effect being accomplished (Bosslet et al., 2015, p. 1319). In another recommendation, they list what they call “less-common situations” such as strict futility and legally proscribed and/or discretionary treatments (Bosslet et al., 2015, p. 1319). The ATS and SCCM statements highlight a shift in thought on futility and a change in what we consider “futile” versus “inappropriate.” Kon et al. (2016) further adapt this to the ICU setting and determine that interventions are inappropriate when there is:

...No reasonable expectation that the patient will improve sufficiently to survive outside the acute care setting, or when there is no reasonable expectation that

the patient's neurologic function will improve sufficiently to allow the patient to perceive the benefits of treatment. (2016, p. 1772)

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This shift, from futility to inappropriate interventions, shows a temporal discussion from the 1980's to the present. This evolution has two relevant processes, one is the changing of our thought on futility and the other is the changing nature of technology and abilities that influenced what we consider futile. The difficulty in determining futility is not surprising given the relational complexity that occurs around these cases. There is not only patient or surrogates and providers but "...hospitals, public and private insurers, ethics committees...(Bonanno, 1995, p. 155)." Patient autonomy is a principle that overrides many others and has been further complicated by right-to-die principles in addition to "...technological innovation that sustains body functions for longer periods...(Bonanno, 1995, p. 156)." The concept of futility has been shaped by these issues which are also intricately tied to other problems facing our healthcare. In fact, I believe, and will hope to show, that issues such as futility are unintended consequences of specific mechanisms in our healthcare structure.

Analyses and reports of futility in the literature focus on the instance that futility is invoked, which is always by clinicians. The common point of analysis is focused on the decision-making around the care that is deemed futile rather than the preceding interactions, roles, and responsibilities. Ethical issues that nurses, and other caregivers, are faced with often have systemic or structural causes due to unintended consequences of those systems or flaws in the structures within healthcare. Futility is no different, regardless of the dispute over the concept itself, the feeling exists, and the causes of this feeling are often the powerlessness of persons on either side given the insurmountable causality of the system. In the case of futility, the system operates in such a way where futility exists; so why is this?

An example is the case of Baby K, a child with anencephaly and dependent upon LST. Baby K's mother disagreed with the care team, who recommended withdrawal and do-not-resuscitate (DNR) orders. Baby K's mother believed further rescue care and mechanical ventilation was not futile and had benefits for the child. In this case there is a disagreement over whether further care was futile, which became a judgment of value. However, there is a practical issue of what can be maintained reasonably in society. Someday anencephalic children may be kept alive without great burdens. However, today there are large disparities where the cost of a child breathing brings forward several moral and practical questions such as the dichotomy between ventilating an anencephalic child and enough resources and care for a child with asthma.

In pediatrics, the issues around futility are especially complex due to the status of children in our society- the concept of an open future (Feinberg, 1980), best interests and harms (Bester, 2018; Diekema, 2004), and decision-making (Brunnquell & Michaelson, 2016). Though there have been many attempts to define, identify, and respond to futility, it remains present and problematic with no formal resolution (Helft, Siegler, & Lantos, 2000). Even attempts to move beyond the concept have not removed it from the health care lexicon (Bosslet et al., 2015; Brody & Halevy, 1995; R D Truog et al., 1992). It seems clear that intractable conflict must or typically exists prior to futility disputes or publication around futility discourse.

I believe that cases of intractable conflict around conceptions of futility are not unique and individual dilemmas, and are instead symptoms of structural flaws in the American healthcare system (Chambliss, 1996). My larger hypothesis is that futility is a result of a system where value and obligation are poorly distributed and leads to problems of futility and disparity. The way the social structures and systems around healthcare work generates this dichotomy. An instance of a futility dispute is a

breakdown of the system, a critical or pathological situation that provides an opportunity to study the structures and mechanisms around it (Danermark, Ekstrom, Jakobsen, & Karlsson, 2002, p. 104). 8

### Research Question and Specific Aims

The immediate aims of this research are to investigate the social phenomenon of intractable conflict invoking futility in pediatric critical care with the question “what is happening within the social structure around a case as it progresses to intractable conflict?” Focusing on attempts to mitigate conflict after it has happened excludes the voices of those existing around the case before, during, and after. The roles, relations, responsibilities, concepts, policies, and artifacts are important to understanding how a case of intractable conflict develops and happens. This research will expand knowledge by how it analyzes these types of problems and in particular; through an examination into what is happening prior to, during, and after conflict begins around conceptions of futility.

The question that drives this research project is: “what must exist for this to happen?” Specifically, what is happening within, among, and around the social structure of a case that progresses to intractable conflict? The second question asks what is happening within and among members of the social structure involved which must be present for this to happen, and what concepts, policies, roles, obligations, and artifacts work to contribute to an intractable conflict?

Specific Aim 1: perform a critical retrospective longitudinal case study on a single case of intractable conflict that elicits the concept of futility.

Specific Aim 2: provide critical analysis of chart review, interviews, and policy data relevant to the specific case.

Specific Aim 3: perform ethical analysis using Margaret Urban Walker's expressive-collaborative model of morality.

Specific Aim 4: extrapolate principles from this case to aid in evaluating other cases.

### Theoretical Foundation

“What must exist for this to happen?” This question is inspired by systems theory and critical realism whose founding tenet is the question: “What must the world be like for this to occur or to be intelligible (Mingers, 2014, p. 17)?” This question, which is integral to critical realism, the philosophy of Roy Bhaskar, is also a fundamental idea for systems thinking and complex adaptive systems theory related to the notion of initial conditions (Bhaskar, 2000; Schneider & Somers, 2006). Rather than looking at outcomes as direct effects of some variable, critical realism insists that there are mechanisms at work that are often unseen or go unnoticed that influence a larger set of structures to produce outcomes. Systems thinking also has a basis in an anti-reductive theme which believes:

...We cannot explain the behavior of objects and entities purely in terms of the nature and constitution of their parts or components. Rather, the parts are related together in such a way that the whole has behaviors or...properties that are distinct from and irreducible to, the properties of the parts. -Mingers, 2015, p. 29

An expansion of the first research question is “what must exist for a case of medical futility or dispute over futility to happen?” There is a need to identify the structures around cases of futility and the distinctions, systems, relationships, and perspectives to understand why they happen (Cabrera & Colosi, 2008). In this case, structure means the systems, components, relationships, and processes that surround and affect a phenomenon. Andrew Sayer, a social scientist working in realist philosophy, also conceptualizes structure as “...a set of internally related objects or practices...(Sayer, 1992, p. 92).” Related objects or practices can include

departments, people, processes, and/or resources (Easton, 2010). Within the context of a pediatric case there is nurses, aides, physicians, ventilators, parents, concepts, policies, and practices that are all connected and related that make up a system. This messy intertwining that makes up healthcare fits well within the definition and elements of a complex adaptive system (Plsek & Greenhalgh, 2001; Schneider & Somers, 2006).

A complex adaptive system is a collection of individual agents with freedom to act in ways that are not always totally predictable, and whose actions are interconnected so that one agent's actions changes the context for other agents. (Plsek & Greenhalgh, 2001, p. 625)

Therefore, there is a need to not only conduct an ethical examination around intractable conflict invoking futility, but a critical systems analysis as well.

There are these structures that exist, such as in a hospital, where roles exist independent of the person in the role. That person is transformed by and, in turn, transforms that role, so there are both inherent and particular qualities. This is similarly conceived by systems theorists who view a system as "...a perceived whole whose elements "hang together" because they continually affect each other over time...(Senge, Kleiner, Roberts, Ross, & Smith, 1994, p. 90)." Systemic structure for systems thinkers is defined as "...the pattern of interrelationships among key components of the system..." to be distinguished from an organizational chart or work flow diagram (Senge et al., 1994, p. 90). This is better described as a complex adaptive system through complexity theory, a type of systems theory (Mingers, 2014; Plsek & Greenhalgh, 2001). The relationships between the actors and objects make up a structure. The internal relations, roles, and objects are of great importance when investigating futility in the pediatric intensive care unit (PICU) because how, when, and why these situations happen are determined by the structures in place that make it possible for them to exist.

The relationship of nurse-patient-doctor-administrator-parent-etc. exists prior to<sup>1</sup> the individual entering that role. These roles, through their relations, create a structure, which has causal powers that may determine what happens independent of an individual action or decision. The context of this structure, as well as its historical and pertinent context, needs to be identified and analyzed.

I am guided by feminist ethical naturalism and Margaret Urban Walker's view of moral theory as situated discourse, "...a culturally specific set of texts and practices produced by individuals and communities in particular places at particular times (Walker, 2007, p. 4)." It is not enough to look at only nurses, or only physicians, rather we must analyze and understand the entire structure of the hospital system and the relations that make up this structure related to the phenomena in question. Knowing this structure is important to finding out how or why it is contributing to the phenomena in question (Mingers, 2014, p. 186). This approach is used by systems analysis and based in systems theory and critical realism (Mingers, 2014).

Examining a case from within the hospital is one step toward a larger goal of putting together the pieces that make up the whole of this issue, which would also require assessment of legal, political, and cultural institutions. I believe pediatric critical care adds an additional layer of complexity as opposed to adult critical care due to the age of the patient and the issues of best interests versus patient wishes. It seems odd to me that we live in a world that produces futility debates while at the same time showing evident disparities in health outcome and access. I believe questions around how futility can exist along with disparity must be answered to inform appropriate and reasonable policy interventions.

### Significance of the Study

Moral and ethical challenges in nursing...are systemic features of the contemporary hospital; they are a normal part of its operations rather than external or accidental.  
(Chambliss 1996, 180)

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Daniel Chambliss, a professor of sociology, noted the above insights in his book, *Beyond Caring: Hospitals, Nurses, and the Social Organization of Ethics*, in which he reported his extensive field research inside hospitals (1996). Although this was published in 1996, there has been little discourse since then around ethical issues as structurally related. In addition, discussion of moral and ethical challenges in nursing is relegated to intra-professional discussions, and mostly only in education. Chambliss's insights deserve attention, particularly when we are faced with growing issues around futility and disparity. It is worth investigating these instances as resultant from complex structures.

I take Chambliss's statement about these challenges as part of the "contemporary hospital" farther upstream and argue that these challenges are systemic features of the contemporary American healthcare "system," of which the hospital is a major part (Chambliss, 1996, p. 180). Viewing, and subsequently intervening, on ethical issues through the frame of "difficult dilemmas" ignores the existence of the structural flaws that contribute to their existence. Nurses, as caregivers and advocates, are constantly running into these types of structural flaws that create moral and ethical challenges to their work. Nurses are often repeatedly confronted with systemic failures that contribute to moral distress. Viewing these failures as individual dilemmas only allows them to continue and cause more distress. In this conceptualization, the distress a public health nurse feels from powerlessness over health disparities in their patients is like the distress felt by ICU nurses faced with care that is felt to be futile. We have reached a point in our society and our profession in which we are obligated to confront systemic causes and structural flaws of the institution of healthcare and

how it not only affects patients but also affects nurses and other agents operating with that institution, even if inadvertently.

I hope to show and understand how many problems in healthcare, such as futility, are socially and structurally created and abetted by how value and obligation are perceived and distributed. Just as "...an inequitable distribution system [has] the power to cause poverty..." (Mingers 2014, 19) so too does a poor distribution system in healthcare have the power to cause futility and disparity; something already evident in the US healthcare system (Cutler, 2018). Investigating the social structures and systems around an outcome will aid in emergence of the causal powers and liabilities that lead to certain types of events or outcomes (Easton, 2010).

#### Barriers to progress

The ethical problems of nursing...are neither random occurrences nor are they individual dilemmas of particular nurses. They are, rather, structurally created and occur in bulk. (Chambliss 1996, 117)

...Ethical problems in health care are inseparable from the organizational and social settings in which they arise.  
(Chambliss 1996, 182)

Historically, futility has been discussed as a singular phenomenon that occurs at some specific timepoint, just as disparity and equity issues are often relegated to patient irresponsibility, or "non-compliance." In this way we look at futility, or non-compliance as unique and individual cases rather than complicated social phenomenon. Daniel Chambliss saw this in 1996 during his investigation into the social organization of ethics in hospitals. Chambliss disagrees with this view of ethical problems in isolation, showing how ethical problems such as futility are structurally created and inseparable from the social world in which they are found

(Chambliss, 1996). In futility discourse, the focus has been on the disagreement, 14 interventions, and policies aimed at futility going forward rather than focusing on the structures, objects, and relations that are necessary for the phenomenon to exist.

A critical barrier towards progress in resolving issues of futility and improving our health systems is the normative view of health outcomes as unconnected cases in need of intervention rather than symptoms of poorly functioning systems in need of analysis and change. Margaret Urban Walker shares a similar view to Chambliss and believes that morality is social and contextual (Walker, 2003). Normative ethical principles continue in the tradition of, what Walker terms, the theoretical-judicial model that examines outcomes as unconnected, isolated, and non-relational, able to be subsumed under specific principles (Walker, 2007). There is a need to look beyond normative bioethical principles of autonomy, beneficence, and maleficence and towards how caregivers and providers view their moral spaces within their roles and identities and how they accept, deflect, and assign responsibility (Walker, 2007).

While interventions aimed at resolving futility disputes are good and necessary, we must at the same time be looking at the upstream root causes in the systems and structures that are causing them to come into being. There is a need to look at what is going on for a conflict like this to happen, how individuals involved navigate the moral space and context they find themselves in. The normative viewpoint that is used to analyze ethical problems only works towards mitigation of the further sequelae and not towards the spaces within which the ethical issue arises. We must remove the barrier that normative ethical analysis leads us to and begin to look at ethical issues as resultant from structural flaws.

This critical barrier to analyzing ethical issues as structural flaws has implications towards the progress in American health care. This research will have significance not only in how we examine and respond to intractable conflicts around futility but how

nurses can analyze and respond to ethical problems that are systemic and create 15  
barriers towards progress in care.

## Chapter 2: Literature Review

The current discourse on futility in pediatric critical care<sup>1</sup>

### Literature Search Strategy

The literature review used OVIDMedline, CINAHL, EthicsShare, and Google Scholar. The strategy was to look for the keyword futility with pediatric intensive care. The review specifically aimed to assess futility in critical or intensive care areas of pediatrics in the United States, inclusion criteria were formulated accordingly. All articles not written by an American scholar or researcher were excluded. When articles were found where there were sectioned commentaries from different scholars, the commentaries from American institution-affiliated scholars were used. To assess futility in a structural way it must be analyzed within its setting. American healthcare is arguably like no other, and social and cultural differences are important.

All articles not involving pediatric critical or intensive care were excluded. In addition to this, articles about neonatal futility were also excluded because of the differing nature of a newborn neonate and a pediatric patient. Several articles discussed “infants” and in-depth reading was done to ensure the setting was a PICU versus a neonatal intensive care unit (NICU). Issues of viability are vastly different than survivability and futility in the pediatric patient. A neonate in the NICU has, typically, never left the hospital where a pediatric patient admitted to a PICU has or has progressed to issues beyond neonatal viability. This small distinction has larger implications around futility discussions and how staff and parents conceive them. No year limits were set since the intention is to assess the literature over time.

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<sup>1</sup> A version of this literature review which was the preliminary written exam to this dissertation was published under Wolfe, Ian. (2019) A Critical Analysis of Futility Discourse in Pediatric Critical Care. *Journal of Pediatric Ethics*. 1(2) 82-90.

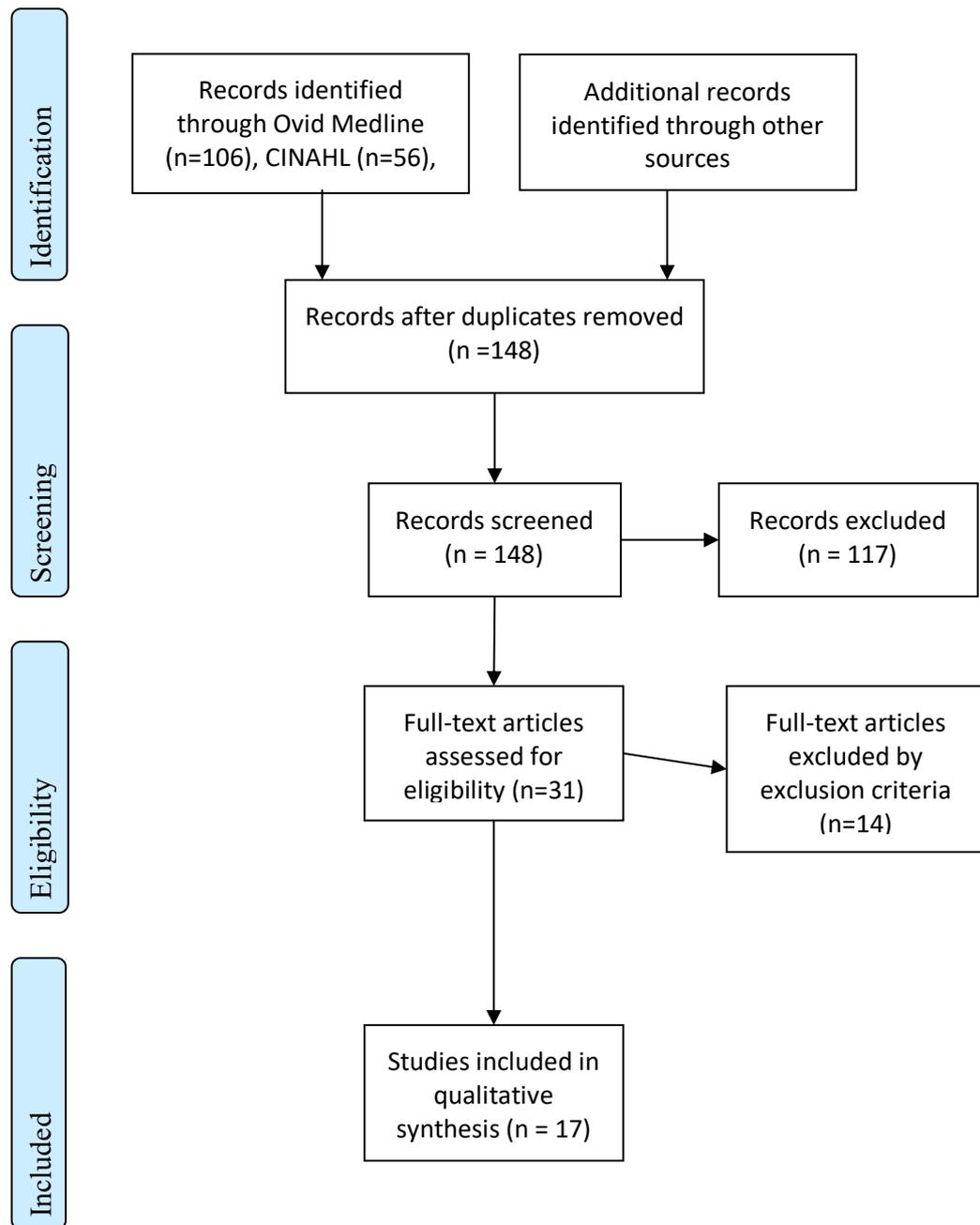
The search strategy utilized for this review was eclectic due to the specific nature of the subject. There is a paucity of literature on futility in pediatric critical care compared with neonatal care where there is abundance. Futility in general has been discussed more so in the past few years culminating in the “American Thoracic Society multi-society policy statement” (Bosslet et al., 2015). Overall, futility literature is far more abundant in adult literature. This is an interesting finding that would lead one to conclude either that there is less of a discussion in pediatrics or that there is a hesitation to use a concept like futility.

The initial search performed with a librarian yielded many results in Ovid Medline, CINAHL, and Ethicshare, but few that met inclusion criteria. A more exhaustive search was done once results were assessed for inclusion from title and abstract. Google Scholar was searched to exhaustion using several combinations of the terms “pediatric,” “futility,” “medical futility,” “intensive care,” “critical care,” and “PICU” and results were searched and collected until a page of results no longer contained relevant results. Articles were read to assess the inclusion criteria was met in the text. Some articles were found to mention futility in the title but not discuss it at all in the text, these were excluded. In addition to this, articles were found to discuss futility and meet inclusion by text but not by title and abstract. Figure 1 displays the PRISMA<sup>2</sup> flowchart describing the process.

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<sup>2</sup> Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA). Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & PRISMA Group. (2009). Reprint--preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Physical therapy*, 89(9), 873.

Figure 1. PRISMA Flowchart



### Data Analysis and Synthesis

Seventeen articles met inclusion for critical review and were kept for synthesis after initial analysis of content. All results were initially reviewed in entirety for

inclusion and then read again for summative content analysis prior to synthesis.<sup>3</sup> This type of content analysis is described by Hsieh, H.F. & Shannon (2005). Summative content analysis was used to assess content related to three contexts: how futility was conceptualized, the tensions that existed, and the variables present around the issue of futility being discussed. After review of included results, articles that were excluded were reviewed again to ensure they did not meet the inclusion criteria. Summative content analysis was performed on included material. Initial analysis was performed for the purposes of assessing the entirety of the results. This was followed by second analysis to identify codes and themes. Several articles were of the “round-table” or “discussion” format where there were different view-points or commentaries by different scholars. The content was coded to each author when delineated in the text as distinct. Three articles did not discuss the concept of futility and in Wightman, Largent, Del Beccaro, & Lantos (2014), only two of the authors discussed it. In Gunn et al. (2004) only the American authors were analyzed. Overall, four codes were developed in relation to the conception of futility; futility as an unclear concept, futility as against medical standards, futility as value judgments, and futility decisions as not unilateral. There was a total of seventeen authors with these codes.

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<sup>3</sup> This type of content analysis is described by (Hsieh, H.F., & Shannon, 2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15, 1277-1288

Table 1. Summative Content Analysis Description

Futility Codes	Number of Authors*	Years Published	Profession(s)**
Unclear	4	1993, 1995, 1995, 1995	MD, JD JD PhD JD
Against medical standards	4	1994, 1992, 1990, 2014	PhD JD, MD SJ PhD, MD, JD RN, JD, PhD PhD
Subjective/Value judgments	5	2006, 2001, 2002, 2015, 2004	SJ PhD SJ PhD MD, PhD MD MD, MD
Not unilateral	4	2014, 2004, 1993, 2014	MD MD JD MD

\*Authors counted either individually or as a group based on presentation of article.

\*\*Commas separate authors coded as a collective, speaking as one.

### Futility as an unclear concept

Futility as an unclear concept was described by four authors all in the 1990's. Ackerman (1993) is a Medical Doctor (MD) writing a commentary in *Critical Care Medicine*, the journal of SCCM. In reviewing some studies about limitation of care and resuscitation in the PICU, Ackerman (1993) found that it was unclear how determinations to limit care were met. In addition, Ackerman comments that the decision-making process in these studies, or how these decisions and/or determinations were made, were not detailed though there is a presumption that some type of severity of illness determination was used (Ackerman, 1993). However, the use of futility as a concept in the studies Ackerman is discussing is unclear and seems to embrace a combination of subjective and objective data combined.

Bonanno (1995) is a Doctor of Jurisprudence (JD) writing in the *Annals of Health Law* using the case of Baby K to explore the concept of medical futility. He also gives an analysis of medical futility in pediatrics as an "imprecise" term (Bonanno, 1995, p. 154). Bonanno writes that medical futility as a concept emerged from the struggle for comprehensive health care combined with the technological imperative, reduction in

physician authority in decisions, and cost-containment pressures (1995, p. 154). 21

Origins of the debate around futility and construction of the concept, he goes on to say, has "...roots in right-to-die principles, [and] technological innovation that sustains body functions for longer periods of time... (ibid., p.156)."

Bonanno details some factors that are present around futility such as the notion of "...an emerging distrust of doctors making medical decisions..." because of modernization in medicine away from the private house calls to the production line model, which erodes the doctor-patient relationship (Bonanno, 1995, p. 156-157). He believes that with the empowerment of patients who have more decision-making authority, doctors are turning to other strategies to regain power and control, and this leads some to hang "...treatment decisions on the concept of medical futility (Bonanno, 1995, p. 157)." Bonanno (1995) also admits there may be an implicit or explicit links to futility debates from financial concerns (p. 157). However, Bonanno (1995) reports that medical futility as a concept is poorly defined, misused, and very subjective (p. 157). Bonanno (1995) suggests that some uses of futility are value-laden, whether rightly or wrongly. He concludes that there is no definitional consensus or objectivity in futility and that disagreements will occur leading this issue to be deliberated in the courts (1995, p. 160).

Flannery (1995) is a JD writing an analysis of the Baby K case in the *Journal of Law, Medicine & Ethics*. Flannery, it is noted at the end of the article, was a partner in the law firm that represented the mother of Baby K. Flannery starts out her reflection by discussing "futility" and "medically inappropriate care" as vague concepts (Flannery, 1995, p. 11). Mechanical ventilation being the main issue in care for Baby K, Flannery goes on to state that it is "...neither futile nor medically inappropriate..." because it treated the respiratory distress of the child and thus preserved the child's life (Flannery, 1995, p. 11). Flannery discusses that the

judgment of futility in this case was viewed, by the court, as a subjective judgment<sup>22</sup> based in values and thus not within the expertise of physicians (1995, p. 11). The concept of ethics is not given an explicit definition by Flannery, instead she discusses the absence of clarity on futility in addition to confusion over who gets to determine it.

Post (1995) is another JD writing on the case of Baby K in the *Journal of Law, Medicine & Ethics*. He is also a PhD researcher and ethicist who argues for the free exercise of religion. In this article he argues four claims, two of which are concerned with futility. In one, Post argues that the free exercise clause of the U.S. constitution should not be overridden "...in the name of a concept so vague as futility... (Post, 1995, p. 20)." The other claim is that the free exercise of religion should be a component of any futility debates and religious accommodation ought to be included in any futility policies, whether societal or institutional (Post, 1995). Post is not disagreeing that futility is concept that exists, nor is he stating there should not be futility policies, instead he is arguing for religious accommodation using his argument that the concept itself is too unclear (Post, 1995).

#### Futility as against medical standards

Futility as a concept describing treatment against medical standards was described by four authors ranging from 1990 to 2014). Annas (1994) is a JD holding a master's in public health (MPH). This article discusses the case of Baby K and examines the case through the courts. This case challenged the idea of futile care as held by physicians and hospitals largely due to a vague application of the emergency treatment and active labor act (EMTALA). The issue brought forth was how EMTALA applied to the hospital's obligation to resuscitate Baby K as she presented in an emergency. There was also a question around discriminatory application of

EMTALA regarding Baby K's disability. The hospital deemed further care for Baby K's episodes of respiratory distress futile because her main issue was anencephaly and instituting mechanical ventilation would not improve this condition. Annas (1994) uses this case to examine many issues and highlights key points regarding how we conceive futility and what we do with parental request. He argues that a parent's request "...for treatment does not alter the physician's obligation to exercise reasonable medical judgment (Annas, 1994, p. 1544)." Instead medical standards must be followed by the physician, not whatever the parents request. Treatments can have a physiologic effect while still not being in the best interests for that patient "...as a person, not on the patient as reduced to a group of separate organ systems (Annas, 1994, p. 1544)." Annas makes the distinction between a treatment that may have some effect versus one that falls within standards of medical practice; if it can't meet the latter then it may be futile.

Lawrence Nelson, a JD as well as a PhD, and Robert Nelson an MD, also adopt futility as a concept meaning against medical standards (1992). These authors appear to be the first, noted by this review, to separate this concept into two different terms, that of "strict futility" and "disproportionate burden" (Nelson & Nelson, 1992). Strict futility, they argue, should be used when "...treatment will fail to reverse a physiologic disturbance that will lead to the child's proximate death..." such as CPR in a decapitated person (Nelson & Nelson, 1992, p. 428). They admit that any other use of futility is a value judgment.

Disproportionate burden is used by these authors as another form of futility that has two parts. First, they argue that a treatment is futile if it "...will not, with reasonable medical certainty, preserve a physiologic function necessary to maintain life..." again with the child's death being proximate (Nelson & Nelson, 1992, p. 428). As in strict futility, the authors say that the physician is under "...no ethical or legal

obligation to provide or even offer..." care that falls into these categories, regardless<sup>24</sup> of demands by parents (Nelson & Nelson, 1992, p. 429). The second part of disproportionate burden is that treatment can be deemed futile if it "...will not serve any useful purpose for the patient, may cause the patient needless pain and suffering, and does not achieve the goals of curing and restoring the patient to an acceptable quality of life (Nelson & Nelson, 1992, p. 429).

Paris, Crone, & Reardon (1990) write a discussion of a case of physician refusal to treat a child called Baby L. Paris is a Jesuit priest-Society of Jesus (SJ)-and PhD, Crone is an MD, and Reardon is a JD. In this article, using the case of Baby L, they dispute a claim by John Lantos and his colleagues that reportedly regarded futility judgments as those belonging to the goals of the patient and family, not the physician (J. J. Paris, Crone, & Reardon, 1990, p. 1013). The authors dispute this concept of futility and instead argue that despite pleas from a patient or family the physician must only submit to demands if the treatment has a realistic expectation of prolonged benefit. These authors embrace a concept of futility that closely aligns with medical standards as judged by the medical team.

Emily Largent Registered Nurse (RN), JD, PhD responds in an ethics roundtable article as one expert in Wightman, Largent, Del Beccaro, & Lantos (2014). In this discussion over allocation of ICU beds with a patient occupying one in whose care is considered "futile" Dr. Largent reports that the concept of futile is "...generally taken to mean that additional care is not in a patient's best interest (Wightman, Largent, Del Beccaro, & Lantos, 2014, p. 911)." This can be interpreted as meaning it is against medical standards as "not in a patient's best interest" would seemingly mean that it is not within medical standards. Though the overall discussion is about who should be able to utilize the "last PICU bed" it is wholly about futility. If there were no scarcity to PICU beds the issue may still be important in this concept of futility as it would

still be against medical standards. The amount of scarcity makes a difference as far<sup>25</sup> as the amplitude of the distress caused by futility as against medical standards.

### Futility as a subjective or value judgment

Futility was described as either a subjective or value judgment by five authors all writing after the year 2000. Baergen (2006) is a PhD professor of medical ethics writing in *Pediatric Nursing* about responding to “unreasonably” optimistic parents. Baergen brings forth several insightful issues around how parents’ decisions are shaped in end-of-life situations (2006). He argues for a thoughtful approach through many encounters and rapport building in addition to managing uncertainty (Baergen, 2006). Though he admits that when those processes break down, the use of limitation contracts and futility determinations can be helpful in limiting harm, but that they should be used with “...good judgment... (Baergen, 2006, p. 486).” Baergen argues that all futility judgments are value judgments (2006, p. 486). He also argues that these judgments are “...employed as a means of overriding parents’ decisions...” when the success of the treatment is low and the suffering of the child is high (2006, p. 486). The difficulty with these judgments, Baergen admits, that trying a treatment is often the only way to determine if it will be effective (2006). This provides a problematic layer for the treating team.

Clark is a PhD, bioethicist, and Jesuit Priest (SJ) writing two articles on futility policy for pediatrics in 2001 and 2002. Clark seems to suggest that there is some consensus around futility in medicine but that it is “...a subjective judgment, but one that is realistically indispensable (P. A. Clark, 2001, p. 181).” This first article was published in *Pediatric Nursing*. He goes on to detail some other definitions and determinations other ethicists have formulated. Clark believes in futility policies as a step towards improving end-of-life care for children and aiding parents and physicians

in decision-making (Clark, 2001). In his 2002 article published in the *Journal of Public Health Policy*, Clark is proposing policies for medical futility in pediatrics and neonatology. He repeats his definition of futility has a subjective judgment (Clark, 2002). Interestingly, he argues also that this debate around medical futility "...comes down to a conflict between patient autonomy versus physician beneficence and distributive justice (Clark, 2002, p. 77)." This notion of distributive justice in medical futility is an interesting idea.

Jonna Clark, an MD, and Dudzinski, a PhD, writing in *Pediatrics* in 2013, discuss the performing of CPR in terminally ill children. Through their analysis of case discussions involving CPR attempts they discuss the issue of withholding in certain cases and whether clinicians should perform CPR even when if it is wholly symbolic. They also discuss issues of benefit towards the child or parents. The concept of futility as based on value is agreed upon by these two authors but with the caveat that "...it remains a recognizable phenomenon in clinical medicine (J. D. Clark & Dudzinski, 2013, p. 574)." They also argue that determination of futility should be intervention specific and goal relative (Clark & Dudzinski, 2013, p. 574).

Dan Thompson is an MD and ethicist who wrote the discussion section of an article reporting opinions from international scholars about a pediatric critical care ethics case in *Critical Care* (Gunn et al., 2004). Thompson, an American and thus fitting inclusion into this review, states that futility "...is a difficult and value laden concept... (Gunn et al., 2004, p. 217)." Interestingly he goes on to argue that, in the case presented in the article, he does not believe that futility has a role to play. Whether this is because he believes it to be a value laden concept and therefore not relevant to any case is unclear. He does discuss a more compassionate approach that assumes parental agreement.

The final theme was futility as being unable to be conceptualized unilaterally. This was found in four articles/authors and seemed to argue against the concept's use as one-sided. The first article to show this conceptualization was Ganeson & Hoehn (2014), both MD's, in *Pediatric Critical Care Medicine*. Within the article, there is a section dedicated to "unilateral decision making and futility" (Ganeson & Hoehn, 2014). The authors use data from surveys to support their interpretation that most physicians do not support unilateral decisions on futility or withholding treatment (Ganeson & Hoehn, 2014). Based on this, the authors make their recommendation towards support of families and providers when there are disagreements. Next the article moves on to conflict resolution and improving communication around best interests. The authors conclude that medical decisions will be made by a child's legal guardians, with advice from clinicians (Ganeson & Hoehn, 2014).

Scott Gunn, an MD writing the American opinion in Gunn et al. (2004) in *Critical Care*, argues that the "...wishes of the patient should prevail (Gunn et al., 2004, p. 215)." Gunn discusses the many factors that are affected by disagreements and attempts to a process for mediating conflict. In this, he defers to the family to define what they consider to be futile. He then goes through the process of deliberation that is like many futility policies where deliberation is sought to allow and assist the family to make decisions. If the family does not choose withdrawal then Gunn takes the standard path towards facility transfer since cases which appeal to a court will almost always end in continued care (Gunn et al., 2004).

Landwirth is an MD and JD writing about issues in resuscitation in the *Annals of Emergency Medicine* (1993). For Landwirth, futility is a judgment that is made relevant to a particular goal obtained through medical decision making, which "...implies participation of patients and families (Landwirth, 1993, p. 503)." In this

commentary section he echoes this sentiment in the context of CPR that might be<sup>28</sup> futile saying that withholding CPR "...without prior discussion with parents is virtually never appropriate (Landwirth, 1993, p. 506)."

Del Beccaro, an MD writing an opinion in a case about futility and resource allocation in Pediatrics, discusses a decision matrix around futility of care (Wightman, Largent, Del Beccaro, & Lantos, 2014). This article has a different context because it looks at a scarce resource situation involving limited PICU beds and futile cases. Del Beccaro, in this context, believes that there should be discussions with family around the futility that is present in their child's case (Wightman, Largent, Del Beccaro, & Lantos, 2014). However, he argues that if this does not work towards the conclusion sought after then the ethics committee should be involved (Wightman, Largent, Del Beccaro, & Lantos, 2014). While this is not quite the same as the previous article's concept of futility as not unilateral it is similar in that Del Beccaro is arguing for discussions with family that seem to aim towards convincing them followed by the ethics committee involvement if that should fail.

#### Futility: tensions, dynamic structures, and polarities to manage

Relational tensions emerged through this summative content analysis of the content of this critical review. The concept of a tension being referred to is the meeting of two parties with competing interests in disagreement; "...internal parts and relations that are in tension with each other (Elder-Vass, 2011, p. 37)." These tensions seem to assist in maintaining what Dave Elder-Vass would call a "dynamic structure" by "...constantly striking a balance between internal parts and relations that are in tension with each other (2011, p. 37)." These structures will either lead to a constrained pattern of convergence on a variable, adaptive steps over time, or collapse of the structure itself (Elder-Vass, 2011). In analyzing the literature obtained in this

review, tensions were discovered that seem to make up the structure necessary around cases and/or discussion of futility. Most articles discussed the tension between family and physicians (hospitals, staff, etc.).

The main tension mentioned in nearly every reviewed article was the demands of the parents/guardian against the obligations of the physician, a relational tension. This was described in different ways but provided the same theme of a conflict between what parents demand and what the physician is obligated to provide, or refuse. A second tension appeared as a goal-oriented tension, that is, a tension between what the goals of care are or should be. This tension emerged as differences in goals between parents and providers as well as internal tensions of the provider. Third, there was a tension between beliefs and values present within and between parties involved. Finally, tensions of responsibilities were present, though like relational tensions but different as they seemed to indicate less of a tension between relations and more of a tension in who or whom is responsible for what. Table 2 shows the tension codes that make up the themes

**Table 2. Tensions existing within futility discourse.**

Relational Tension		Goal Oriented Tension		Belief/View Tension		Responsibility Tension	
1.	Medical team versus Patient/Family	1.	Treatment versus caring	1.	Value versus chance of survival	1.	Medical indication versus consumer desire
2.	Demands of the family versus physician obligations	2.	Use of technology /severity of illness	2.	View of life	2.	Conception of futility
3.	Medical standard versus parent demands	3.	Sustaining life versus Relief of suffering	3.	Physiologic versus Religious	3.	Causation versus responsibility
4.	Paternalism versus rights	4.	Goals of care	4.	Hope versus acceptance	4.	Impact of decisions by parents
5.	Autonomy of patient versus MD practice			5.	Value versus reality		
6.	Moral demands of MD to child versus wishes of parents			6.	Free exercise of religion		
7.	Role as parent						
8.	View of parental decisions by staff or other parents						

Relational tensions were found in thirteen of the seventeen results. Ackerman, 1993; Annas, 1994; Baergen, 2006; Bonanno, 1995; Clark, 2001; Clark, 2002; Clark & Dudzinski, 2013; Flannery, 1995; Ganesan & Hoehn, 2014; Gunn et al., 2014; Landwirth, 1993; Nelson & Nelson, 1992; Paris, Crone, & Reardon, 1990; Truog, 2007 all describe a tension between the patient's family and the physician or provider. This was described either in terms of patient and family wishes or demands, patient autonomy against physician obligations to the patient, medical standards, and physician practice. These are not always simply disagreements between what the right course of treatment is but often a tension or conflict between the moral demands and obligations that exist. Baergen (2006) describes the tension of how parents feel their decisions will be viewed by medical staff and other families, even themselves as they continue to live; whether their decisions will be viewed as giving up, putting their child through too much, etc. This tension seems to be present within the parents themselves and between other people involved. The role of the parent is a powerful tension within the parent that has some impact on how they interaction relationally with medical staff. Clark & Dudzinski (2013) also discuss the decisions that parents must make and how critical illness can threaten their role as a parent as well as the identity of being a parent if the child were to die (p. 577). The necessary relation of the parent to the child seems to conflict with the decisions about limiting treatments or resuscitation interventions that need to be made or are viewed as expected to be made.

The medical staff tensions in the literature results discuss a tension with physicians or other providers with parents but also in what or how they are treating the patient. Gunn et al. (2014) reported the two authors observations on whether physicians feel that they are sustaining life as opposed to relieving suffering or sustaining life and

practicing medicine that is morally or clinically inappropriate. There are also tensions<sup>31</sup> between what the physician is obligated to provide against the demands of the parent(s) (Bonanno, 1995; Clark, 2001; Landwirth, 1993). Nelson & Nelson (1992) argue that parents should not dictate the "...moral values of pediatric practice (p. 427)," and that refusal of treatment is acceptable if such treatment is inconsistent with their professional obligations, suggesting a tension around what treatment must be provided when demanded.

### Goal-oriented tension

There was a theme of tensions existing around what the goals of care in the treatment of children are, both within and between parents and providers. Ackerman, 1993; Annas, 1994; Baergen, 2006; Flannery, 1995; Gunn et al., 2014, described some aspect of tensions in goals of care. Ackerman (1993) described this tension as the use of technology and severity of illness. Ackerman describes this in the context of using our technology simply because it exists despite a severity of illness that indicates imminent death (1993). Annas describes the case of Baby K who was born with anencephaly which prompted a disagreement between the mother and hospital and physicians over what the goals of treatment should be and whether further resuscitation attempts were appropriate (1994). This case has many tensions but this one about goals of care existed due to the mother's goals (and argued by her attorney) of treating the respiratory distress versus the hospital's opinion that the anencephaly was the underlying condition causing the need for resuscitation; anencephaly is untreatable (Annas, 1994).

Baergen (2006) brings forward the tension of treating versus caring to describe the phenomenon where we call medical treatment medical care, thus confusingly linking treatment to care. Baergen puts forward a discourse discussing the confusion that

families have when we discuss stopping or not performing treatment as the same as not giving care (2006). This tension has serious implications in how patients and families view goals of “care” or “treatment.” Flannery (1995) presents an interesting perspective as one of the attorneys representing the mother of Baby K. In this case, Flannery describes the tension between the goals of care around further mechanical ventilation of Baby K where the hospital felt it was not a goal that provided any benefit and was futile and the mother believed the goal to be towards life-saving (1995). Finally, Gunn et al. (2014) describes the physician’s goals as being “...to sustain life and relieve suffering (p. 215).” Gunn, in his opinion, describes the effects of disagreements regarding goals of therapy as affecting patient care and family satisfaction with “...the health care team’s ability to function (Gunn et al., 2014, p. 215).” Thompson, in Gunn et al. (2014) the difficulty in unrealistic goals of parents that may lead to conflict with staff who may be asked to perform treatments they do not view as necessary and possibly harmful. Goals of care are seen here as a major tension not only within the physician, as sustainment of life and relief of suffering, but between the family and care team.

### Belief and value tensions

Tensions between beliefs and values was seen in the data in views of what life is, physiologic values versus religious values, value of life or continued treatment versus chance of survival, belief values versus objective reality, hope versus acceptance, tension between the value of autonomy and belief in the right to demand, free exercise of religion, and hope versus acceptance. Annas, 1994; Bonanno, 1995; Clark & Dudzinski, 2013; Gunn et al., 2014; and Post, 1995 all contained discourse of tensions between beliefs and values between the medical team and parents, between hospital

and courts, and between social and religious values and beliefs and values of the 33  
medical team.

Annas (1994) describes the case of Baby K and the tension between the mother of the child, the hospital, the guardian ad litem, and the father. The mother is reported to view all human life as having value based in Christianity and a belief in miracles while the latter involved believed that further assistance with mechanical ventilation, and thus continued life, was "...medically and ethically inappropriate (Annas, 1994, p. 1542)." Bonanno (1995) discussed the tension between a family's value in each additional moment of life and the chance of survival. Bonanno also discusses this as the physician wanting to end treatment due to these having no benefit which often conflicts with the family's belief or value in seeking any additional time (1995). These disagreements, when brought to court, almost always end with the court deciding in favor of the family as the patient surrogate (Bonanno, 1995, p. 152).

Clark & Dudzinski (2013) discusses the tension of value versus reality in performing what might be viewed as futile CPR. These authors maintain a conception of futility that is value based and not helpful, and instead focus on discussing the role of the parent in making decisions as well as the nuance between value and the reality that cannot be controlled (Clark & Dudzinski, 2013). In Gunn et al. (2014) the author Dan Thompson discusses the tension between hope of the parents and reality of the prognosis and argues for consensus building to mediate this tension (p. 217). Post (1995) discusses the Baby K case in terms of the free exercise of religion and describes how this value can create tension between family and providers. Post ultimately argues that while there may disagreement in the amount of treatment, or overtreatment, in futile pediatric cases such as Baby K many of the effects of this overtreatment do not warrant restriction unless the burdens of the treatment are inhumane (Post, 1995, p. 22).

Tensions around responsibility were seen in the literature results in the form of whether a physician is responsible to medical indication and standards for treatment or the patient as a consumer's demands, who is responsible for the conception of futility, causation and responsibility, and the impact of parental decisions. Ackerman, 1993; Baergen, 2006; Clark & Dudzinski, 2013 reported these tensions. Ackerman (1993) argues that responsibility for determining a "diagnosis" of futility and when to limit and/or withdraw care is wholly that of physicians. Baergen (2006) and Clark & Dudzinski (2013) both discuss the difficulty for parents being responsible for making decisions around life and death for their children. In connection to the belief and value tensions, the role responsibility around limiting care and thus either eliciting tension within the parent over their responsibility to their child or the tension with others over making certain decisions. This is described in two ways, one where there is belief that we should help families accept this role and decision and that we should remove the decision and responsibility all together.

Table 3. Variables present in literature

Variable	% Articles	Correlated Futility Conceptions
Life-Sustaining Therapy <ul style="list-style-type: none"> <li>• Mechanical Ventilation</li> </ul>	61%	<ul style="list-style-type: none"> <li>• Against Medical Standard</li> <li>• Value/Subjective</li> <li>• Unclear</li> </ul>
Neurologic Devastation	44%	All
Terminal Illness	11%	<ul style="list-style-type: none"> <li>• Value/Subjective</li> <li>• Not Unilateral</li> </ul>
Parent/Provider Disagreement	100%	All
CPR/DNR	28%	<ul style="list-style-type: none"> <li>• Unclear</li> <li>• Not Unilateral</li> </ul>

Aggressive Treatment	28%	<ul style="list-style-type: none"> <li>• Value/Subjective</li> <li>• Unclear</li> <li>• Against Medical Standard</li> </ul>	35
Uncertainty	17%	<ul style="list-style-type: none"> <li>• Value/Subjective</li> </ul>	

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Variables:

Life-Sustaining Therapy (LST), Mechanical ventilation

The tensions that were found within the literature have implications towards constructing the social structure around cases of pediatric futility. There are several variables that seem to be necessary or contingent to these tensions. One finding in eleven of the eighteen results was the presence of the need for mechanical ventilation or LST, which is the presence of at least mechanical ventilation. This may be simply a variable present in the condition of being critically ill but also seems to indicate a level of devastation that also correlates with conceptions of futility. None of the results, after all, discussed futility about a child who is cognitively intact and reliant on mechanical ventilation. The case of Baby K discussed a reliance on intermittent mechanical ventilation (Annas, 1994). This review of the literature suggests that there is something about the presence of mechanical ventilation that correlates with discussions of pediatric futility.

Neurologic devastation and terminal illness

Differences in patient status between terminally ill and neurologically devastated were seen in the literature search results. The cases of Baby K and Baby L both described neurologic devastation, the former was the subject of four articles found in this search and referenced by others (Annas, 1994; Bonanno, 1995; Flannery, 1995; Ganesan & Hoehn, 2014; Paris, Crone, & Reardon, 1990; Post, 1995; Truog, 2007; Wightman, Largent, Del Beccaro, & Lantos, 2014). There was also a group of literature results that discussed children who became terminally ill from some disease

process such as cancer (Clark & Dudzinski, 2013; Gunn et al., 2004). Forty-four 36 percent of the results discussed neurologic devastation compared with 11% of results that discussed terminal illness in futility discourse, which may suggest that there is something about neurologic devastation (or severe neurologic injury) that invokes futility disagreements more than imminent death or children who are terminally ill. One reason for this may be the fact that a child with neurologic devastation can reasonably survive for quite some time dependent on technology where a terminally ill child has a much shorter survival and the disagreement is less around the question of “what is life and death” and more on when to stop and how aggressive to be.

#### Parent and provider disagreement

A disagreement must be present for the presence of pediatric futility in the literature. All the results of this literature search had the presence of a conflict or disagreement between the family and some or all members of the medical team.<sup>4</sup> Four of the articles reported that futility judgments or determinations should not be a unilateral process (Ganesan & Hoehn, 2014; Gunn et al., 2004; Landwirth, 1993; Wightman, Largent, Del Beccaro, & Lantos, 2014). This suggests that futility is either not present when there is agreement or that since both parties agree, either that there is futility or agree to not continue care, it does not lead to disputes and subsequently does not have academic literature written about it. There is a theme that indicates there is a conflict between what parents request and what is viewed as against medical standards, such as aggressive treatment with little chance of benefit, CPR in terminal illness for example (Annas, 1994; Nelson & Nelson, 1992; Paris, Crone, & Reardon, 1990; Wightman, Largent, Del Beccaro, Lantos, 2014). Clark & Dudzinski (2013)

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<sup>4</sup> The two outlier articles were not analyzed for variables. However, they did present a disagreement between practitioners and parents.

argue for an informed non-dissent approach to CPR where providers tell parents that CPR will not be performed rather than asking for consent. It is interesting that these authors seem to be arguing for more decisional control around treatments that have little benefit even though they believe futility to be a value-laden concept (Clark & Dudzinski, 2013). Though not all the authors were arguing from one side of the debate, such as Flannery (1995) who was one of the attorneys for the mother of Baby K, the fact remains that the parental and family side of these disagreements is wholly absent.

### CPR/DNR

CPR and Do Not Resuscitate (DNR) variables are present in 28% of the discourse found in this review. There was also one article that mentioned CPR, DNR, and extracorporeal life support (ECLS) (Clark & Dudzinski, 2013). CPR was mostly discussed in the literature when there was an issue of terminal illness such as a hematological or ontological condition. In Baby K the issue was not whether to perform CPR but rather whether to reinstate mechanical ventilation, though CPR in that case may have also been an issue, it was not discussed.

### Aggressive treatment

Five articles mentioned the concept of “aggressive treatment” (Baergen, 2006; Bonanno, 1995; Clark, 2001; Clark, 2002; Paris, Crone, & Reardon, 1990). These authors are by nature of this critical review publishing in academic literature and are arguably representing one vantage point of the structure and relations around futility. This limited vantage point may affect how “aggressive” is perceived. Where clinicians may consider something aggressive more so than a parent or non-clinician. There may be as much clarity around what is “aggressive” as there appears to be

around what is “futile.” However, the use of the term “aggressive” suggests that the authors view certain treatments as either not standard or not recommended.

### Uncertainty

Uncertainty was mentioned in three articles when discussing issues of prognostication, diagnosis, and morbidity and mortality (Baergen, 2006; Clark, 2001; Clark, 2002). Two of these articles were written by the same author. Clark (2001) also discusses the confusion within stopping, withholding, and withdrawing treatment, in the context of uncertainty around who is the agent or what is the cause of the death. Parents making a choice to stop, withhold, or withdraw, may feel that they are the agent of their child’s death and this is an important complexity to consider.

### Futility results: outliers

There were two articles that were outliers because they met initial inclusion criteria but did not fit the definition of discourse, both were empirical studies and were therefore not a discourse and were excluded. Sachdeva, Jeffereson, Coss-Bu, & Brody (1996) is a prospective cohort study to determine the resource consumption and extent of futile care in a pediatric intensive care setting. The authors developed three definitions of futility that were used to measure and group patients into imminent demise futility, lethal condition futility, and qualitative futility. This article did not fit into the current review because it was not a method of discourse about futility but rather a quantitative attempt to measure resource consumption. The authors found that very few patient-days were associated with futile care across the definitions used (Sachdeva, Jeffereson, Coss-Bu, & Brody, 1996). They also concluded that according to their data, a focus on care that is deemed futile to control or reduce resource consumption may be unsuccessful due to very few patients in their study meeting

criteria of “futility” and very few patient-days associated with this type of care 39  
(Sachdeva, Jefferson, Coss-Bu, & Brody, 1996).

Morparia, Dickerman, & Hoehn (2012) is another outlier that was a survey sent to members of the Critical Care section of the American Academy of Pediatrics. The survey contained four clinical vignettes where families were requesting care that may be perceived as futile and were asked if they would go against the parent’s wishes and how they would work towards resolution if there was a conflict. This article is an outlier because it is not taking a position such as the other results around futility discourse in pediatric critical care. It does add some interesting insights into this topic, however, and is therefore being discussed here as an outlier. The authors do not discuss a specific concept of futility but in their clinical vignettes with two of them being about terminal illness related to an oncologic condition, with one progressing to a brain death consistent state, the other two are neurologic conditions (Morparia, Dickerman, & Hoehn, 2012, p. e312). The survey received a 43% response rate which is fairly poor, and they found no consensus for unilateral decision making (Morparia, Dickerman, & Hoehn, 2012). While their conclusions lack statistical support for unilateral decision making due to their response rate the lack of consensus is consistent with the findings in this literature review that suggests there is not one conception or approach that is more popular.

#### Synthesis: limitations

The limitations to this critical review involve the eclectic nature of literature around the discourse of futility and pediatric critical care. Attempting to capture results around this topic presented significant challenges. There has been much more literature written about futility in adult intensive care. There is also a fair amount more literature around futility in pediatrics in journals from outside the United States,

or from authors who are not American and not writing in the American cultural and social context. Despite these limitations the nature of the debate was arguably well captured by the results in this review as most authors are either responding to other authors or exploring the debate itself. Authors taking a position tend to reference other articles in their discourse. There were also articles that had many authors as part of a discussion. This was difficult to quantify for the purposes of a review looking at discourse.

### Conclusion and implications

As indicated by other authors (Brody & Halevy, 1995), conceptualizing futility continues to cause problems and appears to hinder the process towards resolution of these tough cases. The results of this review seem to confirm this as no one concept emerges more than others. Futility as a subjective value judgment was found to be the majority but only by one, followed by being discussed as unclear and against medical standards (Table 1). The same number of authors discussed futility not in conceptual forms but as something that should not be decided unilaterally (Table 1).

Conflict between family/parents and providers emerged as a main variable in all articles, even the two outliers which were not counted in totals (Table 3). This suggests that this may be the variable that is the impetus for publication of discourse on futility because it seems to be the main subject of the articles. In fact, the nature of the discourse around pediatric intensive care and futility seems to be sparked by a conflict; agreement, after all, eliminates the need for discussions about futility. The differing conceptions of futility (shown in Table 1) suggest that there are differing opinions between authors in the literature results. The concept of futility itself seems to be a point of conflict, therefore it is no surprise that conflict is a major variable present in discussions around futility.

The second main variable found was mechanical ventilation (Table 3). This is ~~not~~<sup>41</sup> surprising since “critical care” was a term of focus. The use of technology is a tenet of critical care, and the cause of much debate. Typically, a child who progresses in their illness to the need for mechanical ventilation is very ill. More research on mechanical ventilation is warranted here. My hypothesis would be that it’s not so much the mechanical ventilation as it is the pseudo-stability that the ventilator can provide and the issues around withdrawing the ventilator. What I mean is, that after the chaos of critical care resuscitation, the quiet peacefulness of a child who is neurologically devastated but breathing on a ventilator may hide the reality of this devastation; it hides the illness by displaying a quiet and calm presence. It is perfectly acceptable to withdraw a ventilator but once a child with neurologic devastation is on the ventilator they can reasonably “live” for quite some time.

There are children who live while dependent upon mechanical ventilation without neurologic devastation. This is where the third most common variable associated with futility, neurologic devastation, becomes relevant (Table 3). A child who is sick and progresses to mechanical ventilation and continues to progress towards terminal illness (the fourth variable, Table 2), as described in Clark & Dudzinski (2013), would have more issues around aggressive treatment, such as CPR, in the presence of terminal illness where death is likely and not amenable to rescue therapies. This may be why neurologic devastation is present in the results more often, because it is not often self-resolving. In the case of Baby K (Annas, 1994; Bonanno, 1995; Flannery, 1995; Post, 1995) the child’s neurologic status is a central point. In Baby K, CPR was not the issue presented, rather it was whether to institute mechanical ventilation or not.

The pattern that emerges around pediatric futility in critical care seems to suggest that when there are disputes involving a child with terminal illness the discussions of

futility are around performing CPR as a type of aggressive treatment. In contrast, 42 most articles discussed neurologic devastation with the presence of mechanical ventilation and disputes between family and providers that brings these discussions to publication contain variables of uncertainty and treatment decisions (Appendix B). The tensions that were found in these articles were mostly relational in nature, followed by belief and value tensions (Table 2). Goal-oriented tensions and responsibility tensions were both mentioned equally (Table 2). Beliefs, values, and goals are all tensions that would arise secondary to relational and responsibility tensions as the former require the latter to exist. Tensions in our relations with the roles involved in cases around pediatric futility are due partly to how we view our responsibility to the various parties involved. These are influenced by our beliefs and values and affect how we formulate goals.

...there is little appreciation that the structure of social relations, together with their associated resources, constraints or rules, may determine what happens, even though these structures only exist where people reproduce them. In such circumstances it is futile to expect problems to be resolved by the discovery of a guilty persons and their replacement by a different individual. –Sayer, 1992, p. 93

Andrew Sayer discusses the idea of how necessary and contingent relations work within a social structure. In examining the tensions found in the results we can see that there are necessary-relational and responsibility, and contingent- belief/value and goal-oriented sets of relations. Necessary relations, doctor to patient, parent to child, are necessary but when the contingent relations create tensions there is dispute which is seen in all cases where futility is discussed. Walker (2007) provides an insight into how to begin using the findings in this review through her expressive-collaborative model. In Walker's model, morality is viewed as a "...socially embodied medium of understanding and adjustment in which people account to each other for the identities,

relationships, and values that define their responsibilities (2007, p. 66-68).” How ~~we~~ <sup>43</sup> account to each other and how we accept, deflect, and assign responsibilities is a way forward in investigating the social structures around conflicts of futility (Walker, 2007).

This seems to answer the question that Sayer (1992) suggests that social scientists should be asking: “What is it about the structures which might produce the effects at issue? (p. 95).” In this case, futility in pediatric critical care, the findings of this critical review suggest focusing on tensions around responsibility and relations for identifying strategies to mitigate conflict around cases of futility. Combining Sayer’s conception of social structures and Walker’s philosophy of the expressive-collaborative model of morality which includes responsibilities, relationships, identities, and values, has potential for a unique and effective methodology to address not only conflicts around futility but how health care is practiced, received, accessed and who is responsible to whom for providing and receiving care. Viewing social structures as having causal power can aid in addressing many other structural and embedded problems.

#### Gaps, potential areas of future research, and significance

There are clear gaps in the state of the science around futility in pediatric critical care. I have identified three critical gaps from this review: 1) the viewpoint represented, 2) the temporality of the discourse, and 3) the reductive view towards this phenomenon as singular problems rather than as inherent results of a system where these problems are an undesirable but inevitable result. These gaps speak to the traditional way that ethical cases are viewed and analyzed. This traditional method has been that of viewing them through a legal lens compared to previous cases, legal accountability, and risk. This view, as pointed out in this review, is likely due to the

inability of these disputes to be resolved in the clinical setting thus negating any 44 usefulness or impact of an ethics service or committee and ensuring the continuance of these disputes and their trajectory towards the courtroom.

Addressing the first critical gap I have documented the discipline of the authors. Authors from results of the review were mostly physicians (MDs) and lawyers (JDs) (see Appendix A, and Table 1). The remaining were PhDs with one RN who was also a JD. This is a major gap because the view at which these are discussed is severely limited to clinicians and legal and ethical clinical experts. Although one author (Flannery, 1995) was writing as a patient and family advocate as the mother's attorney, there were not parental viewpoints. At the very best there was some representation of the parents in their decisions that was written by the author anecdotally. There was also an absence of other voices who would have been intimately involved in the care around these children. These voices that are absent include parents, nurses, caregivers, social workers, etc. This leads the literature into a sort of echo chamber of which all are arguing one vantage point.

The second critical gap that came through was around the temporality seen in the discourse around futility in pediatric critical care. The bulk of the literature analyzed this phenomenon as it happened, or at the point of disagreement where one side, usually the clinical side, identified that there was futility against another side who disagreed, typically the parent or parents. This may be due to the influence of casuistry involved in many of these cases because of the legal issues around them as well as risk aversion and publicity within the institution. It also may be influenced by how we view and when we view outcomes as being undesirable. Rather than looking at complex structures that produce an incidence of a futility debate, the focus is on the current state of the situation. I believe that conditions are set up far earlier in the chain

of events and by only looking at the futility of the moment we are doomed to continue<sup>45</sup> to have these situations.

A final critical gap identified through the course of this critical review is the way in which the literature focused on this phenomenon in a singular view or not as a phenomenon rather as a singular and unique event. There was discussion of similar cases or landmark cases, but these were in the manner of casuistry to show precedence. All the authors attempted to discuss the cases towards resolution. Other authors presented ways to protocolize a response. Instead, or in addition, this phenomenon should be examined or analyzed towards identifying the system and structure that works together and has generative mechanisms that lead to these outcomes. These cases are the result of a structure. These cases may be the negative outcome of a system that is designed for a positive reason. The only way to reduce incidences of this phenomenon is to examine how they come into being in the first place. I will next discuss how to do this.

### Significance and next steps

The first step towards better understanding how these phenomena come into being is to recognize how these systems, such as hospitals, units, clinics, and families work together. This can be best studied through non-linear dynamical systems theory, complexity theory, or complex adaptive systems (Mingers, 2014; Plsek & Greenhalgh, 2001). Complexity theory, through its modeling and investigation of complex adaptive systems, recognizes the interrelatedness of individual agents with the freedom of acting unpredictably and changing the context for other agents (Plsek & Greenhalgh, 2001). This embracing of complexity and chaos is necessary to investigate social structures where interactions happen outside of rigid boundaries, in an open rather than a closed system. This is how a case of intractable conflict in

pediatric critical care must be studied, as a living, co-evolving system of interactive agents and structures working within a socially constructed moral space. <sup>46</sup>

Within complex adaptive systems, there exist structures and mechanisms that hold certain powers and liabilities that generate events (Mingers, 2014, p. 36). These structures and mechanisms are not always physical “things” but can be concepts, actions, behaviors, feelings, relations, etc. The causal structures must be brought to light in order to show the mechanisms that generate the continuance of a problem. Looking only at interventions towards an outcome caused by a system will only mitigate the effects, but the system will remain and continue to produce the problem. The system and structures must be identified in order to understand how they cause a problem to come into being. Dave Elder-Vass proposes five questions for a methodological framework towards identifying causal powers in social structures:

1. What are its parts
2. What are the relations between those parts that are characteristic of this particular type of entity
3. What set of morphogenetic causes has produced the entity in its current form
4. What set of morphostatic causes stabilises [sic] the entity and ensures its continued survival
5. Through what mechanisms do its parts and relations produce the specific properties of the entity

(Elder-Vass, 2011, p. 39)

The parts must be identified as well as the relations involved among and between them. Morphogenetic causes are those “...processes which tend to elaborate or change a system’s given form, structure, or state (Elder-Vass, 2011, p. 34).

Morphostatic causes are those “...processes in complex system-environment exchanges that tend to preserve or maintain a system’s given form, organization, or state (Elder-Vass, 2011, p. 34). Identification and understanding of the interactions between the parts, relations, mechanisms, and structures will help bring emergence of the complex system’s behavior and causal power and how the system continues to exist.

## Chapter 3: Methodology

### Approach and Theory

Drawing from the philosophical principles of critical realism and complex adaptive systems theory, this research will focus on a single case of intractable conflict where conceptions of futility were present. Initial conditions, social structure, relations, and parts existing around a specific outcome drive the framework that must be examined in order to understand how something like intractable conflict can exist. The method used for this study will be that of qualitative case study constructed through critical realism and complex systems theory regarding the larger structures and Walker's expressive-collaborative model of morality to examine how persons within the social structure navigated within the moral space. Case study method has been discussed as an appropriate method for examining complex adaptive systems (Schneider & Somers, 2006) and Walker's expressive-collaborative model of morality has been used to examine moral spaces in ethical and practice situations (Mohammed & Peter, 2009; Peter & Liaschenko, 2013).

In looking towards an approach for future research around this issue, the DSRP model designed by Derek Cabrera will aid in analyzing the systems structures and extrapolate principles for future research (Cabrera & Colosi, 2008). This model examines distinction (D), system (S), relationships (R), and perspective (P). This model is a useful tool to examine complex systems and relations.

Intractable conflict in critical care cannot be separated from the contextual and social conditions in which it exists. An investigation into real life events of a complex phenomenon and its contextual conditions is well-served by the qualitative case study method (Munhall, 2012, p. 359). For the study of a complex phenomenon and its contextual conditions many different actors, agents, objects, and experiences must be

examined. Yin's five rationales for single-case designs are that the case is critical,<sup>48</sup> unusual, common, revelatory, or longitudinal (Yin, 2018, p. 49). In addition, Yin also discusses a replication strategy that requires an initial single case study to develop patterns that can be used to examine successive similar cases (2018). Intractable conflict and futility have not previously been studied in this way and this will therefore provide initial patterns for further investigation.

The case that will be used for this analysis is that of a child who spent many years in a pediatric intensive care unit (PICU) who transitioned through many physiologic changes and conflicts which ultimately led to an intractable conflict when caregivers felt further treatment was futile and parents disagreed. This case is an exemplar case because it touched many different disciplines and roles within the unit and hospital. The case shows how complex these situations can become. In addition, this case is important because it shows what caring for a child throughout this process is like for bedside caregivers, consultants, and administrative agents.

This case meets the rationale for a single-case method because it will aid in analysis of a situation that deviates from common occurrences, it can help capture circumstances and conditions, the descriptive information alone will be revelatory, and the longitudinal study of the case can aid in studying how the conditions and underlying processes changed over time (Munhall, 2012, p. 363; Yin, 2018, pp. 49–51). Performing a qualitative case study for the goals of this research fit within the aims of comprehensive understandings of a phenomenon with rich contextual detail, understanding the social context will require firsthand view, subject interaction and personal meaning is important, and actual experiences are required to meet with the goals of the project (Munhall, 2012, pp. 361–362).

The research questions aim at identifying a complex social situation and its context and therefore the explanatory case study and elements of descriptive case study have

been chosen (Baxter & Jack, 2008). The descriptive and explanatory case study 49 method as described by Yin (2018) and Munhall (2012) is well suited to attempt to answer the research questions. Data collection methods will be primarily through recorded semi-structured interviews and secondarily through chart and policy review. This case study is retrospective and longitudinal in that it will explore the case through a temporal context from admission to final discharge.

Interview, policy, concept, and artifact review will be used for this case study. The child had several different points throughout his inpatient stay: critically ill, recovery, stability, decompensation, and finally intractable conflict. This case provides a unique opportunity to explore different views from various roles involved in the care of this child throughout the transitions in care towards conflict.

Specific Aim 1: perform a critical retrospective longitudinal case study on a single case of intractable conflict that elicits the concept of futility.

A case study of an instance of intractable conflict will be performed. This will take place through interviews and relevant hospital policies. Chart review will provide objective data such as procedures, physiologic data, dates and events, as well as clinician notes. Key documents such as history and physical, notes, etc. will be identified through investigator review. A document that is considered a key and integral part of the case will be collected. This will be an iterative process as interviews may reveal other key documents important to the aims of the research. Interviews of the parents, primary nurses, physicians, surgeons, social workers, case managers, ethicist, risk managers, and administrators will provide rich descriptive data to augment the chart review. Policy review will also add to the case by reporting the institutional policy standards. Concepts such as futility, best interests, etc. that are brought forward during interviews will be explored within the context of the case.

Artifacts, such as healthcare technology etc. will also be analyzed in the context to the case. <sup>50</sup>

The case will be studied around four timepoints: first, the initial admission and period of critical illness, second the period of recovery and stability will be studied, followed by the initial critical event that led to neurologic devastation, and will then be followed by the final readmission following another critical event.

Specific Aim 2: provide critical analysis of interviews and policy data relevant to the specific case.

Interviews will be recorded and transcribed. These sources of data will be open coded and analyzed critically as a structure. They will be open coded separately then, along with policies collected, compared and analyzed.

Specific Aim 3: perform ethical analysis using Margaret Urban Walker's expressive-collaborative model of morality.

Interview transcripts will be coded a second time specifically looking at themes around practices of responsibility from Walker's expressive-collaborative model of morality. Analysis of how each participant viewed these will be analyzed then as a whole or social structure existing around this child.

Specific Aim 4: extrapolate principles from this case to aid in evaluating other cases.

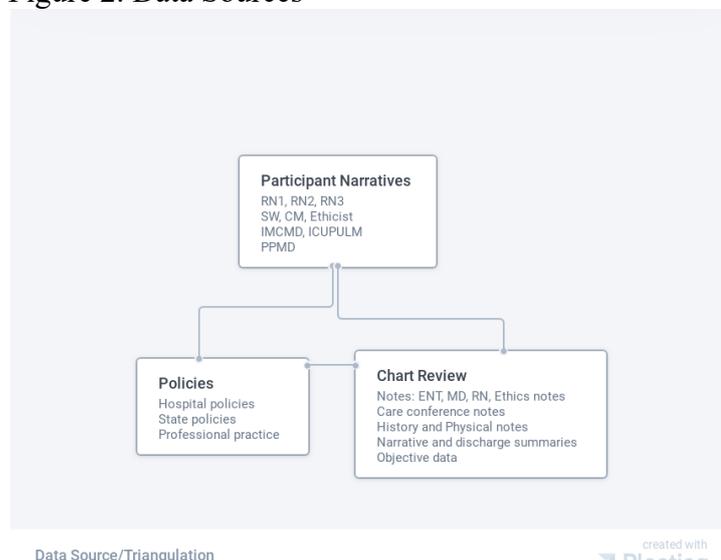
Finally, the ethical analysis will provide principles to aid in an approach towards practical application in evaluating other cases or other outcomes of structural flaws. This approach and the principles found will provide a path towards analyzing and hopefully emancipation from social processes that continue these ethical problems.

## Data collection

Data collection will be performed through semi-structured interviews, chart review, and policy review. Consent will be obtained from each participant agreeing to an interview. Interviews will be conducted with key agents involved in the case. Interviews will be semi-structured around the key points of interest as well as experiences with caring for the child and interacting with other members of the care team. Interviews will be recorded and transcribed for analysis. Interviews will be anonymized to code for each person, such as RN1, RN2, MD1, surgeon1, etc. Data sources obtained for purposes of analysis and participants who consented to participate are reported below (Figure 2.)

Key documents from the chart will be sought out such as history and physical, notes around key timepoints, ethics notes, and any other relevant documents found through the chart review process. Documents will be printed with identifying information redacted, and then scanned to aid in analysis of themes and codes. These documents will be analyzed separately from the interviews. Policy review will be performed during and after data collection through interviews and chart review.

Figure 2. Data Sources



Data Source/Triangulation

created with  
Plectica

Consistent with qualitative case study method, data analysis will occur concurrently with data collection (Munhall, 2012; Yin, 2018). Interview recordings will be sent for transcription to a professionally trained, HIPPA compliant transcription company. Once returned, open coding for codes and themes will be an ongoing process. Memos and research journal entries will be utilized during this process. An eclectic process of analysis will be used that is consistent with case study method (Munhall, 2012; Yin, 2018). Both deductive and inductive analysis will be used. Critical realism describes a process called “abduction” or “retroduction” in which facts are studied and then an explanatory hypothesis is formed (Mingers, 2014, p. 53). This has also been called “generative causality” and is a mode of reasoning at the heart of critical realism which seeks to understand things that exist unknown to us that work to cause events known to us (Mingers, 2014).

The interviews will be semi-structured around specific themes of interest and so there is a deductive element. A deductive analytic process will be used to examine how participants viewed their role, obligation, interactions, and conceptions about futile care in general and in the case. Analysis will also be performed in an inductive process to discover themes and concepts happening that are unknown prior to the study. Overall, abduction or retroduction is the process that the entirety of the study is based upon and is informed by the main question around what is going on within and around a case that leads to intractable conflict? What are the causal factors?

Through the philosophy of Margaret Urban Walker and her expressive collaborative model of morality, data will be analyzed through how participants view:

1. Identity-relationship: how understanding occurs through responsibilities that are assigned, accepted, and deflected.
2. Moral accounting-authoritative and shared in social setting through: evaluative language, exemplary

judgments, deliberative formats, and distributions of responsibility.

3. Constructive and transformative as tasks of human life: self-direction, responsiveness to others, and mutual accountability.

4. Structure of responsibility: contact/relationship initiation of moral claims, interests that are vulnerable to actions/choices, and obligations to respond to others when dependent on us.

Identity-relationship (1) seeks to discover how participants "...understand themselves as bearers of particular identities and actors in various relationships that are defined by certain values (Walker, 2007, p. 10). Moral accounting (2) examines the way in which the participants viewed the way the moral space is constructed regarding responsibilities. Morality is constructed and transformed (3) in and among people and data will be analyzed for how participants viewed how they directed themselves, responsiveness to others, and how they were accountable and to whom (Walker, 2007, p. 10). Finally, the structure of responsibility will be analyzed (4) in the data on how participants initiated moral claims, vulnerabilities, and obligations.

Walker believed in ethical 'naturalism,' that morality is a structure within all human social groups and can be seen from observing shared understandings (Walker, 2003). Through this lens, transcripts will be analyzed towards how participants viewed their role and responsibility and how they viewed others' roles and responsibilities within this moral space. Examining this moral space will aid in some understanding of the morality that is present in this community and between these different persons. The process of analysis will begin with interview transcripts as they are obtained. Results from the deductive analytic process will be reported in the results chapter categorized through the theme of the structured questions. Contextual information, policies, concepts, and pertinent artifacts such as technology will also be identified.

Margaret Urban Walker's expressive-collaborative model of morality will be used<sup>54</sup> in an inductive analytic process to discover the moral and ethical content found in the data, particularly that of how participants viewed acceptance, deflection, and assignment of responsibility (Walker, 2007). Identification of practices of responsibility will be actively sought out with Walker's expressive-collaborative model of morality in mind. Moral and ethical phenomena exist in relational contexts and how we perceive our role or identity, relationships and responsibilities are integral to how morality is experienced and shaped (Peter & Liaschenko, 2013). How a person views their role and responsibility is important to how they view moral claims and obligations that they have towards others. The moral claims, obligations, and ultimately responsibilities are essential to understanding and reconstructing the morality within a social structure. Themes that emerge inductively through this process will be reported in the data analysis chapter.

Chart review documents such as clinician notes will be analyzed using open coding as well. Objective physical data will later be used for comparison with interview and chart note data. The purpose here is to have three streams of data, agent experience and interpretation, official clinical note documentation, and objective physiological and temporal data. Policies collected will also provide a background for analysis for theory development as well as for specific aim four.

### Trustworthiness

In keeping with principles of qualitative research, validity and credibility will be provided through several deliberate strategies. The study question will be clearly stated, design appropriately constructed, data collected and managed systematically, and data analyzed correctly (Baxter & Jack, 2008). Data triangulation will occur with collection of narrative interviews and chart data. Rapport with participants and this researcher is already established and issues or questions that come up from interview

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data will be checked with the participant it came from. Multiple perspectives are one of the aims of this research and will be purposeful. It may be the case that some sought after participants decline to be interviewed, in this case these perspectives will be dealt with by examining them openly, generally, and with respect. Dependability will be addressed by consensus of data analysis with other researchers trained in qualitative methods. This will be done through independent coding and analysis then through group consensus. Credibility will also be pursued through critical philosophical discussion and data will be presented in detail to ensure validity and credibility of the analysis (Baxter & Jack, 2008)

#### Ethics, privacy, and data security

The purpose and protocol of this research project was submitted to the IRB at Children's Minnesota and the University of Minnesota and was deemed not to be human subject research and was therefore exempt from review. There are no interventions in this study. Participants will be consented by their participation. Names will be anonymized into codes. The child in the case will be given a pseudonym. The institution will not be named. Consent to examine this child's case as a study for educational purposes has already been obtained by the child's parents, and has already been published in a brief report (Wolfe, 2016).

Consent was obtained through agreement to participate. Interviews will be recorded using recording device owned by the investigator. Interviews will be transcribed. Interview recordings will be stored on the investigators personal external hard drive locked in a personal safe. Transcripts will be kept on a personal password protected computer during analysis.

## Chapter 4: The Story

Chase<sup>5</sup> was born in the hospital at 38 weeks gestational age via caesarean section and was transferred to the neonatal ICU with respiratory distress with concerns for meconium aspiration and the possibility of a heart defect with phenotypical appearance for Trisomy 21; he was the third child for this family. Chase was only in the NICU for a day and was then transferred to the special care nursery. He had an uneventful course after that first day and was ready for discharge at nine days old with follow-up routine newborn screenings as well as a testing for Trisomy 21. ([Link to timeline here](#))

Roughly eight weeks later he presented to the emergency room (ER) with a two-week history of on-and-off breathing difficulties. In the ER he was found to be in respiratory distress with increased secretions, inspiratory and expiratory stridor. He was given nebulized racemic epinephrine and Heliox- a mixture of helium and oxygen that can be easier to breathe- with little effect.

Upon transfer into the PICU he decompensated and required endotracheal intubation. Due to large amounts of secretions this was rather difficult and attempts by the intensivist to place a breathing tube were not successful. Bag-mask ventilation resumed but he continued towards respiratory failure. Anesthesia was called to the bedside as well as an ear, nose, and throat (ENT) surgeon. A laryngeal-mask airway was placed but was unsuccessful in improving ventilation. A certified registered nurse anesthetist (CRNA) was able to place a very small breathing tube past the vocal cords but had difficulty placing it deeper within the trachea. Chase was then taken to the operating room (OR) with anesthesia and ENT for direct laryngoscopy and bronchoscopy as well as the potential for tracheotomy.

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<sup>5</sup> Name changed for privacy and respect to family

Securement of a breathing tube was achieved in the OR by ENT, however, over<sup>57</sup> the next few days he continued to have issues with ventilation and oxygenation and on day five the decision was made by the intensive care team in consultation with ENT to initiate extracorporeal membrane oxygenation (ECMO). Chase's parents were not initially able to be reached via telephone prior to him going to the OR but presented in person to the PICU and consented, though it was emergent and necessary and would have been done without consent. The ENT surgeon's note the following day relates a phone conversation with Chase's father concerning cannulation for ECMO; Chase was two-months old.

It was determined that Chase's trachea appeared tortuous and with severe malacia- a softening of the cartilage- which explained the difficulty in endotracheal tube placement as well as difficulty ventilating his lungs once a breathing tube was in place. This was later termed "long segment tracheal stenosis." Due to the severe nature of Chase's structural defect the ENT surgeon recommended transfer to a national institution better equipped to handle this type of repair. According to persons present in his care at this time the ENT surgeon discussed long-term planning and offered three options: transfer to a more specialized institution out of state, attempt to reconstruct the trachea at the present institution, or withdrawal and comfort care; Chase's father chose reconstruction at the current institution.

Tracheal reconstruction was attempted on hospitalization day thirteen. After this initial reconstruction the ENT surgeon was called to the bedside as the child was again having respiratory issues. On airway exam in the OR it was found that he had developed crusting and obstruction on the distal aspect of the grafting in his trachea, the reconstruction had failed. This crusting required removal and the ENT progress note reports:

I discussed the findings over the phone with the father for an emergency airway exam under anesthesia for

removal of the crust and opening of the airway. I described the procedure to father. The risks, benefits, and alternatives were discussed. I again impressed on him that the child is in critical and serious condition and the procedure has a very high risk of morbidity and mortality. (ENT progress note)

On day fifty-one, at around four months of age, Chase received an aortic homograft and tracheoplasty with ENT working alongside a cardiothoracic surgeon. He was able to come off of ECMO after eight days. Sometime after this there was an attempt at reconstructing his trachea. This latest attempt ultimately failed, and it was determined the tracheotomy tube would be needed for the time being. After a long recovery from this surgery, he was eventually weaned off of sedation, weaned off the ventilator and began to have more stability.

After the surgery, we had a trach placed, and we sat and we watched. We were looking to see if it would be an effective airway, and a lot involved the position of the trach, the length of the trach, and where it was in the airway due to the new reconstruction that had just occurred. Then it just became more of a let's keep fixing the repair, fixing the repair, and moving the trach, manipulating the trach, to promote life. (RN1)

Chase was almost one year of age and developing normally except for his airway. His tracheostomy was very tenuous and the tube difficult to replace when it came out due partly to the structural issues with his trachea and the stoma site itself. He was completely dependent on the tracheotomy tube and could not tolerate it being out for any length of time. "Some days were nice, quiet, and boring; others, it was frequent near-death experiences (RN1)." Chase continued to require many bronchoscopies and dilations in the OR and at the bedside requiring intermittent periods of anesthesia and sedation. Despite this, and in between events, he was able to be off the ventilator and supplemental oxygen. He began a phase of rehabilitation and outside of the dependence on his tracheostomy tube he was quite stable and active as any child his age with Down's Syndrome.

We went from less critical to almost a chronic phase, and with that we were dealing with a little boy who was starting to grow and develop, and I felt it very important to nurture that part of it, to let him experience a little bit of the world going on around him, because he was starting to interact and behave just like a regular kid his age, and I wanted to show him off. (RN1)

Children who are active and dependent upon medical devices often need very close attention because of their limited understanding between their curiosity and spontaneity and the consequences of removal of those devices. Normally, a child healthy enough to pull at their tubes and lines is no longer in the PICU.

Usually, when they get to that point, they go upstairs, so we don't get to interact too much with them. With [Chase], it was interesting, because we all got very close to him because his family wasn't there that often, so we became daycare, kind of, for him, and just his entertainment...He would sit on our laps and type on the computers, and he would never really be in his room. He was always being passed around or strolled around. He became like a little unit mascot. He would just be there all the time...It was more like a parenting role... (RN3)

Due to the seriousness of decompensation that Chase experienced when his trach came out, he was kept in the PICU. "There was something [procedures] happening every week (RN1)." In between these procedures he would be up in his crib watching a movie, held by staff and walked around the unit, and sometimes even in an "exerciser" in the hallway so his nurses could balance the needs of their other work, such as their other patient, and Chase's need to be active. This also allowed others to keep an eye on him. Often times, the nursing assistant would be tasked with carrying him around the unit, hooked up to a portable pulse oximeter, to have some time out of his room socializing.

And as a team of nurses we would all pull together. Whoever was in the neighborhood had your back. Half of the time you never even had to say anything, because everybody was always keeping track of him. (RN2)

I had a couple of situations where I was paired, and that was really difficult, because, like I said, he could just lose his airway at any minute and then you would have to be in there. I do feel like the unit as a whole kept an extra eye on him, but that was difficult, to get a new admit with him. You always felt like you had to have somebody watching him. You had to pass that off constantly, all the time. You couldn't just go in your other room and know that he'd be fine. (RN3)

If there was no availability of support staff, and if the unit was busy, Chase often stayed in his crib unless he was playing with physical and occupational therapy. He could be alone in his room for quite some time depending on the needs of his nurse's other patient. It was known on the unit that this was an issue, and it was almost unspoken knowledge that everyone had an ear out for the alarms on Chase's monitor. If his alarms went off, someone responded. "It was extremely stressful to take on that assignment knowing that his life depended solely upon that trach, and knowing that if it fell out, he could easily die (RN1)."

Most of the time it was his game of pulling off his EKG leads or pulse oximeter cord as he had learned that this would get him some attention. "He got to a point where he would just get attention by pulling it out... That's how he we would get somebody in there to play with him (RN3)." Other times he had moved too much or in the wrong way to where his tracheostomy tube dislodged and was out. One of his nurses described how he would pull out his trach for attention and once it was reinserted and he had come to, he would often assist in squeezing the anesthesia bag that the nurse was using to give him ventilation and oxygen, something he learned from requiring it so many times.

In fact, he would bag himself sometimes. It was so cute. You'd put the anesthesia bag on, and sometimes that was enough just to open him up, but he would sometimes just need a few breaths, and he got used to doing that, too (RN3)."

These removals led to instant decompensation and an urgency to reinsert the tube, which could be difficult to those not used to inserting it due to the appearance of his

stoma. This made taking care of him scary to many staff members who did not know him as well.

I remember a lot of us talking, like, 'I don't want to be that one. I don't want to be that nurse that he decannulates on,' because [ENT] was very clear about it being a very big possibility that if we couldn't get the trach back in, it would be devastating to him. (RN3)

During these first two years in the PICU where he was unable to leave due to the tenuous nature of his airway, many staff members noted that parents would come in only on Sundays after church, or to consent prior to another procedure. There was concern about this because typically in this stage of care where the child was awake and active, parents were at the bedside. However, most children in the PICU who are this awake and active do not stay that long. This presented an interesting challenge because outside of his airway he was developing as usual. There were attempts to try to find supports for family so they could be present more. However, given the length of time Chase was in the PICU, life goes on, people need to get back to work, other kids require care, etc. Also, for some time he was unable to be touched and held due to his critical status and once he was less critical his airway was still quite terrifying, and he would often have events after a dislodgement.

We see a huge gap when the kids transition from ICU side to IMC side...when you have a child that's acutely ill and we're telling you, 'Stay away from him. Don't touch him, that's disturbing him. That's making him sicker,' then, like any parent, if your child is taken away from you, in a sense, for several months, you start, I think, detaching as self-preservation, and maybe not knowing exactly how you fit into helping him or her get better... (CM)

Caring for Chase, as the unit mascot, was almost a rite of passage to begin working in the unit. He was a very happy and engaging child and during a little over a year of interaction only within the PICU, he became close to many of the staff. Some animosity began to grow towards the parents from the weight of the responsibility

around his care and the expanded roles nurses were taking with him. For many, taking on a care role expanded to everyday growth and development, and risk around his airway, led to disappointment in the situation that seems to have been directed at parents. After all, it was the nurses who were there during his good days, bad days, critical events, and so on. This requires a lot of practical and moral work.

I think there was a global perspective that he would at some point succumb to his multiple medical complexities...I think it was challenging to get a handle on him and feel confident that he was going to sustain on your shift, and maintain stability...also knowing that he had this potential to go sideways pretty quickly...the nursing staff bore a lot of the care and process...but I think everyone's goals were a little bit different in their investment. (SW)

Unfortunately, at two years and one month of age, one of his many decannulation events led to a hypoxic ischemic brain injury. One evening, at two years his alarm went off while his nurse was in their other patient's room. Those outside noted the alarm and responded and his nurse returned to the room as well. His trach had come out and others were summoned, including the intensivist. As attempts were made to reinsert the tube, he became pulseless and CPR was initiated. During this episode his implanted central line broke as a medication was administered and a peripheral IV had to be inserted. Parents were called to come in. Although he had always recovered quickly from these events, he was slow to respond this time. Resuscitation protocols were followed. He was put on the ventilator and radiographic scans were obtained.

I was sad. I immediately thought which nurse did it happen to and how are they dealing with it, knowing that his airway was so fragile. I experienced that many times, where he'd pull his trach out and literally within 10 seconds he'd pass out. I'd put the trach back in and he was right back up playing again. And I knew it would only take mere seconds before something catastrophic could happen, and hearing that it did happen, it was like...Shocking, but definitely not surprising. (RN1)

So when I came in [the day after], I was caring for him that day. That was terrible. That was a hard day. We all got close to him, I think, so it was more like I was his auntie. That's how it felt to me. It was heartbreaking. But we all knew it was possible. (RN3)

Normal post-arrest protocols were followed, and care was directed towards preserving as much function as possible. He was kept sedated and was requiring extra doses to keep him comfortable due to severe muscle contractions and autonomic storming. Pain and Palliative care were consulted to help manage his now complex medication regiment required to maintain safety and comfort. Staff on the unit were saddened at the tragic event, though not surprised. There was empathy for the nurses that had been there when it happened, and some relief to those who hadn't had him in their care when it happened. As time passed it became clear that Chase would not recover to the happy and interactive child he was previously. The thought was that maybe he would be able to smile, cry, feel pain, etc. but not return to his previous status.

It was difficult to get his discomfort under control and he continued to receive doses of powerful sedatives intermittently. For a time after his event, he required sedative boluses throughout the day for agitation until Pain and Palliative care were able to get his comfort under control. For staff this was hard to watch and hard to convey to a family who saw a calm and quiet sedated child when they arrived. It was difficult to convey what was required to maintain his calm state and what he looked like prior to it.

The divisions between staff and family, already present, were starting to widen. There was a meeting held to review the event. There was some concern that Chase did not have an ECG monitor on at the time, (which was not verified) or it had come off, and that this was a reason that led to the injury. However, nursing staff, and some physician staff members disagreed. This conclusion seemed to disregard the complexities around an active child in a rehab plan of care whose nurses were

routinely given other patient assignments and thus would not be at bedside continuously.

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There was also suspicion of an additional episode of hypoxic injury during a bronchoscopy after this incident. There were feelings that Chase's injury, though tragic, were a very probable outcome that was bound to happen despite all precautions in place in the PICU. However it was viewed by different staff members, the care team came to the conclusion that it was no longer in Chase's best interests to maintain on life-sustaining therapies, withdrawal of these technologies was recommended.

The medical team felt that due to his new static encephalopathy, which reduced the desire to continue to perform surgeries on his airway, that Chase could now safely go home, preferably on hospice with a DNR in place. Parents, per notes, continued to feel that they do not wish to care for him in their home even with home care nursing.

We turned to discussion of hospital discharge for [Chase], and the fact that the parents continue to feel that they do not wish to and cannot care for him in their home even with extensive home care nursing.

(Ethics note from care conference)

I think he was too complex, in their [parents] point of view, to be managed at home. Some of that was our own messaging of saying, 'He's too complex, he's too complex, you can't take him home,' and then all of a sudden we went through a dramatic shift from, 'There's no way, if we're on this course of him being here until I don't know what happens,' to, 'He had this incident, he can go home.' (CM)

Parents also rejected the recommendation to withdraw the ventilator and allow natural death. The next option presented was that of group home placement. As time passed, with Chase still in the hospital, parents were intent on resolving all of Chase's medical issues of which the particulars were unclear. The team contended that dealing with current and ongoing medical issues and preparing for discharge was not only a parallel process, but that Chase had been ready for discharge for some time.

...The team emphasized that this is a parallel process, and that [Chase] would remain in the hospital if his medical condition warranted, but has been ready for discharge for many months. [CM] noted that she had been in touch with the group home and that they are open to a visit by the parents any day of the week. For that reason SW on behalf of the team said that the family should make a visit by...and let us know if they had questions and would accept moving forward with the group home placement in [local area] or if they had decided to take [Chase] to their home, and if not we would move forward with a referral to Child Protective Services regarding the fact that [Chase] is medically ready for discharge but the parents are not actively working towards plan for discharge.

(Ethics note, care conference)

During this process there continued to be a disconnect around the responsibility of the parents for touring and choosing a group home and what the team felt as their responsibility over Chase's disposition as not needing to be in the hospital.

Eventually, the team felt that parents were not meeting their responsibility, and it was decided to set a deadline for parents to decide. If this deadline was not met, then child protective services (CPS) would be contacted, and medical foster care would be sought. The options on the table for Chase were either to go home with parents with home care nursing, to a group home, or to medical foster care. Through this, the team continued to recommend comfort care and hospice while parents continued to desire aggressive life-sustaining treatment.

Chase eventually was accepted into a group home. Group home nurses came to the hospital to learn Chase's cares from the PICU nurses. Care management worked with the outside companies to line up all the medical and equipment needs. One of Chase's primary nurses put together a book about him, his history, surgeries, life, care, etc.

The day came, an ambulance transport team arrived in the morning. Chase was loaded up onto the stretcher and was rolled down the hall back through the main area of the PICU to the transport elevators; and he was gone.

Twenty-four days later, the intensivist on service received a call that there was a 66 three-year-old child coming in after a respiratory/cardiac arrest. The history was relayed to the intensivist and it became quite clear who the child was. The details of what happened are unclear, but his tracheostomy tube had somehow become decannulated and he was found unresponsive. The trach was reinserted, and CPR had been administered, his circulation returned, and he was brought back to the PICU. Standard post-resuscitation measures were implemented and the PICU nurses who had cared for him for so long were now caring for him once again.

Once post-resuscitation measures had been done, it had become clear that Chase had suffered some further brain injury due to anoxia. Once sedation was weaned off his neurological assessment proved poor and plans for brain death testing were made. The first brain death testing proved to be consistent for death by neurological criteria according to the hospital policy informed by state law and professional society recommendations. Consistent with the clinical standards and state statutes, a second brain death exam was performed 24 hours later by a pediatric neurologist. This second exam was also consistent with death by neurological criteria with no respiratory effort after his carbon dioxide levels reached 108 (normal is 35-55) during the apnea test.

The attending intensive care physician wrote a discharge note in Chase's chart declaring him dead. Consistent with hospital policy, as well as national practice standards, if the child is not a candidate for organ donation, or if family refuses, the family has some time to gather prior to removal of the ventilator. In this case, family declined both organ donation and postmortem examination. His family requested time to investigate how they may transport him home to let him pass there instead of in the hospital. While this isn't common it has been done by some families at their own expense. Somewhere in this time, Chase had an agonal breath that continued to

happen once every so often. While this breath was not enough to sustain life, it did<sup>67</sup> invalidate the diagnosis of death by neurological criteria.

Chase continued to have a flat line on his EEG monitor as well as show clear signs of having sustained a massive hypoxic-ischemic injury. Chase's parents were informed that he no longer satisfied the criteria for brain death. Parent's had been told of Chase's potential demise many times before and he had always come back, including a time where they were told an innominate artery in his trachea would imminently burst and he would bleed out, yet he survived. Now here they were, once again, seeing their child alive after being told their child had died.

The medical team continued to maintain that while he was legally alive, they still recommended compassionate removal of the ventilator and to allow natural death and/or switch to a comfort care/hospice approach. The team voiced to parents, per ethics notes, that the treatments being asked to be performed were being done *to* him and not *for* and that further interventions would not be beneficial. Parents continued to look towards recovery and despite the team's recommendation parents also did not consent to withholding any resuscitation measures if Chase's heart stopped.

Chase was three and a half years of age, and there continued to be ongoing discussions with the family in the hopes of coming to some agreement towards the medical team's recommendations. Despite this, family continued to state their goals being that of recovery with less medical equipment and the removal of his tracheotomy tube and reconnection of his airway, which had been, at this point, anatomically separated. The team continued to try to clarify the situation as much as possible for the parents in hopes of coming to a reasonable end. There continued to be intractable discussions around taking the child home and allowing the child to pass. Parents rejected this and requested time to think about and make these choices. The

team clarified and held steadfast that keeping him on the ventilator *is* making a choice for him. The bedside caregivers' distress was mounting.

After he had his first hit, there were things that brought him comfort. You could see that they were comforting to him. He loved to have his legs massaged, and who knows if he was smiling or not... We would play The Little Mermaid, and he would smile and his heart rate would go down. So there were things that we were able to do to give him comfort and give him some quality of life, and I felt like, okay, this is the quality of life that he has now. At least it's something. After his second hit, there was nothing. He would just have this twitching, and sometimes nothing at all. I just didn't feel like there was anything in there, and if there was something in there, it was painful to him, or like futility: no matter what we did, we would never get him to have any quality of life. No matter what. (RN3)

The other piece of that was that the dad was insisting that his airway keep getting dilated. I think my stance was, okay, fine, if you don't have to do anything to him medically ever again and you can just leave him here in this body, you can maybe find some way to give him comfort. But the fact that we had to keep dilating his airway and keep doing things to him to keep his body here, for me that was too hard...(RN3)

The family and team came to some initial decisions around working towards training parents and getting Chase home and if he stopped having agonal breaths then they would let him go. Chase continued to demonstrate no brain activity on the EEG monitor.

At this point, the home care agency reached out to the medical team and reported that they would not re-accept care for Chase without a DNR order in place. This came about after some home care nurses came to Chase's bedside in the PICU to view some of his care where they witnessed his atypically low heart rate in the thirties, and his temperatures that were typically around 35 degrees Celsius.

Given his overall condition and the high likelihood of further deterioration and the recent events in which changes in his cardiac status required fluids and his low heart rate, they realistically anticipated that a cardiac deterioration is likely at home, and in view of his overall status the nurses felt it was not appropriate to

attempt resuscitation and stated that they would not  
provide care for him at home without a DNR in place.  
(Ethics note)

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The medical team continued to reiterate their recommendation of compassionate extubation of his trachea. The note from a care conference around this discussion also notes an extensive description of the concern from caregivers that they were doing potentially harmful things to Chase. At this point, a dispute resolution process put together by the hospital and physician group was proposed to the family with the goal being to identify a mutually agreeable plan of care.

This process outlined the limits of current care for Chase in the hospital and that there will be no escalation of major treatments such as dialysis, ECMO, and cardiac device or structural interventions. There would be continued effort to contact home care agencies and Chase would be transferred when medically stable enough. Discharging to the family home was now officially abandoned as a goal. The medical team stated their pursuance of second opinions from various relevant specialties. Transfer to another acute care institution would be attempted through hospital to hospital contact.

National institutions in different states were contacted, all refused. Some of these institutions seemed interested in the airway problem itself but due to Chase's overall condition they were not willing to accept him in transfer. These refusals of transfer were discussed with the child's father who seemed to disagree with how clinicians were connecting the airway and neurologic problems. This was explained that to attempt to fix the airway became for many clinicians and experiment with no benefit to Chase. The final piece of the resolution process stated that if it does not end in some mutually agreed upon plan, that court intervention would be pursued.

Second opinions were obtained from specialists in intensive care, neurology, and ethics. The reports from these were shared with the parents. Of note is a section of the

conference:

The likelihood of meaningful recovery is nil and that his tracheal stenosis is not capable of being repaired due to his development of scar tissue and stenosis. His airway is critical and not able to be repaired in a more meaningful way, and thus, he would never be able to leave the hospital. Due to his unfixable compromised airway, it is unlikely that a group facility would accept him unless his parents agreed to DNR status. Per the chart, his parents are not accepting of this option and thus discharge from the hospital is not a possibility. Based on my careful review of [Child]'s medical records, imaging, and physical exam and discussions with his medical team and [father], the combination of severe hypoxic ischemic injury and lack of cortical functioning with an unstable airway lead me to conclude that continued provision of life-sustaining treatment is non-beneficial and potentially inappropriate. (Outside Ethics Consult note)

This outside ethics consultant had met with Chase's father. This didn't seem to move the needle any further. The longer discussions went on the more intractable they seemed to become. Parents continued to look towards a goal of treating Chase's airway along with hoping for recovery from his brain damage. There was some discussion from parents around construction of a 3-D trachea, hyperbaric oxygen therapy, and other experimental treatments. At this point the two options going forward presented to parents were mediation and continued attempts by parents to find another institution willing to treat Chase in accordance with the parents' wishes.

Disagreement around further treatment and benefits to Chase was ongoing. Parents continued to ask for him to stay in the hospital until he is well, while the hospital team believed that he could not get any better.

[Father] asked why [Chase] just can't stay in the hospital until he can get well. I noted that there is a basic disagreement of understanding between them as parents and the hospital team, with the health care team believing that [Chase] can not [sic] get better, and the parents believing that he can. [Father] asked what the law says about situations in which there is not

possibility of getting better. He then added that the problem is people feel that they do not want to treat [Chase] anymore, and I acknowledged that this is true for many because they feel they are not helping [Chase]. (Ethics note)

At this point, the ethicist recommended an outside mediator to become involved given that there is disagreement around the central concept of Chase's ability to improve. Parents stated concerns that the mediator was a way for the hospital to pressure them into removing life support from Chase. The parents also discussed concern that mediation was a way to build a case for CPS.

Continued intermittent testing of Chase by EEG continued to show no brain activity, a flat line. The intensivist explained his finding that there is limited cranial nerve function and upper brain cortical function did not return on exam or EEG. The team continued their recommendation to shift towards comfort care/hospice plan. The parents at this time stated their desire to have Chase out of the hospital with a stable airway. During this conversation the intensivist stated that it is unlikely that Chase's airway will ever be stable enough to be cared for outside of the hospital and did not believe that Chase could get home safely. The intensivist stated the probability that Chase will arrest either in the hospital or home and no home nursing will take Chase on without a DNR order.

The mediation went forward with questionable success. Chase did finally discharge to a different group home a year after his final admission. He was four years and four months of age. His final narrative summary lists twelve active problems:

severe static encephalopathy with profound neurologic dysfunction, tracheal stenosis with aorto-homograph with limited granulation tissue but patent airway, complete laryngeal occlusion, tracheostomy and ventilator dependence with pseudomonas and candida colonization, intercurrent urinary tract infection, Trisomy 21, hypertension, ischemic bowel injury-feeding intolerance, past TPN support; enteral feeding dependent, iliofemoral thrombus on Lovenox, adrenal insufficiency with baseline and stress steroid deficiency,

iron deficiency anemia, and precocious puberty of central origin. (Narrative summary from chart)

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Chase had multiple bronchoscopies and dilatations throughout his hospitalizations, multiple procedures, and over ten surgeries including ECMO cannulation. He discharged on twenty-two medications. It was decided by parents but encouraged by the hospital that they would transfer Chase's future care and/or stabilization to another institution. At the time of writing, in 2019, he is still alive and would be almost seven years-old. Before his final discharge, one of his primary nurses had the following discussion with Chase's father:

It's interesting, because I did get into a conversation with Dad shortly before the final discharge. He had asked me something like, 'Do you think my son will ever be who I remember?' Then he showed me a video at 3 months of age where he's sitting in a high chair laughing -- or maybe it was in infancy, because at 3 months he probably wouldn't be in a high chair -- just laughing and attentive, playing with toys, and he said, 'Do you think I will ever see this again, [RN2]?' and I said, 'It is a beautiful memory. I have never seen that. It's refreshing to see. But that is a memory from the past. It's not current. And I think you need to see your son as who he is right now. And if you enjoy that, and you value that, and you find that worthwhile, and you love him, what more do you need?' But I said, 'If you're using that as your goal, I don't think that will be in the future.' So he was crying, and I felt awful. But I couldn't not answer. I'd never not answered him. And I apologized for the tears, and then he discharged. Probably in the best situation -- of what we can do here, on earth. (RN2)

## Chapter 5: Results

This chapter will report the results of this investigation and analysis into the main research questions that undergirded the study: (1) what must exist for this [intractable conflict] to happen? and (2) what is the social structure around this case and how is it operating? This can be more clearly stated as discovering how participants viewed their role in relation to the roles of others to include organizational and institutional components. The social structure is in a sense, everyone and everything involved or intertwined with the point of reference, the case or child. The data collected and reported here will be analyzed critically and ethically using Margaret Urban Walker's expressive-collaborative model of morality as stated in the third specific aim of this study. Walker's expressive-collaborative model of morality provides a useful tool for analysis of this data because of its ability to examine moral practices critically within the complexity of a social structure. Walker's model can aid in analysis of this data as it locates moral practice through the complexity of identities, relationships, and practices (Mohammed & Peter, 2009, p. 296).

To answer the research questions and the study aims, a single case study design was developed drawing from systems theory and critical realism to explore the social structure through semi-structured interviews and chart review, analysis of policies, concepts, and artifacts referenced in the data. Of particular interest was how participants involved in the case viewed their roles, responsibilities, and obligations around a very complex case. Participants were specifically asked how they viewed their role and responsibility, obligation, and their conception of futility. Findings from this study can help us examine how these cases happen and provide a lens into the institution of healthcare to examine causality, social structure, and the moral spaces that exist.

Interviews were conducted by the researcher with persons who were primary providers and caregivers in this case. Subjects were identified by previous knowledge of this case, chart review, as well as report from other study participants. Consent was obtained through agreement to be interviewed and recorded. Three nurses were identified as primary nurses to the child and agreed to participate (RN1, RN2, RN3). One social worker (SW) and one case manager (CM) who is also a nurse by profession, agreed to participate. Three physicians agreed to participate, one intermediate medical care physician who was the child's physician the longest (IMCMD), one intensive care physician and pulmonologist (ICUPULM), as well as the child's pain and palliative care physician (PPMD). The hospital ethicist at the time also agreed to participate (Ethicist). Requests to participate were also sent to the primary ENT surgeon and the hospital risk manager, however these requests went unanswered. Risk management did answer one request, but this researcher was unable to meet within the offered timeframe, further requests to reschedule went unanswered.

Much consideration went into the question of an interview request to the parents of this child. Ultimately the answers to the research questions would be strengthened by the inclusion of the parental view. However, inclusion of parents was weighed against any burdens that participation would put on them. An email request was sent to the email contact provided to this researcher by one of the parents during a discussion around using their child's case for research and education. The request was for either email questions, phone, or in-person interview. A reply to this request was never returned.

Data Analysis

Interviews averaged forty-five to ninety minutes, recordings were sent for transcription. All names of persons and places were removed for privacy, as well as

any other personal information. Relevant data, such as clinician notes, were retrieved<sup>75</sup> from chart review. During analysis of this data names of persons and places were removed, as well as any information about the family. Structured questions were asked about the participants role, responsibilities, obligations, and feelings and thoughts around futility throughout the timepoints in the case.

Once interviews were transcribed, analysis began in an ongoing process. Any errors in transcription were verified with the audio and/or clarification with participant. Initial open coding was performed with another researcher experienced in qualitative analysis until consensus in analysis was reached. Predetermined themes were identified in a directed coding process towards how the person perceived their role and what concepts, policies, and objects were discussed, and how they viewed the idea of futility. Other themes were identified in an open coding process. After preliminary data analysis, consensus with two researchers trained in qualitative methods was reached.

Chart review data was collected in an ongoing process as relevant information was referenced in the interviews. Initially, history and physicals and narrative summaries were collected as these are generally known to be the primary summary of admissions and discharges. These documents, along with care conference and ethics notes were utilized for constructing the story.

### Findings:

The following were findings from data analysis of participant narratives. Following pre-conceived outline adapted from Walker's expressive-collaborative model of morality, narratives were analyzed for themes. Results are grouped into nurses, allied staff, and physicians, or individually identified. Of note, the care manger (CM) is a nurse but for ease of data analysis and presentation the current role that participant is in fits well with allied health. Tables 4 through 6 below will report

the findings of how participants viewed their role. Table 7 will describe the process<sup>76</sup> of how responsibility was accepted, assigned, and deflected which emerged from the data throughout the different timepoints. While accepting, assigning, and deflecting are used to group the data, a more nuanced analysis will be presented in the interpretation section with reference to the outline adapted from Walker in chapter three.<sup>6</sup>

### Nursing Role

While nursing participants reported many roles, their primary obligation was reported to be to the patient through caregiving, advocacy, and educating and coordinating with family and other staff (Table 4). Each of these nurse participants had taken on the role of primary nurse for this child. The primary nurse role, in the institution where this case took place, means that any time one of these nurses is scheduled they will be taking care of this child. This means that they will be experts in the care of this child, familiar to the child and his parents, and provide seamless and consistent care from the time of signing on as primary to when the child leaves the PICU; often when a child is readmitted as well. It is discouraged to remove yourself as a primary without valid reasons. This commitment is a major one given that signing up as a primary can mean being with the patient through the critical phase and possibly a lengthy rehab phase in the intermediate care side of the unit, which is often less exciting than the ICU side.

These nurse participants report an obligation and role towards rescue or care in responding to the child's many events due to his treacherous airway in the initial

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<sup>6</sup> While this first section will refer to role and responsibility, the following section will deal more specifically with "practices of responsibility." It is impossible to remove responsibility completely from how participants view their particular role but I separate them due to the differing analytic process of deductive versus inductive. Meaning, I asked participants specifically about how they view their role, but how they assign, accept, or deflect responsibility, structure it, and morally account for practice is analyzed inductively.

timepoint in his hospitalization (Table 4). Their role also included monitoring and<sup>77</sup> translating information to parents and between staff members.

Table 4. Nursing Role and Responsibilities

Nursing Role and Responsibilities	
Roles	Narrative
RN1 Primary caregiver, advocate, teacher, translator, protector	<p>“First and foremost it’s the patient. I’m going for the patient. That’s my assignment, and that’s what I’m going to do: promote and advocate for the patient...I get advice from the team on how to care for the patient, and from there I go to the parents and say ‘this is what’s going on.’”</p> <p>“...doing primary care of the child: monitoring vital signs; keeping him safe; keeping the parents informed of what’s going on; keeping the docs informed of what progress he’s making, where he stands; and also interpreting what the docs are saying to the parents and how the parents are interpreting that.”</p> <p>“...I explain the details of past histories of patients I’ve dealt with and reference those, and I explain the life-altering and life-changing processes that will and can occur if certain medical interventions occur...”</p> <p>“...I felt it very important to nurture [growth and development], to let him experience a little bit of the world going on around him...”</p> <p>“...still advocating for him, making sure that he was cared for, and then trying to figure out where we were going to go from there.”</p> <p>“Teaching the home care nurses how to take care of him.”</p> <p>“I couldn’t leave him. I signed on as the primary, and for me a primary continues until that discharge—my obligation.”</p>
RN2 Cheerleader, primary caregiver, primary teacher, advocate, protector	<p>“Just to cheerlead, to praise them [parents], to encourage them, to support them, to lift them up that what they’re doing is just what they would do for their other kids...It’s a lot more medical than what they would do for their other children, but it just takes love and common sense and watchful eyes, and parents can do it, and they need to be praised and encouraged when they do a good job. Did I ever believe that this child would ever go home? No. But do you know what? The child and the family deserved the best chance. I knew he would have nursing in the home, so the education and the training would continue on at home, and he would be safe.”</p> <p>“...First to the patient...even if I have a different viewpoint or see something different...Second, to family, to help them understand an honest and truthful picture of their child, and always tackling those difficult, awkward, uncomfortable topics...quality of life, how to interpret changes of condition...”</p> <p>“...A lot of listening and understanding parents’ perspective...the listening there then helps me formulate ideas and suggestions to the team of how we might be able to better approach [the goal].”</p> <p>“Because ultimately parents are the back-up, so they have to believe that they can do it. And trying to teach them little idiosyncrasies of their son, like how to read the nonverbal communication that maybe a diaper needs to be changed, and catching it early on so that he isn’t into a full-blown agitation episode, things like that.”</p> <p>“Having to advocate for active treatment for a chronically ill child is like pulling teeth sometimes.”</p> <p>“I don’t know that I would evaluate my cares for this child as valuable, but what I did have going on in my mind was that I knew this child as a person, he knew me, so he was deserving of my time and energy. Just as I do for every child, I want to make things better, not worse, and if I can do that, I’ll figure out how to do that.”</p>
RN3 Coordinator, advocate, responder, protector, primary caregiver, caretaker	<p>“...Try to coordinate with the family well and...be very thorough. I see that as a primary responsibility, to advocate for him and just give some consistency to get good care.”</p> <p>“He had a really, really treacherous airway, so just to be ready for any intervention that he could possibly need.”</p> <p>“...I felt like giving him the most we could give him in that situation, giving him the consistency and giving him...compassion...”</p> <p>“...[Responsibilities] became more restorative: more rehab, more looking at him and seeing how much more we could back neurologically...”</p> <p>“I felt like I was caring for a body, at that point. After his second neuro hit, there wasn’t anything that resembled him left...”</p>

Allied Staff Role

Allied staff, for lack of a better word, consist of the care manager (CM), social<sup>78</sup> worker (SW), and clinical ethicist (Ethicist). The roles of the participants in this group are quite varied and it was not expected that similarities would necessarily be seen. However, in their own way, via their professional lens, they were the most consistent clinicians who took on the responsibility of maintaining the communication and narrative of the case. CM reported planning, coordinating, and forecasting in relation to discharge disposition. CM reports a primary responsibility to the child and their needs which includes working with the parents to achieve that. SW reports a role supporting parents and helping them navigate the hospital system, bridging communication between hospital care team and family, as well as connecting family with any outside resources. SW does also report supporting the patient, which in this case involves supporting the family primarily as the child is critically ill and young.

These participants do have a duty to the patient in the same way the hospital or other staff would through a more broad interest in a child's welfare. In this particular case SW reports taking on the role of managing and maintaining what amounted to a complex communication web. Ethicist reports an obligation to understand the different viewpoints and perspectives around the case. Ethicist takes a management role of the situation by looking at the case from many different aspects and investigating strategies for mediation. It is interesting to note that these allied staff members are both a part of the healthcare team structure and also separate from the main clinical staff. The allied staff seem to sort of exist within and just outside the main relational node that connects the nursing and physician staff to the child. The allied staff have a more broad relational position that is connected through relationships to the whole of the structure- child, nurse, physician, parent- contrasted to that of nurse and physician who see primary relation to the patient and then family.

SW reports a role shift when the team developed new goals and recommendations after the first neurologic injury. Once the case became more complicated SW reports supporting staff as well as managing expectations and perspectives of staff coming into this situation which seems to have sparked distress or confusion. SW reports helping staff maintain perspective, understand the global picture, and keeping the narrative straight amongst constantly changing nursing staff and physicians who rotated every seven days. Ethicist, once consulted on the case, joined SW in managing the complexity of the situation and the constantly changing clinicians.

Table 5. Allied Staff Role and Responsibilities

Allied Staff Role and Responsibilities		
	Roles	Narrative
CM	Coordinator, planner, forecaster	<p>“...We now follow every child in the hospital...with their insurance reviews to their discharge planning, so we review every case...”</p> <p>“I meet with providers to identify a discharge timeline and identify their discharge needs; I talk to families to help coordinate those services at home, explaining what going home entails, what equipment is needed, what training is needed...We also plan care conferences...coordinate with the outside services, the family, and the providers to get everything they need in place...”</p> <p>“I like to view myself as here for the kids. A lot of the discharge planning requires parent involvement, so I like to try to put the child’s priorities first and then work with the family to make those needs happen.”</p>
SW	Supporter, navigator, communicator, narrative keeper,	<p>“Support the family; support for the patient; helping them navigate the hospital system; navigating community resources, if needed, or community-based resources; and aiding in communication between team and family.”</p> <p>“...My role shifted to help navigate what the team's new goals or expectations and recommendations were...”</p> <p>“A lot of my work was supporting the staff and helping them maintain some perspective. A lot of people were dropping into this situation.”</p> <p>“... Helping them understand that the family had had this course to this point, that it would be hard for any family to appreciate a recommendation knowing that he survived some of those... understanding that there are realities that we all have to face, and we have to support that.”</p> <p>“...Supporting the primaries that were in there routinely, knowing that they had a point of reference for who he was, and then helping the people that were new to his situation understand the global picture.”</p> <p>“...We started to, at times, villainize the parents, when we were just as culpable in what his course was and what our role was in communication and expectation.</p> <p>“I was eyes and ears, I guess, on the unit,”</p> <p>“It was Ethics and I trying to help maintain that common thread across the whole team, knowing that every seven days you had potentially a new provider, a new nursing group, a new whatever...my primary interaction was with catching people up to speed, or one more of a social dynamic of what was going on and where we were in that, trying to move things forward, and engaging with Ethics and what were other options to see some kind of resolution to the now-developing solid conflict that we were in.”</p>
Ethicist	Mediator, analyzer, complexity manager	<p>“The first role is to try to understand the different points of view about what has happened and then to come up with some formulation of what actions might be helpful...”</p> <p>“The first responsibility is always to the patient, to the child. The second circle of responsibility is the family. The third...is direct caregivers. The next...would be the people who support the direct caregivers...The next circle...is the institution...”</p>

Physician

Physician roles are also not expected to be similar because all three have different viewpoints. That being said, IMCMD and ICUPULM are both intensive care physicians. While IMCMD primarily cared for the child during his lengthy rehab and recovery phase, timepoint two, ICUPULM cared for the child during all timepoints both as a primary intensivist and consulting pulmonologist and took on a primary role in the end timepoints. PPMD reports a much different role that seems to be more complex or broad. It is interesting to contrast PPMD and the RN's multitude of roles described, to the two other physicians. One way of looking at this may be to consider whether a broader or less concrete the responsibilities are the more role codes are found. A striking difference between other participants and the physician participants is the way in which they related their narrative, in a much more objective and less personal way. One could interpret from this that the more personal the role the more role codes there are or at least are more complex and nuanced.

Table 6. Physician Role and Responsibilities

Physician Role and Responsibilities		
Roles		Narrative
IMCMD	Physician, Partner	<p>"We didn't have as much help as we do now, so I did a lot of the helping things."</p> <p>"You're obligated [to provide care] until there is a futility policy...that legally is seen throughout this country."</p> <p>"As a group, we had a couple of other cases...where we discussed this, whether we wanted to do this [override parents] and be the first to do it."</p>
PPMD	Pain and Palliative care physician, Symptom management, Decisions and goals coach, consultant,	<p>"...Medication management of some symptom versus a medical decision-making and goals-of-care conversation..."</p> <p>"...My role is to try to explain in great detail what these options really are and clarify each option they're presented with; help families weigh the benefits and burdens of each of these options, even to the granular level of what day-to-day life is like; and help them as they try to weigh what that means for their child."</p> <p>"...The biggest thing we do is to try to outline their goals of care and how they see the situation."</p> <p>"I think a lot of people have expectations of us, but my primary responsibility is to the child."</p> <p>"Eventually I signed off. I gave my best recommendation: that this was an ethical issue... and needed to go through formal mediation...That was not accepted by the team, so, given that the child was comfortable, I didn't see another role for myself..."</p> <p>"...I don't think I was actually serving him so much as coming to provide an outlet for the nurses with the moral distress that they were feeling, and trying to show up for the medical team to help shoulder the burden..."</p> <p>"...I'm a consultant..."</p> <p>"Really, our primary palliative care role was to identify the goals and help family make sure they understood the risks and benefits of all things being offered."</p>
ICUPULM	Intensivist, pulmonologist	<p>"I was either playing intensivist or pulmonologist..."</p> <p>"As an intensivist one is more proactive with decision making. As a pulmonologist in the ICU you're a consultant and the role is reduced to consulting, not necessarily making the decision to move forward in one direction or the other."</p> <p>"We treated him like really any airway surgery patient, which involves nutrition, analgesia, airway support."</p>

[As a pulmonologist] “Once this got into the land of tracheostomy, there’s education, interventions, technical skills that have to be mastered by the family, home care arrangements have to be made, and there has to be a collective decision that the patient is safe enough to go home...from a physiologic point of view.”  
“I think the dilemma we have as providers is that we often fall prey to the notion that if we just do this, the child might survive.”  
[After 2<sup>nd</sup> event] “All I can say is consciousness was not available to this child to experience pain. For me, the person in the bed meant much, much less than the people caring for that person in the bed.”

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### Process of Responsibility:

The process of responsibility refers to the way in which the particular identity-relationship influences the way responsibilities are assigned, accepted, and deflected. These themes identify how participants viewed the structure of responsibility, construction and transformation of the moral space, and moral accounting within and throughout the case. The results will be interpreted through the different time points. While accepting, assigning, and deflecting are used to organize the data, these do not necessarily represent strict lines of delineation, rather it is more complicated.

### Timepoint 1

On admission, as with any critically ill child, the focus was on stabilization and determination of the situation. There was fewer narrative data about this time than there was about the later times, particularly as the case progressed towards conflict. This is interesting as it could signify the ‘routineness’ of the initial timepoint being that the child was critically ill and following the normal order of the PICU. Later timepoints deviated from this norm and thus, arguably, stands out more for the participants.

The main themes that resonate from the data with regard to this timepoint is how the responsibility over the decisions were structured. It was described by RN1, as well as ICUPULM, that three options were presented to the family: pull the breathing tube and allow the child to pass, transfer to a center for transplant or one that specializes in this issue or attempt reconstruction in the current facility (Table 7). This assigning of responsibility for these choices to parents is interesting, and one could argue that it is

almost a deflection. As ICUPULM describes how we as a care team don't always do a great job of explaining choices such as this, and that maybe we should have insisted on the specialty center (Table 7). This could be seen as the providers assigning the responsibility to the parents to make a decision that they may not necessarily be equipped to make, which is in line with normal practice.

The gravity of the responsibility in taking care of this child is reported by SW (Table 7). Assigning, or being assigned to his care (or accepting his care) was challenging due to his propensity to spontaneously decompensate. Nursing assignments are made by the charge nurse and therefore this duty is both assigned and accepted, as a nurse technically can refuse an assignment. Accepted to a lesser degree for most nurses and to a higher degree for the nurses in this study who took on care as a primary nurse. This commitment, given the responsibility of assuming his fragile care, seems quite monumental. Assignment and acceptance are less clear with allied and physician participants because if they are on service then the child is under their responsibility with less of an ability to refuse it or deflect it.

This first timepoint is where we start to see how moral accounting and structures of responsibility emerge. As a child is acutely ill there is an increase in responsibility of the nurse and other medical staff. As reported by CM, parents often cannot even touch their critically ill child due to its fragility (Table 7). This seems to represent more of a removal or a loss of responsibility, albeit necessary. And as CM, further reports, it seems natural that a parent may detach, particularly if it becomes a prolonged time. The admission by ICUPULM around well we explain difficult procedures to parents, such as the one the child in this case required, speaks to a sort of deflection of responsibility by assigning decisions to parents (Table 7). What ICUPULM is questioning is whether we should have offered the choice. This suggests that while we seem to feel required to offer choices, there is concern that there are

choices offered that parents should not be allowed to or expected to make. What is<sup>83</sup> interesting here is that while choice is seen to empower parents over a paternalistic healthcare provider the actual offering of more choice may be just as depowering, particularly if the gravity of the choices is not fully understood, and/or the choices elicit competing interests for parents and child.

### Timepoint 2

As the child aged and improved in his condition he became more interactive. The second timepoint finds the responsibilities shifting away from continuous critical intervention towards intermittent and potential problems. With the child's increased awareness of the world around him, RN1 reports a responsibility to nurture the child's growth and development (Table 7). Again, the commitment of the role of primary nurse sees the acceptance of responsibility for the child-as-child, rather than simply child-as-patient. This distinction of the child-patient and child-child is an interesting finding. This speaks to a deeper commitment than an assumption of a patient assignment but a responsibility towards the child's course, care, and needs. At the same time the data that suggests that there was an expectation from staff that parents should be more present at the bedside.

There was also a great fear that was present around the stability of the child as reported by RN3 (Table 7). This was also reported CM, where the data suggests that due to the tenuous nature the staff accepted responsibility around keeping the child in the PICU while at the same time expecting (assigning) responsibility towards the parents where earlier this responsibility of parents was removed or unassigned by staff due to the child's status. The notion of staff accepting responsibility to keep the child in the PICU seems a more global theme though. The decision-makers, the agents who endeavored down the path that led to the child's fragility, weren't really

accepting the responsibility, rather they were assigning it or it was assigned to them<sup>84</sup> by necessity, whether intentional or not.

There is no data that suggests the outcome of having to stay in the PICU was known, however, as a consequence of the decision to reconstruct the airway, this was the consequence and through continued interventions and care there is an implicit acceptance of responsibility. The participants who are not the main decision-makers seem to accept this responsibility differently. One could say they are assigned this responsibility, though if this is considered a possibility within the realm of pediatric critical care acceptance could be viewed by continued involvement in the domain, though this would be a derivative view that could be argued as problematic.

Deflection of responsibility in timepoint two became complicated. As SW reports, there is a reasonable assumption that given the longevity of this child remaining in the PICU, that life goes on, and the parents have other responsibilities that are also important (Table 7). As CM reports, the child's airway was not stable enough to go home and have parents assume the responsibilities for their child's care (Table 7). However, during this time there was an assigning of responsibility from CM to nurses to begin educating them on their child's cares (Table 7).

Given that the child had an unknown length of time until discharge and an unknown trajectory towards his cares at discharge, while CM's role is to begin discharge planning early (Table 5), the question becomes whether parents accepted, or should accept, responsibility at this stage. What the unintended consequence of this problem may have been, as evidenced in the data by SW, is that parents did not see the day-to-day care and crises that staff bore. Here, the findings suggest a responsibility for seeing or bearing witness to the child's struggles and successes. Within this data there is some moral accounting and structuring of responsibility that appears important to the moral space and community around this child (Table 7).

There seems to be a moral construction around the experience of bearing witness <sup>85</sup> that is important to the participants in this case where those, the parents, who are perceived to not being witness to it are not within the moral community, and are thus deflecting some responsibility (or having responsibility deflected), according to the participant data.

### Timepoint 3

This time period begins after the child's first neurological injury following one of his many events where his trach came out and he decompensated, which is to say, he almost died, and his brain was starved of oxygen. Nurses continued similar roles and responsibilities which was to care and advocate for him (Table 7). The nurses continued their commitment as primary nurses and the roles and responsibilities that came with that, the goals, or how those are carried out may have changed. RN1 reports continued responsibilities to the child related to the new potential path forward (Table 7). This suggests that the acceptance of primary nursing is still present but that instead of advocating towards ensuring growth and development it may change towards comfort. RN3 echoes this in the data as reported by showing a commitment to providing the child with best possible care, and at the very least, compassion (Table 7).

Data from this timepoint show the emergence of moral distress and the beginnings of a moral community. PPMD discusses taking on the responsibility to help the nurses and alleviating some of the burden of the medical team (Table 7). This timepoint shows SW and PPMD as purposefully attempting to support staff members and helping cope through maintaining a continuity and perspective of the situation (Table 7). This suggests that significant distress and possibly confusion around the situation was emerging and these two participants felt a moral claim to aid the other caregivers in this. There seems to be a certain vulnerability to the situation of the nurses and

other staff coming into a now complex and chaotic situation. SW and PPMD, report<sup>86</sup> responding to this and attempting to mitigate some distress or help clarify the situation, or at least help shoulder the burden.

The data also shows how responsibility for the child's safety had to be balanced with parental requests and needs. At this point the child still had a tenuous airway and was difficult to move due to the ventilator tubing and his muscle contractions. While this may have been seen, as is suggested by RN2, as inconsistencies to parents, there is a reality of ownership of any further injury towards the child on the nursing staff. There is a sense that there was a conflict between attempting to aid parents in having physical time with their child and balancing the vulnerability of the child to movements along with responsibility the nurses had to the child's safety. Nurses seem to have had conflicting responsibilities with no clear way to balance them among the many demands put upon them.

This timepoint brought out data that suggests there was significant confusion around how responsibility was assigned. SW points out the multitude of attempts to convey the fragility of the child on parents in what seems like an attempt to bring them in to the moral community, to bear some witness to the work required to keep this child alive (Table 7). This confusion of control is also evident from RN2, who articulates how this lack of control puts the nurse in a vulnerable spot with responsibility being assigned through the perceived lack of any agent accepting or being assigned overall responsibility. At this point there were ongoing discussions between parents and physicians on what to do, with significant disagreements. As SW indicates, the parents had been told several times that the child was likely going to die, and he didn't, and so why should they understand the fragility (Table 7). Given the data around the fear nurses felt, and the responsibility for the child's possible decline, and the parents perceived viewpoint of how durable the child seemed to be,

there seems to be a shared view among direct bedside nursing staff that bears more<sup>87</sup> responsibility, or hazard, than other actors within and around the child's case. The resentment inevitable from this fractured moral space is found in the data from SW, in the description about villainizing the parents (Table 7). There is fear and thus an anger among nurses around the situation they are being put in, and it seems to be felt despite SW's attempts to provide perspective. The moral sentiment around the child's care, and the moral weight of it on the nursing staff at the bedside was too great.

Deflection of responsibility is seen in the data during this timepoint in several different ways. PPMD reports signing off the case because attempts to assist the situation and take on some of the responsibility was rejected by the main team, as well as that PPMD's responsibilities for this participant, comfort of the child, were satisfied (Table 7). Deflection out of fear was also found due to risk of litigation. In addition to this, as CM's narrative shows, the medical team had been telling the family how complex the child was and that he had to stay in PICU, and then there was a change and suddenly he could go home (Table 7). There is evidence in the data at this point where there was an attempt to reassign responsibility to parents, who had previously seen their responsibility unassigned. Provider responsibility to make the decision they felt was best was deflected due to fear of litigation or bad press for the hospital. There seems to be multiple views of differing responsibilities, all of which either were confusing, conflicting, unrealized, unassigned, or expected but not explicit.

#### Timepoint 4

The data from this timepoint shows a detaching from the case by nurses and physicians who were not primary caregivers. There was an acceptance of responsibility only when there was a crisis that had to be dealt with. Evidence of ongoing distress particularly around the change in personhood the child underwent is

seen and SW continuing to take on responsibility to support the primary nurses (Table 7). At this point, data from RN2, finds that the child's father affirms responsibility, whether accepted or taken back, is seen and this is an interesting point as previous data suggests that the team had been attempting to reassign responsibility to the parents through discharging him home. Here, the father, is giving a time and goal of his responsibility.

At this timepoint there is an attempt to assign responsibility or to bring parents into the moral space that the caregivers are existing in by getting them to witness the moral work of continuing to rescue this child. This attempt was aimed at getting the parents to understand the gravity of the responsibility that the nurses bore. Yet, it seems to have only assured parents that they could not take responsibility for the child's care in their home. The attempts to assign the responsibility to the parents may not be ideal, as PPMD indicates, but at the same time the norm seems to be that it is the parents who ultimately have to make the decisions around life-sustaining therapies. The data suggests that while this is the accepted norm, it is problematic. The decisions are burdensome to parents and ultimately, as evidence here, nurses seem to bear the brunt of the hazard of this process while some participants could easily deflect and distance themselves, nurses were inherently bound to the bedside.

The data discusses blunting responsibilities that parents have in making decisions they don't seem equipped to make (Table 7). ICUPULM discusses this reality within decision-making that indicates the complexity of how responsibilities are accepted, assigned, and deflected within this space. The data shows this fracturing and complexity, and how it influences the space that this child exists in. In deflection of responsibility in this timepoint (Table 7). There are expectations of parents assuming care and responsibility with the acknowledgement that the care is very complex that had required trained nurses for years, with a sudden shift of responsibility. Also

evident is a firm belief in what is best for the child which conveyed a responsibility<sup>89</sup> to make a particular decision which is deflected on the parents or assigned to parents depending on whether you think parents should be making these decisions or not.

Also evident in the data in this timepoint is the structure of responsibility and the ability to disengage or deflect. There is data that speaks to an isolation of bedside staff who are ultimately responsible for the child’s status and must work hard to get other staff members to accept responsibility for the needs of the child. There is also some deflection around advocating for the child as person and responsibility to the parents as decision-makers. At this point, deflection of responsibility it seen through disengagement and reluctance to make decisions that are seen as best for the child. Much of this deflection is understood and fitting within the norms of the space but are also seen as problematic in the data. Participant data suggests that there was consensus on what was best for the child, and that parents shouldn’t be solely responsible for that choice, yet due to fears around bad press and litigation there is a shared responsibility towards parents, hospital, and legal to all weigh in on the choice.

Table 7. Process of Responsibility

Process of Responsibility		Narrative
Timepoint 1	Accepting	“...Try to coordinate with the family well and...be very thorough. I see that as a primary responsibility, to advocate for him and just give some consistency to get good care.” (RN3)
	Assigning	<p>“Pull the breathing tube and let him go, transfer him for a transplant, or the ENT would attempt to rework his trachea.” (RN1)</p> <p>“ENT, at that point, sat down with Dad in the room and discussed ‘these are the alternatives that we have,’ and he explained every one of them, and then Dad said: ‘We will go forth with reconstruction.’” (RN1)</p> <p>“The ENT surgeon involved gave the family the option to take their child to an airway center...but the family chose to have it done here.” (ICUPULM)</p> <p>“How well we explained to them the difficulty with this type of procedure, I don’t know how good a job we did with that...one also could have made the admonition of we don’t do this here; you need to go to an airway center.” (ICUPULM)</p> <p>“...I think it was challenging to get a handle on him to feel confident that he was going to sustain on your shift, and maintain stability...knowing that he had this potential to go sideways pretty quickly.” (SW)</p>
	Deflecting	<p>“The parents did not come in very frequently. Mom was busy at school, raising two other kids, doing all her homework...That first stage was a pretty long time...” (IMCMD)</p> <p>“...When you have a child that’s acutely ill and we’re telling you, ‘Stay away from him. Don’t touch him, that’s disturbing him. That’s making him sicker,’ then, like any parent, if your child is taken away from you, in a sense, for several months, you start, I think, detaching as self-preservation, and maybe not knowing exactly how you fit into helping him...” (CM)</p>

Timepoint 2	Accepting	<p>“...I felt it very important to nurture [growth and development], to let him experience a little bit of the world going on around him...” (RN1)</p> <p>“I remember a lot of us were talking, like ‘I don’t want to be that one. I don’t want to be that nurse that he decannulates on,’ because [ENT] was very clear about it being a very big possibility that if we couldn’t get the trach back in, it would be devastating to him.” (RN3)</p>
	Assigning	<p>“You always felt like you had to have somebody watching him. You had to pass that off constantly...You couldn’t just go in your other room and know that he’d be fine.” (RN3)</p> <p>“...Trying to encourage the bedside staff, when the family is here, to try to maximize that time, to have them start performing cares...sometimes if the family’s here the nurses don’t always have time...” (CM)</p> <p>“With him being more awake and more interactive, the presence of family was not there. The expectations as caregivers would be to see the family a lot more frequently than we did.” (RN1)</p>
	Deflecting	<p>“At that point [timepoint 2], people did not think his airway was stable enough for him to discharge home. The family wasn’t even allowed to do trach changes; ENT was doing the trach changes...we were talking to the family about coming in and starting to practice learning his care so when he was ready to go, they’d be trained...” (CM)</p> <p>“...Dad had to return to work. I mean, life goes on, and they had other kids and other responsibilities, so they had to move forward knowing there was an unknown time frame of how long he was going to need to be here. But in doing that, I think they...were unable to see what his day-to-day cares were, what those day-to-day crises could potentially be, and their engagement with the process...was hampered by that.” (SW)</p>
Timepoint 3	Accepting	<p>“...Still advocating for him, making sure that he was cared for, and then trying to figure out where we were going to go from there.” (RN1)</p> <p>“Teaching the home care nurses how to take care of him.” (RN1)</p> <p>“...I felt like giving him the most we could give him in that situation, giving him the consistency and giving him...compassion...” (RN3)</p> <p>“...I don’t think I was actually serving him so much as coming to provide an outlet for the nurses with the moral distress that they were feeling, and trying to show up for the medical team to help shoulder the burden...” (PPMD)</p> <p>“A lot of my work was supporting the staff and helping them maintain some perspective. A lot of people were dropping into this situation.” (SW)</p> <p>“I really wanted to partner with the rest of the team and help them take on what was clearly a distressing, burdensome process of negotiation...” (PPMD)</p> <p>“...The inconsistencies among the nursing staff who felt comfortable with certain things and who did not, and trying to help Dad understand that’s just how we are as human beings, and to have the responsibility as the nurse to keep your son safe while you are enjoying that closeness together. It’s a lot of responsibility...it isn’t just simply, oh, trach falls out; put it back in. It’s a whole big to-do, and that nurse will take ownership and will take the blame.” (RN2)</p> <p>“Mom would let go: ‘Okay, today I can’t hold him. That’s okay. I’m fine with that,’ and Dad was: ‘No, I am holding my son.’ And then trying to figure out, and trying to let them know not every nurse feels the situation is safe.” (RN2)</p>
	Assigning	<p>“We had gotten a year and a half under our belt of telling them routinely that he was going to die and he had a precarious airway...and he kept surviving...” (SW)</p> <p>“...I think there was such confusion in control: who had control, who should have control, who’s making decisions. And yet, at bedside, those were questions that weren’t answered in the hall. So if you were a bedside nurse, you had to decide then and there what you were going to do for your 8- to 12- hour shift. Yes, you had general guidelines. There was a range of things that you could do if the situation was safe. But ultimately this kid could decompensate at any moment, and what are you willing to be responsible for?” (RN2)</p> <p>“... We started to...villainize the parents, when we were just as culpable in what his course was and what our role was in communication and expectation.” (SW)</p>
	Deflecting	<p>“Eventually I signed off. I gave my best recommendation: that this was an ethical issue... and needed to go through formal mediation...That was not accepted by the team, so, given that the child was comfortable, I didn’t see another role for myself...” (PPMD)</p> <p>“...There were so many people involved, and there was a lot of fear of upsetting the family—fear of being sued, on some level—that drove people not to give clear ultimatums to the family on their decision-making. And they were savvy in delaying things.” (PPMD)</p> <p>“A lot of things leading up to that point had signaled that they were just not interested in taking him home. I think he was too complex, in their point of view, to be managed at home. Some of that was our own messaging of saying, ‘He’s too complex, he’s too complex, you can’t just take him home,’ and then all of a sudden...’He had this incident, he can go home.’” (CM)</p>

		<p>“It became an issue for nurses taking care of him: ‘Why are we continuing to do this and in lieu of...this devastated child;’ but the conflict was that this was a family who would never give up.” (IMCMD)</p> <p>“This is kind of the issue in medicine: could you, in a hopeless situation, should a hospital go against the family’s wishes and withdraw support?” (IMCMD)</p> <p>“Our hope was that in the home setting, the family, who would only see him on weekends, would now see him day after day after day after day, see what he was like, and this would begin to change their minds.” (IMCMD)</p> <p>“The docs—and I—understood the neurological devastation that was occurring, and to try to convey that to the parents was extremely challenging. They would not readily accept it, or if they did hear you, they would give other alternatives or other explanations or have many other questions pertaining to cares...” (RN1)</p> <p>“At that point it was very challenging, because trying to bring the family...The first phase, when he came in and had the different surgeries, I believe family was still hopeful of going home. Then he had the significant event...such a significant change, and they started to really distance themselves...” (RN2)</p> <p>“They never really took over the caring role, the ‘I’m going to change diapers, I’m going to take care of his trach, I’m going to do his G-tube cares’ consistently so that every time they were here, they did those cares.” (RN1)</p>
Timepoint 4	Accepting	<p>“In the fourth phase when I did interact with them [physicians], it was usually on a crisis basis and they were having to come in.” (RN2)</p> <p>“...Supporting the primaries that were in there routinely, knowing that they had a point of reference for who he was, and then helping the people that were new to his situation understand the global picture.” (SW)</p> <p>“...Dad had this idea from when he reentered his son’s life...I remember him telling me, ‘From this point on I believe I need to do everything I can for my son until he’s age five. If nothing has improved by then, I think then I’ll be able to let him go.’” (RN2)</p>
	Assigning	<p>“...All physicians were starting to call Parents to bedside when emergencies were happening. That’s how I think they chose to deal with it: so that Family would see it happen, in hopes that they would change the DNR status...They would just hear the situation over the phone...So then it was almost like it never happened. ‘Well, that’s good it happened at the hospital, because we wouldn’t be able to do it.’” (RN2)</p> <p>“I don’t know why we would give the family a choice on something that clearly isn’t a family choice...We don’t let families choose which antibiotic they want. No matter how much they like the color of the liquid...And yet we put burdens on them when they’re not able to make these decisions about things like ECMO.” (PPMD)</p> <p>“...nursing staff bore a lot of the care and process...but I think everyone’s goals were a little bit different in their investment.” (SW)</p> <p>“...I think we can influence [parental decisions to withdraw care], but invariably it falls upon them and we can blunt their sense of responsibility, but often times we don’t do that well and/or they see through it.” (ICUPULM)</p>
	Deflecting	<p>“...But a parent knowing: ‘It has been nurses 24/7 taking care of my child, all I am is Mom. I don’t have a nursing degree. How am I going to be able to do it?’ Parents have to believe that they can do it. Otherwise, they’ll sabotage that discharge planning every time. Which is what happened here.” (RN2)</p> <p>“Having to advocate for active treatment [from physicians] for a chronically ill child is like pulling teeth sometimes.” (RN2)</p> <p>“Basically, at that point [after brain death], I think [ICUPULM] sat down with them and said, ‘We as a group and we as a hospital, and with the hospital’s support, are no longer going to take care of him. We’re going to send him back to the group home, and he will have to go elsewhere for any future care.’” (IMCMD)</p> <p>“We talked about this with the nursing leadership and with nurses, and in pediatric cases, there was no precedent for this, going against a family’s wishes and withdrawing support without the family’s consent...The hospital didn’t want to cross that ground.” (IMCMD)</p> <p>“I think the extra challenge in this situation was that the family was rather disengaged with his day-to-day care, so it was hard to see him here alone, and people were kind of dictating what should happen, but not being here...caring for him, turning him, rolling him...” (CM)</p> <p>“I felt caught in the middle of a couple of different things, and I thought that, for myself, I had to sign myself off.” (CM)</p> <p>“...Never ever would [the family] agree to withdraw support, and the hospital wasn’t going to do it, nor our group. The hospital especially was not going to set the precedent of withdrawing support against the family’s wishes...it was more ‘I really don’t want to take care of him anymore.’ There was just the sadness of taking care of him, watching him with no...” (IMCMD)</p> <p>“I don’t feel like we always do a good job of advocating for the child as a person, but the families dictate how far to go.” (CM)</p> <p>“...As health providers, at some point we as a group disengaged with the child, because the person we knew no longer was...and I think that confused the situation as to how each doc wanted to handle a so-called health emergency or a change of condition.” (RN2)</p> <p>“One of the strangest things that I found through this experience is that I felt extremely isolated...they did not want to come into the child’s room, did not want to really discuss what was happening for the day. (RN2)</p>

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“They said, ‘We cannot have him at our home.’ They, in essence, wanted him to stay in the hospital, which is not a reasonable situation.” (Ethicist)  
“Dad specifically could not bring himself to withdraw. I think Mom would have done it a long time ago...” (Ethicist)  
“...There’s no way...a decision to withdraw life-sustaining treatment against the wishes of the parents would be undertaken without hospital administration.” (Ethicist)

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### Relations:

Specific moral claims on us arise from our contact or relationships with others whose interests are vulnerable to our actions and choices. We are obligated to respond to particular others when circumstances or ongoing relationship render them especially, conspicuously, or peculiarly dependent on us. (Walker, 2007, p. 113)

How we interact and how we view our relations is important to exploring moral spaces. The role of nurse or physician elicits obligations when put in context of a relationship such as to a child as patient, parent of patient, colleague, hospital, employer, and so on. While there are typical obligations such as professional codes of ethics, normative rules, and other laws and guidelines there are also obligations and feelings that can be found in particular situations given the context and circumstances. This particular space, a wholly moral one, is where we find the ethics being practiced by people. A view of naturalized ethics looks to these moral spaces to find how we construct morality in our society. By exploring the way responsibility is accepted, assigned, and/or deflected within these relationships we can see how ethics are practiced and viewed.

In this case study we can analyze these relations in how participants discussed their interactions with others through how they experienced their actions, inactions, responsibilities, and how they viewed other’s interactions. Not all persons involved in this case were able to participate or responded to participation requests. The persons that did participate, however, make up the more intimate relations around the care of this child. In the way these participants discuss how they viewed their relationships and responsibilities to the child as well as to other people involved in the case, we can

get a sense of how the moral space around this child was constructed, and how it led to an intractable conflict.

### Clinicians and Parents

As this research only was able to collect data from the clinician viewpoint, the relations with parents are viewed from the perspectives of particular clinicians. There was an overall perspective that parents were not at the bedside or present for the child's care as much as expected by the clinical staff. There were two participants, CM and SW, whose perspectives were more understanding to the larger picture of life for a family whose child is hospitalized for a lengthy period of time; an acknowledgment that parents have responsibilities to attend to. This is fitting with their roles as reported in Table 5.

...When you have a child that's acutely ill and we're telling you, 'Stay away from him. Don't touch him, that's disturbing him. That's making him sicker,' then, like any parent, if your child is taken away from you, in a sense, for several months, you start, I think, detaching as self-preservation, and maybe not knowing exactly how you fit into helping him... (CM, Table 8)

Several clinicians reported an effort to reach out to parents and assist them in being able to be present more. This suggests that there is an expectation by staff towards parents around presence at the bedside, though unwritten. This is present in the way nurses and CM described reaching out to see if parents need assistance in finding time to be present. None of the participants mentioned particular rules or specific obligations, just expectations.

This theme of expected parental obligations is interesting considering the instability the child faced in the beginning and inability of parents to perform many standard parenting tasks. However, this absence is felt during the child's recovery phase, as RN1 notes specifically that:

With him being more awake and more interactive, the presence of family was not there. The expectations as

caregivers would be to see the family a lot more frequently than we did. (Table 8).

There was clearly an expectation that became stronger during timepoint two, but it is unclear if there is a delineating point where this begins or whether there is communication about when this expectation begins or becomes an obligation on the part of the parents as perceived by the clinicians.

Another theme that emerges is that after the child's first event, timepoint three, there was an observation that the father became more involved and there were some different feelings about this from the father reestablishing responsibility or obligation to fear of the father and family viewing them as controlling. On the other hand, as reported by SW, the team had been repeatedly telling the family that the child could die from one of his many events, but this constant warning seems to have only bred distrust, from SW's perspective. It seems clear from the physicians and ethicist perspective that this family would never agree to withdraw support. There was a fear around lawsuits expressed as well. There is an interesting power dynamic happening here. On one hand the expertise and knowledge lay with hospital staff, yet the family was offered a choice between going to a center that specialized in the type of problem that this child had or having it repaired at the current institution, or withdrawal. ICUPULM questioned how clear they were on this (Table 8) but the option itself is interesting.

Table 8. Clinician and Parent Relation Themes

Clinicians and Parents	
RN1	"...Interpreting what the docs are saying to the parents and how the parents are interpreting that." "The parents were not present the majority of the time, and a lot of discussion was occurring: what should we do, how can we do it, what's best for the child?" "They would frequently call in, or they would make an appearance once a day, and I would tell them what the doctor was saying." "I reviewed what they heard and clarified any misinterpretations or anything they didn't hear correctly. I did not offer any opinions at that point." "I explain the details of past histories of patients I've dealt with and reference those, and I explain the life-altering and life-changing processes that will and can occur if certain medical interventions occur..." "The docs—and I—understood the neurological devastation that was occurring, and to try to convey that to the parents was extremely challenging. They would not readily accept it, or if they did hear you, they would give other alternatives or other explanations, or have many other questions pertaining to cares..." "With him being more awake and more interactive, the presence of family was not there. The expectations as caregivers would be to see the family a lot more frequently than we did."

- “We asked many times, ‘Are you having difficulties coming? Is your job affecting your ability to visit?’ Are his siblings interfering with that part of it? What’s preventing you from coming here, and is there anything we can do to help alleviate that?”
- “...It was more heart-wrenching not to see the family involved with him.”
- “...It was the where are we going from here, going from healthy to devastated, and now it was this devastation and I’m still caring for him, I’m still advocating for him; but the hard part was the parents’ idea of where they wanted to bring him and what their goals were, versus the medical team’s goals...”
- “Again, the more stressful part is that the parents were saying stuff but not doing anything.”
- “They never really took over the caring role, the ‘I’m going to change diapers, I’m going to take care of his trach, I’m going to do his G-tube cares’ consistently so that every time they were here, they did those cares.”
- RN2 “At that point it was very challenging, because trying to bring the family... The first phase, when he came in and had the different surgeries, I believe family was still hopeful of going home. Then he had the significant event...such a significant change, and they started to really distance themselves...”
- “And I think at some point in that phase, family decided, or Dad decided, that he wanted to do more for his son, but at that time, the child was so agitated...and was in pain.”
- “And not always was the desire of the family appropriate, for the moment, for the child, for parents wanting to hold him, and yet he was so uncomfortable and so difficult to work with that just holding him wasn’t safe.”
- “Mom would let go: ‘Okay, today I can’t hold him. That’s okay. I’m fine with that,’ and Dad was: ‘No, I am holding my son.’ And then trying to figure out, and trying to let them know not every nurse feels the situation is safe.”
- “Definitely the parents understood the risk of decannulation...”
- “...The inconsistencies among the nursing staff who felt comfortable with certain things and who did not, and trying to help Dad understand that’s just how we are as human beings, and to have the responsibility as the nurse to keep your son safe while you are enjoying that closeness together. It’s a lot of responsibility...it isn’t just simply, oh, trach falls out; put it back in. It’s a whole big to-do, and that nurse will take ownership and will take the blame.”
- “I think it was fear, and I there was such confusion in control: who had control, who should have control, who’s making decisions.”
- “I would get the to-do list from Care Management, which was fine, because it worked out well, and then I just planned and did the educating and training and answering questions.”
- “...But a parent knowing: ‘It has been nurses 24/7 taking care of my child, all I am is Mom. I don’t have a nursing degree. How am I going to be able to do it?’ Parents have to believe that they can do it. Otherwise, they’ll sabotage that discharge planning every time. Which is what happened here.”
- “...All physicians were starting to call Parents to bedside when emergencies were happening. That’s how I think they chose to deal with it: so that Family would see it happen, in hopes that they would change the DNR status... They would just hear the situation over the phone... So then it was almost like it never happened. ‘Well, that’s good it happened at the hospital, because we wouldn’t be able to do it.’
- “...Dad had this idea from when he reentered his son’s life... I remember him telling me, ‘From this point on I believe I need to do everything I can for my son until he’s age five. If nothing has improved by then, I think then I’ll be able to let him go.’”
- RN3 “There was also some fear of parents. Dad was pretty intense, so there was also some fear that if something bad happened on our watch, there would be legal ramifications...”
- “...[Parents] just didn’t come around all that often when he was younger...”
- “...There was enough of a feeling when Parents would talk to you that you should be careful what you say...it was never said by Parents, but it was just a feeling we got.”
- “It was after his neuro hit that [Parents] started coming more consistently, but it was upsetting, because he really needed them there before...He wanted to be held all the time. He needed that parent, that nurturing piece that he never got.”
- “Then Dad got really controlling...which I could understand...”
- “...Parents were really resistant to taking him to their house.”
- “[Dad] would come in and be very, very, very specific on everything that happened to him, but then he would leave...I think that...he was trying to show [the child] love, but he didn’t know how to do that. He didn’t bond initially with him...”
- “I didn’t agree with their decisions, so I think that was partly why I was fired from the room.”
- CM “...When you have a child that’s acutely ill and we’re telling you, ‘Stay away from him. Don’t touch him, that’s disturbing him. That’s making him sicker,’ then, like any parent, if your child is taken away from you, in a sense, for several months, you start, I think, detaching as self-preservation, and maybe not knowing exactly how you fit into helping him...”
- “At that point [timepoint 2], people did not think his airway was stable enough for him to discharge home. The family wasn’t even allowed to do trach changes; ENT was doing the trach changes...we were taking to the family about coming in and starting to practice learning his care so when he was ready to go, they’d be trained...”
- “[Parents] weren’t at the bedside a lot, so we were trying to encourage them to be here to start learning his cares and, even if they couldn’t do certain things, to do other aspects of his cares in order to ease the transition.”
- “A lot of things leading up to that point had signaled that they were just not interested in taking him home. I think he was too complex, in their point of view, to be managed at home. Some of that was our own messaging of saying, ‘He’s too complex, he’s too complex, you can’t just take him home,’ and then all of a sudden...’He had this incident, he can go home.’”
- SW “...The family was repeatedly told this might be the thing that tipped him over the edge and he may die as a result—but then he would recover, to a point, and then we would have another incident...So there was an up and down course for him...”
- “I think they lost trust in: ‘You told me he was going to die this time and he didn’t, and now he’s doing what he was doing before.’”

- “It became challenging to impress upon them what this meant and where we were going each time he had these setbacks...”
- “...Dad had to return to work. I mean, life goes on, and they had other kids and other responsibilities, so they had to move forward knowing there was an unknown time frame of how long he was going to need to be here. But in doing that, I think they...were unable to see what his day-to-day cares were, what those day-to-day crises could potentially be, and their engagement with the process...was hampered by that.”
- “More often than not, they saw him at his best.”
- “We had gotten a year and a half under our belt of telling them routinely that he was going to die and he had a precarious airway...and he kept surviving...”
- IMCMD “The parents did not come in very frequently. Mom was busy at school, raising two other kids, doing all her homework... That first stage was a pretty long time...”
- “...The Father’s stance was that technology would save the day, that in five years we’d be able to create a good airway for him... and we’d have figured out ways with these kinds of patients to be able to restore their brains.”
- “It became an issue for nurses taking care of him: ‘Why are we continuing to do this and in lieu of...this devastated child;’ but the conflict was that this was a family who would never give up.”
- “This is kind of the issue in medicine: could you, in a hopeless situation, should a hospital go against the family’s wishes and withdraw support?”
- “Our hope was that in the home setting, the family, who would only see him on weekends, would now see him day after day after day after day, see what he was like, and this would begin to change their minds.”
- “Basically, at that point [after brain death], I think [ICUPULM] sat down with them and said, ‘We as a group and we as a hospital, and with the hospital’s support, are no longer going to take care of him. We’re going to send him back to the group home, and he will have to go elsewhere for any future care.’”
- PPMD “...There were so many people involved, and there was a lot of fear of upsetting the family—fear of being sued, on some level—that drove people not to give clear ultimatums to the family on their decision-making. And they were savvy in delaying things.”
- “‘I don’t know why we would give the family a choice on something that clearly isn’t a family choice... We don’t let families choose which antibiotic they want. No matter how much they like the color of the liquid... And yet we put burdens on them when they’re not able to make these decisions about things like ECMO.’”
- Ethicist “They said, ‘We cannot have him at our home.’ They, in essence, wanted him to stay in the hospital, which is not a reasonable situation.”
- “Dad specifically could not bring himself to withdraw. I think Mom would have done it a long time ago...”
- ICUPULM “The ENT surgeon involved gave the family the option to take their child to an airway center...but the family chose to have it done here.”
- “How well we explained to them the difficulty with this type of procedure, I don’t know how good a job we did with that...one also could have made the admonition of we don’t do this here; you need to go to an airway center.”
- “...I think we can influence [parental decisions to withdraw care], but invariably it falls upon them and we can blunt their sense of responsibility, but often times we don’t do that well and/or they see through it.”
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### Clinician and Clinician

Interactions between clinicians is also an important context to understanding the moral and social structure of any care provided. While this research samples a very small proportion of care providers who cared for this child, the participants all played major roles in his care. The participants also had the most exposure and interaction with this child’s care and course. Therefore, they can be said to be reflective of the overall experience of their particular roles. This does not limit the contingent relations these participants bring into their relations necessary for their role. What I mean is, each participant brings their own experience, perceptions, and distinctions towards the role that they enter into as a clinician, which as a role has its own relations necessary for that role. I enter into the role of a nurse which has necessary perspectives, but I

also bring my own life experiences that are contingent into the role with me. You<sup>97</sup> cannot separate someone from their life and their role, the two experiences and identities are intertwined. This study did not seek to discover those contingent aspects of the participants lives but it must be understood that they exist, that reality cannot be researched in a vacuum with metaphysical people.

There is evidence that during the first timepoint the interactions between clinicians was typical of any child in the PICU. RN1 discusses typical responsibilities within the care team about monitoring and reported progress. RN3 discussed collaborating with ENT about the severity of the child's reliance on the trach and having to coordinate with other bedside staff to help watch the child if other responsibilities arose due to the tenuous nature of his airway. Of particular interest is RN2 who describes the later timepoints as interactions on a crisis basis which seems, as reported, due to the more chronic nature of the child. What RN2 is saying here is that due to the distress around caring for a child most clinicians thought should be allowed to die, or was now a "chronically" ill child, there was a perception of some clinicians disengaging from what would normally be more attentive care. RN2 reports feeling isolated because as the child was more severely devastated staff disengaged from the child completely to include dealing with any issues that may have arisen in his care. Getting a physician to come to the bedside to assess what RN2 thought was a change in condition was difficult and getting assistance and support from other nurses was difficult because of this level of disengagement, which was probably somewhat a protective mechanism against further moral distress.

From the allied staff and PPMD there is a sense of trying to maintain the narrative and communication between clinicians as the case became more fraught with conflict. The other physician participants did not mention interactions between other clinicians at this point but in these timepoints there was more of a sense that they were acting as

a group versus individual physicians, as the case had reached this level. There is a<sup>98</sup> sense of retreat or disengagement consistent with how RN2 describes the feeling. There are, after all, other patients that need to be seen, but for the nurse who is still caring for the child this is not as easy to walk away from, thus RN2's feeling of 'advocating as pulling teeth.' PPMD reports wanting to partner with the team but feeling unable to do so because her belief in how to proceed was rejected.

Table 9. Clinician and Clinician Relation Themes

Clinician and Clinician	
RN1	"...Keeping the docs informed of what progress he's making..."
RN2	"In the fourth phase when I did interact with them, it was usually on a crisis basis and they were having to come in." "Having to advocate for active treatment [from other clinicians] for a chronically ill child is like pulling teeth sometimes." "...As health providers, at some point we as a group disengaged with the child, because the person we knew no longer was...and I think that confused the situation as to how each doc wanted to handle a so-called health emergency or a change of condition." "One of the strangest things that I found through this experience is that I felt extremely isolated...they did not want to come into the child's room, did not want to really discuss what was happening for the day."
RN3	"I remember a lot of us were talking, like 'I don't want to be that one. I don't want to be that nurse that he decannulates on,' because [ENT] was very clear about it being a very big possibility that if we couldn't get the trach back in, it would be devastating to him." "You always felt like you had to have somebody watching him. You had to pass that off constantly... You couldn't just go in your other room and know that he'd be fine."
CM	"...Trying to encourage the bedside staff, when the family is here, to try to maximize that time, to have them start performing cares...sometimes if the family's here the nurses don't always have time..." "...When you have a child that's acutely ill and we're telling you, 'Stay away from him. Don't touch him, that's disturbing him. That's making him sicker,' then, like any parent, if your child is taken away from you, in a sense, for several months, you start, I think, detaching as self-preservation, and maybe not knowing exactly how you fit into helping him..."
SW	"...We started to...villainize the parents, when we were just as culpable in what his course was and what our role was in communication and expectation." "It was Ethics and I trying to maintain that common thread across the whole team, knowing that every seven days you had potentially a new provider, a new nursing group..."
PPMD	"...I think there was some dissent among the team about whether or not we should be very clear in giving a final deadline and time for things to move on..." "Eventually I signed off. I gave my best recommendation: that this was an ethical issue... and needed to go through formal mediation... That was not accepted by the team..." "I really wanted to partner with the rest of the team and help them take on what was clearly a distressing, burdensome process of negotiation..."
Ethicist	"... [The Intensivists] were split as a group, but unwilling to act as a group unless they were unanimous as a group."

### Clinician to Hospital

A necessary relation in this case and others like it is the relationship between clinicians and the institution itself. Of course, there is no one entity that can be said to be "the hospital" but there are interests that individual actors have in the context of

what is best for the hospital, or the intersection of a clinician's care towards the 99 patient and adherence to hospital norms and policies. Unfortunately, most of the administrators during this time have moved on. Risk management was contacted but was unable to participate. However, hospital *qua* hospital would be in a position to balance many different factors: that of the child, the staff, the parents, and the standing of the hospital and its ability to provide care to the community, which does include a legal and PR interest. Risk aversion due to PR and legal implications could be criticized but this is a real concern and one a hospital is not necessarily wrong to consider.

The nurses report the difficulties of being paired with a child who could so unexpectedly decompensate. As this child transitioned to a more chronic period, nurses often had a second child to take care of, in fitting with hospital staffing policies and norms. This meant not being in direct view of this child and therefore leading to an increased sense of fear around the inevitability of an event happening. There seems to be a sense from participants that there was an unspoken agreement around watching out for this child. Though given the workflow of others around the child, this may have been difficult at times. The norms of the staffing in PICU saw this child as "pairable," meaning his nurse could take on another patient assignment, and yet the nurse participants' reports suggest he needed constant and close supervision which suggests he was not pairable.

Ultimately the hospital appears to have been involved, from the participants perspective, once the child had an event and the conflict with parents began to emerge. From the data it seems as if the hospital attempted to find a path of least resistance. Not forcing withdrawal but allowing parents to take the child home or to a group home would at least remove the distressing conflict from the PICU and satisfy parents. This seems like an understandable path to take, after all, no one sets out to

engage in intractable conflict. The most interesting data to come out of this relationship, since there is a lack of perspectives involved, is the idea that even if the hospital supported the feelings of the medical team, the PR and legal repercussions outweighed those concerns. It is also interesting here and was reported also by IMCMD in addition to PPMD in the table below (Table 10), that since the physician group of intensivists was a private group there was concern about legal support from the hospital towards the physicians. The private physician group seems as if they would have supported unilateral withdrawal of medical treatments without parental consent if the hospital also supported that position. In this relationship, there is an acknowledgment of what was felt was the right thing to do and a concern over the repercussions of any legal challenge, whether successful or not. One can't ignore the fact that even if the hospital and private physician group prevailed in a legal battle that the PR could be more damaging considering the fact that the hospital and clinicians have restrictions on public discourse around private health data whereas the family does not.

Table 10. Clinician and Hospital Relation Themes

Clinician to Hospital	
RN1	[Question on paired with another child as nurse assignment] “Yes, because he was in stable chronic mode”
RN2	[Question on primary obligations] “Well, within the guidelines of the hospital and what their expectations are of a nurse, it would be first to the patient—ultimately, the patient, even if I have a different viewpoint...” “... Whenever I had to receive his care at 3, I would make sure there was a nursing assistant in his room at bedside so that we could have report safely, and if they couldn't be at bedside, then the day nurse and I would be gowned and gloved, ready to go in an intervene if we had to.” [On having a second patient] “... You just kind of juggled And if you could keep him happy... And as a team of nurses we would pull together. Whoever was in the neighborhood had your back. Half of the time you never even had to say anything, because everybody was always keeping track of him.”
RN3	[On caring for a second child] “... Especially if the pairing wasn't next to [child], that was sometimes really hard. I had a couple situations where I was paired, and that was really difficult, because, like I said, he could just lose his airway at any minute and then you would have to be in there. I do feel like the unit as a whole kept an extra eye on him, but that was difficult, to get a new admit with him. You always felt like you had to have somebody watching him. You had to pass that off constantly, all the time. You couldn't just go in your other room and know that he'd be fine.”
CM	“Any time a child is medically ready to go and we're getting into this kind of conflict getting him out of the hospital, we get Risk and other people involved.”
SW	“Once he passed a year, people were watching for a multitude of reasons, but once he had that event, and the conflict... I think the whole administration, everyone, was engaged in trying to understand where the family was coming from, what could we do as a hospital to continue to move this forward...”

IMCMD	“We talked about this with the nursing leadership and with nurses, and in pediatric cases, there was no precedent for this, going against a family’s wishes and withdrawing support without the family’s consent...The hospital didn’t want to cross that ground.”
PPMD	“This went all the way through the hospital to the top...and they were trying to sort out an easier way, but there really wasn’t one.” “I think they [hospital/administrators] supported the medical team in feeling that the care the family was asking for was inappropriate care. Their concern was whether or not there would be PR repercussions or legal repercussions...” “...I think an additional complication was that the physician group was a private group, not employed by the hospital, so that contributed to more concerns that the hospital wouldn’t be able to back up the physicians that had to carry this out.”
Ethicist	“...There’s no way...a decision to withdraw life-sustaining treatment against the wishes of the parents would be undertaken without hospital administration.”

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### Moral Community

A moral community was built around this child, who was a part of that community, what drove those connections, and what barriers and divisions were present that split the community emerged from the data. The lack of narrative around the initial timepoint, admission with critical illness, is telling because it may indicate routine PICU care and structured responsibilities that didn’t fall outside the norm. The data shows this shift when the child became more awake and stable and descriptions of family as not present as much as expected begin to emerge. Later in timepoint four there were attempts to call in family during emergencies to bring them into the moral community, to bear witness. These moral claims, or expected responsibilities, connect with barriers to building moral community, as CM reports around the ambiguousness of when we want families involved and in what role (Table 11). If moral claims are not connected or reciprocated, then barriers and divisions emerge.

There were many barriers and divisions in this case that prevented the construction of a moral community that included the parents, and that held together throughout the child’s hospital stay. The length of time the child was in the PICU and the uncertainty over how long he would continue to be there contributed to a division between staff and parents as it seemed to disrupt a normal process where the transition from a more critical status is met with an increase in parent involvement. In this case we can see this norm through the fracture between staff and parents around the expected presence

at the bedside without clear a clear sense of what that was or when that should 102  
happen.

Normally a child requiring more parental involvement at the bedside would be planning to go home, yet there was never any clear timeline for this child and there were ongoing procedures. The narrative from CM reports a significant insight into how this unspoken shift in responsibility plays into this barrier when you have a case with uncertain timelines and no clear demarcation for parental responsibilities re-emerge. As SW also reports, the parents began to be villainized, which is evident through the data from bedside staff as well through the narrative data that reports parents' perceived absence at the bedside (Table 11). Given the deviation of this case from more normal cases, it isn't unusual to see fractures like this because there is a normal process where parents may not be required to disengage for so long as the usual.

Further divisions in the moral community, or in building a moral community, were seen as the conflict emerged. The data shows an increasing fear around litigation coupled with the distress of caring for the child which seems to have led to a disengagement from some staff members who were able to disengage. For the primary nurses, who were still committed to the child, this disengagement was not possible. This shows up in RN2's statements about feeling isolated and earlier reports (Table 9) about the difficulty in engaging physicians and other nurses around care issues for the child. The commitment of the primary nurses is still to this child whose care they are faced with intimately, for better or worse, and this led to rifts with both parents and other providers. These primary nurses were continuing to perform the work while others decided what happened.

Another interesting finding that worked to divide the moral community is the way in which the system of staffing physicians and nurses is set up. As ICUPULM notes,

it is a system that is set up for ninety-five percent of patients and so a patient like <sup>103</sup> the one in this case where uncertainty, conflict, and longevity become an issue, the system falls apart (Table 11). This also leads into another finding within the theme of moral community, that of moral ambiguity. This ambiguity is present in the way in which decisions were proposed and made, how responsibility was deflected, and trust between the parties involved.

The ambiguity present in the data is evident through how decisions were offered and made. In a normal case, part of the ninety-five percent of patients, there is likely a typical course and treatment plan. In this case decisions were made that participants questioned. This doesn't mean that they were wrongly offered, after all the offering of options is well within normal practice. However, in this case participants report the decisions as maybe not ones that parents could really make, and maybe no *one* party really could. As ICUPULM notes, how the choice was offered may have not been sufficient (Table 11). Also evident is that many decisions around best interests for the child were discussed without parents present (Table 11). It seems that there was a lack of clarity over what to do, who should make decisions, how well those decisions were understood, and a lack of trust and/or understanding around the severity and feasibility of the effort.

A positive aspect of the moral community being built and sustained was seen in the data as accountability between nurses. Inevitably there was a more intimate connection between nursing staff and the child as they became more responsible for his development as he aged. There is also an element of the nurses being accountable to each other through the precarious nature of the child's airway and ability to decompensate rather rapidly. The data shows an unspoken agreement between nurses on the unit that everyone around the child would watch out for him, particularly when his nurse had other patients and could not have a constant eye on him. Also evident is

the grieving of nurses noted by IMCMD, where they saw his neurologic injury as a<sup>104</sup> loss of personhood and distress over what appears to be the inability to let the child go.

Table 11. Moral Community

Moral Community	
Moral Claims/ Expected Responsibility	<p>“With him being more awake and more interactive, the presence of the family was not there. The expectation as caregivers would be to see the family a lot more frequently than we did.” (RN1)</p> <p>“The hard part for me was the lack of interaction by the family...it was more heart-wrenching not to see the family involved with him.” (RN1)</p> <p>“...The more stressful part is that the parents were saying things but not doing anything... They never really took over that caring role...” (RN1)</p> <p>“...All physicians were starting to call Parents to bedside when emergencies were happening. That’s how I think they chose to deal with it: so that Family would see it happen, in hopes that they would change the DNR status... They would just hear the situation over the phone... So then it was almost like it never happened. ‘Well, that’s good it happened at the hospital, because we wouldn’t be able to do it.’” (RN2)</p>
Barriers/ Division	<p>“...Dad had to return to work. I mean, life goes on, and they had other kids and other responsibilities, so they had to move forward knowing there was an unknown time frame of how long he was going to need to be here. But in doing that, I think they... were unable to see what his day-to-day cares were, what those day-to-day crises could potentially be, and their engagement with the process... was hampered by that.” (SW)</p> <p>“More often than not, they saw him at his best.” (SW)</p> <p>“...When you have a child that’s acutely ill and we’re telling you, ‘Stay away from him. Don’t touch him, that’s disturbing him. That’s making him sicker,’ then, like any parent, if your child is taken away from you, in a sense, for several months, you start, I think, detaching as self-preservation, and maybe not knowing exactly how you fit into helping him...” (CM)</p> <p>“...We started to...villainize the parents, when we were just as culpable in what his course was and what our role was in communication and expectation.” (SW)</p> <p>“The parents did not come in very frequently. Mom was busy at school, raising two other kids, doing all her homework... That first stage was a pretty long time...” (IMCMD)</p> <p>“...There were so many people involved, and there was a lot of fear of upsetting the family—fear of being sued, on some level—that drove people not to give clear ultimatums to the family on their decision-making. And they were savvy in delaying things.” (PPMD)</p> <p>“...As health providers, at some point we as a group disengaged with the child, because the person we knew no longer was...and I think that confused the situation as to how each doc wanted to handle a so-called health emergency or a change of condition.” (RN2)</p> <p>“One of the strangest things that I found through this experience is that I felt extremely isolated... they did not want to come into the child’s room, did not want to really discuss what was happening for the day.” (RN2)</p> <p>“That’s what I mean by falling prey to a system that developed for the average length of stay in the ICU, which at the time was about three-and-a-half days. So if you’re an ICU patient and you need three-and-a-half days, you don’t need continuity. You need good care and to get out. Once you get past two weeks you need continuity and it’s not something we do well, but recognize that only about 4-5% of patients are in the ICU for greater than two weeks. You can see why this system evolved, not for the 5% but for the 95%.” (ICUPULM)</p>
Moral Ambiguity	<p>“The ENT surgeon involved gave the family the option to take their child to an airway center... but the family chose to have it done here.” (ICUPULM)</p> <p>“How well we explained to them the difficulty with this type of procedure, I don’t know how good a job we did with that...one also could have made the admonition of we don’t do this here; you need to go to an airway center.” (ICUPULM)</p> <p>“The parents were not present the majority of the time, and a lot of discussion was occurring: what should we do, how can we do it, what’s best for the child?” (RN1)</p> <p>“...The family was repeatedly told this might be the thing that tipped him over the edge and he may die as a result—but then he would recover, to a point, and then we would have another incident... So there was an up and down course for him...” (SW)</p> <p>“I think they lost trust in: ‘You told me he was going to die this time and he didn’t, and now he’s doing what he was doing before.’” (SW)</p> <p>“The docs—and I—understood the neurological devastation that was occurring, and to try to convey that to the parents was extremely challenging. They would not readily accept it, or if they did hear you, they would give other alternatives or other explanations or have many other questions pertaining to cares...” (RN1)</p>
Accountability	<p>“...We all got very close to him because his family wasn’t there that often, so we became daycare, kind of, for him...” (RN3)</p> <p>“You always felt like you had to have somebody watching him. You had to pass that off constantly... You couldn’t just go in your other room and know that he’d be fine.” (RN3)</p>

I had a couple of situations where I was paired, and that was really difficult, because, like I said, I could just lose his airway at any minute and then you would have to be in there. I do feel like the unit as a whole kept an extra eye on him, but that was difficult, to get a new admit with him. You always felt like you had to have somebody watching him. You had to pass that off constantly, all the time. You couldn't just go in your other room and know that he'd be fine. (RN3)

And as a team of nurses we would all pull together. Whoever was in the neighborhood had your back. Half of the time you never even had to say anything, because everybody was always keeping track of him. (RN2)

"It became an issue for nurses taking care of him: 'Why are we continuing to do this and in lieu of...this devastated child;' but the conflict was that this was a family who would never give up."

"This is kind of the issue in medicine: could you, in a hopeless situation, should a hospital go against the family's wishes and withdraw support?" (IMCMD)

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### Moral Hazard and Distress

The theme of moral hazard and/or moral distress came up from every participant. Moral hazard is a term that has been used to describe situations in pediatrics where decisions about risk are made by parties who will not bear any of the cost of that risk (Brunnquell & Michaelson, 2016). In healthcare, and particularly pediatrics, this can be seen by either parents or providers making decisions about the care of a child while the burdens will be felt by the child and/or caregivers, whether those caregivers be nurses, therapists, aides, or even the parents themselves. Moral hazard is not arguably only related to parental decisions as decision-making processes often involve more than one party. This concept came up as a theme from all participants in many ways. Some participants felt like parents were making decisions that were not within the child's interests, and the physicians were going along with it. Others reported barriers to decisions from the hospital influence legal and public image risk aversion. Moral hazard may or may not be a precursor to moral distress, but the two concepts are very related, particularly in this context.

Moral distress was initially described by Andrew Jameton who wrote about stories from nurses who were distressed by situations where they felt they knew what the right thing to do was but felt constrained from doing it (Jameton, 2013, 2017). This feeling of being constrained in nursing often coincides with an obligation to perform cares that are felt to be painful, noxious, or non-beneficial on their patients (Austin, Kelecevic, Goble, & Mekechuk, 2009; Austin, Lemermeyer, Goldberg, Bergum, &

Johnson, 2005; Meade, Pope, Weise, Prince, & Friebert, 2012). In analyzing the data<sup>106</sup> collected for this research, themes of moral distress were identified either by participant report of their own feeling or observation of other staff member feelings.

After the child's first hypoxic ischemic event, all the participants spoke with understanding that there was some part of him left and while they would recommend withdrawal their distress seemed stronger after the second event. This seems to be due to the increased level of injury and a loss of any distinguishable interaction from the child. As the RN's and CM report below (Table 12), there is some sense that after his first neurologic injury he had some comfort or ability to perceive contrasted with his second injury which they perceived that he had no conception of the world. The decrease in personhood perceived seems to increase the distress felt by the participants.

Table 12. Moral Hazard and Distress Themes

Moral Hazard and Distress	
RN1	<p>"I was sad. I immediately thought which nurse did it happen to and how are they dealing with it, knowing that his airway was so fragile. I experienced that many times, where he'd pull his trach out and literally within 10 seconds he'd pass out. I'd put the trach back in and he was right back up playing again. And I knew it would only take mere seconds before something catastrophic could happen, and hearing that it did happen...Shocking, but definitely not surprising."</p> <p>"It was frustrating, knowing what I saw prior to the incident, to see what I was dealing with after that..."</p> <p>"I was caring for a shell, his body. I was not doing any nurturing of him, I was not stimulating his brain."</p> <p>"...It was the where are we going from here, going from healthy to devastated, and now it was this devastation and I'm still caring for him, I'm still advocating for him; but the hard part was the parents' idea of where they wanted to bring him and what their goals were, versus the medical team's goals..."</p> <p>"In this situation, he was dead. That was my thought, knowing where we were, what we were doing, and knowing [him]."</p>
RN2	<p>"...I think there was such confusion in control: who had control, who should have control, who's making decisions. And yet, at bedside, those were questions that weren't answered in the hall. So if you were a bedside nurse, you had to decide then and there what you were going to do for your 8- to 12- hour shift. Yes, you had general guidelines. There was a range of things that you could do if the situation was safe. But ultimately this kid could decompensate at any moment, and what are you willing to be responsible for?"</p>
RN3	<p>"...If you don't have to do anything to him medically ever again and you can just leave him here in this body, you can maybe find some way to give him comfort. But the fact that we had to keep dilating his airway and keep doing things to him to keep his body here, for me that was too hard...It was hard to watch."</p> <p>"Just because he would never get better. He would never be back in any better...better is such a subjective word. Nothing could ever be done that would give him comfort, I guess. Not knowing what he was feeling was probably the most heart-wrenching part, what he was experiencing, if anything."</p> <p>"I remember a lot of us were talking, like 'I don't want to be that one. I don't want to be that nurse that he decannulates on,' because [ENT] was very clear about it being a very big possibility that if we couldn't get the trach back in, it would be devastating to him."</p> <p>"You always felt like you had to have somebody watching him. You had to pass that off constantly...You couldn't just go in your other [patient] room and know that he'd be fine."</p> <p>"I still felt like the care we were giving him was providing him some, even futile...I mean, it was definitely futile, everything that we were doing, but we didn't really have a choice at that point, because we weren't able to make the decision to leave him, let him go."</p>

CM	<p>“After his first event, in-hospital, the nurses could perceive him enjoying certain things. After the second I don't think he moved at all. I know a lot of people caring for him just felt like they were caring for a body. I think the extra challenge in this situation was that the family was rather disengaged with his day-to-day care, so it was hard to see him here alone, and people were kind of dictating what should happen, but not being here, maybe every day. But it was futile.”</p> <p>“I felt caught in the middle of a couple of different things, and I thought that, for myself, I had to sign myself off.”</p> <p>“I think the extra challenge in this situation was that the family was rather disengaged with his day-to-day care, so it was hard to see him here alone, and people were kind of dictating what should happen, but not being here...caring for him, turning him, rolling him...”</p> <p>“I don't feel like we always do a good job of advocating for the child as a person, but the families dictate how far to go.”</p>
SW	<p>“We recommend withdrawal. But the family still maintained, ‘You maintain his care, and you maintain efforts to resolve his airway, and, hey, I've found a bunch of trials about how to fix brains from a hypoxic ischemic event,’ so it was a tennis match...”</p> <p>“...nursing staff bore a lot of the care and process...but I think everyone's goals were a little bit different in their investment.”</p> <p>“...I think it was challenging to get a handle on him to feel confident that he was going to sustain on your shift, and maintain stability...knowing that he had this potential to go sideways pretty quickly.”</p>
Ethicist	<p>“Sad. Just hard for everybody—including the parents. It was miserable for them, too. And for him.”</p> <p>“There was a real concern that this case was going to end up in a malpractice suit...administration, they did not, in this particular case, want to take on the questions of overriding the parents...”</p> <p>“...I think many of them [intensivists] felt that it was an okay thing to do, but there were a few of the intensivists among the more senior members who felt that one should never override a parent's express wish.”</p>
IMCMD	<p>“...Never ever would [the family] agree to withdraw support, and the hospital wasn't going to do it, nor our group. The hospital especially was not going to set the precedent of withdrawing support against the family's wishes...it was more ‘I really don't want to take care of him anymore.’ There was just the sadness of taking care of him, watching him with no...”</p> <p>“But there was significant sadness with having to take care of him, and anger.”</p> <p>“It was very difficult for the nurses to take care of him, but then the goal was that now that he had a stable airway, we could get him out of the hospital and into his home setting.”</p>
PPMD	<p>“...I don't think I was actually serving him so much as coming to provide an outlet for the nurses with the moral distress that they were feeling, and trying to show up for the medical team to help shoulder the burden of what I thought was really difficult for them, and that was to do the right thing.”</p>
ICUPULM	<p>“This is every ICU nurse's, therapist's and to some extent physicians, worst nightmare, coming to work and extending an expertise that doesn't have an outcome.”</p> <p>“For me, there was probably not single case with greater moral distress than this case that I know of.”</p> <p>“I remember thanking people and recognizing with them [bedside staff] how difficult this was. I felt badly for them.”</p>

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### Inevitability

There is some sense that the outcome faced in the end of this child's care was so likely that it was almost inevitable. This feeling reported by participants, whatever the term used to describe it, begs some important questions for the ways in which clinicians know or feel this and what this knowledge or feeling may mean for discussions around decision-making or care. It can certainly be said that any child in a hospital is there because they are ill and require professional nursing care around the clock, and thus are sick enough that decompensation is always a possibility. However, in this case the description of this feeling by the participants was so rich and strong

that it clearly shows that the whole unit was hypervigilant about this possibility that it was almost always at an incipient point.

This theme had different contexts but mostly to describe the expectation or likelihood that an event would happen. Only one participant, PPMD, did not appear to discuss this. This participant was involved after the first neurologic insult and wasn't involved during the first two timepoints. Since the majority of the feelings of inevitability were felt during the first timepoints it is not surprising that PPMD did not express any feelings on this, in addition to the fact that the role doesn't necessarily involve emergent response, as does the RN's and other physicians. One other participant, ICUPULM, did not express the likelihood of an event happening as probable or as unique to this child as other participants did.

During the child's second timepoint where he was active and moving there seemed to have been more possibilities for the tracheotomy tube to come out. This was seen in the reports around balancing the care of a developing child and the security of his medical devices. It is not surprising that the RN's reported more feelings of inevitability and fear around the tracheotomy tube then because they held ultimate direct responsibility to the child's constant disposition.

Table 13. Inevitability Themes

Inevitability	
RN1	<p>“As a primary, I knew there was a strong potential of that happening, and unfortunately it did.”</p> <p>“I think we were very honest about what was going on and the life and death tightrope we were walking. It was very obvious.”</p> <p>“Some days were nice, quiet, and boring; others, it was frequent near-death experiences.”</p>
RN2	<p>“But ultimately this kid could decompensate at any moment, and what are you willing to be responsible for? And everybody interprets that differently. I think it depends upon your years of experience...[t]here are just so many variables.”</p> <p>“I think you knew it could happen, and it possibly would happen, but it never had a negative outcome after. You would just deal with the situation. I think that's what was so shocking with all of it: that that time, that was the time it just all fell apart, and he became a very different person from that point on.”</p>
RN3	<p>“...[ENT] was very clear about it being a very big possibility that if we couldn't get the trach back in, it would be devastating to him.”</p> <p>“...He could lose his airway at any minute...”</p> <p>“You always felt like you had to have somebody watching him. You had to pass that off constantly...You couldn't just go in your other [patient] room and know that he'd be fine.”</p> <p>“It [first neurologic insult] was heartbreaking. But we all knew it was possible.”</p> <p>“In the back of your mind you always prep for that day, knowing that this could possibly happen...I think somehow we all felt like we were superhuman, that we could keep him alive and it wouldn't happen to him,</p>

just like our own kids, like where that can never happen. But in the back of our minds, we that was possible.” 109

- CM “With any trach. With the nature of his airway, I think he was probably at a slightly higher risk than other kids...But yeah, it’s a risk to be decannulated, accidentally unplugged.”
- SW “I think there was a global perspective that he would at some point succumb to his multiple medical complexities...”  
“Without repair to what I understand to be a very unique airway, there was no way he was getting out of the hospital, and the possibility for a crisis, and a life-ending crisis, was really quite, I wouldn’t say inevitable, but it wasn’t out of the realm of any possibility.”  
“...I think it was challenging to get a handle on him to feel confident that he was going to sustain on your shift, and maintain stability...knowing that he had this potential to go sideways pretty quickly.”
- Ethicist “...both of those things can be true: that, given the complexity of his care, it is likely that he’s going to have an event, and one of the things that may contribute or lead to an irreversible event can be a failure of monitoring...We knew that he was having these events, but in the complex system we have, that’s part of why it becomes inevitable, or gives the feeling that it’s inevitable. The system is so complex, how long can you maintain all of this?”
- IMCMD “His issue with his airway was always pretty tenuous.”  
“It was a very, very narrow airway, probably the smallest one that we had seen that was surviving.”  
“[His trachea] was always getting really narrow, and needed multiple, almost weekly, dilations, so we never could get to the point of having an airway that was safe enough for him to go home...[he] would decannulate fairly frequently. He was an active little kid, and when he would decannulate, it was not uncommon for him to desaturate quickly...he never, ever got to the point...where his airway was safe enough to go home.”
- ICUPULM “Any child with a trach, an event is a possibility. I have no doubt that we made that clear, but that we had confidence. We expressed confidence that it would be unlikely.”  
“...Trach ventilated children can be in a very safe environment and still have singular events that can be devastating.”
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## Futility

The conceptualization of futility by the participants was one of the few structured questions asked in the interviews. The question was asked in two forms: what do you think of the concept of futility and how was it relevant in this particular case? These questions were asked in different ways and in different times in each interview to avoid leading. The majority of participants took a qualitative view of futility, noting that the child had very little quality of life. Participants also related a view of futility as the limited possibility that their clinical work would achieve particular desired goals. One participant (PPMD) considered futility under the nomenclature of “non-beneficial and/or potentially harmful.” This participant was the only one to use this different formulation or rejection of the concept of futility in this context. Another participant (ICUPULM) discussed two different viewpoints of futility, of which I will call the organ view and the personhood view. In this viewpoint when a treatment is reduced to what it can do to a particular organ it may not be futile but if expanded to

the whole of the person can very much be futile in regard to the benefit to a person's overall being. This will be explored further in the discussion section.

The nurses all reported a practice-oriented view of futility. Whereas RN1 seems to report looking at the feasibility of what had to be done for the child, RN2 and RN3 reported futility around the actual nursing work being successful and gaining a quality of life that they found suitable. CM and SW reported a more personhood-view of futility around quality of life and the ability to engage with the environment. Though Ethicist reports a more nuanced view of futility, there is an element of it related to the amount of interaction and perception a person has. Below, (Table 14), Ethicist reports that it may not have been a case of futility because at that point the child could still experience things. This seems to indicate that, even if value-laden, there is something about interaction with the environment that connects with feelings of futility.

Table 14. Conceptualization of Futility

Conceptualization of Futility	
RN1	<p>"It [reconstruction of the trachea] seemed futile, from the extent that the ENT was explaining what had to be done to manipulate an airway that was pretty much nonexistent, or incapable of life." "Not worth pursuing." "...going down the road we're going to go down, we're not going to get anything positive. Nothing good is going to come out of it."</p> <p>"...Knowing what he was before to knowing where he is now, and knowing that what I saw and what I was taking care of was not recoverable, and that that was going to be his life."</p>
RN2	<p>"...As I was doing all this busyness and aromatherapy and baths and range-of-motion that looked senseless to my co-workers and others. I just wanted him to be able to go, and he never went. So is that futile? Yeah, that's probably how I would say it was futile. My interventions and my motivation just did not work."</p>
RN3	<p>"After his second hit, there was nothing. He would just have this twitching, and sometimes nothing at all. I just didn't feel like there was anything in there, and if there was something in there, it was painful to him, or like futility: no matter what we did, we would never get him to have any quality of life. No matter what."</p>
CM	<p>"I think it's a good term. I think there are definitely cases where that is an appropriate term, especially in regard to this particular case after his second out-of-hospital [arrest]. It felt really hopeless and that we weren't going to do anything to improve his state, and, to me, to keep him alive felt sad and wrong. Futile."</p> <p>"I think at that point he couldn't even control his temperature. He wasn't moving, he wasn't interacting."</p> <p>"After his first event, in-hospital, the nurses could perceive him enjoying certain things. After the second, I don't think he moved at all. I know a lot of people caring for him just felt like they were caring for a body. I think the extra challenge in this situation was that the family was rather disengaged with his day-to-day care, so it was hard to see him here alone, and people were kind of dictating what should happen, but not being here, maybe every day. But it was futile."</p>
SW	<p>"We were left with fairly reflexive systems that were life-sustaining, but his quality of life and his ability to engage with his environment were gone...from our perspective."</p>
Ethicist	<p>"Futility is complicated because futility does, in the end, have a value element to it...Could we keep his heart going with the technology we had? Yes. Barely, but yes, so it wasn't physiologically futile to do what we were doing. So, you could ask, was it qualitatively futile, in that he can't recover? But to me, this isn't an issue just of futility, because up until some point along the way, he clearly still</p>

experienced things. Once he had the event and was essentially brain dead, that event at that point probably takes that away, because I don't think his brain was functioning well enough to have that. But there was a period of time where he was still suffering, so that's a little bit different than futility, because you're actively imposing a negative state on a person, as opposed to not being able to achieve a positive state."

IMCMD

"So you have a child who is irreversibly injured, irreversibly in a situation where they have no or extremely minimal interaction, and you go long enough that it's apparent that this is not going to change, and then those situations become futile, for a meaningful life."

PPMD

"I don't think we can use 'futility,' because what we're talking about is a ventilator. Did it ventilate the lungs? Yes. But I don't think it was beneficial to this patient as a whole, because it didn't improve his quality of life, it didn't improve his ability to interact with or know his family, it didn't improve the likelihood that he would have neurologic recovery -- which was his family's hope but medically was not true. So, in this sense, yes, I think it was under the category of harmful and nonbeneficial..."

ICUPULM

"So on the one hand, yes, a ventilator isn't a futile endeavor if you're trying to keep the person alive. If you're seeking neuro recovery and development it is very futile; it will not do that. It can't reverse that problem."

"And this [second neuro insult] was a more futile situation than we'd had before."

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### Bearing Witness

A theme of "bearing witness" as described by William Cody, was found in the reports from the nurse participants and SW (Cody & Milton, 2001). Bearing witness invokes a sense of moral obligation through experience and presence (Cody & Milton, 2001). This was found in reports from most participants around the perceived lack of presence at the bedside by parents. This was evident in many nursing progress notes as well as reported in these interviews by participants. There were also reports from participants that seemed to elicit a strong sense of presence during the child's acute episodes. As RN2 reports below (Table 15) there was an attempt to call family to the bedside to witness the child's many emergencies with the hope that by witnessing the practice of rescuing the child would bring them into the same moral space as the clinicians. RN2 goes on to report that by the time parents arrived, the issue was resolved, and the child appeared fine. This indicates that there is a distress or something the needs to be witnessed, or participated in, to grasp what the moral community is seeing and feeling, or at least that the community believes one ought to see even if it doesn't change their minds. There is also a sense, from SW, that given the longevity of the hospitalization this was an expected, albeit unfortunate, reality

where parents have to choose between bearing witness to this child or being present in the family outside the PICU.

Table 15. Bearing Witness

Bearing Witness	
RN1	<p>“With him being more awake and more interactive, the presence of the family was not there. The expectation as caregivers would be to see the family a lot more frequently than we did.”</p> <p>“The hard part for me was the lack of interaction by the family...it was more heart-wrenching not to see the family involved with him.”</p> <p>“...The more stressful part is that the parents were saying things but not doing anything...They never really took over that caring role...”</p>
RN2	<p>“...All physicians were starting to call Parents to bedside when emergencies were happening. That’s how I think they chose to deal with it: so that Family would see it happen, in hopes that they would change the DNR status...They would just hear the situation over the phone...So then it was almost like it never happened. ‘Well, that’s good it happened at the hospital, because we wouldn’t be able to do it.’”</p>
RN3	<p>“...We all got very close to him because his family wasn’t there that often, so we became daycare, kind of, for him...”</p>
SW	<p>“...Dad had to return to work. I mean, life goes on, and they had other kids and other responsibilities, so they had to move forward knowing there was an unknown time frame of how long he was going to need to be here. But in doing that, I think they...were unable to see what his day-to-day cares were, what those day-to-day crises could potentially be, and their engagement with the process...was hampered by that.”</p> <p>“More often than not, they saw him at his best.”</p>

### Artifacts:

There were several artifacts referenced by the participants. Artifacts are man-made objects that seem to hold cultural or historical interest.<sup>7</sup> I would extend this conceptualization to include a political, social, and ethical dimension attached to certain artifacts such as the ventilator, as was found in the results. These artifacts are important to exploring how ethical problems are constructed and negotiated. In the preliminary literature review, the ventilator was found to be a major factor in cases of futility and neurologic devastation, and a focal point of argument around life and death.

### Ventilator

The mechanical ventilator is a significant artifact in this case, and as found in the data from the preliminary literature review, becomes a central point of dispute around futility within the context of neurological devastations. In cases where terminal illness is the central factor the ventilator is a part of the dispute around an array of aggressive

<sup>7</sup> Merriem-Webster’s Dictionary

treatments. Initially developed to maintain respiratory function during surgeries in the 1970's, the ventilator has become a standard, and arguably, defining object of intensive care units (Kaufman, 2015, p. 129). In this particular case, the ventilator became a focal point after the child's first hypoxic event with discussions around withdrawal of the treatment, and even more so after his second event and subsequent brain death testing. After the brain death testing and his subsequent breaths, the discussion became on what the random breaths meant for the overall picture as the ventilator was the object keeping the child's body alive.

Discussions of discharge for this child did not occur until after one of his events led to neurologic injury and thus some airway stability. Although he was still receiving interventions to his airway there was a shift towards transitioning out of the hospital. At this point the ventilator seems to become a 'routine' object for clinical staff. The physician group, as reported by IMCMD and ICUPULM, has a relatively large trach/vent population living at home (Table 16). However, CM relates the magnitude of what it means to care for a vent-dependent child at home, just in terms of the in-person monitoring that needs to happen (Table 16). RN2 notes the complexity around just simply moving the child into the father's arms (Table 16). CM also notes the contrast around the routinization for the staff and the expectations of parents. It is worth noting, as brought up by ICUPULM, that the state in this case has very little to no transitional facilities for children with ventilator dependency and thus it is either the PICU or home, with the exception of a few group homes. This has to do with the state's Olmstead plan and how they have implemented this part of the Americans with Disabilities Act (ADA). This was also brought up by CM along with other contributing factors affecting the disposition of vent-dependent children.

There appears to be less distress around the child's dependence on the mechanical ventilator after his first significant event. This seems partly due to the moderate nature

of devastation as described by RN3 who relates that at this point he continued to have 114  
some reactions and possible comfort as opposed to after the brain death determination  
where "...he was being ventilated on the ventilator... (Table 16)." This may relate to  
the spectrum of value judgements around quality of life where moderate devastation  
and vent dependence may be not ideal to clinical staff, but severe devastation is not  
consistent with their views around quality of life. It could also be a part of the way the  
interaction of the child aids in construction of his personhood.

Clinical staff talk about the ventilator as a machine that is keeping the child alive  
as opposed to a part of the child after his severe devastation. This distinction is  
important, again, because it signifies how the clinical staff view the moral status of  
the child and ventilator. "It was just the ventilator giving a breath (RN1, Table 16)."  
The ventilator is giving the breath, the child is not taking a breath. There is a  
distinction here between how much support the ventilator is giving as it relates to the  
status of the child-as-child versus child-as-patient. This separation of action between  
the child or the ventilator breathing signifies a relationship in understanding how  
these clinicians viewed the status of this child. By noting that the ventilator was doing  
the action of breathing without any reference of action by the child, the staff is noting  
the extent to which they see the ventilator as not benefiting the child. This may hold  
logically if we contrast a child with complete neurologic devastation against a child  
who is ventilator-dependent and interactive.

A final finding around the artifact of the ventilator is the special status it seems to  
hold in society, or at least in healthcare, as reported by PPMD and ICUPULM (Table  
16). PPMD suggests there is something different, whether morally, emotionally, or  
clinically, about the removal of a ventilator versus other LST. More research would  
be required to determine where this feeling comes from but given the literature review  
and volumes of discussion in medical ethics, the ventilator does seem to trigger some

complexity as opposed to other interventions. ICUPULM also notes this feeling 115 whether it's about sustaining breathing or feelings of agency in the connection between living and dying as there is more of a direct action-reaction between shutting off a ventilator compared to not doing dialysis.

Table 16. Mechanical Ventilator

	Ventilator
RN1	"It was just the ventilator giving a breath."
RN2	"Technically, weight-wise, one person could have lifted him, one person manage his circuit to his trach and vent..."
RN3	"...By the time he got to us, they thought he was brain dead; but he was being ventilated on the ventilator..."
CM	"That's why we require somebody to be awake for a ventilated patient 24 hours a day and hooked up to monitors." "You're trached and vented. You need somebody awake with you 24 hours a day. That means you require X amount of help in the home because no one, of course, can be awake for 24 hours." "...I feel like sending a child with a trach and a vent has become so routine that we just expect it to happen and the family to get on board."
SW	"...He would now need the trach and the vent permanently, that he would need significant cares for the rest of his life, and that wasn't going away now."
Ethicist	"The second exam was done and also showed brain death. But after that, there was a little bit of a blip on the ventilator he was still on."
IMCMD	"...He basically was trach-dependent, vent-dependent." "Our goals were to, hopefully, stabilize his airway early and see how low we could get down on the ventilator or off the ventilator..." "He always needed the ventilator. He didn't breathe enough to make it." "...We take care of a lot of trach/vent patients and get them home."
PPMD	"...If you've got multisystem organ failure and the kidneys go next, people easily will get behind and stand together and say no dialysis. Or no ECMO. But for whatever reason, stopping a ventilator is not the same thing." "And yet people will offer ventilation, even long-term mechanical ventilation, and they feel obligated if anyone requests it."
ICUPULM	"If the plan includes removing the ventilator, it's being done on behalf of the child. But for many people, removing the ventilator is viewed as sort of actively killing the child and parents have said that...So there's an emotional piece with the ventilator that is different from other life-sustaining maneuvers...dialysis is not less life-sustaining, but there's something different about sustaining breathing, as opposed to a metabolic function, even though both are critically necessary for survival."

### Tracheostomy

The tracheostomy and tube were central to this case. The results from this research show that the child's tracheotomy was a central object of his survival, the focus of his surgical treatment, and a sense of fear amongst bedside caregivers. Though CM discussed children with a trach and vent as becoming seemingly routine, there is acknowledgement of the planning and education involved in a child going home with those needs from ICUPULM (Table 17). However, as ICUPULM discusses this, all of

the requirements for a child to go home with a trach seem very routine but with an<sup>16</sup> interesting distinction towards focus on physiologic versus psychosocial safety as well as casual reference to the fact that, despite all efforts, there is still a possibility of a devastating singular event. This seems to beg the question of how this is discussed, perceived, and/or understood by parents. At one point it has become routine to clinicians but for a family it is life-changing as well as frightening as the threat of a devastating event is much more of a possibility than a child without a trach. There is a sense here of what Barbara Koenig calls 'routinization' of biomedical technology (Koenig, 1988, p. 469). This social process habitualizes the implementation, use, and practice of a technology or procedure and, I believe, creates a dichotomous space between clinicians and parents due to the difference in the knowledge of caring for a child with a trach.

There was also a sense that there was a very quick shift from where the child was too fragile to allow parents to do many cares due to the trach and his airway, and then there to focusing on home care teaching from the clinical staff (CM, Table 17). This child's trach became a very important focal artifact in this case as it was the key to his continued survival as well as the thing, or absence of, that led to his devastation. From the nursing staff the tracheotomy tube was seen as evoking fear due to its connection to the child's fragility and the difficulty of getting it back in if it came out, which it did routinely. RN2 notes the feeling of responsibility attached to the ability to reinsert the trach (Table 17). All three bedside nurses noted the link between life and death in the securement of the tracheotomy tube, yet other staff discussed it merely as an object that factually existed in a technical sense with less emotion of feelings of fear and responsibility around its proper placement (Table 17).

Tracheotomy	
RN1	<p>"I'd experienced that many times, where he'd pull his trach out and literally within ten seconds he'd pass out. I'd put the trach back in and he was right back up playing again. And I knew it would only take mere seconds before something catastrophic could happen."</p> <p>"Usually you can take a trach out and the kid can maintain life for quite a while, but with his, it definitely maintained an airway opening and he relied heavily on that trach."</p>
RN2	"Because it isn't just simply, oh, trach falls out; put it back in. It's a whole big to-do, and that nurse will take ownership and will take the blame."
RN3	<p>"...A very big possibility that if we couldn't get the trach back in, it would be devastating to him."</p> <p>"He [the child] was pretty protective of his trach, instinctually, probably."</p>
CM	<p>"...I feel like sending a child with a trach and a vent has become so routine that we just expect it to happen and the family to get on board."</p> <p>"At that point, people did not think his airway was stable enough for him to discharge to home. The family wasn't even allowed to do the trach changes; ENT was doing the trach changes."</p>
SW	"...Even if he'd still need the trach: like, can we fix and sustain the stability in that airway?"
Ethicist	"...It did stabilize so that we weren't taking him to the OR every five days. But there were all kinds of issues around the trach and the length of the trach and what was happening at the place where the trach met the main stem bronchus."
IMCMD	<p>"He would get his airway looked at very frequently, and he could decannulate fairly frequently, but it was never an issue."</p> <p>Besides having the critical airway...he basically was trach-dependent, vent-dependent, and feeding [gastric tube] dependent."</p>
ICUPULM	<p>"Once this got into the land of tracheostomy, there's education, interventions, technical skills that have to be mastered by the family, home care arrangements have to be made, and there has to be a collective decision that the patient is safe enough to go home. I'm talking safe from a physiologic point of view, not a psychosocial point of view."</p> <p>"Sending children home with a tracheostomy requires that the child not be having airway-related events for at least a month...the environment that they are sent into has people skilled in monitoring and caring for a tracheostomy, too."</p> <p>"...We would not send someone home who we did not feel had a stable airway or an environment in which just a routine tracheostomy could not be cared for."</p> <p>"...Trach ventilated children can be in a very safe environment and still have singular events that can be devastating."</p>

### Policies:

Several internal and external policies were discussed and used in this case. Internal policies were unique to the institution while external policies were from either state, federal, or private agency. None of the institutional policies will be included in order to maintain privacy for the institution, participants, child and family.

### "Futility" Policy

This policy has been renamed several times since the "ATS statement" recommended changing from futility to inappropriate, non-beneficial, and potentially harmful (Bosslet et al., 2015). In reviewing the policy versions over the years, it has essentially retained the core of its deliberative process that holds with similar policies around the nation. While this policy was in place during this case, discussion of it by

the participants was varied. Only one bedside participant, RN1, reported remembering it being mentioned (Table 18). Other participants discussed it in context of decision-making and the difficulties around using it in terms of legality and publicity.

Table 18. Futility Policy

Futility Policy	
RN1	“I remember hearing stories about it, but I don’t remember it ever taking place.”
SW	<p>“...I don’t remember if we actually enacted the futility policy or not. There was a lot of conversation that we could move in that direction even during the first injury, but I don’t know that there was a hospital-supported, administration-supported direction that we could take that stance.”</p> <p>“...From my perspective...I’ve seen the futility policy used rarely, and I think often it’s the result of perception. So if we force families to withdraw, regardless of how steadfast we were in our recommendation and expertise in what we anticipated the recovery to be, if the news got hold of a construed story, that would be challenging to overcome, know that we couldn’t clarify it.”</p> <p>“No one...wants to be that hospital, that lands on a front page that says: ‘You killed my kid. You made me withdraw...’”</p>
Ethicist	<p>“I don’t know that we ever did [use the policy]. I think what happened was that the policy was at least temporarily suspended from being in place because Risk Management and Legal were nervous about it.”</p> <p>“It had been used I think three or four times previously.”</p> <p>“...There were concerns about the policy and where [the hospital] was in relationship to the rest of the community around this. That policy was originally called a futility policy, and it was changed specifically to treatments that were nonbeneficial, harmful...”</p> <p>“Because we went with this policy, we went through multiple iterations with the intensivists about this. They were split as a group, but unwilling to act as a group unless they were unanimous as a group...many of them felt that it was an okay thing to do, but there were a few...who felt that one should never override a parent’s express wish.”</p> <p>“There was real concern that this case was going to end up in a malpractice suit, so within the hospital...they did not, in this particular case, want to take on the question of overriding the parents...”</p>
IMCMD	<p>“You’re obligated [to provide care] until there is a futility policy...that legally is seen throughout this country.”</p> <p>“As a group, we had a couple of other cases...where we discussed this, whether we wanted to do this [override parents] and be the first to do it.”</p> <p>“...When we were looking at a hospital futility process, we took it to judges in [State] and asked them.”</p>
PPMD	<p>“I think there has to be a place for us to be able to bring our expertise to the table, and in these gridlock situations there needs to be some mechanism to proceed with that. I thought we had that with the ethics policy, but if we’re unable to get the administration and the physicians to follow it, it’s pretty tough to carry out.”</p> <p>“It’s hard to know whether it works or doesn’t, because I think the issue comes with whether or not you actually use it...I think there are so many fears about using it that it gets stopped before it even gets started...I feel that as an institution we need to have a solid policy that everyone stands behind and will enact...”</p>
ICUPULM	<p>“...We tried to invoke the hospital futility policy, a policy that has never been fully invoked at this institution, a policy that gives the provider the opportunity to stop care, regardless of the family’s wishes. But we have never invoked that policy, primarily for medical-legal reasons. It’s a policy that has not been tested legally in the courts. There are no cases that give us guidance, whether one can do this and be free of criminal or litigious repercussions. There’s just no case law, so we’re stuck with a policy that we are very reluctant to use.”</p> <p>“If you don’t have the support of the family to allow a child to die, there are potential criminal ramifications of that, though that has never been tested. One doesn’t necessarily want to be contributing to case law as the first one...the group came to the conclusion that unless the hospital, with the full force of its legal department, agree and sought us to stop doing what we were doing, we were not going to do it, and we never received that support from the legal component of the hospital.”</p> <p>“It’s a policy without a population. It probably will never happen here because legally one can’t find support for it.”</p>

### Brain Death Determination

The policy of brain death determination was used and referenced in this case by participants. The institutions policy follows the state law which recognizes brain

death through the Uniform Determination of Death Act (UDDA) in conjunction with accepted medical standards. There was no dispute over the testing itself and in fact there is a discharge note from the physician following the second brain death examination. However, sometime after his declaration of death, the child seemed to initiate a breath on the ventilator. From participant interviews and chart notes this appears to be an unfortunate situation to an already complicated case.

I was there when they did the examinations and found him to be brain dead, and in our policy it says that we can allow up to 48 hours for family to gather and say goodbye between the brain death declaration and removing the ventilator...Father took that as 'I get 48 hours to the dot,' and I think somewhere in that time he had an agonal breath that was irregular, on average, once an hour. (PPMD)

The policy from this institution does indeed allow 48 hours, if needed, to gather family. Considering many events that lead to brain death in children are unexpected, and this institution serves a vast regional geographic area, it is a likely possibility that sometimes a child may be declared brain dead before all family is able to practice whatever parting rituals they may desire. This policy, while not widely mentioned by participants, is playing a considerable part in current social and legal debates in the US currently, and particularly around children.

### Conclusion

The results of this research report the social structure around a particular case that led to intractable conflict. The participant narratives reconstruct a part of the moral space around the care of a child that led to complex conceptions of responsibility, decision-making, fear, distress, and conflict. Reconstructing the intimate work and relations around and throughout a case aids in understanding how morality is perceived and negotiated. Analyzing cases like this at its conclusion by applying principles ignores many of the interactions and relations that construct morality and work to building towards conflict.

The results of this study, through participant narratives, begin to show how we can better investigate the morality existing within complex relationships, responsibilities, and interactions; the moral community. Instead of looking at this case as a problem of futility, this study results construct the many complexities that work together to get to the point of where futility is felt, or in this case how it is felt, by whom, and how it changes. In addition to reporting roles, responsibilities, and relations, many themes were found in the results such as moral hazard and moral distress, inevitability, bearing witness, and conceptualizations of futility. In addition, participants reported how they viewed, conceived, and interpreted policies and artifacts that heavily influenced this case.

## Chapter 6: Critical Analysis

*Solve et coagula*  
(Separate and join together)

The question “what must exist for this to happen?” undergirds this research and provides the impetus for unique method of investigation into ethical dilemmas. Basically, it asks what things (people, objects, concepts, etc.) exist within and during a particular case that leads to intractable conflict. This question is derived from critical realism which believes in a stratified reality between the real world we cannot see, the empirical one, and the actual one that is socially constructed; there is a tension that exists and is acknowledged through its critical method (Easton, 2010). The stratified reality is a main tenet of critical realism, that the world exists independently of our knowledge of it, or how we explain it; what is going on behind the scenes.

Critical realism looks to examine what structures and entities exist in forming the area of study and identification of causality, tendency, and generative mechanisms that are natural or social that work, sometimes unknowingly, to produce certain outcomes (Schiller, 2015). What are the pieces, how do they function both inherently and in particular, and how they work together as a whole? These questions will guide critical analysis of the social structural system.

In the study of a case of intractable conflict in pediatric critical care there were several things that must be present which were also found in the precursory literature review. Parent-provider disagreement of course must exist by definition of an intractable conflict in this context, but as the preliminary literature review noted, this may be the precursor to labeling something as futile. Futility requires that something being done has no usefulness. If there is agreement between providers and parents, providers and providers, or parent and parent, then there is no conflict. This can either

mean all parties are in agreement on what is being done or proposed, the proposed<sup>122</sup> action is within normal standards and thus not being questioned, or there are silent parties who may disagree but feel they cannot speak up. Futility is thus socially created by the lack of agreement around something being done or requested and there is no evidence that it violates any clear laws or standards that would rule it illegal or objectively unethical; it exists within a zone of some uncertainty.

Intractable conflict has been studied through systems theories such as a dynamical systems approach (Coleman, Vallacher, Nowak, & Bui-Wrzosinska, 2007). Healthcare, and particularly intractable conflict in healthcare, fits the definition of a complex adaptive system (Schneider & Somers, 2006). Recognizing health care as a complex adaptive system may provide a better lens to address difficult problems (Plsek & Greenhalgh, 2001).

The critical lens will be used to question the assumptions present in the case that make up the major nodal points, such as decisional power, decision-making, and the complex differentials that exist within this case. Through explication by a systems theory model, I will then critically examine aspects that seem to exist to work to contribute to or cause intractable conflict in a case within the context of pediatric critical care.

This chapter will incorporate the results of a case examination of intractable conflict and synthesize the information with a systems theory strategy designed to tackle “wicked problems” (Cabrera & Cabrera, 2015). The DSRP model was developed by systems thinker Derek Cabrera and provides a tool for framing complex interactions among human and non-human elements (Cabrera & Colosi, 2008). The DSRP model provides a way of thinking about complex issues through using four simple rules:

Distinctions Rule: Any idea or thing that can be distinguished from the other ideas or things it is with;

Systems Rule: Any idea or thing can be split into parts or lumped into a whole;

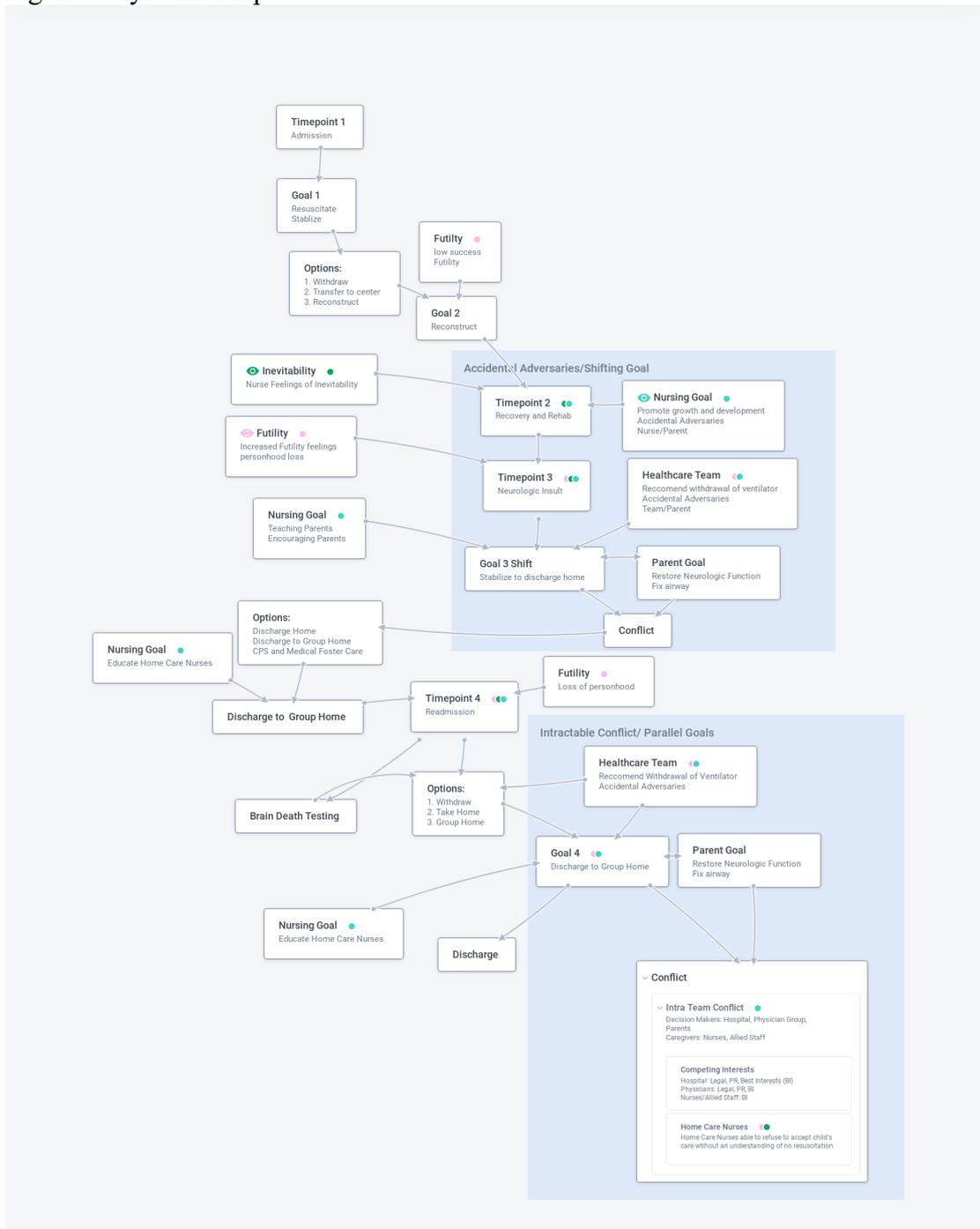
Relationships Rule: Any idea or thing can relate to other things or ideas;

Perspectives Rule: Any thing [sic] or idea can be the point or the view of a perspective (Cabrera & Cabrera, 2015, p. 45).

I will use the DSRP model to input the results from the data analysis, critically analyze and output principals that seem to have causal power or importance to the workings of the structure around an ethical conflict. How we make distinctions, split things into parts or lump them together, connect things and ideas, and how we view things are important considerations to think about thinking and examining complexity (Cabrera & Cabrera, 2015).

This merging of critical realism and systems theory has already been discussed (Mingers, 2014). I would add that an addition of feminist ethics through the lens of Walker adds a needed social and ethical construction that is necessary to examine how people are navigating their roles and responsibilities. This eclectic amalgam of critical realism, systems theory, and feminist ethics provides a novel method for analyzing clinical and organizational ethical issues in the future. Prior to synthesis through the DSRP model, I will review a systems map of the case.

Figure 3. Systems Map



Shifting Goals/Accidental Adversaries

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### Systems Process

And there could be arguments made for that 5% because they actually take up 60-70% of the ICU days. So think about that. 5% of the patients take up 60-+% of ICU days. One could say don't look at the patient

number; look at the days when you're evolving this system. The problem with a system that focuses on continuity, it would be irrelevant for 95% of the patients. (ICUPULM)

It's an inadequate system and everyone who works in it knows it. As long as things are going well, that deficiency isn't fully exposed. As soon as something breaks or there's unintended harm or preventable harm, emotional distress, the system really falters. (ICUPULM)

There are many different systems archetypes (Senge et al., 1994). This particular case fits two but also embodies a complexity that seems to create a new archetype, which I am calling the success/failure nebulous. In this archetype, which embodies the archetypes of shifting goals and accidental adversaries, there is an initial agreement on a path forward, a goal or decision. However, since success and failure are not, or cannot be, clearly articulated the path leads towards parallel goals in the context of a complicated and competing power structure with no clear absolute or unilateral decision-maker. Figure 3 shows how this particular case flows down to intractable conflict.

Once it was clear what the cause of the child's critical illness was, the parents were presented with three options. Reconstruction at the current institution was chosen by the parents, there was a process initiated towards this goal, which was reconstruction of the airway. This is where the first perspective of futility is reported in that what needed to be done seemed so unlikely to be successful that it was viewed as futile (RN1). However, at this point, there was a common shared goal.

Once timepoint two began, there were feelings of inevitability around the child's propensity to decompensate so rapidly and the tenuous nature of his airway. Also seen at this time, as the child began to become more interactive, was a goal described by nursing in the perceived absence of parents at the bedside to support growth and development. This created an adversarial relationship between parents and nurses, as

nurse participants seemed to carry some animosity around this. PICU nurses are not typically best situated, both on a practical skill level and an organizationally supported level, to tend to a growing and developing child. This was evident in the participant reports around taking on an additional assignment in addition to this child.

Timepoint three marked a reported loss of the child's personhood, from what his level of interaction previously was. This loss or reduction from previous level of personhood is also reported by the nursing and allied participants as invoking how they conceptualize futility. At this point the treatment goals for this child shifted. This point marks where clinical staff thought it was best to withdraw medical interventions, such as the ventilator, from the child. Parents disagreed and desired to continue to fix the child's airway. At this point his level of devastation was in a grey zone where it would be reasonable to allow the child to pass by removing the ventilator or allow parents to take the child home.

Nurses at this point, already adversarial with parents, looked towards educating parents to take the child home. As the parents refused to allow death, they were presented with three options: take the child home or to group home, or CPS would be contacted to place the child in medical foster care. The parents refused to take the child home. The child would then discharge to a group home and nurses switched to educating home care nurses.

Timepoint four began with this child's readmission following cardiac arrest. Following the child's brain death testing and reversal of the death declaration, the conflict escalated to another level. At this point participants note their feelings that there was nothing of this child's personhood left. This timepoint brings some of the more complicated conflict around parallel and incompatible goals between clinicians and parents, competing interests between clinicians, hospital, and parents.

From this archetype (Figure 3) we can start to see the way goals shifted towards<sup>127</sup> parallel goals that reinforced adversarial relations and fed back into further conflict. After the initial event (timepoint 3), parental goals emerged that were different from the medical goals. The parental goals remained constant while the medical team goals seemed to shift to try to reach some mutually agreeable pathway, but instead became parallel. Nursing goals seemed to adapt to the overall situation while feelings of inevitability and futility emerged and continued to help reinforce conflict. As more parties became involved there was not only conflict between clinicians and parents but within the team and hospital.

Below I will go through each agent within this case explicating their distinctions, systems, relationships, and perspectives. Above each section is a rudimentary representation of the agent's distinction and relationships that make up the system they exist within. The DSRP rules are then further explored in the text from each perspective.

### The Child

{child/patient ↔ not adult/not autonomous

↔ dependent on ↔ family/clinicians ↔ PICU ↔ state}

Presented above is the system with its relations and distinctions around the child. While we cannot analyze the child's views we can speak generally about the status of a child. The child, both particularly and in general, can be distinguished in several ways. The child is distinct from an adult as not autonomous (at least in most younger ages). In this way we are defining children as without self-direction, without the ability to choose, to protect itself, to survive on its own, and that has a necessary dependency and vulnerability (Garrett, 2018). There is a need to protect the child's open future as some would call it, to protect the future autonomy (Feinberg,

1980). What is not distinguished is to whom that dependency is toward though it 128 would seem that on a larger level children belong to us all (Lantos, 2017).

The child invokes a necessary dependency toward and responsibility of the parent. The child also invokes a responsibility, and sometimes then dependency, on the state, healthcare providers, social service providers, teachers, etc. The child is distinct from (most) adults in that there are many more adults that have a responsibility for the child. This may be mostly from the parents but teachers, nurses, physicians, social workers, etc., also have a responsibility toward the child that they do not necessarily have towards an adult. Heimer & Staffen write about the social organization of responsibility in the hospital and home (1999). These authors make a distinction that while the hospital is responsible for the child as a patient, the parents are responsible for the child (Heimer & Staffen, 1998, p. 149). However, the boundaries between child and patient are not clear. There is a higher threshold for state intervention and this makes the boundary between child and citizen much clearer as the state also respects parental autonomy.

Table 19. Nature of Obligations

Participants	Child's** Relationship	Nature of Obligation
Family	Child**	Particularistic Direct Long-term Broad scope
Hospital/PICU**	Patient	Universalistic Direct Short-term Limited scope
State	Young citizen	Universalistic Indirect Long-term Limited Scope

\*Adopted from (Heimer & Staffen, 1998, p. 138). \*\*Child was changed from Infant, and NICU was changed to PICU.

*Parens patriae*, Latin, roughly meaning ‘parent of the nation’ holds that the ‘state’ has a decisional power for a child as a ‘disinterested protector’ that has a universal, or broad interest, in a child as a citizen over the parents’ particular interest (Heimer & Staffen, 1998, p. 151). In this conception, the state is essentially a backstop if the

parents cannot or are not able to properly perform their role. It is the basis for legal<sup>129</sup> intervention against negligent or abusive parents or guardians often guided by a standard of best interests or protection from harm for the child (Bester, 2018; Diekema, 2004). Within healthcare, there is a concept of ‘mandated reporter’ as a role held by nurses, physicians, and social workers. This holds that if there is a suspicion of abuse or neglect towards a child that comes into their care there is a mandate that holds them responsible to report it to the appropriate state agency and/or law enforcement. This distinction shows that the child is both the responsibility of the parent but also of other figures in society, and society itself. This can create, and did in this case, a dynamic tension between and within the family and healthcare/society.

The distinction between child and patient for the clinician seems more complicated and less clear. For the nurses, this child was seen as child-as-patient *and* child-as-child. The child makes up one aspect of a larger system along with parents, siblings, extended family, teachers, caregivers, neighbors, and so on. Within the realm of a critically ill child, the three main parts of this network are the family, hospital staff members, and various representatives of the state, whether active or not (Heimer & Staffen, 1998). In this particular case we see that some of the participants noted the longevity with which the child was on the unit and the connection this led to. In looking at Heimer & Staffen’s conception of the social structure within the NICU (Table 19), there are some obligations that may have become skewed in this case (1998).

Participants reported that there was a sense of responsibility felt towards his development in addition to his critical care needs which during some timepoints were minimal, which indicates a shifting of obligations that the child was eliciting by his status. The child made up a part of the community in the unit, the connection that was shared if only by the knowledge that the nurses would collectively listen for his

alarms and intervene if his tracheotomy tube came out. The relationship of the child to the nursing staff was that of protectee/protector, nurtured/nurturer, the child connected the unit. The perspective of the clinical staff saw the child as their responsibility and since he was stuck in the PICU, they felt responsible not just to him as a patient but as a child.

The child was also a part of a family system, even if this may have shifted due to the length of his hospitalization. For parents, as life goes on and responsibilities outside the PICU need attention, there is a necessary separation. When a child is in the PICU months and years, what parent can come every day when there are other children, households, work, etc., to attend to? However, this child was also part of the family system, even if not present he was still dependent on parents. There is also an element of the child as a part of society as the state has an interest in the children within it.

### The Parents

{parent ↔ not patient ↔ family ↔ responsible for ↔ child ↔ patient ↔ dependent upon ↔ clinicians ↔ PICU/hospital}

Parents can be said to have ultimate decisional authority for their child. In this distinction, however, they are not healthcare professionals, or at least not the professionals in the current role towards their child. It is certainly true that some parents are also healthcare professionals. The conception of parents is to choose for their child, to protect future rights, and have the child's best interests in mind. Parents enter into a hospital setting and become a part of a complex system with many parts that also have a role with a perspective towards the child as the central connector of this system. This is the impetus for the connection of many different systems: family to hospital team, nursing team to medical team, etc. So, parents merge their structure

with that of the hospital structure. There is an implicit expectation that agreement will happen. When it doesn't, the two systems find conflict.

It is not the case here that parents did not have the child's interests in mind, it's that they had differing or competing interests. The parental perspective towards the child differed from the clinician perspective. (It could also be the case that clinicians could disagree). The parental perspective could view, as the healthcare staff did, that technology failed to achieve an outcome that is desirable. Parents could also perceive that technology had gotten the child this far, and it was said he would die before, and he didn't, and the child still has breath, is still living. In this view parents could continue to see their role as making the decision to maintain their child's life. The child is a part of their family, they are the parents, they make the choices for their child, the hospital and its technology saved the child, kept him going, and can therefore solve this problem as well.

Parents enter into a complex system in the hospital comprised of different roles and responsibilities working together. Parents develop their role from the interaction they experience with the hospital, they become a "parent of a sick child" (Heimer & Staffen, 1998). This new role seeks definition through interaction with social structure engaged with in the particular unit of the hospital. Care for their child is given over to staff and the parent's responsibilities are then delegated from clinical staff. In this case we do not know the specific parental view but can suppose that there were complicated interactions.

In this case, something that emerged from the data was a sense that there was an unclear demarcation where parents were expected to be more involved in day to day care. However, given the longevity of the child's critical illness and fragility there was a seemingly prolonged period where parents couldn't do anything, couldn't practice their role as parent. The only way they could be a parent was to return to

work and thus maintain health insurance and financial stability for their ill child and<sup>132</sup> their other children. Even when the child was more awake and interactive there was a sense by participants that while they would have expected parents to be more present there was some unpredictability and fear with the child's airway. If experienced PICU nurses felt fear around the airway what must parents have felt? After all, a parent is not a PICU nurse, they require education on their now chronically ill child, for which they are dependent on the PICU nurses for. The parents are no longer the experts on their child, and initially there was a goal to not go home with a tracheotomy tube, so should parents even begin to learn about the airway?

In this case it appears that parents became a more distant relation and part of the system. One can surmise that there could well be some resentment from parents when clinicians came to them and told them what they should decide now once the child had a neurologic injury. Even if withdrawal of the ventilator and the allowance of death was the right thing to do, there may be a parental perspective that viewed the hospital structure as taking over parental responsibilities. Likely there was a disconnect between the relations in the hospital and the parents and this led to two different perspectives and distinctions, and an experience that was not shared between the hospital staff and the parents. So instead of a connected set of relations between and among clinicians and parents there were two systems, the clinicians and the parents. Within the data there was many comments around the perceived absence of parents at the bedside which may indicate a breakdown of what would be considered the normal presence and involvement yet there doesn't seem to have been or to be a clearly articulated description of scope and responsibility of a parent with an ill child.

### The Nurses

{nurse ↔ not parent ↔ responsible for ↔ patient ↔ works in ↔ PICU ↔ within ↔  
hospital ↔ state}

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Within the context of critical care, the nurses saw the child as one who is critically ill. The nurse is not the parent but takes over much care of the child given the severity of the illness. This of course began to change when the child recovered from some of his critical instability towards a child who was not in need of total control of his care. Nursing care in the PICU is not normally a place where growth and development are fostered. However, as the child's airway was tenuous enough to require staying in the PICU, the child existed, for the nurses, in this grey area. It is no surprise then, that there were feelings of fear and inevitability as the sole reason for the child's requirement to stay in the PICU was his potential to decompensate so rapidly.

Nursing staff saw this child as one who both did and did not need to be in the PICU, didn't need critical care nursing but also did. Nursing staff were caring for him essentially to prevent a catastrophic event that they felt was inevitable given their capabilities and the child's anatomy. This may present an originating point of moral hazard as the relationship of nursing to physician staff and parents begins to show signs of adversarial undertones. Through nursing staff's feelings of inevitability, we see a sense that they felt they could not prevent what they were being asked to, at least not forever.

Physicians, by requiring the child to stay in the PICU due to his airway, were viewing the nurses as the treatment and thus the cure for the risk of decompensation. So, for nursing staff, the care of this child was essentially a time bomb waiting to explode on some unsuspecting, or unlucky, nurse. The repercussions of which were that the burden of failure was felt on that particular nurse. This sentiment from nursing staff never appears to have been an integral part of the social structure or conversation between physicians and parents. Thus, the decisions around this were made between parents and physicians with the moral risk existing at the bedside among nursing, intensivist, and other caregivers on shift when an event happened.

Once an event leading to devastation happened, and the hospital, that as any 134 hospital, who is inherently risk averse, begins attempting to look for a deficiency that led to the adverse event, a reason why this happened. However, if nursing had been more powered within the conversations prior there would have been a voice to this inevitability, maybe. While there was this feeling of inevitability by the nurse participants, and even an acknowledgement by other participants, this didn't seem to stimulate conversations around possibility or what failure looks like, or what would happen if it did occur.

Once the child had his first neurologic injury nurses still viewed him as having some semblance of himself, though not the child he was previously. There was still a fear around his airway but there was a less of a sense of inevitability, or at least a worry about it. This is likely because the outcome that nurses' thought was inevitable had come to fruition. Now decisions would be made about what to do next, which would not involve them explicitly. This is where the concept of bearing witness really comes through. Nurse participants report witnessing the child's distress and further episodes and by the time parents came to the bedside the child was calm. There was also some sense of bearing witness from RN2 towards physicians during the later timepoints. RN2 reports some inconsistency between physicians on how involved they would be with medical issues. Some physicians would be more dismissive. This may be a sense that while nurses couldn't change their level of involvement, physicians seemed to be disengaging.

### The Allied Staff

{SW/CM/Ethicist ↔ coordinates with ↔ PICU team, parents, hospital ↔ responsibility to ↔ patient, parent, PICU team ↔ works within ↔ PICU ↔ hospital}

Allied staff saw themselves wholly in a coordination lens. SW, CM, and Ethicist all reported some aspect of tending towards the structure of relationships between

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clinicians, child, and the family. This was evident through their reports of tending to the social structure around the child. SW as a social worker is less responsible to the child than to the family, at least in this case. In the PICU, generally, social work is directed towards families as the child is typically young and critically ill. CM as care manager is responsible for discharge planning around care needs. Ethicist has a more complicated distinction due to a presence that is predicated on the belief or report of ethical concerns by some party involved, whether parent or clinician. Ethicist role is not necessarily responsible to any party, outside of the child, and is instead more tied to resolution or some best outcome; managing the situation or dilemma.

CM reports a role as primarily responsible to the child through coordinating, planning, and forecasting. CM's responsibility requires discussion with parents to help establish what the child will need after discharge. CM's distinction here is that the child has needs and the parents will require support in obtaining training and equipment to meet these needs. CM follows every child through insurance reviews and discharge planning. The perspective for CM is towards discharge. CM reports working with family, staff, and outside services to set up appropriate and needed care after discharge, as well as setting up care conferences. From CM's personal perspective, there is some disconnect between parental involvement at the bedside, as well as discrepancies between messaging to the family around the child's complexity and ability to discharge.

SW reported providing support and assistance in navigating resources for the family as a responsibility. SW also was communicating within and between the team and family. SW also reported keeping the common story among different caregivers. Support was also given to the staff as well as parents. This responsibility was quite substantial and along with Ethicist seemed to be the primary connection between all the parties involved. SW seemed to be the most consistent person in this case which is

interesting because SW is arguably the only role that doesn't have a direct relationship to the child in this situation. 136

Ethicist had the most complex responsibility and relationships through having to understand the perspectives of all parties involved. Ethicist also reported circles of responsibilities from the child to the hospital. Ethicist reported the responsibilities of being the mediator, analyzer of perspectives and situation, and managing the situation.

### The Physicians

{physician ↔ not parent ↔ responsible to ↔ patient ↔ family ↔ PICU ↔ group ↔ hospital}

Physician participants had several distinctions evident in the results. While only a few key physicians were interviewed for this study they were integral to the child's case. Two of the physician participants were primary physicians of the child distinct from the third physician who was a consultant. ICUPULM did also have a consultant role during the case as well. In this distinction between primary and consultant there is an important relationship. A primary

There was an interesting difference in the number of role codes between PPMD and the RN's and the two other physicians. This could indicate the limits of our role conceptions around the work done by nurses and pain and palliative care practitioners. For instance, we know what "nurse" is, we know what "physician" is but when we look at PPMD's codes, or the RN's codes there are more because there are narratives that describe responsibilities that don't fall under our normative conceptions of what it is to practice as a nurse or physician. This limitation in our conceptions may indicate or reflect what kinds of practices are promoted and valued, especially within an interventional-bases health system. The fact that the role codes of PPMD and the RN's more personal and intimate in nature and are not necessarily a part of the

normative conception of these roles, could indicate that these practices exist in a 137 space that is not visible, not recognized as important, and/or not a normally highlighted aspect of general good healthcare.

Walker, and other feminist philosophers, would certainly note that the role codes of PPMD and the RN's would be considered more caring practices, more historically female roles, and therefore do not fit well within the scientific view of allopathic medicine for which American healthcare is dominated (Lindemann, Verkerk, & Walker, 2008; Walker, 2007). Since this is a case study it is limited in its ability to generalize. Whether an expanded role code set is symbolic of a more gendered and complex set of responsibilities or a result of the way we conceptualize the roles of physician and nurse would need to be answered by further studies. What is interesting is that both of these explanations could be true. We may better conceptualize more male-oriented roles and therefore have a better understanding of what a "physician" does and this results in less role codes and/or more caring or female-gendered roles are more difficult to define under the umbrella of one concept such as "nurse" as compared with the conceptualization of "physician." Of note, it is interesting that the pain and palliative care physician shared similar amounts of role codes as the nurses did. Pain and palliative care has been said to be originating from a more nursing-oriented theory.

### The Hospital

{hospital ↔ responsible to patients ↔ dependent on ↔ clinicians ↔ responsible to  
↔ parents ↔ community ↔ board}

While I was unable to interview anyone that makes up the hospital, the hospital itself has some situated distinctions. Certainly it is true that a place like a hospital cannot be described by the persons who compose it. By interviewing administrators and risk managers we cannot obtain a sense of the hospital but since these persons

drive the decisions that the hospital took, we could certainly get a sense of the concerns from that perspective. From the other participants there were reports of the decisions involved leaders in the hospital took and this seems to be related to the risk of legal and PR repercussions. 138

### The Social Structure

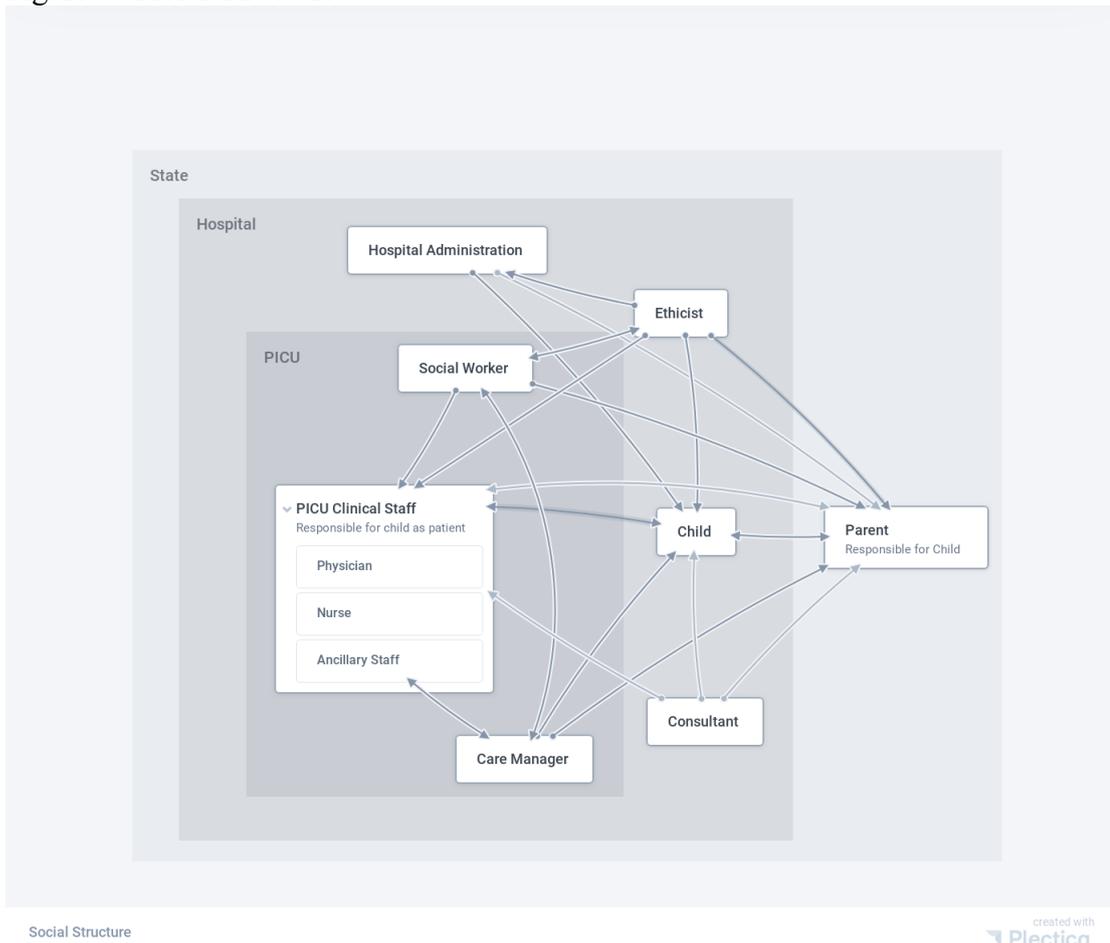
{State {Parent ↔ {Child ↔ Clinical Staff ↔ SW ↔ CM} PICU} ↔ Consultant ↔  
Ethicist ↔ Administration} Hospital} State}

The relations that make up this social structure are clearly complex. Below, (Figure 4) the figure shows the complex relations and domains. The arrows show a directional relationship, either one or two-way. The PICU clinical staff have a relationship through responsibility towards the child-as-patient who has a dependent relationship on the PICU clinical staff. The parents have a relationship through responsibility to the child who is dependent upon the parents, who have decisional power over the child. The parents and the PICU clinical staff have a bi-directional relationship as they form a necessary relationship. This necessary relationship is connected through aggregate interests that can be in agreement or disagreement. The child is both dependent upon the clinicians and parents, to the clinicians as patient and parents as child. This duality seems to be central node that can lead to either agreement or disagreement, and is likely a source of many ethical conflicts in pediatrics.

Social workers and care managers, in this case, exist within the social area of the PICU and work as the link between the network of parent and clinical staff. Social worker has a direct relationship with clinical staff and parents, while holding a bi-directional relationship with care manager and ethicist. The social worker appears to act, as the results noted, as a sort of keeper and manager of the social structure by

tending to the clinical staff and parents, working with care manager and ethicist. Care manager, for their part, has a bi-directional relationship with the clinical staff as they work together on understanding what cares will be needed for the child and what education is needed for the parents or home care nurses. Care manager notes an obligation to the patient as a guiding motivation, this could be due to their background as a nurse. A bi-directional relationship with social worker is seen as they worked together, with different foci, to manage the social structure of clinical staff and parent. Ethicist has mostly one directional relationship as duties towards, with the exception of social worker. Ethicist is the link to the larger hospital picture and relationship.

Consultant, through reports from PPMD and ICUPULM, holds a duty to the child, parents, and clinical staff, but this is not bi-directional as the role of consultant is to advise as reported by PPMD. Consultant, like Ethicist, is a part of the hospital structure that exists outside of but embodies the PICU. Hospital administration has an ultimate obligation to the child and parents both as individuals and as part of a larger community. The parents exist within the realm of the state, where the child moves in and out of. Once the child is in the hospital, that child becomes an obligation of the hospital and staff through its dependency. The state has an interest in the child, the parents, and the hospital.



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### Shifting Goals and Accidental Adversaries: The failure/success nebulous

We discussed [child]'s condition, and that the [Hospital]'s team recommendation to the family has been to move to a comfort cares only/hospice plan of care certainly after his most recent arrest but also over the past year, but that the family has requested continued treatment. (Ethics note)

The main causal themes that emerged from analyzing the social structure is the subtle shifting of goals, emergence of adversarial relations, and the lack of defining failure. As the central node to the social structure appears to be the duality of the child existing as child-as-patient and child-as-child, this seems to be the point of departure from a unified goal to shifting and parallel goals, accidental adversaries, and ambiguity around success and failure.

Initial goals at the time of admission were inherent of any critical care admission<sup>141</sup> to resuscitate and stabilize. After this, however, there was a point at which the belief in the goals seemed to fracture. The offering of three options seems to be a point at which there was some varying conceptions of how achievable this child's stability would be. Within the data there is little mention around discussing the options between going to a specialty airway center and doing the surgeries at the current institution. One would think that given the choice to remain in the institution currently in that is not a specialty airway center would indicate that success would be less likely. The option to withdraw being offered would also indicate there was some view that success was uncertain and/or risky. RN1 notes that success felt like a very unlikely chance. It seems there was a sense from the clinical participants, though not explicitly noted, that failure to them meant death or severe devastation. This comes forward in participant report after the first neurological devastation. However, from the chart review data and participant data failure as death or devastation does not seem to have been discussed with parents at the juncture of the initial options.

From this initial agreed upon goal towards airway reconstruction and stabilization, the participants described the progression from critical to a more stable rehab focus while the child still maintained a critical status due to his tenuous airway and increasing activity related to his age and development. Normally, once a child is in more of a rehab phase of care they would be out of the PICU and not requiring lots of cords and monitors, which allows the child to play and be active. However, due to this child's risk of death being so high he remained in the PICU hooked up to monitors.

Timepoint two appears to be the beginning of shifting goals from nursing where parents, who had not had a role in his care due to his critical status, were not as present at the bedside and the nurses began to have an expanded case load which didn't seem to allow them constant one-on-one time with the child. As the surgical

goal remained towards reconstruction and stabilization and the medical goal remained towards stability and maintenance, the nursing goal shifted or expanded to include promoting development, something for which the PICU is not typically geared towards. Inevitably then, there seems to have been some notice, as reported by participants, that parents were not present during this time as would be expected. This may have led to some adversarial beginnings between nurses and parents as the fear of the tracheotomy tube coming out increased and this distress found an outlet towards viewing the parents as absent; the structure was fracturing.

At timepoint three the goals seem to have shifted after the neurological injury became evident. At this point there was a recommendation from the healthcare team that withdrawal of the ventilator and allowing the child to die was the most appropriate goal. As parents rejected this plan, the goal then was to recover as much function as possible, address any new symptoms or issues, ensure that the airway was stable and discharge home. Since the child was no longer as active his airway was more stable. This goal was different than the original because the focus was less on reconstruction and more on stabilization. However, considering how tenuous the child had been throughout his hospitalization, and the many near-death experiences, parents did not feel comfortable taking him home. This seems to be a point where, while the goals shifted, the rest of the healthcare team became accidental adversaries along with the nursing staff.

The goals I think shifted, at least temporarily, to try to help the family recognize how injured this child was. Again, we were working off of just partial brainstem function. By neural imaging, the child was what we call neocortically dead. That is the cerebrum or thinking areas of the brain were infarcted; they were gone. So we had someone who was neocortically dead and not expected to develop any improvement in those things that contribute to personhood, sense of presence, interaction, responsiveness. In that setting we were hoping to move the family to a non-resuscitation mode,

At timepoint three and four there seems to have been co-existing or parallel goals. The clinical staff maintained the goals they thought in the best interests for the child-as-patient and child-as-child, while the parents had goals in the best interests of the child-as-child. While the child was now more devastated as explained in the narrative report above, the goals remained the same with the exception of secondary provider goals trying to help the parents understand the futility that staff saw. This brings up questions around the complicated power dynamic and differentials within pediatric decision-making in critical cases such as this.

#### Power Differentials and Decision-Making

I feel like sometimes we put families in unfair positions where like, 'We can do this, or you can go palliative, or we can go full throttle,' and I think there are some families who literally know the right choice isn't to go full throttle, but...They can't be the ones to say it. (CM)

We often think of power differentials as who holds the power of choice over another. In this case it is easy to see the parents as having more power in the ability to choose, but this would neglect to consider the complete picture of how power is distributed as seen through how practices of responsibility were assigned and deflected in the previous chapter.

The medical team holds the knowledge of what can and could be done. The parent then hears these choices and is expected to decide despite having less understanding about the downstream realities of each choice. For example, the choice of going to a specialized center seems to indicate that the child had something unique that has led to, in the past, the creation of a center that specializes in the issue. It seems odd then that a third choice between withdrawing or transferring was offered. It may certainly be reasonable for parents to decide to stay in the current state and let the surgeon

attempt reconstruction knowing that you are not at a specialized center. However,<sup>144</sup> a family with other children and lives in the current area may feel competing interests and therefore feel obligated to remain and try to reconstruct not at the specialized center, but this then begs the question of how much this decision is understood. This may be where the issue of undefined failure may have emerged, in that parents may have had an idea of success, the medical team may have had an idea of success and what failure could look like without this failure being made explicit with parents. This shifts power, unknowingly, to the medical team whereby they grasp the gravity of the choice and parents are making the choice ignorant of this perspective. Parents, in this way, are making the choice out of what is best for the family, understanding that there exists a successful situation but not a failed one, thus making it difficult to define failure later on. This power differential in choice is seen later as well with the issue of withdrawing support.

There are more important nuances present in these shifting obligations and power. On one hand parents are delegating care over to staff because their expertise is needed but whenever there is a decision to be made the obligation and power shift to the parents, even if there is a consensus between clinical staff about a particular path. In addition, it may be the case that parents are being obligated through clinician's deflection of responsibility to the parents even while they know what the best decision for the child is. It could be said, and certainly is true, that these are the ethical and legal norms in US healthcare, that parents are the ones assigned the responsibility to make these decisions. However, this doesn't mean parents should be making these decisions in a vacuum. Clinicians are present to assist parents in making decisions but the complexity of some decisions, as in this case, seem so complicated that it is reasonable to question how responsibility is apportioned between parents and clinicians. Some decisions may be said to be completely reasonable for parents to

make unilaterally while others should be made unilaterally by physicians; sometimes<sup>145</sup>  
by the absence of giving a choice.

...In our society parents drive that decision, and we can influence that decision. We can influence that decision I think in positive ways, but it takes a fair amount of experience with listening. It takes probably more than anything else, an appreciation for time; these decisions aren't made overnight. People have to arrive at them and if there are two parents they both have to arrive at a similar decision and, invariably, one person is at a different place than the other. (ICUPULM)

While we are always concerned about keeping families abreast of their options, expecting parents to make a choice for which they have limited knowledge may be as irresponsible as unilateral decisions are often viewed. This would be an issue of deflecting responsibility then by clinicians knowing the right path but putting the choice on the parents; whether this is a legal constraint or clinician obligation. That being said, clinical staff are doing this because it is the norm, expected, and in keeping with social and legal practice. As ICUPULM notes: "...invariably it falls upon them [parents] and we can blunt their sense of responsibility, but often times we don't do that well and/or they see through it..." The attempt to blunt responsibility suggests that as a clinician, ICUPULM knows there is a problem with how responsibility is distributed for these decisions, a sense that putting these choices on parents is an undue burden or at least, that we don't do a good enough job thoroughly explaining the options, again, from the clinician perspective. This brings forward complexities around a child's interests, who is best to decide them, and the ethics around risk aversion in the face of ethical conflicts.

#### Best Interests/Competing Interests and the Ethics of Risk Aversion

I often tend to think of it more as aggregate interests: let's look at all of them compared to each other. That's, in a sense, a reformulation of 'best interests', to get away from that comparative element of good, better, best. The

shorthand way of talking about it in society is: what is in the best interests of the child? But what we're really asking is: what is in the best overall aggregate interests of the child? That's, I think, what we're actually talking about. Once he's essentially brain dead, what interests does he have? There are certainly people that argue that once you're brain dead, or even once you're in a PVS, you have no direct interests. (Ethicist)

While evoking themes of accidental adversaries, there is a complicated discussion and realization of best interests and harms in pediatric decision-making that has significant relevance in bioethics and emerges in this case (Diekema, 2004; Garrett, 2018; Lantos, 2017; Winters, 2018). Though it was a small part of the data from participants, the relation of the hospital to the other parties involved was interesting and important. The fact that there was a division noted between the hospital, the private physician group, and the bedside clinical staff shows a lack of a unified system and an unequal distribution in power of voice. The latter is more interesting as the former is not surprising. Even the use of “system” to describe anything in our healthcare is somewhat problematic. This case provides an insight into the nexus of where these decisions can go awry, where how you view the child, either as a child-as-patient or child-as-child, can lead to competing interests based upon one’s responsibility and perceived obligations.

Further medical intervention towards this child after the severe neurologic devastation is seen as inappropriate by the participants. The nurses felt like they were caring for a shell of person, a body. The physicians recommended withdrawal as the interventions being implemented had no benefit to the child-as-patient. Yet, the physician group could not go forward with unilateral withdrawal of the medical interventions due to the legal risk and lack of institutional support. The hospital would not move forward due to the same legal risk, as well as PR risk.

Assuming that the hospital, or whoever was its representatives, agreed that further<sup>147</sup> medical intervention was not in the child's best interests, they were hindered, along with the physician group, from acting in the child-as-patient's best interests. The parents were adamant, by all reports, that they would not withdraw medical interventions that were keeping their child alive. This left the nursing staff and other bedside staff seemingly out of any decisional equipoise. Since the parents were not taking the child home, this left the PICU nursing staff, and subsequently the group home nursing staff, the most affected by these decisions yet with none of the voice, except for the home care agency nursing staff after timepoint four.

There are three logical problems following a best interests standard that are relevant here:

- If the clinicians' best interests for the child were correct, then the hospital was not acting in the child's best interests.
- If the parent's best interests for the child were correct, then the hospital was acting in the child's best interests (assuming they were acting for reasons of the child's best interests).
- If the hospital had the interests of the child in mind, and the hospital's best interests for the child were correct, then the clinicians were not acting in the child's best interests.

Of course, if we view this differently within the context of aggregate interests or competing interests there is a necessary balancing of interests. The hospital has an interest in mitigating bad press and legal risk so if we look for a path of least resistance this would be to concede to parental perspectives and against those of clinician perspectives. This may be for several reasons relating to risk aversion. The hospital has a large community of patients as well as a need to generate financial sustainability. Any risk to this, through bad publicity and legal action, may harm more than the distress caused by one particular case. After all, parents are free to speak about the details of the case in the press while the hospital is bound by privacy and confidentiality. The path of least resistance by the hospital and physician group by

way of risk aversion begs an important ethical question on whether these are credible principles to

A critical view of risk aversion, or an ethics of risk aversion, however, would find some logical problems with an overly risk-averse institution. As the previous logic model eluded, there is some aspect of overriding the very standards of care that clinicians within the institution hold. Certainly, one could say that those are only a few clinicians and it is subjective, but this presents a problematic way of adhering to standards of care that are established by the professional societies that those clinicians are a part of and represent. Furthermore, risk aversion through the path of least resistance may become an insidious pathway if we seem to only accede to parental demands when they feel empowered enough voice them. Only allowing some parental wishes when risk becomes higher could easily wind up benefiting those in positions of power, or those who speak up; there is something inherently wrong about this.

Risk aversion towards paths of least resistance benefits parents who speak up, which invokes questions around outspokenness as a causal factor. It requires us to ask about the parents who don't speak up. It also requires us to look at this from the perspective of whether there is some ethical obligation embedded within this space that is being realized when parents don't speak up, but not when parents speak up. What I mean is, if clinicians feel something is ethically right, such as to withdraw the ventilator in this case, and there is conflict when parents speak up against this, there seems to be a morality that is not being recognized; what is it? Conflict seems to highlight some morality that is not institutionally supported whether this is by the hospital or legally in society. Taking a more risk averse position seems to hide or suppress some moral claims and accounting. The absence of precedent doesn't necessarily equate morality to legality, or vice versa. Just because something is not legally supportable doesn't mean it is unethical. It is interesting, after all, that risk

aversion played a larger role after the conflict became intractable and not previously<sup>149</sup> when the child's care seemed to be quite risky.

What is the morality of the hospital in regard to its acting against the clinical staff and the child's best interests, if the hospital agreed with the clinicians? What does this say about society that an institution will weigh legal and publicity risks against ethical practice or use of resources? These questions are not easily answered, and they are further challenged by the fact in this case that the home care nursing agency refused to care for the child further unless there was a DNR in place. It would seem that some organization was able to set limits around what care they felt was appropriate. There was apparently never a time when a unilateral DNR order was able to be implemented in the hospital.

Does the state play a role in having a decision about the child's best interests? This seems to speak to the need to reconceptualize how we look at the best interests of a particular child. It may well be within the parents' view of best interests for the child to be alive and at the same time not be in the child's best interests from the clinicians to prolong LST. I don't know that these two things necessarily have to cancel each other out. The interest to be alive doesn't necessarily negate the interest to not be kept alive by technology. Technology after all is just as fallible as people and may provide more opportunities for something to go wrong, as was seen in the fear around the child's trach. There appears to be a confusion or lack of agreement in our society over what adequate biological survival is, what it means, what needs it entails, and who and when adequate biological survival becomes a point of focus (Walker, 2007).

### Inevitability

I think you knew it could happen, and it possibly would happen, but it never had a negative outcome after. You

would just deal with the situation. I think that's what was so shocking with all of it: that that time, that was the time it just all fell apart, and he became a very different person from that point on. (RN2)

The concept or question of what can be considered inevitable, probable, or likely when referring to something happening such as a patient decompensating is an interesting concept elicited by this case. Nursing staff reported feeling like taking on his care was similar to 'Russian roulette,' you never knew if today was going to be the day. This type of stress felt by staff daily can be minimized by some saying that any child in the PICU could decompensate at any time. This may be true but there seems to be a different way these participants discussed the feeling around this child. I would hesitate to say that this is a common feeling about all PICU patients. And we see this same feeling reported by other participants as well. However, it could certainly be a more prevalent feeling than thought. The question would then be is it more prevalent with riskier or more experimental cases?

While this concept remains difficult to explicitly apply it to a particular situation it seems important to decision-making. Arguably subjective, feelings of inevitability may signal the need to discuss expectations with patients and families. Given that there are some instances in NICUs, PICUs, and cardiovascular ICUs in pediatrics, or in healthcare in general, where things are attempted that haven't been done before, the feeling of inevitability may be a signal. This feeling from staff may indicate that defining or discussing when to stop could be beneficial to both parents and providers.

Feelings of inevitability may also signal that nursing staff, or those more directly at the bedside, ought to be involved in the decisions around what things are done and how feasible or how much moral risk should be taken on. This is particularly notable considering the knowledge of the moral hazard present. In this case, when the child had his first neurological insult it was fairly clear that the PICU staff and providers thought it best to stop and let the child pass, or at least change to a comfort measure

only treatment plan. If such risk is taken on it seems wise to include those that will<sup>51</sup> take on most of the hazard, and defining when to stop, defining failure, may be a reasonable thing.

Defining failure is not something common in healthcare. A surgeon may say that they will have two options in a case where the first is more desirable and the second less so but stands as a possible plan B once in the operating room. For physicians, trained to conceive illness as a pathology of organ systems, literal organ failure remains the standard for failure, and legal recognition.

Given his overall condition and the high likelihood of further deterioration and the recent events in which changes in his cardiac status required fluids and his low heart rate, they [home care agency nurses] realistically anticipated that a cardiac deterioration is likely at home, and inn [sic] view of his overall status the nurses felt it was not appropriate to attempt resuscitation and stated that they would not provide care for him at home without a DNR in place. [Agency owner] conveyed to me her agency's stance that they would take him home only with a DNR. (Ethics note)

It is interesting that the home care nurses were able to insist on a DNR order prior to return to their care where the hospital nurses were not able to make the same request. This point is interesting as this was after his more devastating neurological incident that happened in the care of the nurses at the agency, timepoint four. What is interesting is that there is, here in this time, a documented feeling of inevitability. While this is after he was further devastated, it was felt that particularly then the child was even, or further, at risk for events or death.

### Policy and Artifact

Non-biological elements play important roles within social structures. We are concept-dependent beings and we conceive our world by how we conceptualize the things we interact with. The policies in place, or not in place, technologies present or

absent, and belief-structures all play a part in how we interpret the world. There were <sup>152</sup> necessary policy and artifact elements that were integral to how the case unfolded and how perceptions and distinctions were made.

The major policy that was relevant found in the data was the futility policy. Futility policies have many different and constantly changing names. In this case it seemed that if it was used it was a modified version of what many institutions use. Namely, that it allowed the family to search for other institutions. However, the formal policy does not appear to have been used or felt that it could be used. This, as the physicians IMCMD and ICUPULM report, is likely due to the precarious legal standing it holds in the particular state. When this issue was posed to a legal scholar and bioethicist this sentiment was confirmed:

The [state] statute specifically forbids overriding the surrogate when they are a POA [power of attorney]. But the absence of specific prohibition is hardly permission (when the surrogate is a guardian or family member). The normal rule is that the clinician follows the patient or the surrogate. One can go to Probate Court (as in the Barnes case) for the judge to green light the clinician CMO [comfort measures only] treatment plan. But to proceed on one's own surely does entail risk.

Some institutions are more risk averse than others (with respect to both legal and PR risk). And even if the institution is okay with the policy, individual clinicians are not willing to take the risk or even invest the time the policy requires. (T. Pope, personal communication, Jan. 9<sup>th</sup>, 2019).

The futility policy was viewed by participants from uncertainty that it was even used to a certainty that it is a policy without a population. This policy, which exists in many facilities as well as legislation in Texas, seems to be an object that symbolizes the intersection between practice, ethics, and law. Clinicians, and these participants, have a clear view that there are treatments that they prefer not to do or prolong yet seem incapable of stopping them. Futility policies were meant as a force to reduce

having to do things clinicians feel are inappropriate. Yet, legally, as pointed out here<sup>153</sup> by participants, going against parental autonomy has very few, if any, test cases outside of Hunt v DFS, which was a state case in Delaware and therefore not relevant in other states (Hunt v. DFS, 2015).

This type of policy seems stuck in a sort of limbo where, in this case, the participants that were direct bedside caregivers were aware of it but unsure about its use. Other participants discussed the feasibility of its use while acknowledging if you don't use it then it will not ever work. There was also a sense, as reported by some participants, that unless you have a united front it won't go forward.

The brain death policy, which in this institution as with many others, is influenced by professional society policy statements and formulated from state law, played another role in this case. While the testing itself was performed by clinicians well-trained and experienced in performing brain death examinations, clearly the child was not brain dead. Since the ventilator was still in place the child was able to initiate a breath. From the data it seems that participants viewed this as an aberrant finding that didn't change the overall status of their view that he was, for all intents and purposes, dead from the view of his personhood, or "neo-cortically dead" as ICUPULM states. The brain death policy is simply a line in the sand we as a society have drawn as objects like the ventilator have skewed the conception of life and death. In this case, these two things worked together to complicate the situation and evoked differing views and decisions for this child.

The Hospital's fear of bad publicity and legal ambiguity shift the path of least resistance and ceding to parents against what clinicians in their expertise feel is appropriate. There is an odd sort of logic that came forward in the data from the physician and ethicist participants that acknowledges the interventions being asked for are not appropriate and/or non-beneficial, and maybe even futile. Yet these

participants report feeling compelled to provide these treatments despite their 154  
expertise because other agents involved requested them and the agencies at the higher  
level are unprepared, or even fearful, to back up the expert opinion. Intractable  
conflict, in one view, appears as a problem of our own making.

In critically analyzing this there are some reasonable arguments against it. One  
could say that once they are declared dead that is it, and clinicians should remove all  
medical treatments that are thus inappropriate for a deceased person and not offer or  
allow forty-eight hours for family to gather. After all, they are dead, it is tragic, but a  
child dying is inherently tragic, and the presence or absence of medical equipment  
does not change this. However, I would challenge this logical practice against the  
personal interaction of explaining this to a family member. Many parents don't get to  
say goodbye to their children when they die, but this may not be an argument to  
justify the instant removal of life support. Suppose one parent is on their way and one  
is present. Both parents may fully understand that their child is dead but there is  
something about saying goodbye that is morally relevant and may assign a moral  
claim towards bedside staff. I may personally believe that a child near brain dead is  
dead but the ability to touch my child's warm body one last time has such a powerful  
feeling that I would find it hard to be so cold as to deny this.

Another factor around brain death is that some children declared dead by  
neurological criteria qualify for organ donation. In this case these children may be  
kept alive on the ventilator, sometimes longer than forty-eight hours. The issue of the  
forty-eight-hour grace period within this policy seems to be less of an issue in this  
case. Instead it seems that this case was an anomaly as it concerns brain death. It just  
so happens that this child took some agonal breaths, and this seems to indicate more  
that it is an aberrant finding and not necessarily a policy failure; though it could be an  
indication of needed modification. I don't know that the logical conclusion to his

taking a breath after death declaration is that we should have removed life support<sup>55</sup> sooner. If anything, it would argue that this case was unique, or that our definition of death by neurologic criteria is too strict, or not strict enough depending on your view. From the perspective of the participants it is clear that for all intents and purposes, in their view, this child was dead.

In this case the tracheotomy and the ventilator were key artifacts with significant meaning. The tracheotomy was the key to life for the child and a great sense of fear to the nursing staff. It is also the reason he stayed in the PICU rather than transferring to a lower acuity floor or discharging home. It is also interesting that after his neurological devastation, there was more stability and seemingly less fear about it. However, while the tracheotomy was seen as an object of fear and necessity, the ventilator became more present as an impacting artifact during the later timepoint where the intractable conflict began.

The ventilator within the context of a child with a devastating neurological injury seems to play a very significant role in how we conceptualize the situation. Without the presence of a ventilator this child, and many others, would not be alive. Their hearts would stop because nothing would be ventilating the lungs and providing oxygen for the heart. The feeding tube can be said to do almost as much in this context, and it was mentioned sort of as an aside in the data, but the ventilator seems to hold a unique position from the perspectives of the participants and the family.

The ventilator has become a main staple of intensive care for its ability to not only save lives but provide a means for sustaining life, an object that provides the ability to obtain organs for donation more effectively, and at the same time a focal point of disagreement. In this case it seems to have allowed the child to continue to provide some adequate biological survival while having questionable personhood as perceived

by participants. It was also one of the main objects that provided the ambiguity over life and death, and brain death.

### Conclusion

A critical systems analysis of the structure around this case finds several different parties acting in ways consistent with their role. Through separating the parts that exist around this case we can see how each are set to work separately and together. Most relevant is the competing interests around a child in this particular context, power differentials, and inevitability. The lack of practical policies, or the lack of support to use them also played a role. There have been several cases invoking futility and conflict around children, even when there is a policy. As in this case, the system seems to function fine if all parties are in agreement and the normal process is followed. When things deviate, differing goals arise, adversarial stances are taken, and there is no measure of failure save organ failure and death, then the stage seems set towards intractable conflict.

As the case deviated in what the normal structure is designed for, ambiguity around responsibilities also emerged and conflict began. This suggests that when a system is set up for a specific type of patients, deviation from this results in much ambiguity around responsibility and sets the stage increasing conflict. As the competing interests become more adversarial, the level of risk increased towards an institutional one. In this way, institutional risk carries more weight than moral or clinical risk of the caregivers as risk was only considered once it got to an organizational level.

This critical systems analysis provides a part by part view of the whole system. Each part appeared to work well within their role in relation to the other parts. In this working, an ambiguous power differential emerged around how decisions are offered, presented, understood, and who makes them. Further complicating the matter is the

competing obligations toward the child, through his status as patient, child, and citizen.<sup>157</sup>  
There appears to be an inherent tension that exists in pediatric care.

Risk aversion is found to have bearing once it gets to an organizational level while inevitability seems to indicate risk being felt at the bedside almost from the point of admission. There is inherent risk in a PICU but the data from this case provides a rich description that goes beyond normal risk. The fear around the probability of this child decompensating was so entrenched that it built a moral accountability around the child within the unit.

There are some major implications here for the connection, or disconnect as in this case, between clinical and organizational ethics. If we take a best interests standard there are problematic positions present, particularly if the hospital took a position of risk aversion knowing it was against the child's best interests. As noted in this chapter, the hospital has valid reasons for this, however, it presents some problems towards the clinical staff that must be addressed, particularly in considering moral distress, moral hazard, and moral injury. At the very least, it begs a question around the obligations a hospital has to a particular patient and a potential patient such as the community. Taking a risk averse stance against the ethical action for a particular patient within the institution built on an obligation to the community may be ethically precarious as a utilitarian argument within an arguably individualistic duty-based institution.

## Chapter 7: Discussion

This study showed that when the care of a child falls outside the normal established system, when there is ambiguous and conflicting practices of responsibility and power, and a breakdown of the moral community happens, intractable conflict emerges. Nurses in this case bore a large amount of responsibility that was absent from the decisions around the child's care. Competing interests, particularly involving risk aversion, can potentially overshadow the child's best interests and show a weakness in using principle-based ethical theories alone. This case highlighted complex competing ethical interests and divisions within a complex system.

This study also found an inability to define failure among shifting goals while decision-making did not consider moral hazard nor feelings of inevitability. These shifting goals and adversarial divisions led to parallel and incongruent goals between different parties involved. Feelings of inevitability may have been a signal that early discussions and agreement on failure may help avoid the intractability of conflict. Overall these findings speak to a need for early identification of complex cases and need to tend to the moral community through presence and continuity. These complex cases will not be solved by simple algorithmic policies and instead require recognition, attention, and work. Put simply, there is no solution that doesn't involve time spent in the moral spaces where these cases, and other ethical dilemmas in healthcare, exist. Time spent in communication is necessary and must be supported.

While examining a particular case could lead one towards blaming a specific party, everyone in this case acted within the abilities and capacities of their role, as noted in the critical analysis. The findings from this study shows the things that exist to lead to intractable conflict. The choices and paths taken and reported by persons involved in this case are all credible options chosen from a way of reasoning that is allowable or

reasonable for parents, nurses, physicians, allied staff, and the hospital. What I mean<sup>159</sup> to say is that this happened within the confines of the social structure that exists, certain actions by parties involved may be disagreeable another party but they are within the confines of what is allowable. In this same way, ethical dilemmas, whether they be futility conflicts or health inequities, are resultant from the way in which the larger healthcare system works and functions. Through this study we can also see how there is a system and moral community set up for a specific type of care and deviations from this can lead to intractable conflict. A system set up for a specific type of care will inherently devalue or depower some care.

In the literature, particularly in the case of Baby K, Jahi McMath, Charlie Gard and others, we can see that similar and higher levels of conflict were reached (Annas, 1994; J. Paris, 2015; J. J. Paris et al., 1990; Wilkinson & Savulescu, 2019). These cases could also be said to extreme cases on their own, and ones that don't happen frequently. However, this way of thought diminishes the amount of moral work, time, and resources these cases require, in addition to the amount of moral distress and injury on all parties. If one party in any of these cases was clearly in the wrong, there would not have been such a high amount of involvement because there would be a clear path forward. These cases cause a large amount of conflict because the questions they stimulate are difficult to answer but tending to them can tell us valuable things about the way in which we practice as healthcare providers.

In the literature, attempts to mitigate these cases have been discussed by many authors, societies, and groups (see chapter 2). However, the focus of these attempts have been on definitional clarity and then procedures after the fact (Bosslet et al., 2015; Kon et al., 2016; Nelson & Nelsom, 1992). The conceptualization or feeling of futility exists independent of the word used to name it. The attempts to mitigate these cases through policy and procedure seem to only make the conflicts worse. Mitigation

at the policy level also diminishes the voices at the physical level involved within the case, and could lead to further ethical issues around justice (Carnevale, 1998; Robert D. Truog, 2007).

One author, who is a clinician and ethicist has begun to explore the complexity of decisions similar to futility within the neonatal population. Wilkinson provides a framework for decision-making that recognizes different zones wherein there is a grey area between parental discretion and unilateral decisions (Wilkinson, 2013). This begins to get at the nuance and uncertainty around the spaces where these cases happen but continues to address it through logical principal based and end-result focused strategies. Some principal and policy interventions may be necessary in combination with the recognition that these cases require moral and intimate work at the bedside as well. Wilkinson, in a later work, does discuss the idea of refocusing and embracing disagreement, which speaks to this study's conclusion that we recognize the need for tending to these cases through moral work rather than interventions (Wilkinson & Savulescu, 2019). We can hand families, nurses, and physicians all the policies we want but we must also tend to ways in which responsibility is practiced at the bedside, in the moral space.

These situations are conflicts between aggregate interests, relations, and responsibilities. Framing these dilemmas by their end result may only help to continue their existence. Carnevale, an ethicist and nurse, proposes examining how the futility discourse and debate itself requires analysis (Carnevale, 1998, p. 516). Carnevale examines the discourse around futility through a constructionist lens and, much like this study, suggests that we ought to look at the context and how "...problems are constructed and negotiated (Carnevale, 1998, p. 516)." Instead of seeking definitional clarity as a way to stop what is distressing some participants we should instead investigate, as this study has done, what is going on, the context, and how

responsibilities are practiced around these cases, as well as other types of ethical 161 conflicts. As Carnevale, in reference to futility debates, states:

Framing these struggles in terms of a futility discourse disregards this inherent strife over trust, respect and power; indeed, futility talk seems to perpetuate these problems further (Carnevale, 1998, p. 515).

Not only does the current method of futility discourse ignore issues of trust, respect, and power, it ignores how our social constructions within and around healthcare work to produce the conditions for such a thing as the concept of futility to exist or be invoked. The major findings of this study can be separated into three themes: findings around conceptualizations of futility, how the moral community is constructed and negotiated, and the connection between clinical and organizational ethics.

#### Differences in Conceptualization of futility: The organ, personhood, and practice perspectives

Much of the futility debate rests on the notion of qualitative versus quantitative or subjective and objective futility. As much as we try to move away from futility, we realize how ubiquitous the concept really is in our practice. While changing the terms to inappropriate and non-beneficial may seem to pull us out of the logical word games around literal futility they continue to keep us anchored to ideas of objective and subjective use of the concept. Objective futility is the obvious ventilation of lungs on a person with no head, this could be considered an organ-view of futility. This is similar to how ICUPULM describes the ventilator in this case in that it wasn't futile in the context that it would ventilate the lungs but overall it would not fix the neurological injury, the person.

The nurse participants discussed futility related to the probability of their work being successful and towards a personhood view. There is an element in this study

that relates futility to the practice of nursing, the ability of nursing care to achieve its goals. RN1 discussed futility around reconstructing the trachea in terms of probability of a successful outcome. RN2 described the futility in the case around the work they did and the lack of success. RN3 discussed futility in quality of life or the ability to provide a quality life for the child through their work.

After his second hit, there was nothing. He would just have this twitching, and sometimes nothing at all. I just didn't feel like there was anything in there, and if there was something in there, it was painful to him, or like futility: no matter what we did, we would never get him to have any quality of life. No matter what. (RN3)

CM gave some descriptive context to a conceptualization of futility in this case. CM noted that there was no ability to recover any meaningful improvement in the child's quality of life. Of note, is that this conceptualization gives comparative thought to previous levels of function as well as state of ability to interact with the world. SW also described futility through quality of life and ability to interact. Ethicist described quantitative versus qualitative futility but also invoked a sense of ability to experience as being relevant to the concept of futility.

Since qualitative and quantitative futility seem set to continue being invoked in futility it seems logical to look critically at the concept terminology itself as problematic. Do we move towards inappropriate and non-beneficial? These terms seem to fall victim to the same sense of ambiguity and value-laden issues that qualitative futility does. After all, who decides what is beneficial? There are certainly two concepts of futility as certainly treating blood loss with antibiotics is clearly futile as is CPR for a body in rigor mortis. This type of futility may be considered organ-view futility as it is referenced when a particular treatment has no benefit towards achieving an intended goal for a specific organ. This may also be viewed as goal-specific futility. There is also the more value-laden and problematic aspect of

qualitative futility which has been somewhat replaced by potentially inappropriate<sup>163</sup> non-beneficial.

What do we mean by “qualitative futility?” From the participants in this study there is a comparative sense to their conceptions of futility. When quality of life was invoked it was in relation to a previous level of functioning. This shows that futility is conceptualized as a reduction in level of functioning from a previous state. This could be considered a personhood view of futility. In regard to neurologic status, when the child sustained an insult to which he no longer was acting and interacting within his previous level of functioning, participants viewed this as futile. The child no longer had personhood, or *his* personhood. In this conceptualization a child with some neurologic injury at birth may have personhood in their beginning level of functioning and if sustained further injury and lost some functioning may lose personhood. Personhood futility is futile in that treatments to sustain life cannot recover what made someone a person, in fact they may no longer be a person. In this way a treatment could be considered inappropriate and non-beneficial to the loss of personhood.

Rather than finding the right definition it may be more productive to pay attention to the feelings that surround it. The practice view of futility provides some insight into this approach. Subjective and value-laden terms should be embraced rather than tossed aside. If nurses are not feeling like their interventions and care have any utility this should spark conversations. Not to say that doubt around success should always indicate futility or mean that care should stop, but it may signal a need to begin managing interests and expectations. Value-laden sentiments should be legitimized, explored, and acknowledged within a moral community, particularly in the context of resource allocation within the hospital and out in the community.

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If we view people as made up of their organs, then futility relies on the usefulness or function of these organs, but this seems reductive to the person. If we view people as a being through their personhood then futility lies in the nature of their self. Personhood is complicated and the subject of much neuroscientific debate (Farah & Heberlein, 2007). As found in this case, there was an idea of who the child was and then an absence of it. If, as the nurse participants reported, the interventions being enacted won't succeed in achieving an overall goal than there is a feeling of futility in practice. This way of thinking about futility gives us three different views of futility: organ-view, personhood, and practice.

Despite ongoing debates around conceptualizing and defining futility, the participants in this study mostly conceived of futility through qualitative or subjective measures. This suggests that, overall, the participants in this study conceive of futility qualitatively relating to the absence of the ability to interact and engage with one's surroundings; a personhood view of futility. While the term itself, from a logical standpoint, is problematic, the fact that there is a more qualitative view from caregivers suggests that no matter the nomenclature, it has a presence in practice, and this is important to the social structure of the moral community. Futility exists regardless of what we call it, however, reconceptualizing it into organ, personhood, and practice views may help us to reorient its meaning and use in practice.

### Bearing Witness, Moral Hazard, and Moral Distress and the Moral Community

Through participant narratives we can see how the moral community around the care of a child is constructed and negotiated. Though terms like moral distress have been around for some time there is a need to dig deeper into how and why this type of distress can exist. In this case, there are several themes present that shed light on how the moral community is negotiated. There were feelings of distress from nurses caring

for the child with decisions being made by those not at the bedside. There was 165 acknowledgment from participants around distress felt by direct caregiving staff such as nurses and intensivists. Moral distress and moral hazard seem to be intricately linked.

Through participant narratives, practices of responsibility were highlighted that explicate how the moral community constructs itself through a socially embodied ethic. There was a variation in when and who was responsible for what. There were unclear but expected responsibilities that led to adversarial feelings and deflections of responsibility that led to distress. There were also unspoken community responsibilities that seemed to show a united moral community among nurses. The evidence of this socially constructed moral community comes through particularly when it broke down, when the conflict emerged. An important concept that aided in identifying how the process of responsibility was constructed is the concept of bearing witness.

Who is and is not bearing witness is important to the moral community (Cody & Milton, 2001; Djkowich, Ceci, & Petrovskaya, 2019). It was felt that parents were not present at the bedside partaking in the care of the child where staff felt obligations were present. In particular, the absence of parents during the child's recovery and rehab period and his episodes irritability and decompensations invokes strong sense from the data that nurses were taking on the responsibility and burden. The bedside staff were responsible for taking the entirety of the child's care, the good times and the difficult times, and there was an animosity towards parents for not partaking or witnessing these experiences. The feeling of not bearing witness, from the nurses, is seen as a parental deflection of responsibility and a rift in what should be a moral community that sees nurses and parents united.

Related to this practice of bearing witness is the concept of moral hazard. None of the decision-makers were, arguably, the ones involved in the day-to-day physical and mental care of this child. This is observed in many of the narrative themes around moral hazard and distress. The nurse participants discussed this by reporting confusion in who had control of the decisions, conflict between the medical team's goals and parent's goals, and their view that he was, at timepoint four, never going to be himself and was essentially dead. Bearing witness, moral hazard, and moral distress seem intricately linked in the construction and existence of the moral community. These conceptual pillars of the moral community are evident in this case because they broke down, but are certainly present in positive conceptualizations, or in positive polarities, organizationally, clinically, and professionally. Paying more attention to the connections between communities in care rather than individualistic notions of care may aid in navigating these situations more constructively.

#### The relationship between clinical and organizational ethics

Viewing ethical issues as independent dilemmas reduces our ability to examine the elements that contribute to them. There is a need to connect clinical ethics to organizational ethics in order to expand the view of ethics and of ethical problems. In this case, and the critical systems analysis, we can see how the many parts involved within this particular structure worked together to lead to the intractable conflict. Ignoring the connection between organizational structures and clinical decisions leads to a reductive view of ethical dilemmas as isolated incidents and ignores the complexity that is present. By acknowledging the relationship between clinical and organizational ethics we can begin to take a more broad view of how interactions influence care and improve the way we provide care.

In this research, there are clear links between decisions made at the bedside and<sup>167</sup> decisions made at the organizational level. The hospital had to weigh the risks involved with going against family and doing what the clinicians' thought was best for the child versus taking the path of least risk and allowing the child to be maintained. For their part, the physicians, without the support of the hospital looked at taking on all of the risk alone. The physician participants in this study discuss how they pursued using the hospital futility policy, which is a deliberative process similar to many futility policies present in other hospitals. The participants discuss the difficulty around implementing the policy and overriding the parents without a precedent, in their state, doing so. The hospital, for their part, must balance acceding to parental wishes and avoiding risk even if it seems against the best interests for the child according to the clinicians. Unfortunately, with legal risk avoided, the moral risk fell completely to the bedside caregivers.

Only one state has a "futility" policy set in law. The Texas Advance Directives Act (TADA) of 1999 is a dispute resolution process that was passed to provide an efficient and fair adjudicatory process around medical futility (Pope, 2017). The problems found in this study around the fear of being the first hospital or physician group to go against parental requests would be lessened by a state law protecting clinicians from litigation through a process such as the TADA. However, there are some criticisms of this law, particularly in its seemingly inequitable use against African American families, the ease at which it can become a rubber stamp, and its diminishment of the value in discussion and understanding with parents (Robert D. Truog, 2007; Robert D. Truog & Mitchell, 2006). While it seems that legal policy may aid clinicians in resolution or refusal in the context of care deemed futile, there are some concerns around the use of these laws and the institutional power it provides. Overall, this speaks to the importance of time spent

in communication within these cases, continuity in communication, and the importance of presence with families at the bedside, consistent with the findings of this study.

Implications for research, practice, and education:

One major implication from this study is the need to move away from only looking at ethical dilemmas as independent occurrences and searching for simple and unilateral solutions. We need to view ethical dilemmas as resultant from the way we have set up our systems. This view can help us identify ways in which our structures work to cause unintended consequences, self-defeating practices, and conflicts in care. Many of the problems faced in healthcare are happening because of the way we have chosen to value certain systems, types of care, and payment models. For instance, we focus more on interventional and rescue care in the US, but we lag behind in preventative care and social programs that affect health (Papanicolas, Woskie, & Jha, 2018). The US focuses more on individualism than community, and healthcare is set up accordingly, (except it seems when organizational risk is involved).

Our individualistic values create systems set up for certain types of patients that follow the particular expected pathway, namely ones who are deemed to have no fault in their illness. Autonomy, in our society, is a simpler concept to translate to judgements compared with best interests (Garrett, 2018). When care falls outside this norm, we see conflict and seemingly intractable problems. The way we view who is responsible for what, and how moral claims, dependency, and vulnerabilities are distributed is important to how moral spaces are constructed and negotiated (Walker, 2007). The way these spaces are lived in can influence who speaks and is heard. While this case, and most other futility discussions, center around clinicians' feelings of futility, it is a legitimate worry that there are cases where families may think an

intervention is futile and feel powerless in the relationship with a clinician who 169 disagrees. Our moral assumptions and norms often hide the very viewpoints that construct these moral spaces. Conflict and distress emerge from these interpersonal and social features of morality when they are hidden (Walker, 2007).

Moving away from only using ethical principles and towards naturalized bioethics, such as Walker's expressive-collaborative model of morality, can help refocus us towards examining what is going on within the spaces around these problems. Using systems theory and critical realism to examine the inherent parts and relations within the complexity of the space where something is happening and using Walker's model of morality to examine the particular way persons are negotiating their responsibilities can help us examine how we establish better systems. Rather than finding an external principle or solution and applying it simply, we should look within the complexity, acknowledge it, and tend to the voices that exist within it.

In nursing education this may be accomplished by examination of critical cases as they unfold through time, being mindful of different perspectives and relationships. Increased clinical opportunities that allow nursing students to follow a patient through many different interactions in and out of the hospital and over time. Additional study in health systems and policy with a focus on how these affect individual patients. Policy and systems study within the context of how they affect health would help nursing students gain insight into the complexity of health. Knowledge could also be gained by more education into how patients fit into healthcare as complex adaptive systems.

### Rethinking the Moral Community

The findings in this study highlight the need to rethink how we examine these cases and suggests a need to pay attention to the moral community. The many

relations in and around this case that make up the moral community were seemingly<sup>170</sup> silent when it came to mediation and mitigation. This separation from the choices being discussed and the intimate work within the case should be eliminated. The persons doing the moral work of caring for this child should be in the discussions around what was being decided for him. Involvement in these discussions may not change the course of actions taken but would force a more open dialogue between those making the decisions and those who will bear the impact. Open dialogue will promote more insight in all parties as each person will be able to present their viewpoint and view of their responsibility and would aid in understanding that may help manage distress and conflict.

#### Continuity, early identification, and management: the role of nursing and ethics

While this study cannot be generalizable, it does present some implications for attending to these cases going forward. The findings suggest moving away from the search for definitional clarity, categories, and algorithms when dealing with ethical conflicts. Instead, this study suggests that we should embrace complexity, recognize it, and tend to it. We spend significant time and energy trying to find a solution to these problems with policies and concepts. We should acknowledge that these cases require identification and management. If nothing else, this case should show us that when there are feelings that the interventions contain some feelings of inevitability, or are experimental, then conversations should begin among parents and clinicians.

One way to do this is to utilize the clinical ethics service, or a nurse care manager adept at discussing goals of care and decision-making similar to a palliative care clinician. Further research is needed into how to identify these cases, and this may be unique to each institution. Once identified, as this case proves, there is a need for continuity, early communication, and management of the moral space and

community. This could be a reasonable task for a palliative care or ethics consult 171 service, though it may not be a feasible use of a palliative care services time as this does not necessarily require medical management. A clinical ethicist or nurse ethicist seems well positioned to fit within the role of managing complexity around ethical issues such as this case and other ethical issues that abound in and around healthcare.

### Conclusion

This study presents a new approach to examining ethical dilemmas within healthcare. Using feminist ethics, or naturalized bioethics, via Walker's expressive-collaborative model of morality to examine the social construction of morality around an ethical issue provides a unique and inclusive way to examine how initial conditions, identities, relationships, and responsibilities are negotiated. Critically analyzing the dynamic structure and complex adaptive system through critical realist theory and methodology of systems theory provides a way to model the causal powers and mechanisms that work together to produce outcomes. Future research around futility and intractable conflict should be focused towards what is happening that is causing these situations to come into being, and towards identification and management of ethical issues as resultant from how we evolve and operate within a community and structured systems.

### Limitations

There was one important limitation to this study, the absence of parental voices. There is a lack of parental voices within academic literature in general. Some recent journals have addressed this by publishing parental narratives. While this study attempted to include parents, they chose not to participate. ENT, and hospital

administration was also unable to participate or declined. Interpretation and analysis<sup>172</sup>  
is always subject to the researcher.

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