A Critical Analysis of Futility Discourse in Pediatric Critical Care

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ABSTRACT

The primary purpose of this article is to critically examine the state of the medical ethics literature and discourse around the concept of futility in pediatric intensive or critical care. The secondary purpose is to identify the conceptualization of futility by different authors, the tensions that exist in the discourse around futility, and the variables that exist in cases when futility is thought to occur. Identification of concepts, tensions, and variables will help to identify the social structure around issues of futility in pediatric intensive care. Seventeen articles were included for summative content analysis. Four conceptions of futility were found: unclear, against medical standards, a subjective value judgment, and not a unilateral conception. The major tensions that emerged, in order, were that futility is based in relationships and responsibility, is goal oriented, and based in beliefs and values. The most reported variable was conflict between parents and careproviders, followed by mechanical ventilation, neurologic devastation, terminal illness, uncertainty, and aggressive treatment. Given that the main variable found was conflict, the main tension was relational, and no consensus on futility was found, it appears that unless there is investigation into the mechanisms of conflict and relational tensions around futility, this phenomenon will continue to appear in the medical ethics literature.

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INTRODUCTION

This article is a summary of a critical literature review performed as a preliminary written exam for a doctoral dissertation. The purpose of the review was to analyze the medical ethics literature that exists on futility in pediatric intensive care. The aim was to identify the mechanisms, relations, objects, and structures that must be present for cases of futility, or disputes around futility, to come into being. The review specifically looked at the medical ethics literature in an attempt to identify themes in the conceptualization of futility and the roles involved in and around futility, and to isolate the structures around futility in pediatric intensive care.

There is a need to identify the structures around cases of futility to understand why they happen. In this case, *structure* refers to and encompasses the systems, components, relationships, and processes that surround and affect a phenomenon. Andrew Sayer, a social scientist working in realist philosophy, conceptualized structure as "a set of internally related objects or practices."[1] Geoff Easton noted that related objects or practices can include departments, people, processes, and/or resources.[2] This is similarly conceived by systems theorists who view a system as "a perceived whole," the elements of

which "hang together" because they continually affect each other over time.[3] *Systemic structure,* for systems thinkers, is defined as "the pattern of interrelationships among key components of the system" that is unrelated or separate from an organizational chart or chain of command.[4] 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.

Overall, four codes were developed in relation to the conception of futility: (1) it is an unclear concept, (2) it is against medical standards, (3) it is a subjective value judgment, and (4) it is not unilateral.

This review of the medical ethics literature was 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."[5] It is not enough to look only at the outcome in question, rather we must analyze and understand the entire structure and the relations 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.[6] This initial review of the medical ethics literature or discourse is the first step towards an embedded qualitative study of the phenomenon of futility in pediatric critical care.

METHOD

A systematic literature review and summative and directed content analysis were used for this article. A summative content analysis approach was used to identify conceptions of futility and tension. Then directed content analysis was used to identify the variables present. Both types of content analysis were described by Hsieh and Shannon.[7]

This literature review used Ovid MEDLINE, CINAHL, EthicsShare, and Google Scholar.[8] The strategy was to look for the keyword *futility* with *pediatric intensive care* and/or *pediatric critical care.* The review specifically aimed to assess futility in United States, and inclusion criteria were formulated accordingly. All articles not written by a U.S. scholar or researcher were excluded. When articles were found with commentaries by different scholars, only commentaries written by U.S. scholars were used. U.S. healthcare is arguably unique, and its social and cultural differences are important.

Articles that did not involve pediatric critical care or pediatric intensive care were excluded from the study. Articles about neonatal futility were excluded because of the differences between neonatal patients and pediatric patients. Several articles discussed "infants," and indepth reading ensured that the setting of these articles was a PICU and not a neonatal intensive care unit (NICU). Issues of viability are vastly different than survivability and futility in pediatric patients. This small distinction has larger implications around discussions of futility and how medical staff and parents conceive them. No year limits were set, since the intention was to assess the literature over time.

The search strategy utilized was eclectic due to the specific nature of the subject. Futility "in general" has been discussed to a greater extent recently, culminating in an official policy statement by the American Thoracic Society (ATS), American Association for Critical Care Nurses (AACCN), American College of Chest Physicians (ACCP), European Society for Intensive Care Medicine (ESICM), and Society of Critical Care (SCC), "Responding to Requests for Potentially Inappropriate Treatments in Intensive Care Units."[9] Overall, the literature on futility and pediatric patients is far less abundant than the literature on futility and adult patients, which may indicate that there is less discussion of futility in pediatrics or that there is a hesitation to use a concept like futility in pediatrics.

The initial search yielded many results in Ovid MEDLINE, CINAHL, and EthicShare, but few of these articles met the inclusion criteria used for this study. A more exhaustive search was conducted after the

results of the initial study were assessed for inclusion by title and abstract. GoogleScholar was searched to exhaustion using several combinations of the terms *pediatric, futility, medical futility, intensive care, critical care,* and *PICU.* The results were searched and collected until a page of results no longer contained relevant results. Articles were assessed to assure that the inclusion criteria were met. Some articles were found to mention futility in the title, but did not include a discussion of futility in the text, and these articles were excluded. This literature review is exempt from the requirement of IRB (institutional review board) approval.

RESULTS

Seventeen articles met inclusion criteria for review and were kept for synthesis after the initial analysis of content (see the appendix at the end of this article for a list of the articles). All of the results were initially reviewed in their entirety for inclusion, and then read again for summative content analysis prior to synthesis.[10] Summative content analysis was used to analyze results in three contexts: how futility was conceptualized, the tensions that existed, and the variables present around the issue of futility that were being discussed. After the review of included results, articles that had been excluded were reviewed again to ensure that they did not meet the inclusion criteria. Summative content analysis was performed on the included material. Initial analysis was performed for the purpose of assessing the entirety of the results. This was followed by second analysis to identify codes and themes, followed by directed content analysis. Several articles were in a round-table or discussion format, which included the viewpoints of or commentaries by different scholars.

The content of the articles was coded to each author, when distinct authorship was delineated in the text. Only authors who discussed futility or authors from the U.S. were coded. For example, in an article by Wightman, Largent, Del Beccaro, and Lantos, only two of the authors discussed futility.[11] Only authors from the U.S. were coded in an article by Gunn and colleagues.[12] Summative content analysis led to identification of four conceptions of futility and tensions present in the discourse (see table 1). This was reviewed again using directed content analysis to discover variables present.

Conception of Futility

Overall, four codes were developed in relation to the conception of futility: (1) it is an unclear concept, (2) it is against medical standards, (3) it is a subjective value judgment, and (4) it is not unilateral (see table 1).

1. An Unclear Concept

Ackerman, Bonnano, Flannery, and Post described futility as unclear.[13] Their articles were published in the 1990s; they wrote as a physician, attorney, attorney, and academic scholar, respectively. They argued that the concept of futility is vague, imprecise, poorly defined, and unclear.

2. Against Medical Standards

Four articles/authors described futility as a treatment that does not conform to medical standards: (1) Annas; (2) Nelson and Nelson; (3) Paris, Crone, and Reardon; and (4) Largent, a co-author of an article by Wightman, Largent, Del Beccaro, and Lantos.[14]

3. Subjective Value Judgment

Five authors in four articles characterized futility as a subjective value judgment: (1) Baergen, (2) Peter Clark, (3) Jonna Clark and Dudzinski, and (4) Thompson (in an article Thompson co-authored with Gunn and colleagues).[15] Baergen argued that all futility judgments are value judgments (page 486). He argued further that these judgments were "employed as a means of overriding parents' decisions" when the success of the treatment is low and the suffering of the child is high (page 486). The difficulty with these judgments, Baergen admitted, is that trying a treatment is often the only way to determine whether it is effective, which creates a problematic period for the treating team. Peter Clark admitted that futility judgments are subjective, but are also "realistically indispensable" (page 181). Jonna Clark and Dudzinkski found that, even though the concept of futility is value-laden, "it remains a recognizable phenomenon in clinical medicine" (page 574).

4. Not A Unilateral Concept

The final theme found was that futility was not a unilateral concept. This was found in four articles, which argue against the concept that futility is one-

TABLE 1. Conceptions of futility

Unclear
Against medical standards
Subjective/value judgment
Not unilaterally conceived

sided; that is, it was not a unilateral concept. These four articles, authored or co-authored by Ganeson and Hoehn, Gunn (in an article by Gunn and colleagues), Landwirth, and Del Beccaro (in an article by Wightman, Largent, Del Beccaro, and Lantos), were coded to have discussed futility as a concept that should not, or cannot, be determined unilaterally.[16] The authors argued for some level of participation by careproviders in discussions with parents around futility. Two of the articles, by Ganeson and Hoehn and Del Beccaro and colleagues, stated that discussion with family members should be attempted, and then, should no consensus be possible, the case should go before an ethics committee. Gunn advocated deferment to the patient's family, and then transfer of the patient if the family did not agree to withdraw the futile treatment in question, because courts will almost always find for continued treatment. Landwirth, in discussing CPR (cardiopulmonary resuscitation) stated that withholding CPR due to a judgment of futility is almost never appropriate without prior discussion with the patient's family (page 506).

TENSIONS

The concept of *relational tension* emerged in the summative content analysis of this critical literature review. The tension referred to is the meeting of two parties with competing interests that are in disagreement; as Elder-Vass described it, "internal parts and relations that are in tension with each other" (page 37).[17] These tensions assist in maintaining what Elder-Vass called a "dynamic structure" by "constantly striking a balance between internal parts and relations that are in tension with each other" (page 37). In analyzing the literature in this review, tensions were identified that make up the social structure and relations around cases and/or discussions of futility, and the roles that are in relation to one another that appear around the existence of a case of futility. Most of the articles in the review discussed the tensions between family and physicians (hospitals, staff, *et cetera*). Four main tensions that had different manifestations were identified (see table 2).

The main tension mentioned in nearly every reviewed article was the demands made by parents/guardians against the obligations on the physician: a *relational* tension. This tension was described in different ways, but provided the same theme: a conflict between what parents demanded and what physicians were obligated to provide, or refuse. A second tension was *goal-oriented* tension, that is, tension between what the goals of care were or should have been. This tension emerged as the differences in the goals of parents and careproviders, as well as internal tensions within careproviders as persons—what could be called internal conflicts, such as faith, beliefs, duty, and so on. Third, there was tension between the *beliefs and values* present within and between the parties involved. Finally, tension existed around the *responsibilities* of the various parties to a conflict. Although this type of tension was similar to a relational tension, it dif-

TABLE 2. Tensions existing within the futility discourse

Relational	Goal-oriented	Beliefs/values	Responsibility
1. Medical team versus patient/family	1. Treatment versus caring	1. Values versus chance of survival	1. Medical indication versus consumer desire
2. Demands of the family versus physicians' obligations	2. Use of technology/ severity of illness	2. View of life	2. Conception of futility
3. Medical standard versus parents' 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 made by parents
5. Autonomy of patients' versus physicians' practice		5. Value versus reality	
6. Moral demands of physician 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			

fered from relational tension as it indicated less a tension between relations, and more a tension regarding who was responsible for what.

VARIABLES

The tensions that were identified in the literature affected the social structure around cases of pediatric futility. Several variables seemed to be necessary for, or contingent upon, the tensions and conceptions of futility found in this review.

Life-Sustaining Therapy/Mechanical Ventilation

One variable present in 11 of the 17 articles was the need for mechanical ventilation or life-sustaining therapy (LST), which was the presence, at least, of mechanical ventilation. Such treatments may be simply one variable that is present when a patient is critically ill, but their presence also seemed to indicate a level of devastation that correlated with conceptions of futility. That is, none of the articles discussed futility regarding a child who was cognitively intact and reliant on mechanical ventilation. The case of Baby K involved a reliance on intermittent mechanical ventilation.[18] This suggests there is something about the presence of mechanical ventilation for children who are not cognitively intact that correlates with discussions of pediatric futility.

Neurologic Devastation and Terminal Illness

This literature review found differences in patients' status between terminally ill children and neurologically devastated children. The historical cases of Baby K and Baby L both involved neurologic devastation. The former was the subject of four articles in this literature search, and referenced by others (Annas; Bonanno; Flannery; Ganesan and Hoehn; Paris, Crone, and Reardon; Post; Truog; and Wightman, Largent, Del Beccaro, and Lantos).[19] A group of the articles discussed children who became terminally ill from a disease process such as cancer (Jonna Clark and Dudzinski; Gunn and colleagues).[20] Almost half (44 percent) of the articles discussed neurologic devastation, compared with 11 percent of the articles, 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 may be that a child with neurologic devastation can reasonably survive for some time while dependent on technology, but a terminally ill child has a much shorter survival time, and disagreements about futility tend to be less about "What is life and death?" and more about "When to stop?" and "How aggressive should we be?"

This suggests there is something about the presence of mechanical ventilation for children who are not cognitively intact that correlates with discussions of pediatric futility.

Disagreements Between Parents and Careproviders

In this literature review, disagreement was always present in cases of pediatric futility. All of the articles in this literature search included a conflict or disagreement between the family and some or all members of the medical team.[21] Four of the articles reported that making judgments or determinations of futility should not be a unilateral process (Ganesan and Hoehn; Gunn and colleagues; Landwirth; Wightman, Largent, Del Beccaro, and Lantos).[22] This suggests that (1) futility is not present when there is agreement, or (2) when both parties agree that treatment is futile and agree to not continue care, their agreement does not lead to disputes, and subsequently is not a subject in the academic literature. One type of conflict identified in this literature review is conflict created when parents request a treatment that is viewed as going against medical standards; one example would be aggressive treatment that has little chance of benefit, such as providing CPR during a terminal illness (Annas; Nelson and Nelson; Paris, Crone, and Reardon; Wightman, Largent, Del Beccaro, and Lantos).[23] Jonna Clark and Dudzinski argue for an informed, nondissent approach to CPR, in which careproviders tell parents that CPR will not be performed, rather than asking parents for their consent.[24] It is interesting that Jonna Clark and Dudzinski seem to argue for increased de-

cisional control by physicians around treatments that have little benefit, even though these authors believe futility is a value-laden concept. Not all of the authors of the articles in this review argued from the same side of a debate. Yet, even though one of the authors of an article in this review, Flannery, was one of the attorneys who represented the mother of Baby K, the parental and family side of these types of disagreements was wholly absent in any of the literature in this review.[25]

CPR/DNR

CPR and do-not-resuscitate (DNR) variables were present in 28 percent of the discourse found in this review. One article mentioned CPR, DNR, and extracorporeal life support (ECLS) (Jonna Clark and Dudzinski).[26] CPR was discussed when there was an issue of terminal illness such as a hematological or ontological condition. In Baby K, the issue was not whether or not to perform CPR, but rather whether or not to re-instate mechanical ventilation, although CPR, in that case, may have also been an issue, but it was not discussed.

Aggressive Treatment

Five of the articles in this review mentioned the concept of aggressive treatment (Baergen; Bonanno; Peter Clark, 2001; Peter Clark, 2002; Paris, Crone, and Reardon).[27] These authors' articles were published in the academic literature, and arguably represent particular views of the structure and relations around futility. There may be as much clarity around what is "aggressive" as there appears to be around what is "futile." What exactly is aggressive treatment was not defined or elaborated in any of the articles. Generally, it was attached to discussions around CPR and other treatments involved in LST.

TABLE 3. Variables present in the literature on pediatric futilitly

Variable	% articles reviewed	Correlated conceptions of futility
Life-sustaining therapy/ Mechanical ventilation	61	Against medical standard Value/subjective Unclear
Neurologic devastation	44	All
Terminal illness	11	Value/subjective Not unilateral
Parent/careprovider disagreement	100	All
CPR/DNR	28	Unclear Not unilateral
Aggressive treatment	28	Value/subjective Unclear Against medical standard
Uncertainty	17	Value/subjective

Uncertainty

Uncertainty was mentioned in three articles when discussing issues of prognostication, diagnosis, and morbidity and mortality (Baergen; Peter Clark, 2001; Peter Clark, 2002).[28] Two of these articles were written by the same author, Peter Clark. In an article published in 2001, he discussed the confusion regarding causation and responsibility, which found more uncertainty around the agent or cause of a death. In this discussion, he notes that causation and responsibility can affect how parents or careproviders make decisions or interact with the other members of the care team. This is similar to other discussions around parents' consent for the withdrawal or limitation of treatment, in which the parents are viewed as morally equivalent to being the agents of the child's death. For Baergen, uncertainty had to do with issues of prognostication around recovery or survival.[29] For instance, physicians may believe that a child will likely not survive CPR, but often there is no way to be certain, and this inability to prognosticate can add complexity to relational interactions and decision making.

DISCUSSION

As indicated by the authors of other articles in this literature review (Brody and Halevy), conceptualizing futility continues to be problematic and without consensus.[30] The results of this literature review seem to confirm this, as there was no one concept of futility that emerged more than others.

Conflict between family/parents and careproviders emerged as a main variable in all of the articles. This suggests that conflict may be the variable that is the impetus for publication regarding discourse on futility, because conflict seems to be the main subject of the articles. The nature of the discourse around pediatric intensive care and futility seems to be sparked by conflict; agreement eliminates the need for discussions about futility. There are differing conceptions of futility. As the concept of futility itself seems to be a point of conflict, it is no surprise that conflict is a major variable present in discussions around futility.

The second main variable found was mechanical ventilation (see table 3). This is not surprising, since "critical care" was a term of focus. The use of technology is a tenet of critical care medicine, and

it is the cause of much debate. Typically, a child who progresses to the need for mechanical ventilation is very ill. More research on mechanical ventilation in children is warranted. I hypothesize that it is the pseudo-stability that mechanical ventilation offers that exacerbates conflict around its removal. Once a child with neurologic devastation is on a ventilator, the child can "live" for quite some time. This can become problematic when the answer to the question, "What is living?" is subjective.

There are children who live while dependent upon mechanical ventilation without neurologic devastation. This is when the third most common variable that is associated with futility, neurologic devastation, seems to become important (see table 3). Children who are sick and progress to mechanical ventilation and continue to progress toward terminal illness (the fourth variable, see table 3), as described in Jonna Clark and Dudzinski,[31] elicited more concerns about aggressive treatment (such as CPR) when death is likely and rescue therapies are no longer appropriate. This may be why neurologic devastation was present more often in the articles reviewed, because it was not often self-resolving. In the case of Baby K (Annas; Bonanno; Flannery; Post), the child's neurologic status was the central point.[32] In articles about Baby K, CPR was not the issue debated, rather it was whether to institute or maintain mechanical ventilation.

The pattern that emerges around pediatric futility in critical care seems to suggest that when there are disputes involving a child with terminal illness, discussions of futility are located around performing CPR as a type of aggressive treatment. In contrast, articles that discussed neurologic devastation reported disputes between parents and careproviders around mechanical ventilation. The tensions identified in these articles were mostly relational in nature, followed by belief and value tensions (see table 2). Goal-oriented tensions and responsibility tensions were mentioned equally (see table 2). Beliefs, values, and goals were all tensions that would arise secondary to tensions around relations and responsibilities. Tensions in relations between the roles involved in cases of pediatric futility were due partly to how the parties involved viewed their responsibilities towards the other parties involved.

CONCLUSION, FUTURE RESEARCH, AND IMPLICATIONS FOR PRACTICE

This article has presented findings from a critical review of the literature around futility discourse in U.S. pediatric critical care. The findings are consistent with general discussions of medical futility, in that no one conception emerged as dominant. However, the variable that stood out was the presence of intractable conflict in all of the discourses that met inclusion criteria for this literature review. This suggests that future research around futility should focus on intractable conflict rather than on defining futility.

This study proposes a unique way of looking at the structures around futility by examining relations, tensions, and variables. Ultimately, the results suggest that intractable conflict should be the focus of further research, as conflict either instigates futility discourse or is a necessary part of it. A focus on intractable conflict around treatment decisions may reveal a more practical and fruitful path toward mitigating these issues, rather than labeling conflict as an issue in futility and attempting to resolve the conflict after it has begun.

In regard to clinical ethics practice, these findings suggest that attempts to define futility be abandoned, particularly since intractable conflict was the main phenomena identified. This makes sense if we think about the lack of consensus on futility. Futility disputes in practice are not definitional battles, rather they are instances in which one agent believes some action is futile and another disagrees, or there is disagreement and one party invokes the concept of futility.

In resolving disputes, we should use systems analysis rather than describe care as futile. Analysis of the articles in this literature identified two different paths to intractable conflict: disputes over continued mechanical ventilation with neurologic devastation, and aggressive treatment in the face of terminal illness. Therefore, we might spend less time labeling and identifying futility and more time in discussion and mediation, prior to intractable conflict. Spending more time in discussion with parents throughout a child's illness/injury may better communication and understanding. In addition, clinician/hospital unity on treatment offerings and capabilities, and providing a unified front in the face of demands for inappropriate care are needed, as not all cases of futile treatment can be prevented. Sometimes we need to be the ones to say "no," and to tolerate parental anger towards us, as some parents need this as a part of grieving.

As Brody and Halevy recommended so long ago, futility should be considered a futile concept and be retired from the ethics vernacular.[33] Instead we should look at the complexities around relations, tensions, decision making, values, and obligations in real time, not after there is an intractable conflict.

LIMITATIONS

A major limitation of this review is its adherence to the academic literature, which produced results that were mainly written from the view of clinicians and academics, rather than the voices of parents. There was one exception to this: Flannery was an attorney from the firm that represented the mother of Baby K. However, her writing still did not include a parental viewpoint.

Another limitation is the nature of performing a literature review on this topic. It is possible that some literature was missed. In addition, by limiting the review to U.S. literature, relevant results from Canada may have been overlooked.

Finally, this review and its analysis were subject to the interpretations of the author.

NOTES

1. A. Sayer, *Method in Social Science: A Realist Approach* (New York: Routledge, 1992).

2. G. Easton, "Critical realism in case study research," *Industrial Marketing Management* 39, no. 1 (2010): 118-28, doi:10.1016/j.indmarman.2008.06.004.

3. P.M. Senge, *The Fifth Discipline Fieldbook: Strategies and Tools For Building a Learning Organization* (New York: Currency, Doubleday, 1994).

4. Ibid.

5. H. Lindemann, M. Verkerk, and M.U. Walker, *Naturalized Bioethics: Toward Responsible Knowing And Practice* (New York: Cambridge University Press, 2009).

6. J. Mingers, *Ontological Explorations: Systems Thinking, Critical Realism, and Philosophy; A Confluence of Ideas* (New York: Routledge, 2015).

7. H.F. Hsieh and S.E. Shannon, "Three approaches to qualitative content analysis," *Qualitative Health Research* 15 (2011): 1277-88.

8. Ovid MEDLINE is the National Library of Medicine database that contains bibliographic citations and author abstracts from more than 4,600 biomedical journals published in the U.S. and abroad. It utilizes vocabulary thesaurus, known as Medical Subject Headings (MeSH). *http://www.ovid.com/site/catalog/databases/901.jsp.* CINAHL is an acronym for the Cumulative Index to Nursing and Allied Health Literature. "CINAHL Database provides indexing of the top nursing and allied health literature available including nursing journals and publications from the National League for Nursing and the American Nurses Association." *https://health.ebsco.com/products/the-cinahl-database.* "EthicShare is a research and collaboration website designed to help you do research, share, collaborate, and participate in the field of ethics. It was originally conceptualized and developed at the University of Minnesota [UMN] by the University of Minnesota Libraries, UMN Center for Bioethics and UMN Computer Science Department with funding from the Council on Library and Information Resources and the Andrew W. Mellon Foundation." *https://www.ethicshare.org/about.* Google Scholar is a "web search engine that indicates the full text or metadata of scholarly literature. Specifically, its index includes most peer-reviewed online academic journals and books, theses and dissertations, preprints, technical reports, abstracts, conference papers, and other scholarly literature subsuming court opinions and patents." *http://www.google-scholars.org/.*

9. G.T. Bosslet et al., "An Official ATS/AACN/ACCP/ESICM/SCCM Policy Statement: Responding to Requests for Potentially Inappropriate Treatments in Intensive Care Units," *American Journal of Respiratory and Critical Care Medicine* 191, no. 11 (1 June 2015): 1318-30, *https://www.atsjournals.org/doi/abs/10.1164/rccm.201505-0924ST.*

10. This type of content analysis is described by Hsieh and S.E. Shannon, "Three approaches to qualitative content analysis," see note 7 above.

11. A. Wightman, E. Largent, M. Del Beccaro, and J.D. Lantos, "Who should get the last PICU bed?" *Pediatrics* 133, no. 5 (2014): 907-12.

12. S. Gunn et al., "Ethics roundtable debate: Child with severe brain damage and an underlying brain tumour," *Critical Care* 8, no. 4 (2014): 213-8.

13. A.D. Ackerman, "Death in the pediatric intensive care unit," *Critical Care Medicine* 21, no. 11 (1993): 1803-5; M.A. Bonanno, "The Case of Baby K: Exploring the Concept of Medical Futility," *Annals of Health Law* 4, no. 1 (1995): 151-72; E.J. Flannery, "One Advocate's Viewpoint: Conflicts and Tensions in the Baby K Case," *Journal of Law, Medicine & Ethics* 23, no. 1 (March 1995): 7-12; S.G. Post, "Baby K: Medical Futility and the Free Exercise of Religion," *Journal of Law, Medicine & Ethics* 23, no. 1 (March 1995): 20-6.

14. G.A. Annas, "Asking the Courts to Set the Standard of Emergency Care—The Case of Baby K," *New England Journal of Medicine* 330, no. 21 (1994): 1542-5; L.J. Nelson and R.M. Nelson, "Ethics and the provision of futile, harmful, or burdensome treatment to children," *Critical Care Medicine* 20, no. 3 (1992): 427-33; J.J. Paris, R.K. Crone, and R. Reardon, "Physicians' Refusal of Requested Treatment: The Case of Baby L," *New England Journal of Medicine* 332, no. 14 (May 1990): 1012-5; Wightman, Largent, Del Beccaro, and Lantos, "Who should get the last PICU bed?" see note 11 above.

15. R. Baergen, "How hopeful is too hopeful? Responding to unreasonably optimistic parents," *Pediatric Nursing* 32, no. 5 (2006): 482-6; P.A. Clark, "Building a Policy in Pediatrics for Medical Futility," *Pediatric Nursing* 27, no. 2 (2001) 180-4; J.D. Clark and D. Dudzinski, "The Culture of Dysthanasia: Attempting CPR in Terminally Ill Children," *Pediatrics* 131, no. 3 (March 2013): 572-80; Gunn et al., "Ethics roundtable debate," see note 12 above.

16. R. Ganesan and K.S. Hoehn, "Ethics in the Pediatric Intensive Care Unit: Controversies and Considerations," in *Pediatric Critical Care Medicine* (London, U.K.: Springer, 2014), 133-40; Gunn et al., "Ethics roundtable debate," see note 12 above; J. Landwirth, "Ethical issues in pediatric and neonatal resuscitation," *Annals of Emergency Medicine* 22, no. 2 (1993): 502-7; Wightman, Largent, Del Beccaro, and Lantos, "Who should get the last PICU

bed?" see note 11 above.

17. D. Elder-Vass, *Causal Power of Social Structures: Emergence, Structure and Agency* (Cambridge, U.K.: Cambridge University Press, 2011).

18. Annas, "Asking the Courts," see note 14 above.

18. Ibid.; Bonanno, "The Case of Baby K," see note 13 above; Flannery, "One Advocate's Viewpoint," see note 13 above; Ganesan and Hoehn, "Ethics in the Pediatric Intensive Care Unit," see note 16 above; Paris, Crone, and Reardon, "Physicians' Refusal of Requested Treatment," see note 15 above; Post, "Baby K," see note 13 above; R. Truog, "Tackling Medical Futility in Texas," *New England Journal of Medicine* 357, no. 15 (2007): 1558-9; Wightman, Largent, Del Beccaro, and Lantos, "Who should get the last PICU bed?" see note 11 above.

20. Clark and Dudzinski, "The Culture of Dysthanasia," see note 14 above; Gunn et al., "Ethics roundtable debate," see note 12 above.

21. The two outlier articles were not analyzed for variables. However, they did present a disagreement between practitioners and parents.

22. Ganesan and Hoehn, "Ethics in the Pediatric Intensive Care Unit," see note 16 above; Gunn et al., "Ethics roundtable debate," see note 12 above; Landwirth, "Ethical issues in pediatric and neonatal resuscitation," see note 16 above; Wightman, Largent, Del Beccaro, and Lantos, "Who should get the last PICU bed?" see note 11 above.

23. Annas, "Asking the Courts," see note 14 above; Nelson and Nelson, "Ethics and the provision of futile, harmful, or burdensome treatment," see note 14 above; Paris, Crone, and Reardon, "Physicians' Refusal of Requested Treatment," see note 15 above; Wightman, Largent, Del Beccaro, and Lantos, "Who should get the last PICU bed?" see note 11 above.

24. Clark and Dudzinski, "The Culture of Dysthanasia," see note 15 above.

25. Flannery, "One Advocate's Viewpoint," see note 13 above.

26. Clark and Dudzinski, "The Culture of Dysthanasia," see note 44 above.

27. Baergen, "How hopeful is too hopeful?" see note 15 above; Bonanno, "The Case of Baby K," see note 13 above; P.A. Clark, "Building a Policy in Pediatrics for Medical Futility," *Pediatric Nursing* 27, no. 2 (2001): 180-4; P.A. Clark, "Medical Futility in Pediatrics: Is It Time for a Public Policy?" *Journal of Public Health Policy* 23, no. 1 (2002): 66-89, doi:10.2307/3343119; Paris, Crone, and Reardon, "Physicians' Refusal of Requested Treatment," see note 15 above.

28. Baergen, "How hopeful is too hopeful?" see note 15 above; Clark, "Building a Policy," see note 27 above; Clark, "Medical Futility in Pediatrics," see note 27 above.

29. Baergen, "How hopeful is too hopeful?" see note 15 above.

30. B.A. Brody and A. Halevy, "Is futility a futile concept?" *Journal of Medicine and Philosophy* 20, no. 2 (1995): 123-44.

31. Clark and Dudzinski, "The Culture of Dysthanasia," see note 15 above.

32. Annas, "Asking the Courts," see note 14 above; Bonanno, "The Case of Baby K," see note 13 above; Flannery, "One Advocate's Viewpoint," see note 13 above; Post, "Baby K," see note 13 above.

33. Brody and Halevy, "Is futility a futile concept?" see note 30 above.

APPENDIX
The 17 Articles in the Literature Review

Ackerman, A.D. "Death in the pediatric intensive care unit." *Critical Care Medicine* 21, no. 11 (1993): 1803-5.

Annas, G.A. "Asking the courts to set the standard of emergency care—The case of baby K." *New England Journal of Medicine* 330, no. 21 (1994): 1542-5.

Baergen, R. "How hopeful is too hopeful? Responding to unreasonably optimistic parents." *Pediatric Nursing* 32 (2006): 482-6.

Bonanno, M.A. "The Case of Baby K: Exploring the Concept of Medical Futility." *Annals of Health Law* 4, no. 1 (1995): 151-72.

Brody, B.A., and A. Halevy. "Is futility a futile concept?" *Journal of Medicine and Philosophy* 20, no. 2 (1995): 123-44.

Clark, P. A. "Building a Policy in Pediatrics for Medical Futility." *Pediatric Nursing* 27, no. 2 (2001): 180-4.

— "Medical Futility in Pediatrics: Is It Time for a Public Policy?" *Journal of Public Health Policy* 23, no. 1 (2002): 66-89.

Clark, J.D., and D.M. Dudzinski. "The Culture of Dysthanasia: Attempting CPR in Terminally Ill Children." *Pediatrics* 131, no. 3 (2013): 572-80.

Flannery, E.J. "One advocate's viewpoint: Conflicts and tensions in the Baby K case." *Journal of Law, Medicine & Ethics* 23, no. 1 (1995): 7-12.

Ganesan, R., and K.S. Hoehn. "Ethics in the Pediatric Intensive Care Unit: Controversies and Considerations." In *Pediatric Critical Care Medicine*. London, U.K.: Springer, 2014.

Gunn, S., S. Hashimoto, M. Karakozov, T. Marx, I.K. Tan, D.R. Thompson, and J.L. Vincent. "Ethics roundtable debate: Child with severe brain damage and an underlying brain tumour." *Critical Care* 8, no. 4 (2004): 213-8.

Landwirth, J. "Ethical issues in pediatric and neonatal resuscitation." *Annals of Emergency Medicine* 22, no. 2 (1993): 502-7.

Nelson, L.J., and R.M. Nelson. "Ethics and the provision of futile, harmful, or burdensome treatment to children." *Critical Care Medicine* 20, no. 3 (1992): 427-33.

Paris, J.J., R.K. Crone, and R. Reardon. "Physicians' Refusal of Requested Treatment: The Case of Baby L." *New England Journal of Medicine*. 332, no. 14 (1990): 1012-5.

Post, S.G. "Baby K: medical futility and the free exercise of religion." *Journal of Law, Medicine & Ethics* 23, no. 1 (1995): 20-6.

Truog, R. "Tackling medical futility in Texas." *New England Journal of Medicine* 357, no. 15 (2007): 1558-9.

Wightman, A., E. Largent, M. Del Beccaro, and J.D. Lantos. "Who should get the last PICU bed?" *Pediatrics* 133, no. 5 (2014): 907-12.