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Complexities of Communication in Pediatric Medicine

63 **Introduction to the Issue**

Maurice G. Sholas

Features

65 **Your Child Does Not Have Chronic Lyme Disease: A Commentary on Communication, Beneficence, and Consent**

Erin King

68 **Pediatric Oncology Careproviders' Attitudes on and Perceptions of Assent**

Camille Lucjak, K. Jane Lee, and Kellie R. Lang

75 **Difficult Conversations in the Ambulatory Pediatric Setting**

Sheldon Berkowitz

79 **Caring for Patients and Families in Challenging Circumstances: Preparing for and Engaging in Difficult Conversations**

Theresa M. Huntley

82 **A Critical Analysis of Futility Discourse in Pediatric Critical Care**

Ian Wolfe

The Family Voice

91 **Dads Are Parents, Too**

Paige Schram

93 **A Successful Failure**

Beth Wakefield

95 **Without Regret**

Jennifer Wagner

Journal of Pediatric Ethics

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Introduction to the Issue

Maurice G. Sholas

Clinical ethics is a necessary compliment and counterbalance to the explosion of abilities that come with advances in modern medicine. Clear minds and cogent principles of respect for autonomy, nonmaleficence, beneficence, and justice serve as guides to prevent abuses and atrocities in the name of medicine and science. Within the larger milieu of clinical ethics endeavors, pediatric clinical ethics presents unique challenges. The reason for this is the reality that children, because of their lack of developmental maturity, do not directly decide their own fate. Parents and/or guardians serve as a proxy for them in the provision of consent for medical care. As such, communication in pediatric medicine can be complicated by concerns of perspective, determining what is actually in the child's best interest, and potential conflicts between clinicians and family members involved in the care team.

That reality made necessary a forum devoted to pediatric clinical ethics, birthing this journal. This issue starts with the heart of many challenges in providing ethical care to children—the care and communication at the intersection of the clinician, the consent providers, and the actual affected patient.

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The entries in this edition of the *Journal of Pediatric Ethics* look at the challenges around communication and decision making and how they affect care decisions for the child. These decisions are as focused as the presence of intravenous access and as grand as life-sustaining chemotherapy against cancer. There are issues of balancing the belief systems of the parents against what may be more objectively best for the patient as established by data. There is conflict between the principles of autonomy and nonmaleficence. There are challenges of deciding what is indicated and what is not, given that medical certainty is not always an absolute certainty. Finally, perspectives and discussions, using peer-reviewed and objectively rigorous approaches, favor those clinician/scientists and their perspectives over that of laypersons who serve in the role of parents and patients. Thus, there is a chance that academic dialogue is biased. In the end, this collection of articles is not the exhaustive endpoint to the discussion on how to effectively communicate and provide ethical care in pediatric settings. These submissions define the literature around proxied decision making, as happens by parents on behalf of their children, conflicting interests of those involved in the decision-making process, and reconciliation of the rights that parents have to make decisions that may be criticized and resisted by the team of care providers. Ultimately, it is ironic that the one most affected by the medical decisions and communica-

tions in pediatric medicine, the child, has the least powerful voice.

This edition of the *Journal of Pediatric Ethics* includes original data documenting careproviders' attitudes, literature reviews cataloguing the state of understanding, and perspectives provided by parents who have been involved in the healthcare system with their children. It is the sincere desire of the journal's editorial team that these submissions codify the current realities in this area of clinical ethics and spur intensive efforts to find consensus and solutions around areas of dis-synergy and disagreement.

Sincerely,
Maurice G. Sholas, MD, PhD

Features

Your Child Does Not Have Chronic Lyme Disease: A Commentary on Communication, Beneficence, and Consent

Erin King

ABSTRACT

Careproviders who are appropriately acting in pediatric patients' best interests will help them to achieve a developmentally appropriate understanding of their condition, outline the expected outcomes of their tests and treatments, assess their understanding, and solicit their willingness to accept the proposed treatment.

Physicians and those who care for children must "attend to possible abuses of 'raw' power over children when ethical conflicts occur."¹ As a hospital physician engaging in the care of children and adolescents, abuses of power might be difficult for me to identify and even more difficult for me to act upon, but are easy for me to palpate.

Some time ago, I was caring for a 15-year-old adolescent female with a prior diagnosis of chronic systemic pain and chronic abdominal pain. She had been in pain programs at reputable institutions in the past and had "graduated." Despite this, she experienced an acute worsening of her symptoms and came to our facility needing help. Almost immediately her family's struggle to manage her pain and the impact on their lives became clear to me and the inpatient team. She was home schooled. She had

anxiety and depression. She had received a PICC (peripherally inserted central catheter) line from a naturopathic family medicine provider and received a number of medications that were out of my lexicon: several months of high-dose vitamin C, many courses of intravenous antibiotics for her recent diagnosis of chronic Lyme disease, and numerous oral supplements. While our standard of care for PICC lines is in the order of weeks, hers had been in place for nine months.² It was miraculous that she had not yet experienced a complication like line fracture, bacteremia, or clot formation.³ It was clear that her family had weighed appropriate therapies and had chosen those they thought best for their daughter. With great distress at seeing nonstandard care, and disagreement with the patient's diagnosis, I took the opportunity to educate the patient and family about the known dangers of indwelling central intravenous access, and encouraged removal of the line as soon as possible. The family did not agree. In this situation, just who was abusing their raw power over this child?

The American Academy of Pediatrics (AAP) guideline, "Informed Consent, Parental Permission, and Assent in Pediatric Practice," insists that patients participate in decision making "commensurate with their level of development."⁴ Generally speaking, all patients or their surrogates have a right to decide, after consultation with their physician, whether they will or will not accept a particular

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medical intervention. For adolescents, this includes the power of assent; research indicates that their decision-making skills are mature by approximately age 14.⁵ Careproviders who are appropriately acting in pediatric patients' best interests will help them to achieve a developmentally appropriate understanding of their condition, outline the expected outcomes of their tests and treatments, assess their understanding, and solicit their willingness to accept the proposed treatment.⁶ Like many adolescent patients like this patient, physicians often direct their conversations to the patients' caregivers, rather than to the patients, or conversations with patients are then deferred to their caregivers. If physicians are

massage, cannabinoids, healing touch, and acupuncture; however, this treatment seemed inappropriate. In 2000, the AAP created the Task Force on Complementary and Alternative Medicine (CAM).⁹ Since that time the prevalence of the use of CAM has been studied: one study reported that 61 percent of adults in the United States used CAM,¹⁰ another study reported that fewer than 50 percent of children in the U.S. with "chronic, recurrent, or incurable conditions" used CAM.¹¹ The most common reasons for using CAM cited included word of mouth, the belief that the treatments were effective, fear of adverse drug events, dissatisfaction with conventional medicine, and the need for more personal attention

Careproviders who are appropriately acting in pediatric patients' best interests will help them to achieve a developmentally appropriate understanding of their condition, outline the expected outcomes of their tests and treatments, assess their understanding, and solicit their willingness to accept the proposed treatment.

to follow the principal of beneficence, we should acknowledge that parents' refusal of treatment or parents' insistence on a particular therapy are not in our patients' best interests, and we have a duty to act to preserve their best interests.⁷ For my patient, this meant consultation with my institution's pain specialist, a conversation with the patient's prescribing provider, and sharing information with the patient's family. I was surprised to hear that the prescribing provider vehemently disagreed with my recommendation to remove the patient's PICC line.

When considering alternative therapies, physicians are not ethically obligated to offer an intervention that is medically futile, even if it is requested by the patient; however, open conversation is encouraged. I wondered whether my patient had received appropriate consent or assent for costly (according to her parents, more than \$1,000) laboratory testing and intravenous therapies, with promised effectiveness. After all, my patient continued to have pain. If I practiced medical "pluralism," that is, "respect despite honest disagreement" regarding a treatment practice, I would support my patient's autonomy to make treatment decisions.⁸ To do this would be difficult. Within my present practice, I have developed appreciation for many alternative therapies including chiropractic, aromatherapy,

from careproviders.¹² Given patients' ready access to valid as well as inaccurate information online, and rapidly growing social networks, those of us practicing Western medicine may be doing our patients a disservice. We may be so consumed with data entry and staying current on clinical care that we may have missed developments in the CAM field.

Pediatricians should remain abreast of resources such as the AAP's 2001 policy, "Counseling Families Who Choose Complementary and Alternative Medicine for Their Child with Chronic Illness or Disability."¹³ It is our responsibility, too, to know that, as of 2006, less than 5 percent of CAM research was dedicated to pediatrics.¹⁴ We shouldn't ignore the fact that very few CAM providers undergo extensive education or training specific to pediatrics.¹⁵ For example, in a four-year CAM training program, just one rotation, several weeks in duration, may focus on pediatrics. As with our concern for medical abuse and neglect, our eyes should be open to "medical negligence" when other careproviders are providing therapy that does not meet the standard of care, and they may be committing fraud and abuse by charging for therapies that have been deemed to be medically unnecessary.¹⁶ Our duty as physicians to fully inform our patients includes describing the acuity of their illness, our ability to cure their dis-

ease with conventional therapies, the degree of invasiveness of any given procedure, the toxicities of conventional therapy, and the evidence for the safety and/or efficacy of CAM; and to assess patients' family members' understanding of the risks and benefits of treatments. Our professional duty is always to treat the patient. I wondered whether my outpatient colleague had fulfilled his or her duty.

I didn't believe my patient had chronic Lyme disease, but I did believe I could help her, after reading of a recent article in the Centers for Disease Control and Prevention's publication *Morbidity & Mortality Weekly Report*, which noted the complications of treatment of this entity and included hotly debated commentaries,¹⁷ I recalled the personal and professional challenge of treating my patient.¹⁸ Despite our discussions, she left the hospital with her PICC line in place and with a plan for follow up with her naturopathic careprovider, as requested by her family. It was clear to me that this careprovider did not appreciate my willingness to question diagnoses, treatments, and interventions that I thought were unnecessary for the patient. For a brief time, though, she was my patient. I hope I broadened her treatment options and bolstered her decision-making capacity. As her pediatrician, it was my legal and ethical duty to appreciate, support, and defend her competency, no matter how "alternative" her treatment course had been.

MASKING OF THE CASE

Details of this case have been altered to protect the identity of the patient and family.

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Pediatric Oncology Careproviders' Attitudes on and Perceptions of Assent

Camille Lucjak, K. Jane Lee, and Kellie R. Lang

ABSTRACT

Purpose

The purpose of this study was to describe pediatric oncology careproviders' attitudes and perceptions regarding including pediatric patients in decision-making discussions for cancer treatment.

Methods

Potential participants were identified via institutional staff listings and recruited via internal email addresses. Of 27 eligible participants, 16 completed an anonymous online survey consisting of 12 questions, yielding a response rate of 59 percent.

Results

Of the 16 careproviders surveyed, 75 percent strongly agreed that it is valuable to include pediatric patients in decision-making discussions. Those who did not find value in the practice still reported using multiple methods to assess for understanding and agreement in a child. Almost two-thirds (62.5 percent) began in-

cluding children in decision making between the ages of seven and nine. All 16 careproviders indicated that they would proceed with cancer treatment if the child did not agree, but the illness was imminently life threatening, and the parents gave permission. Barriers reported in the study included the child's developmental level, differences in primary spoken language, parental preference, and the child's age.

Conclusion

Careproviders at our institution self-report to be practicing in line with the recommendations of the American Academy of Pediatrics. Next steps might include exploring ways for careproviders to educate parents on the rationale for including children in decision-making discussions. Additionally, finding effective strategies to identify and remove language barriers may improve communication.

INTRODUCTION

Informed consent in the adult population is a widely recognized and frequently discussed topic in medicine and bioethics. But how does the topic apply to the pediatric population? Recognizing that persons under the age of 18 may not legally consent but may have capacity and should have input as to what happens to their body, the concept of pediatric assent has evolved over the last 25 years. William G. Bartholome was one of the first pediatricians to explore the issue and draft recommendations related to informed consent in the pediatric popula-

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tion.¹ The American Academy of Pediatrics (AAP) Committee on Bioethics expanded on Bartholome's work by publishing a policy on assent in 1995.² Described in the policy are four minimum components of assent: (1) helping the patient achieve a developmentally appropriate understanding of his or her condition, (2) telling the patient what to expect with tests and treatments, (3) assessing the patient's understanding of the situation and the factors influencing the patient's response, and (4) attempting to determine the patient's willingness to accept the care. The policy recommends that clinicians seek both parents' permission and patients' assent. In the

ing process regarding enrollment in the research trial.⁷

Most of the studies we reviewed observed or described assent in pre-operative, pre-procedure, or end-of-life situations;⁸ however, many serious decisions are made in the context of longitudinal pediatric care, a setting that has not received as much attention in the literature. In this context, it is argued that even young children can develop and voice their care preferences, as they have been exposed to disease and interventions.⁹ In addition, children with chronic conditions benefit from increasing responsibility and participation in their own medical

Interestingly, only nine of 35 clinicians in the study reported always seeking a child's agreement to a care plan.

more recent literature, clinical ethicists such as Franco Carnevale have argued that children are capable of unique moral experiences, and recommend that parents and healthcare professionals make every attempt to relieve any moral distress experienced by children as a result of tests, procedures, or treatments in the healthcare setting by "attending meaningfully to their questions, objections, and possible protests."³

Since publication of the 1995 AAP policy on informed consent, studies have examined the knowledge and use of its recommendations by pediatric careproviders in specific subpopulations,⁴ and in 2016 the AAP published a revised policy.⁵ In a 2006 qualitative study, a questionnaire was administered to pediatric surgeons, anesthesiologists, and subspecialists regarding their knowledge of assent, the AAP policy, and their practice concerning assent.⁶ It is significant that the surgeons surveyed in this study reported less often than the subspecialists in the study that they were aware of the components of assent. The surgeons were also less likely to be familiar with the AAP policy. Interestingly, only nine of 35 clinicians in the study reported always seeking a child's agreement to a care plan. In a 2010 study, a "quality of assent instrument" was utilized to retrospectively determine children's understanding of, and desire to participate in, oncology research trials that the children had participated in, in years prior. Nearly half of the children recalled having no, very little, or little involvement in the decision-making

care, which will allow them the opportunity to develop self-reliance and positive self-care behaviors that will aid in their transition to becoming autonomous adult patients.¹⁰

For these reasons, we decided to examine pediatric decision making within the field of oncology, a field in which pediatric patients and their families have repeated interactions with a careprovider and must make significant decisions about treatment protocols that are often high risk. A 2002 study observed the use of assent in 14 pediatric oncology care conferences when leukemia treatment was discussed. The authors found that a very small amount of careproviders' communication was directed toward pediatric patients.¹¹ However, all but two of the 14 clinicians sought some degree of input from the children regarding clinical trials. Although this study reported that the clinicians were seeking agreement to treatment, the dynamics of the preceding conversations were not described. The situations were complicated by the fact that a child's assent is required for research, but not for clinical care, making it difficult to determine whether assent was obtained simply because it was required, or because the careprovider found value in including the child. Overall, little is known about the dynamics of decision-making discussions in pediatric oncology or about the attitudes of careproviders regarding including pediatric patients in decision making.

Although there were gaps in the literature related to the content and process of assent discus-

sions, during the project's iterative process, the authors learned of a new initiative at our institution that was designed to improve education on obtaining assent. Faculty are implementing didactic workshops with instruction and simulation of assent discussions. In addition, we discovered that our institution utilizes a structured pediatric assent form, which includes information about the child's diagnosis and treatment plan, and has spaces for parents and children older than seven to sign to indicate their assent for treatment. With this standardized form and the amount of information covered during treatment discussions, it became apparent

choice questions, value-rating scales, and open-ended questions. It was reviewed by two careproviders in the Division of Pediatric Hematology, Oncology, and Bone Marrow Transplant at MCW and a group of 15 medical students at MCW, to assess for readability, bias, and appropriateness of content.

Survey Process

This study was designated an "exempt" status by the MCW Institutional Review Board. Following the grant of an exemption, the concept of the study was introduced at a Pediatric Hematology/Oncology Department meeting. Potential participants were

Regarding challenges to including pediatric patients in decision-making discussions, all of the careproviders indicated that the child's developmental level could pose some challenges.

that there is not typically a great deal of variety in these discussions. Thus, the focus of this study is less on the assent process, and more on careproviders' attitudes and their perception of the value of including pediatric patients in decision making. Another purpose of this study is to describe the barriers that careproviders encounter to when they attempt to include pediatric patients in making decisions about their treatment.

METHODS

Survey Population

There are 43 pediatric hematology/oncology careproviders at the Medical College of Wisconsin (MCW), including physicians, nurse practitioners, and certified physician's assistants. Our inclusion criteria stipulated that careproviders must be actively seeing patients for an oncology diagnosis and conducting discussions regarding assent for treatment. Careproviders who reviewed the content of the survey prior to the study were excluded from the study. Of the 43 careproviders, 27 met inclusion criteria.

Instrumentation

The survey included 12 questions created by the research team to explore gaps in previous studies. Questions were a mix of Likert scales, multiple-

choice questions, value-rating scales, and open-ended questions. It was reviewed by two careproviders in the Division of Pediatric Hematology, Oncology, and Bone Marrow Transplant at MCW and a group of 15 medical students at MCW, to assess for readability, bias, and appropriateness of content.

Data Analysis

Data were analyzed item by item using descriptive statistics such as the frequency of responses. Observations were made about the responses depending on the characteristics of the respondent, such as the number of years in practice and the type of degree held.

RESULTS

Of the 27 careproviders who were sent invitations to participate, two responded they did not currently see cancer patients, and so were not eligible to complete the survey. Two participants opened the survey link but did not complete any of the questions. Of the 16 participants who began the survey, all completed all of the questions. This yielded an overall response rate of 16/27 or 59.2 percent.

Demographics

Of the participants, 69 percent identified as a doctor of medicine (MD) or doctor of osteopathy

(DO), while the remaining 31 percent were nurse practitioners (NP) or certified physician assistants (PA-C). Half of the respondents identified as female; half as male. The mean and median number of years of practice in pediatric oncology were 11 to 15 years. See table 1 for the distribution of years in practice.

Pertinent Findings

Of the study participants, 75 percent ($n = 12/16$) strongly agreed that it is valuable to include pediatric patients in decision-making discussions along with their parents or guardians for cancer treatment. There were 12.5 percent ($n = 2/16$) who agreed with this statement; notably, 12.5 percent strongly disagreed. Careproviders who strongly disagreed were NPs/PAs.

None of the careproviders indicated that they would begin including pediatric patients in discussions if they were under the age of seven. However, 62.5 percent ($n = 10/16$) indicated that they would begin including patients between the ages of seven and nine. See table 2 for the full distribution of ages of inclusion in decision making.

TABLE 1. Years in pediatric oncology practice, including fellowship

Years	%	Responses
0-5	12.5	2
6-10	18.8	3
11-15	31.3	5
16-20	25.0	4
21-25	0.0	0
26-30	0.0	0
31+	12.5	2
Total:		1

TABLE 2. Ages at which respondents begin to include pediatric patients in decision making

Ages	%	Responses
Under 7 years of age	12.5	2
7-9 years of age	62.5	10
10-11 years of age	6.3	1
12-13 years of age	6.3	1
Over 14 years of age	6.3	10
Don't typically include in discussions	0.0	0

Regarding challenges to including pediatric patients in decision-making discussions, all of the careproviders indicated that the child's developmental level could pose some challenges. Other barriers reported were parental preference for the child to not be included ($n = 15/16$), the child's primary language not being English ($n = 13/16$), the acuity of the child's illness ($n = 10/16$), and the child's age ($n = 9/16$). Only two careproviders indicated that a time constraints were a challenge. Write-in responses indicated that it was a challenge if the parents' primary language was not English, and if the patient did not want to be included in decision making.

Of the options that were provided regarding beliefs on important aspects of a visit, careproviders put the highest priority on parents understanding their child's diagnosis, parents understanding the proposed treatment, parents agreeing with the proposed treatment, questions from either the parents or the child, and fears or concerns from either the parents or the child. When it came to the child understanding the proposed treatment, 25 percent of those surveyed ($n = 4/16$) indicated it was "very important," while 62.5 percent ($n = 10/16$) believed that it was "important," and the remaining 12.5 percent ($n = 2/16$) were split between "neutral/indifferent" and "somewhat important." Very similar results were seen in response to the importance of the child agreeing to the proposed treatment, with one additional careprovider indicating "neutral/indifferent."

Although the least importance was placed on the child's understanding of and agreement to the treatment plan, in follow up, all of the careproviders indicated that they ensured that a child understands and agrees. The most common methods for assessing understanding reported by the careproviders were asking the child directly ($n = 11/16$) and having the child repeat information back ($n = 11/16$). Almost as prevalent was watching for nonverbal signals from the child, such as nodding ($n = 10/16$). Some write-in responses included verbally quizzing the child ($n = 3/16$), asking the child if she or he had questions ($n = 1/16$), and having the child work with a child life specialist to express feelings through art or play ($n = 1/16$). As far as assessing genuine agreement, 87.5 percent of careproviders ($n = 14/16$) stated that they asked the child directly, and 75 percent ($n = 12/16$) indicated that they would have the child sign a document. Of the 50 percent who said they would utilize nonverbal signals to assess agreement, only 6.26 percent ($n = 1/16$) would use that as their only technique. The rest combined it with the aforementioned techniques.

Because our institution's practice includes using a standardized assent for treatment form to guide discussions, along with signature lines for the pediatric patient and parents, we inquired about careproviders' opinions regarding its purpose and value. Careproviders could select multiple responses.

Most commonly, 62.5 percent ($n = 10/16$) stated that its purpose is to indicate agreement to the proposed treatment. Other popular choices were to indicate understanding ($n = 7/16$) and to have documentation for legal purposes ($n = 6/16$). Interestingly, only one careprovider stated that the purpose of the form is to begin transitioning the child into an autonomous adult patient. Other notable write-in responses were that signing the form is useful for therapeutic buy-in, to help the child understand the seriousness of the discussion, or simply that it is required for participation in clinical trials.

When questioned about the value of the patient and parents signing an assent for treatment form, the most frequent response in a "select all that apply" style question was that the signature is valuable to the institution ($n = 12/16$, 75 percent). The second most frequent response was that the signature is valuable to the pediatric patient ($n = 9/16$, 56 percent). When analyzing the distribution of the responses, only two of the careproviders answered that the signature was valuable solely to the patient, but five careproviders indicated that it was valuable solely to the institution. The rest answered various combinations of value to the careprovider, the patient, the patient's parents, the institution, or the institutional review board. One of the 16 careproviders (6.25 percent) did not feel that the signature was valuable to anyone.

The final question of the survey was scenario-based, in an attempt to apply careproviders' opinions regarding assent in a clinical matter. Careproviders selected from several situations in which they would proceed with cancer treatment without having some of the assent process complete. See table 3 for the distribution of careproviders' responses to the various scenarios.

DISCUSSION

Overall, most careproviders in the study reported that they found value in including pediatric patients in decision-making discussions for cancer treatment. This led to the conclusion that, in pediatric oncology, at this institution at least, the ideals and practices of careproviders fall in line with AAP recommendations and the requirements for clinical trial participation. For example, the earliest age of

inclusion in discussions reported in this study was seven to nine years. This finding correlates with the AAP suggestion that children have some potential for logical thought beginning at age seven, and that seeking their assent can help "foster moral growth."¹² Almost all of the careproviders in this study indicated that they at least began to include patients at this point.

Interestingly, although two careproviders indicated they strongly disagreed that including pediatric patients in decision-making discussions is valuable, all of the careproviders indicated an age by which they began including children in these discussions. It is unclear the reasons that careproviders engaged in obtaining assent if they did not find value in doing so. It may be that the careproviders were simply practicing to an expected standard of care. Further research addressing this question is warranted, especially given that our research team could not hypothesize a reason in which differences existed between nurse practitioners and physicians.

Similarly, some careproviders indicated that they were indifferent towards the importance of a child's understanding and agreeing to a proposed treatment plan, but all of the careproviders indicated multiple ways that they assessed for these items during a discussion. In contrast to simply including the patient in the discussion, seeking assent, at least for participation in a clinical research trial, is federally mandated. This may be why some careproviders were continuing practices they personally did not think were important.

In the recently updated AAP policy statement on pediatric assent for treatment purposes, as well as for research, it is stated that dissent for research by a minor should be respected, but that a waiver

TABLE 3. Distribution of respondents' responses to scenarios

Scenarios		%	Responses
If the child is too sick to sign the form, but the parents give permission		100.0	16
If the child is not present at the decision-making discussion, but the parents give permission		56.3	9
If the child does not agree, but has an illness that is immanently life threatening		62.5	10
If the child is too young to comprehend the impact of the signature on the assent form, but the parents give permission		100.0	16

may be granted if direct benefit may only be obtained in the context of research.¹³ Our findings regarding situations in which careproviders would proceed with treatment without some components of assent corresponded with these recommendations. Careproviders were unanimous that they would proceed with treatment in situations in which an assent form could not be physically signed, but the parents had given permission. This finding suggests that these careproviders believed that assent was more about

for treatment decision making was a strength of the pediatric oncology department at this institution. However, there was a significant burden of barriers reported in the survey, such as the child's developmental level, the parents' preference for the child to be excluded, or language barriers. Although our institution constantly has in-person, telephone, or video interpreters available, we did not inquire whether careproviders in this study utilized these services. Thus we cannot draw a conclusion on the

Overall, this study found that most pediatric oncology careproviders at this institution reported that it was valuable to include pediatric patients in decision-making discussions.

the process of providing information, and assessing for understanding and agreement, rather than a simple signature on a document. There was less uniformity when it came to proceeding with a treatment if the child was not present at the assent discussion, but the parents had given permission. Again, this finding suggests that these careproviders usually did wish to educate the child and include the child in the decision-making process. An interesting scenario that the survey asked careproviders to consider was when a child dissents, but has an illness that is imminently life-threatening. Overall, 62.5 percent ($n = 10/16$) in this study said that they would still proceed with cancer treatment. Decision making in this case likely centered around the evaluation of risks and benefits to the child, in the context of the child's developmental level. In young children, the AAP suggests not giving the child an option, if the child's dissent would not be respected, regardless. In adolescents, the suggestion is to engage in thoughtful discussion to elucidate the patient's goals and values, and to be aware of state legislation on adolescent treatment refusal.¹⁴ However, refusal would only be considered when a curative option was unlikely and burdens were high.

Regarding the barriers to pediatric inclusion, it was fascinating that only 12.5 percent of the careproviders in the study felt that they were challenged by the amount of time available to have these decision-making discussions. Time is a factor that is often described as interfering with quality physician-patient interaction, but it seems that adequate time

effects of a language barrier versus difficulties with video or audio quality, or availability of an interpreter with the specific language required.

Regarding the implementation of the assent simulations and workshops for pediatric oncology fellows at our institution, more research may be indicated to see how careproviders' practice and opinions change over time. Per a 2016 cross-sectional survey of pediatricians, a formal ethics curriculum in residency was not found to correlate with increased ethical knowledge using a validated instrument.¹⁵ However, a 2015 literature review found an overall theme to be a desire for more "real-life context" in ethics training, and an interdisciplinary approach over the span of medical school, residency, fellowship, and practice. This review also found that most residents preferred informal discussions with their mentors about cases, rather than a formal, lecture-based ethics curriculum.¹⁶

The educational initiative at the authors' institution regarding simulated discussions related to treatment and assent is a promising sign for an integrated curriculum. Perhaps our institution could implement an evaluation tool to determine the residents' learning needs, and the strengths and weaknesses of the ethics training they are receiving.

The limitations of this study include a small sample size at a single academic medical center. The survey questionnaire that was utilized was not previously validated by other studies. Another potential limitation is that participants' self-report may not reflect their actual behavior.

Overall, this study found that most pediatric oncology careproviders at this institution reported that it was valuable to include pediatric patients in decision-making discussions. Even those participants who did not find value in the practice still reported multiple methods that they assess for understanding and agreement in a child. The careproviders' priorities regarding decision-making discussions were described, and barriers to communication were elucidated. The next steps in this area of study might include exploring ways for physicians to educate parents on the rationale for including children in discussions. Additionally, there seems to be room for improvement in communication between careproviders and patients in the context of language barriers.

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Difficult Conversations in the Ambulatory Pediatric Setting

Sheldon Berkowitz

ABSTRACT

Complex conversations about pediatric care occur in many different settings. Some of the most difficult conversations surround vaccine resistance which is a topic that is frequently discussed in ambulatory pediatric clinic visits. The MMR (measles, mumps, and rubella) vaccination has prompted significant resistance in some communities, leading to ongoing discussions in the primary care setting. The recent measles outbreak in Minnesota¹ provided a unique opportunity to broaden this discussion about vaccination to include community leaders, leading to more effective changes in parental perceptions about the vaccine.

Most people assume that all difficult and complex conversations with patients and families occur in an in-patient setting, either in NICUs or PICUs (neonatal or pediatric intensive care units) or oncology units. However, difficult conversations can and often do occur both in out-patient clinic settings and also within broader community settings. In some situations, the community conversations have even more of an impact on patient care than what happens in the exam room.

CASE

The mother of a 20-month-old child brings her daughter in for a well-child visit. The pediatrician,

while reviewing her immunization records, notes that she is up to date for all immunizations except for her MMR vaccine, that is typically given between 12 and 15 months of age. In further discussions with the mother, the pediatrician is informed that, in this family's community, there are concerns about many children being diagnosed with autism, and the subsequent conviction that it is due to MMR vaccination. Despite extensive conversation with the mother about (1) the lack of scientific evidence for any association between the MMR vaccine and autism, (2) discussion about the risk of contracting measles if another outbreak was to occur, (3) a reminder of a recent large outbreak of measles in this community, and (4) the information that other members of this community are vaccinating their children with the MMR vaccine, the mother refuses to give consent for the MMR vaccination.

These challenging situations occur frequently in our general pediatric practice, which cares for a large number of Somali children.² However, vaccine refusal is not unique to the Somali population, and is also seen in many other settings where some or all vaccines may be refused by parents.³ Since the clinician's (pediatrician's, pediatric nurse practitioner's, or family practitioner's) primary obligation is to meet the needs of the child, those needs can at times be in conflict with the needs or desires of the parents, who are acting in their role as surrogate decision makers for their child, who is unable to

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express a preference or is not legally of age to make medical decisions. There are multiple issues for clinicians to keep in mind when having challenging discussions about care decisions with families, such as (1) what is motivating the family to act in a way that is contrary to what is being recommended, (2) how to work with the family to follow the recommendations offered by the clinician, (3) how much to push on an issue at a particular visit versus ongoing conversations with the family over time, and (4) when the refusal to follow through on a recommendation rises to the level of neglect and requires clinicians to contact child protective services.

learned during the recent measles outbreak about working with community leaders (religious and cultural leaders) to help them understand and share knowledge with their communities. While the discussions that occur in the community are important, in the end, it's the discussion that occurs in the exam room between a family and their clinician that either results in agreement or a refusal to immunize. One of the main lessons I have learned is to listen and respond to the family's fears without solely focusing on the goal of immunizing their child. In partnering with a family, there is a greater chance of accomplishing the ultimate goal of protecting the

One of the main lessons I have learned is to listen and respond to the family's fears without solely focusing on the goal of immunizing their child.

In the case described, the clinician needs to balance doing what is right for the child—by balancing the benefits of the vaccination against its known side-effects—while trying to respect the family's belief that the vaccine may cause their child to develop autism, and the family's right to refuse the vaccine (in their role as surrogate decision makers).

In the spring and summer of 2017, this particular issue of vaccine resistance took on additional importance as Minnesota experienced the largest measles outbreak in decades.⁴ Ultimately, close to 80 patients were infected with measles, and a large percentage of those patients were children in the Somali community who had not been immunized by the MMR vaccine.⁵ Most of the families in this community were not resistant to all vaccines, but were specifically resistant to the MMR vaccine. This fear started more than 10 years ago when a British physician, Andrew Wakefield, claimed an association between MMR vaccine and autism. He later came to the Twin Cities' Somali community to promote this belief during the 2011 measles outbreak in Minnesota.⁶ Despite the fact that Wakefield's views had been discredited and he lost his license to practice medicine,⁷ his views, as well as those of others in the anti-vaccine community at large, led to a significant decline in MMR vaccination.⁸ Many articles were written dealing with how to overcome vaccine resistance from families,⁹ and much was

child from contracting vaccine preventable illnesses, such as measles.

During the most recent measles outbreak in Minnesota, I was fortunate to participate in conversations about how to effectively immunize our patients against measles with a variety of stakeholders. The conversations began in our own institution as we grappled with the best way to reach out to our patients and whether to confront the anti-vaccine groups who were planning "events" in our community. There were concerns that attending such events could do more harm than good, and alienate the families we were trying to reach. To add to the complexity of the situation, when Wakefield had spoken in Minnesota years earlier, with no organized clinician response against his views, the Somali community felt that no one cared about investing in their health.¹⁰ Ultimately, a number of clinicians (including myself) attended the first of these "anti-vaccine" events, but did not acknowledge what institution we were from. Over time, working groups developed between Children's Minnesota, the University of Minnesota, Mayo Clinic, Hennepin County Medical Center, as well as the Minnesota Chapter of the American Academy of Pediatrics, the Minnesota Department of Health, and a number of imams and other leaders of the Somali community. In the work groups that I participated in, it was agreed that the best way to reach out to the Somali community and

effect change was to meet with religious and other leaders of the community in their mosques.

I had the opportunity over several months to meet with and talk with imams, sheikhs, and other community members in four different mosques. It was at the first meeting, early in the epidemic, that one of the imams stated that he could not stand by and risk seeing his community's children get infected with measles and possibly die, and that seemed to make the difference. He stated that it was the imam's responsibility to make sure this doesn't happen. From there, many clinicians started being invited to mosques to meet with the community and talk about measles, MMR vaccine, and autism. While the conversations were always cordial, they were not always easy. We clinicians learned to listen to the stories of the Somali community, including stories from parents who were convinced that their children "changed" or "stopped talking" after getting the MMR vaccine, and were later diagnosed with autism. I listened as parents talked about not having known about autism prior to immigrating to the United States. I listened as families talked about the shame in their community of having a child who was "different" with autism. Even though I have often heard that the Somali community has a strong "oral tradition," which is why written Somali documents have typically not been utilized, learning that this oral tradition also includes more attentive listening was an important lesson. In addition to listening, we shared what we knew about measles, the MMR vaccines, and autism. We talked about the current outbreak and why it was spreading, the benefits and risks of the MMR vaccine, and what is known about autism—incidence,¹¹ presentation, and causes. We also made a point to answer every question asked of us to the best of our ability. In the end, it was these conversations within the Somali community, in their houses of worship, that had the most impact and led to large numbers of previously underimmunized children now receiving the MMR vaccine.

In the first one to two weeks of the measles outbreaks, families in our clinic continued to refuse the MMR vaccine. However, after the first few weeks, as the number of infected children started to increase, we all started seeing more willingness of families to vaccinate their child with the MMR vaccine. The parents heard the message, both at their mosques as well as from others in the community, that the theoretical (and nonscientificallly supported) risk of that their child might develop autism after the MMR vaccine was less important than the real risk of their child contracting measles and needing

to be hospitalized, or, in the worst-case scenario, dying (as happened in Minnesota's previous measles outbreak in 1990, when 460 people became ill and three people died¹²). Unfortunately, now that the outbreak is over, I am once again having the same conversations with families about refusing the MMR vaccine due to their fear that their child will develop autism.

I have had patients die of vaccine-preventable diseases, and I watched an older cousin live with the effects of polio when he was a young child in the 1950s, before polio vaccination was available. As a pediatrician, my conversations with parents who refuse to vaccinate their child for one or more preventable diseases are among the most difficult conversations I have. Even though I try to use the lessons learned over the previous several months, during the Minnesota measles outbreak, I fear that community-held beliefs about the MMR vaccine are again taking hold. If we are to make long-lasting changes in vaccination rates, it is essential that we continue to work on this issue, not only inside our clinics, but also in the communities where our patients and their families live, work, and worship. We will need to build on the trust that has developed between the Somali community and health-care providers by continuing to meet with them and address their concerns.

BLINDING OF THE CASE

Details of this case were altered to protect the identities of the patient and the family.

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Caring for Patients and Families in Challenging Circumstances: Preparing for and Engaging in Difficult Conversations

Theresa M. Huntley

ABSTRACT

As clinicians we have the privilege of caring for patients and families who are living with an often unexpected illness or injury. While we have chosen our profession, those we care for are here due to their circumstances. We have undoubtedly experienced the successes and challenges inherent in this work and know that difficult conversations are an inevitable part of it.

In our effort to provide high-quality care, it is essential that we spend time in self-reflection and develop a practice of good self-care. Knowing who we are as caregivers, while also nourishing our mind, body, and spirit, will enable us to bring the best version of ourselves to work.

JOINING TOGETHER WITH PATIENTS AND FAMILIES

Having been in the field of healthcare for many years—initially as a nurse and then as a clinical social worker in a pediatric cancer and blood disorders program—I am acutely aware of the difficul-

ties associated with providing care to patients and families as they face unexpected health crises. I know the courage, strength, and perseverance required. I also understand the privilege it is to walk with patients and families through experiences they rarely could have anticipated or imagined. As healthcare practitioners we have selected this challenge; we have studied and prepared for our vocation. We choose to come to work each day ready to deal with the numerous demands for our expertise, skill, and time. When meeting patients and families I often comment, “You are embarking on a journey that may be frightening and unfamiliar. It is likely something you didn’t plan on and you may feel ill equipped for the obstacles you will encounter along the way. In a sense, it is similar to being in a foreign country—the language is unfamiliar and the terrain seems confusing and strange. You are an unwilling guest and will be required to learn things at a time when you are not the best student. We are fluent in the language and can traverse this land with relative ease. As a healthcare team, it is our role to help you become well versed, to assist you in navigating the geography. We want to help you become as comfortable as possible in this setting.”

As professionals immersed in the field of healthcare, we must acknowledge that each day can have a life of its own. We may start it with a plan of what

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the hours will hold, only to find it take a different direction based on the needs of the patients who present themselves. We learn to be flexible, to adapt to our circumstances. At times we will do this well; at other times it can pose a significant challenge.

In order to provide exceptional care in our various roles, it is imperative for us to spend time in reflection and to develop the practice of good self-care. Contemplating on who we are as individuals—

CARING FOR OURSELVES AS WE CARE FOR OTHERS

It is important we take time to care for ourselves as we simultaneously care for our patients and their families. As the saying goes, we need to put on our own oxygen mask before helping others with theirs, lest we become unable to breathe and therefore useless. We must understand what refreshes and nour-

Patients and families have a right to honest and accurate information regarding their health.

understanding the values and principles that inform our practice—will serve us well as we strive to meet patients and families where they are. Implementing self-care as part of our daily routine will enable us to refresh and rejuvenate our mind, body, and spirit. This, in turn, will allow us to bring the best version of ourselves to work, each and every day.

KNOWING OURSELVES AS WE CARE FOR OTHERS

We do our best to provide exceptional care. We accept that it will require commitment and sacrifice. Do we take the time to reflect on this? Have we pondered the following?

1. Do we recognize our genuine intent to do well by our patients, while also understanding that myriad issues will surface that make this difficult?
2. Have we spent time contemplating what is meaningful to us in this work?
3. Do we understand the value we place on life? Do we pursue it with little or no thought for the burden or cost it may exact?
4. Are we able to acknowledge death as a reality and to accept that there are limits to what we can do to save or cure a patient?

It is essential to contemplate these and other related questions if we are to provide compassionate clinical care. Families have entrusted their loved one's life to us, believing our care will be comprehensive and stellar. We need to be confident that we have given to the best of our expertise and ability, regardless of the outcome.

ishes our being and build it into our daily routine, to the extent possible. If we become depleted, we will have little, if anything, to share. We must be intentional in our efforts to replenish and rejuvenate. It is time well spent, a gift to ourselves and to the patients and families we serve.

ESTABLISHING RELATIONSHIPS IN DIFFICULT SITUATIONS

We all know the desire to protect those we care for from harm and to promote an optimal experience for ongoing growth and development. At the same time we must recognize our human limitations. While we may not be able to prevent an illness or injury, there are important things we can do once it has occurred. We can provide honest information and offer medical recommendations based on our knowledge and expertise. We can offer care and compassion in a comprehensive, professional manner.

Patients and families have a right to honest and accurate information regarding their health. As healthcare providers we develop relationships based on trust and mutual respect. We engage in an agreement to provide safe and high-quality care and expect people to participate in ongoing decision making regarding it. We recognize our responsibility as medical experts to inform, guide, and direct, while also understanding the virtue of patient/family self-determination and autonomy. When we provide information, we know we must do so in a way that is clear and comprehensible to our audience. We need to be cognizant of any bias. This can be particularly difficult when a decision is made that differs from what we believe is in the other person's best inter-

est. We need to accept that while we think we may know what we would do if faced with similar circumstances, we can never really be sure. If we are truly offering an option for care, we need to be prepared to accept and support a decision that has been carefully made, regardless of potential disagreement.

UNDERSTANDING AND WORKING WITH CHALLENGING DYNAMICS

At times in our interactions with patients and families we may encounter behaviors and psychosocial dynamics that are a challenge to manage. Patients and families are often in intense, emotionally laden situations, and their responses may reflect such strain. Although it is difficult, it is imperative that we separate the circumstances from the person, recognizing that we are meeting people at their most vulnerable. They are working through private matters in a public setting that allows them limited control. They look to us for our professionalism and compassion, not judgment or blame.

When I interact with families who are in the midst of struggle and uncertainty, I find myself wondering:

1. If I were in a similar situation, what labels would be assigned to me in my floundering attempts to advocate for myself or others? Would staff see me as a strong champion or would they perceive me as adversarial?
2. How would I feel in a situation where I experienced little if any control? Would others allow me opportunities to make choices, irrelevant as they might seem, in order that I regain a sense of focus?
3. Would my dignity as a person be respected? Would people be willing to meet me where I was, or would they attempt to impose their own way on me?
4. Would others understand the difference made by consideration of these concerns? Would they recognize the positive impact of such thoughtful care?

ENGAGING IN DIFFICULT DISCUSSIONS

When we engage in difficult conversations with patients and families, our intent is to present necessary information respectfully in a manner that doesn't overwhelm, intimidate, or patronize. There are strategies we can employ to promote a meaningful discussion. In preparing for a meeting with a patient and family, we can:

1. Identify the professionals who are integral to the

case and ensure there is agreement about the issues to be addressed.

2. Clarify whether information is being presented primarily to facilitate an informed decision that takes into account risks, benefits, and alternative options, or if a specific medical recommendation is being made.
3. Consider whether the patient and family will have time to pause, reflect, and get back to us in a specified time frame, or whether the circumstances necessitate a more immediate response.
4. Allow time for staff to process their emotions so they can engage in a respectful, nonjudgmental manner.
5. Ensure that healthcare providers are prepared to accept a decision that the patient and/or family determine to be in their best interest—regardless of our potential disagreement—if it is proposed as a viable option.

During a meeting we can:

1. Have a staff person identified to facilitate the discussion and take notes so the patient and family can focus, without worry about the need to retain information.
2. Begin with introductions and a shared agenda.
3. State your expectations and define a time frame for making decisions.
4. Have someone from the psycho-social team present to provide emotional support, and to articulate questions or concerns raised in previous conversations if the family is in agreement.
5. Ensure that the patient and family are acknowledged and heard. Let them know there will be ongoing conversation during the delivery of care.
6. Be mindful of your verbal and nonverbal communication, understanding that more may be conveyed through tone and inflection, gestures and mannerisms, than the actual words spoken.

Difficult conversations are inevitable, and it is essential that we be prepared to engage in them with competence, integrity, and compassion. As previously stated, we have each chosen to deliver care in the context of the healthcare setting. In doing so, we have invariably experienced the successes and challenges inherent in this work. It is my sincere hope that you take time for reflection and self-care. By doing this you become self-aware, which, in turn, will convey a sense of confidence to those who turn to you for your expertise. It will also ensure you are strong in body, mind, and spirit, and therefore in a position to be the best version of yourself, as you provide exceptional care.

A Critical Analysis of Futility Discourse in Pediatric Critical Care

Ian Wolfe

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.

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

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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.

ity 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

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 futil-

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 con-

cept, (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, Bonnanno, 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 Dudzinski 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			

ferred 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.

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

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.

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

"What is life and death?" and more about "When to stop?" and "How aggressive should we be?"

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.

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

TABLE 3. Variables present in the literature on pediatric futility

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

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 con-

sistent 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

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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/>.

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

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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.

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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.

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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.

The Family Voice

Dads Are Parents, Too

Paige Schram

ABSTRACT

The mother of an infant born with a heart defect reflects that the focus of careproviders is often on mothers, to the neglect of fathers, even when fathers are the primary caregivers. She urges careproviders to move beyond expectations that may seem most expedient, but which may negatively affect their relationship with children's parents.

As our family moved through our experience with a medically complex child, it became clear to my husband and me over time that the mothers and fathers we encountered have very different interactions with careproviders. In almost every other arena, men experience preference and privilege over women. In wages, education, and nearly everywhere else, men carry distinct advantages in our society. However, our experience has been that, in a medical setting, fathers are often the second-class citizens when it comes to communication with the members of the care teams.

It started while we were still expecting. We discovered our son's heart defect at 20 weeks, halfway through a "normal" pregnancy, and knew that he would need surgery within the first week of life. We

had a series of prebirth meetings with the Obstetrics, Neonatal Intensive Care Unit, and Cardiac Care teams to review what the care plan would be once our son arrived. Throughout those appointments, the members of the care teams spoke primarily to me, and only asked me if I had questions—even though my husband was sitting right next to me. At our last appointment, when we met with the surgeon, he did engage both of us equally, and it was only after that meeting that my husband finally said something to me because that experience was so dramatically different from the rest of the day. Due to the hectic nature of the day, I had not even noticed, but he felt like he was an afterthought, not really a part of the conversations.

The story repeated itself after our son, Owen, was born. More often than not, physicians, nurses, and the support staff spoke primarily to me as the mother despite the fact that, once again, my husband was sitting in the room right next to me. We became used to it and would sometimes make jokes about it, but it was a pervasive thing that did cause some resentment.

After Owen was discharged, I went back to work and my husband stayed home to care for our son because his health status would not allow us to expose him to a day care setting. When it came time to choose a primary cardiologist for Owen's ongoing care, we ended up choosing the doctor who spoke

Paige Schram is the Mother of a medically complex child who receives care at Children's Minnesota in Minneapolis, Minnesota. ©2019 by *Journal of Pediatric Ethics*. All rights reserved.

directly to us both. Since my husband was the primary caregiver, it was important to have a doctor that he was comfortable with. Over time, and as the careproviders got to know us, they would observe our dynamics and began engaging us both.

It seems as though careproviders make assumptions out of expedience. They tend to assume fathers are less engaged and too often they focus their discussions and questions on the mothers. This invalidates the experience and the importance of the fathers, and reinforces traditional gender stereotypes with respect to the roles of mothers and fathers as they relate to caregiving. Fathers feel the same stress, pain, and worry that comes with a child who is ill or has a chronic condition. Fathers need to be equal participants in interactions with the members of the care team. The unique voices of fathers are too often missed when the focus is placed solely on the moms.

A Successful Failure

Beth Wakefield

ABSTRACT

The author is the mother of a child who is medically complex. This article documents the importance of communication and of all interactions between the family and medical team during a complication and unplanned hospitalization.

Communicating with medical professionals has become common for our family. Our daughter was born with a very rare chromosomal difference. Due to that, she has developmental delays and special needs. She sees more than 10 specialists and receives rehabilitation therapies. Neither my husband or I have a medical background, but after six-plus years parenting our daughter, we have grown more familiar with medical jargon and the routine of the hospital. The rapport we have with the medical team is important to our daughter's care. While that is true for both inpatient and outpatient experiences, it is particularly important when our child is hospitalized. Although it is a professional and temporary "relationship," for that small time in our lives, it is profound. The way something is communicated can make or break the fragile trust between parents and the care team.

A few months ago, it was suggested that our daughter have a routine endoscopy. With that, we were able to coordinate a few other tests and procedures. It was all planned to be a three-to-four-hour sedated outpatient event. We had not reason to expect that this cluster of outpatient procedures would land our daughter in the hospital as an inpatient for over a month.

Several days into her hospitalization, we learned our daughter had developed hematomas in her digestive tract related to the endoscopy.¹ She was quite ill. Our previously healthy daughter was now hospitalized, unable to eat like she normally does, battling infection, and losing a concerning amount of weight. She was on several new medications, and with that came some medication errors and near misses. Many things did not go as planned. Trust was fragile at times and information sharing was always important.

In one instance, good communication and a genuine partnership between us and the medical team helped to improve the outcome. Early in her stay, our daughter came down with an infection. The medical team was quick to try to identify the issue. With that came many tests, including an abdominal CT scan.² Our daughter was going to need another abdominal CT scan in a few weeks, and I was hesitant to do another one because of the additional sedation and radiation. After expressing my reservations to our daughter's nurse, she was able to con-

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tact the hospitalist, who was willing to talk more with us. Shortly after we had this discussion, results from an earlier test came back identifying the infection. Based on that, the team held off on the second abdominal CT. Had we not slowed things down and had the careprovider not taken the time to talk with us about it, our daughter would have undergone more testing, that would not have been necessary. Obviously, in an urgent situation, there is not time to pause and discuss. In this case, we appreciated the medical team's willingness to include us in the conversation.

were not quite what we had hoped for, and that more information would be available later. Soon, my daughter's hospitalist arrived and she was able to provide more details, including that the issue was not nearly as bad as I feared it could have been. Despite being disappointed that our daughter was not healing faster, for me this was a relief. I was so grateful that the hospitalist came down to radiology to personally tell me. I grabbed her by the arm and thanked her, after which she gave me a hug. It is times like this, when information can be communicated personally and empathetically, that can really

***It is times like this, when information can be
communicated personally and empathetically,
that can really solidify the trust between
families and the medical team.***

Our daughter continued to have ups and downs for the next couple of weeks. After speaking with the hospital social worker, we decided that a care conference would be beneficial to get everyone on the same page. It was very helpful to sit down together with the care team and discuss everything in more detail. Walking out, we felt more comfortable and prepared for the next procedure.

Unfortunately, that next procedure did not go as well as we hoped. Our daughter had a sedated procedure with a vascular access nurse to place a PICC line.³ After the procedure, the nurse told us that the PICC line was not in the ideal location. Shortly after the nurse left, the anesthesiologist entered the room and rather abruptly announced that he thought a radiologist should have done this procedure. Without much more added detail, he departed the room. I was dumbfounded and upset. I am sure he had his reasons for saying what he did. However, at that time and under those circumstances, it might have been better for him to come in with the nurse to discuss the outcome, and potentially make some suggestions to keep in mind for future procedures. Overall, it was not the best interaction, and it made us more frustrated and distrusting as a result.

A week later, the abdominal CT scan was completed. Afterward, we were notified that the results

solidify the trust between families and the medical team.

From my perspective, this hospitalization was a successful failure. Many things went wrong, but despite the complications and setbacks, working together we were able to get our daughter back to her healthy, happy self. There were moments of great communication and opportunities for improvements. We learned more about our daughter through it, and appreciate the partnership we had built with the medical team.

NOTES

1. A hematoma is a swelling of clotted blood. An endoscopy is a nonsurgical procedure used to examine the digestive tract, using an endoscope—a flexible tube with a light and camera attached to it. Biopsies can be taken during this type of procedure to further evaluate the digestive tract.

2. CT is an acronym for computed tomography. A CT scan combines data from several X-rays to produce a detailed image of structures inside the body.

3. PICC is an acronym for peripherally inserted central catheter. A PICC line is a thin, soft, long tube inserted into a vein that is used for long-term intravenous antibiotics, nutrition, and medication, and for blood draws.

Without Regret

Jennifer Wagner

ABSTRACT

The mother of a child with a very rare, severe genetic condition that affects many body systems writes about the importance of respectful, honest, empathic communication with the care team.

Our first child began to show abnormalities not far into my pregnancy. In her first year of life, one symptom after another began to appear. We had a grocery list of specialists, including three geneticists, yet we still did not have a diagnosis. Finally, at three years old, she was diagnosed with Schinzel-Giedion syndrome, which carries a life expectancy of two and a half years.¹

Our care team continued to grow at a steady pace. Meeting and orienting hospital and clinic professionals, as well as home care staff, to our daughter and her needs became a constant practice, and one at which I became quite skilled. A successful relationship with our team was 100 percent dependent on effective and respectful communication. We learned that, although our care teams were the experts in medicine, we were the experts on our daugh-

ter. Professionals who did not grasp this concept or respect it were dismissed. Our daughter's quality of life and the care she received were always the number one priority.

Most of the physicians and staff we encountered respected our wishes, listened to our concerns, and valued our input. The best example was the relationship we had with our daughter's palliative physician. Over the years we had countless conversations that resulted in improved care for her and quality of life for our entire family. One of the most difficult conversations came after two serious illnesses resulted in sepsis,² and she nearly died. We had to accept that something undeniable had changed and that it was time to discuss hospice. With the most incredible sincerity and honesty, we shared an intimate conversation with this physician about her prognosis and the new, terrifying boundaries we would have to live within.

During the year and a half our daughter lived on hospice, many situations arose where she required some sort of intervention to manage ever-changing distressing symptoms, some of which resulted in surgical options. While her palliative doctor voiced concern for our daughter's ability to survive a surgical procedure, he also allowed us the space to make our case for surgical repair and share our strong feelings that our daughter's increasingly painful condi-

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tion was not the quality of life she deserved. The palliative doctor not only heard us, he stood behind us and helped us to make arrangements for the surgery. Unfortunately, one week before the scheduled procedure, our daughter took another turn for the worse, and we all agreed to postpone surgery indefinitely. It was a heartbreaking conversation to have, but it was handled with compassion and empathy that I will not forget.

Our sweet girl died less than a month after that conversation, at seven and a half years old. My husband and I were able to face her death without regret because our supporting physician cared enough to honor our need to know we had given her every chance to have the best quality of life possible.

Respectful, honest, empathic communication from a care team can make a profound difference in the lives of patients and their families. Our experience with her palliative physician is evidence of that.

NOTES

1. According to the National Institutes of Health, “Genetics Home Reference,” “Schinzel-Giedion syndrome is a severe condition that is apparent at birth and affects many body systems. Signs and symptoms of this condition include distinctive facial features, neurological problems, and organ and bone abnormalities. Because of their serious health problems, most affected individuals do not survive past childhood.”

U.S. National Institutes of Health, “Genetics Home Reference, Schinzel-Giedion syndrome”: October 2018, <https://ghr.nlm.nih.gov/condition/schinzel-giedion-syndrome#synonyms>.

2. Sepsis is a serious illness that happens when the body has an overwhelming immune response to a bacterial infection.