

# Journal of Pediatric Ethics

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# Journal of Pediatric Ethics

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***From the Editor***

# Everyday Ethics and Partnering with Families in Children's Hospitals

*Ian D. Wolfe*

**ABSTRACT**

Partnering with families is everyday ethical work. We meet families where they are in their life and rarely is this a place that was ready to take on a hospitalization. Rather than focusing on difficulties, we ought to provide equitable work at partnering with families where they are at, not where we might want them to be. Partnering with families begins at the point of entry into the hospital and extends to building partnerships in departments and units. Recognizing that this is ethical work and providing this to families within a pluralistic society is often the unspoken hard work of clinicians and hospitals. This issue of the *Journal of Pediatric Ethics* is focused on this space that greatly impacts the ethical climate within the hospital walls.

Partnering with families is an integral part of caring for children. Every child and family are unique, bringing their own strengths, values, struggles, and perspectives. Clinicians must meet these families where they are at in the world, which is sometimes not the ideal place we might like them to be. Schopenhauer wrote, "the present is always inadequate, but the future is uncertain, and the past irrecoverable."<sup>1</sup> Envisioning ideal situations distracts us from the task in front of us. The present situation is always inadequate if we are constantly

trying to avoid accepting the past and hoping for some certain solution in the future. Rather, we should accept where we are and start from there.

The families of children who become ill may already be facing challenges and stressors, and the hospitalization of their child adds to this. How well we meet families in these situations can have significant impacts on the children we are caring for.

Partnering with families isn't only done through clinicians at the bedside, it starts at the first point of entry into the healthcare environment. Families enter hospitals with their children through emergency departments or transfers from other institutions. Families may enter by way of a front desk in a clinic or a welcome center in a hospital. First impressions can make significant impacts that can resonate through communities.

Partnering with families in an ethical manner starts at the institutional level through visitation policies, equitable welcoming environments, and community engagement. These continue in the departmental level in how each department meets the needs of and works to build relationships with the families they serve. Individual clinicians and healthcare staff must learn to be skillful in connecting with families from a multitude of backgrounds, cultures, and faiths.

This is ethical work, and how well these pieces fit together impacts the ethical climate. In this issue of the *Journal of Pediatric Ethics*, we present an important and novel investigation into visitation poli-

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cies in a children's hospital. Shim and colleagues investigate visitation policies through the practice of exceptions to restrictive visitation COVID-19-era protocols.<sup>2</sup> COVID-19 necessitated visitor restrictions for reasons beneficial to all patients and staff in hospitals. It also provided a look at how structural racism may insidiously affect families with hospitalized children. While there has been considerable discussion around racism in visitation policies in the COVID-19 era, the authors point out while COVID-19 provides a visible and measurable case, policies such as these exist in "normal" times in hospitals in the United States.

clinicians and families never consider the nuances of parental rights, nor do they consider the different ways that ethical and legal rights might intersect. The authors point out that there is an important difference in how we conceptualize a parent who has lost legal rights and a parent who has not legally established parental rights. It is easy for clinicians to consider these to be synonymous, but this easily comes at the peril of the parent.

Finally, our "Family Voices" provide two important narratives from the parent perspective in partnering with clinicians. A mother, Amanda Bekric, writes about the importance of a care team

***Clinical ethicists are often faced with difficult situations, in which parents find themselves in awful scenarios with no good choices; clinicians who are trying to do their best to balance what they see as their professional obligations to patients, to their family, and to the team sometimes feel the stress of seemingly competing obligations.***

Shim and colleagues provide a systematic descriptive analysis of the nature of requests for exceptions to pediatric visitation policies, as well as an analysis of the demographics associated with requesting and receiving these exceptions. Their major findings highlight an important aspect of how institutional policy can impact partnerships with families. They found that families of younger patients who identified as either White or Hispanic/Latino were more likely to request exceptions to visitation policies. They also found small but significant evidence of this same bias in critical care units where Black families were less likely to have their request for an exception granted. A major factor the authors point out is that the granting of these exceptions is disparate, but, more importantly, the requests were as well. They offer some thoughtful discussion as to why this might be, and it has direct implications for the ethics of how we partner with families.

Also in this issue of *JPE*, Wolfe and Turk provide a clinical report that highlights the complex intersection of social policy, law, and institutional policy and the pitfalls that can have real ethical implications in how we partner with families.<sup>3</sup> Many

having transparent conversations and building a strong partnership.<sup>4</sup> A cancer diagnosis sparked a journey through the complex world of healthcare. As the journey progressed, it became increasingly difficult. Having a strong partnership with the team, as well as the team's continuing to center parents in the space with the child, helped the family and team understand one another and navigate difficult ethical and moral spaces that arose in the child's course.

Beth Wakefield writes about an experience in which even experienced parents of a medically complex child felt overwhelmed and stressed.<sup>5</sup> This space she writes about is one that often goes unnoticed: when members of the same care team give a family differing opinions. Parents are unfortunately often stuck between difficult choices in children's hospitals, and how teams partner with families and how they approach communication, both with the family and between the rotating clinicians, can have significant impacts on the family and the child.

Clinical ethicists are often faced with difficult situations in which parents find themselves in awful scenarios with no good choices; clinicians who are trying to do their best to balance what they see as their professional obligations to the patient, to

the family, and to the care team sometimes feel the stress of seemingly competing obligations. Often, as many things go in ethics, there are no good solutions, or what is “best” is in dispute. Recommendations in these situations often take a more pragmatic approach that focuses on how we engage and approach the situation. This approach recognizes the parents’ narrative while it validates the clinical difficulty of the situation, while it seeks to reframe the situation as partners in care, rather than as adversaries. A focus on “everyday ethics,” sometimes called micro ethics, is a recognition of the ordinary but integral factors involved in everyday clinical encounters.<sup>6</sup> An everyday ethics approach to partnering with families might start with the following assumptions and questions.

Parents want what is best for their child, clinicians do as well, and most people we interact with on a daily basis are not walking around doing unethical actions. We meet parents where they are at, not where we might want them to be. They come with their own grief experience, their own trauma, and their own ways of coping. Clinicians want to provide what they feel is good care. How can we partner with *this* family going forward, even if we disagree with their choices, recognizing (assuming) that their choices are within an ethical zone of parental discretion? What are our obligations to the patient and family in this partnership? How can we satisfy these obligations and be there for the family and patient, allowing them grace and compassion?

#### NOTES

1. A. Schopenhauer, ed. E. Thacker, *On the Suffering of the World* (London, U.K.: Repeater Books, 2020).

2. A. Shim et al. “Do the Rules Always Apply? An Analysis of Exceptions to a COVID19-Era Pediatric Visitation Policy,” in this issue of the *Journal of Pediatric Ethics* 2, no. 1 (2022).

3. I.D. Wolf and D. Turk, “Paternal Rights: The Ethics of Misunderstanding the ‘Legal Right to a Child,’” in this issue of the *Journal of Pediatric Ethics* 2, no. 1 (2022).

4. A. Bekric, “Transparency Conversations that Build Strong Partnerships,” in this issue of the *Journal of Pediatric Ethics* 2, no. 1 (2022).

5. B. Wakefield, “Help Me Understand—Contemplating a Novel Therapy Versus Waiting and Hoping,” in this issue of the *Journal of Pediatric Ethics* 2, no. 1 (2022).

6. S. Kalevor, M. Kurtz Uveges, and E.C. Meyer, “Using Everyday Ethics to Address Bias and Racism in Clinical Care,” *AACN Advanced Critical Care* 33, no. 1 (2022): 111-8.

*Feature*

# Do the Rules Always Apply? An Analysis of Exceptions to a COVID-19-Era Pediatric Visitation Policy

*Ashley Shim, Madison P. Searles, Roger Wong,  
and Amy E. Caruso Brown*

**ABSTRACT****Background**

The COVID-19 pandemic abruptly reversed the long-standing practice of open visitation in children's hospitals, due to the concern that hospital visitors might contribute to the spread of disease. However, little is known about the unintended consequences of such policies, including the potential that they may disproportionately impact children and families of color and those from low-income communities.

**Methods**

We reviewed requests for an exception to a pediatric visitation policy made between August and November 2020 at a mid-size American children's hospital and collected data regarding details of the requests, demographics, family characteristics, and the patients' medical histories. We compared the sample to the general patient population using bivariate tests and developed a

logistic regression model to explore factors associated with the receipt of requests for an exception to a visitation policy.

**Results**

Regression models indicated that Black families were less likely to have their request for an exception to the visitation policy granted, compared to White families (odds ratio, OR = 0.06; 95 percent confidence interval, CI 0.01-0.84;  $p < .05$ ). The families of children who were admitted to critical care were more likely to have their request for an exception granted (OR = 28.35; 95 percent CI 1.43-562.37,  $p < .05$ ). Two of the three reviewers of requests for exceptions were found to be less likely to grant a request for an exception (OR = 0.05; 95 percent CI 0.00-0.84;  $p < .05$ ; OR = 0.03; 95 percent CI 0.00-0.67;  $p < .05$ ).

**Conclusions**

Our findings highlight the need to reconsider the risks and benefits of highly restrictive visitation policies that disproportion-

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ately impact vulnerable and marginalized children and their families. This study also provides a model for the broader, prospective analysis of the potential for disparities in the impact of any institutional policy.

## INTRODUCTION

Over the past 150 years, the general trend in pediatrics has been toward the promotion and adoption of increasingly unrestricted visitation policies, recognizing that children, families, and healthcare professionals *all* benefit when families are able to be closely involved in their child's care.<sup>1</sup> The COVID-19 pandemic abruptly reversed that trend due to concern that hospital visitors might facilitate the spread of the virus in an especially vulnerable setting and population. However, there was not a nationwide consensus among the facilities on how to standardize these visitation policies. Guidelines ranged from extremely restrictive (for example, no visitors permitted at any time) to mildly restrictive (for example, two adult visitors of any relation permitted at the same time).<sup>2</sup> The psychological and moral trauma that such policies have inflicted upon patients, families, and health professionals has been widely reported in the literature.<sup>3</sup>

For example, a recent "Ethics Rounds" in the journal *Pediatrics* described a case involving the single mother of a five-year-old girl who was admitted to the intensive care unit who had no close family or friends to care for the patient's younger sibling during the admission; the option of temporary childcare potentially posed new, unquantifiable risks to the sibling. At the same time, the patient's agitation in her mother's absence presented a risk to the patient, perhaps greater than the risk of the sibling being allowed to stay in the confines of her sister's room.<sup>4</sup> The impact of these types of situations is not equally distributed nor equitably experienced, with families who have fewer resources due to historical and ongoing structural oppression and systemic racism being more likely to be negatively affected.

To date, however, no studies have systematically described the unintended consequences of such policies, particularly the potential for them to disproportionately impact children and families of color and those from poor communities. We sought to explore this through an analysis of requests for an exception to one pediatric hospital's visitation policy. The manner in which a policy is implemented and the exceptions that are permitted to such a policy provide a lens through which to better understand the impact of structural racism and inequity.

Here, we characterize the nature of requests for an exception to a pediatric hospital's visitation policy that were made during the pandemic and analyze what demographic, family, and medical characteristics were associated with making a request and with having a request granted.

## PARTICIPANTS AND METHODS

### Eligibility Criteria

The study was conducted at a 71-bed pediatric tertiary care facility that is part of a large academic medical center in the Northeastern United States that serves a 19-county region with a population of 1.8 million. During the time period of the study, pediatric patients were initially permitted one visitor at the bedside, with no changes in the visitor permitted during the patient's stay; the single visitor was also not permitted to leave the patient's bedside. The policy was subsequently modified to permit up to two visitors at the bedside. Although an exception to the policy could be requested, families were not formally educated regarding the exception process nor were criteria specified for the review of such requests.

Requests for an exception to the visitation policy were submitted by staff who were involved in direct patient care to one of three pediatric administrators who rotated being on call for this purpose and who made decisions independently, although they could choose to consult one another. Administrators served in this capacity for one week at a time and evaluated all requests submitted during their call block. Families were informed of the visitation policy at the time of admission but were not formally or consistently educated regarding the possibility of obtaining an exception or the mechanism to use to request an exception. Requests for an exception that were made during the study period were logged in a paper file that was stored in the department's administrative offices. All requests for an exception ( $N = 157$ ) that were placed between 11 August 2020 and 29 November 2020 were included in this study.

### Collection of Data

Data were extracted from the logbook for requests for an exception (a paper file) into a REDCap database created specifically for this purpose. The logbook included the nature of and reason for the request, the patient's location in the hospital, the staff member who filed the request, the administrator who reviewed the request, and whether and how the request was granted; identifying information

(patients' name, medical record number, and date of birth) was sometimes recorded in the logbook. The nature of and reason for the request for an exception to the policy were recorded as both narrative and categorical data. For each request for an exception that included identifying information, the patient's electronic medical record was reviewed for additional information, including the patient's diagnosis, prognosis, length of stay, age, gender, race, ethnicity, language spoken at home, place of residence, and insurance status. Qualifying factors such as smoking, breastfeeding, caregiver's health concerns, and childcare and custody issues were also documented. Identifying information was not extracted into the database.

hour), presence of custody/childcare issues (yes or no), and presence of any caregiver's health issue (yes or no). Medical variables included: the admitting service (all inpatient pediatric units, the pediatric intensive care unit, or "other," which included rehabilitation, psychiatry, day surgery, and the emergency department), and short-term prognosis (fair, good or excellent, poor or very poor, or end of life). A variable for the reviewers (three individuals) was also included.

#### Data Analysis

When we compared our sample population to our broader pediatric general population, we used a series of binomial tests to analyze whether there

***For admitting service, the most commonly granted requests for an exception to the visitation policy were for caregivers with a child who was admitted to the pediatric intensive care unit (84 percent).***

For our statistical analyses, comparison data regarding the broader population served by the children's hospital were extracted from the hospital's internal database (Clarity), which is updated daily with information from the hospital's electronic medical record system (Epic). All encounters between 11 August 2020 and 29 November 2022 in the emergency department, inpatient, and surgery were included. Data extracted included visit type, patient age, gender, race, ethnicity, primary language spoken at home, and insurance type.

#### Variables

For our regression model, the dependent variable was whether or not a request for an exception to the pediatric visitation policy was granted. Independent variables consisted of demographic, family, medical, and reviewers' characteristics. Demographic variables included: age (continuous), race and ethnicity (White non-Hispanic, Black/African-American, or Hispanic/Latino), gender (male or female; included a nonbinary/nonconforming category but no patients identified as such), and insurance status (private or employer-based insurance or non-employment-based public insurance). Family variables included: distance from hospital (zero to 30 minutes, 30 minutes to one hour, or greater than one

were significant differences in gender, language, and insurance status between the two groups. A one-sample *t*-test was used to examine whether our sample's mean age was significantly different from the mean age of the general population. A *chi*-square goodness of fit test was used to analyze whether the observed racial composition in our sample differed from that of the general population.

We developed a multiple logistic regression model to explore whether any demographic, family, medical, and reviewer variables were associated with whether a request for an exception to the visitation policy was granted. Missing data were removed with listwise deletion, which left 73 people who had complete data for our dependent and independent variables. The highest correlation coefficient was 0.42 between age and custody/childcare issues. There were no independent variables with a variance inflation factor (VIF) greater than 10. Specifically, the highest VIF was 1.8 for the custody/childcare issue variable, and the average VIF for the whole regression model was approximately 1.5, which indicated there was no multicollinearity. All analyses were performed using IBM SPSS Statistics version 28.0 (Armonk, New York) and, unless otherwise indicated, with two-tailed tests at a .05 significance level.

### Ethical Approval

The study was reviewed by the SUNY Upstate Medical University Institutional Review Board and was declared exempt (project no. 1691025-1 and 1809398-1).

## RESULTS

### Sample Characteristics

Among 157 individuals in the full sample, 117 (74 percent) were granted an exception to the pediatric visitation policy. Most in the sample were male (64 percent), White (64 percent), and had non-employment-based public insurance such as Medicaid (69 percent) (see table 1). Most families lived zero to 30 minutes from the hospital (40 percent), did not have custody or childcare issues related to the request for an exception (63 percent), and did not have any caregiver health issues (80 percent). Slightly more than half of all of the patients were admitted to inpatient pediatrics (56 percent), most commonly with a fair, good, or excellent short-term prognosis (86 percent).

The demographic, family, and medical characteristics for those who were granted an exception to the visitation policy are listed in table 1. A higher percentage of White (79 percent) and Hispanic/Latino (79 percent) caretakers received an exception to the visitation policy than did not; slightly more than half (57 percent) of those who were Black had received an exception to the visitation policy. For admitting service, the most commonly granted request for an exception to the visitation policy was for a caregiver with a child who was admitted to the pediatric intensive care unit (84 percent). Short-term prognosis had the greatest impact when a child was deemed to be at the "end of life"; 100 percent of their caregivers were granted a request for an exception (see table 1 for more detail).

The nature of the request was stratified by the exception to the pediatric visitation policy that was granted, to determine which types of requests for an exception were most commonly granted and declined. Most commonly, caregivers requested an exception for an additional caregiver, followed by a request for an exception for a caregiver to return or leave (see figure 1). Most often, an exception was granted for an additional caregiver (81 percent), followed by an exception requested for a caregiver to return or leave (70 percent).

### Comparison to the General Population

For the purposes of this study, "general population" referred to all patients who were admitted or

treated at the children's hospital during the study time period, regardless of whether an exception to the visitation policy was requested on their behalf. Significant differences were noted with regard to age, gender, the language spoken at home, and race. The average age was significantly lower among our sample (mean = 7.36) compared to the general population (mean = 8.99,  $t[127] = -2.86$ ,  $p < .05$ ). The proportion of female patients for whom a visitation exception was requested (36.3 percent) was lower than the proportion of female patients in the general population (51.4 percent) (binomial test, one-tailed,  $p < .05$ ). The proportion of patients who primarily spoke English at home in the study sample (88.5 percent) was lower compared to the proportion of English-speaking patients in the general population (95.8 percent) (binomial test, one-tailed,  $p < .05$ ). The racial composition in our sample was significantly different compared to the general population ( $\chi^2[2] = 9.94$ ,  $p < .05$ ); the study sample included relatively more White and Hispanic/Latino patients and fewer Black patients compared to the general pediatric population treated during the study period. A binomial test indicated no significant difference between our sample and the general population with regard to insurance status (one-tailed,  $p > .05$ ).

### Regression Analysis

When looking at demographic variables, results from the multiple logistic regression indicated race was significantly associated with a granted exception to the pediatric visitation policy. Those who were Black were 0.06 times less likely to have their requested exception granted compared to those who were White (OR = 0.06, 95 percent CI 0.01-0.84,  $p < .05$ ) (see table 2). The primary service was also significantly associated with receiving an exception. People who requested to visit a patient in the pediatric intensive care unit were about 28 times more likely to have their request for an exception granted compared to those who requested an exception to visit a patient on an inpatient pediatric unit (OR = 28.35, 95 percent CI 1.43-562.37,  $p < .05$ ). The reviewer who was assigned to a request was also significantly associated with an exception to the pediatric visitation policy. Compared to Reviewer #1, Reviewer #2 was 0.05 times less likely to grant an exception (OR = 0.05, 95 percent CI 0.00-0.84,  $p < .05$ ), and Reviewer #3 was 0.03 less likely to do so (OR = 0.03, 95 percent CI 0.00-0.67,  $p < .05$ ). All of the other variables were not significantly associated with a request for an exception to the pediatric visitation policy. The logistic regression model was statistically significant ( $F[15] = 25.89$ ,  $p < .05$ ). Our

**TABLE 1:** Sample characteristics of all exception requests (N= 157) placed between August 11 and November 29, 2020

	Study sample		Exception granted		Exception not granted	
	Mean	Standard deviation	Mean	Standard deviation	Mean	Standard deviation
Age	7.36	6.46	6.86	6.21	9.39	7.02
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Sex						
Data missing	--	--	18	2	12	3
Male	79	7	60	6	18	5
Female	45	4	36	3	9	2
Data missing	--	--	21	2	13	3
Race						
White	83	7	65	6	17	5
Black/African American	14	1	8	1	6	2
Hispanic/Latino	14	1	11	1	3	1
Data missing	--	--	33	3	14	4
Insurance status						
Private	36	3	30	3	6	2
Medicaid/CHP	81	7	59	6	21	6
Data missing	--	--	28	3	13	3
Family's Distance from hospital						
0-30 minutes	49	4	35	3	13	3
30 minutes-1 hour	32	3	25	2	7	2
>1 hour	43	4	35	3	8	2
Data missing	--	--	22	2	12	3
Presence of custody/childcare issues						
None	84	7	68	6	15	4
Custody issues	19	2	10	1	9	2
Childcare issues	30	3	24	2	6	2
Data missing	--	-	15	1	10	3
Presence of caregiver's health issue						
No	21	2	17	2	4	1
Yes	85	7	63	6	21	6
Data missing	--	--	37	3	15	4
Admitting service						
Inpatient pediatrics	88	8	59	6	28	8
Pediatric intensive care unit	43	4	36	3	7	2
Other	27	2	22	2	5	1
Data missing	--	--	0	0	0	0
Short-term prognosis						
Poor or very poor	15	1	14	1	1	0
End of life	3	0	3	0	0	0
Fair, good, or excellent	111	10	84	8	26	7
Data missing	--	-	16	1	13	3
Visitation exception request reviewer						
Reviewer #1	40	3	32	3	7	2
Reviewer #2	69	6	49	5	20	5
Reviewer #3	42	4	29	3	13	3
Data missing	--	--	7	1	0	0
Total 1,153	1,071	372				

model has adequate model fit, indicated by 83.6 percent cases correctly classified and a nonsignificant Hosmer-Lemeshow test ( $\chi^2[8] = 5.25, p = .73$ ).

**DISCUSSION**

To our knowledge, this is the first study to systematically describe the nature of requests for an exception to a pediatric visitation policy and to analyze the demographic variables associated with making a request and receiving an exception. We found that the families of patients who were younger, male, White, or Hispanic/Latino and/or English-speaking were more likely to request an exception than those who were not. We also found that the families of patients who were White and/or admitted to the critical care unit were more likely than others to receive an exception, once requested.

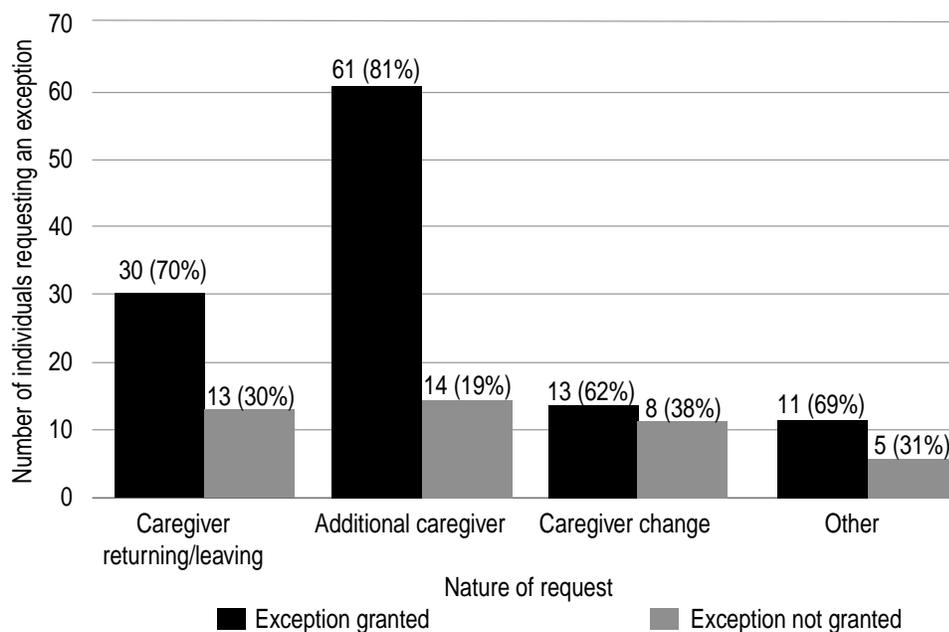
While the latter is understandable—admission to a critical care unit is a marker of the severity of a disease and may portend a poor prognosis, or at least a high likelihood of medically complex decisions to be made—the small but significant bias against Black patients in granting an exception to the visitation policy is not. Although the policy itself was not race-conscious, and the reviewers of the requests for an exception were not deliberately informed of the patient’s and family’s race, there are many ways that racial bias might have inadvertently influenced the process, beginning with families’ institutional

literacy and self-advocacy. The process to request an exception was not widely advertised, and families with a greater understanding of how hospitals function may have been more likely to recognize the possibility that an exception to the policy might be requested. Barriers to communication between bedside caregivers and families of color and/or those who did not speak English—both of which are widely recognized in the literature—may also have contributed, leading staff to be less likely to suggest requesting an exception to Black families.<sup>5</sup> Further, as bedside staff were then most likely to convey a request for an exception to the administrators who evaluated them, their own biases may have influenced how requests were presented. The significant variation between reviewers is further evidence of the subjectivity inherent in this process. As Crear-Perry and colleagues have noted, merely wanting “not to be racist” does not make just policy.<sup>6</sup>

Some studies have reported that Black patients are less likely to self-advocate in medical encounters than their White counterparts, while other studies have reported that Black patients are more likely to be labeled as “difficult” or “demanding.”<sup>7</sup> It is possible that Black families who made a request during the time of this study were less likely to advocate for themselves and/or more likely to have had their advocacy perceived negatively. Additionally, the reasons behind the requests and the nature of the requests themselves may have differed between Black

and White families. As Black families are more likely to have lower household incomes, to work in lower paying jobs, and to be headed by a single parent,<sup>8</sup> they may have been more likely to make a request for an exception that was motivated by work and child-care obligations than White families would have been, and their request may have been perceived unfavorably in comparison with families with greater resources who were able to make alternative child-care arrangements, take family leave, and/or work from the hospital during their child’s ad-

**FIGURE 1:** Pediatric visitation exception stratified by nature of request



mission and whose reason for requesting an exception may have therefore been quite different.

Such inequities, while not separable from structural racism, also affect families regardless of their racial and ethnic identities, and while our study identified systemic concerns, it is important to remember that individual families experience these injustices, and to call attention to the balance of power in such situations and question how the risks and benefits of restrictive visitation policies are

weighed, whose needs are prioritized, and whose judgment is trusted. Health professionals have long noted concerns about inequity in restrictive visitation policies and that such policies are often arbitrary and unrelated to the evidence.<sup>9</sup> This has been particularly evident through the COVID-19 pandemic: despite passing the two-year mark, to date, no published evidence supports the most restrictive visitation measures nor has it demonstrated that more flexible policies lead to harm. Virtually all ar-

**TABLE 2:** Multiple logistic regression exploring the relationship between visitation exception and demographic, family, and medical variables

	Odds ratio	95% CI	p value
Age	0.94	0.81 - 1.11	.48
Sex			
Male		reference	
Female	0.52	0.09 - 2.94	.46
Race			
White		reference	
Black/African-American	0.06	0.01 - 0.84	.04
Hispanic/Latino	0.17	0.01 - 1.94	.15
Insurance			
Private		reference	
Medicaid/CHP	1.31	0.19 - 8.98	.78
Family's distance from hospital			
0-30 minutes		reference	
30 minutes-1 hour	6.87	0.41 - 114.79	.18
>1 hour	2.55	0.31 - 21.11	.39
Presence of custody/childcare Issues			
No custody or childcare issues		reference	
Custody issues	17.75	0.70 - 448.06	.08
Childcare issues	1.97	0.19 - 20.25	.57
Presence of caregiver's health issue			
No		reference	
Yes	1.18	0.11 - 12.76	.89
Admitting service			
Inpatient pediatrics		reference	
Pediatric intensive care unit	28.35	1.43 - 562.37	.03
Other	1.13	0.08 - 15.57	.93
Short-term prognosis			
Fair, good, or excellent		reference	
Poor or very poor	1.64	0.08 - 35.43	.75
Visitation exception request reviewer			
Reviewer #1		reference	
Reviewer #2	0.05	0.00 - 0.84	.03
Reviewer #3	0.03	0.00 - 0.67	.03
Number of observations	73		
Model significance	$\chi^2(15)=25.89$		$p < .05$

guments that support restrictions are based on studies of the transmission of other respiratory viruses, pre-COVID-19, and of seasonal visitation restrictions, which have rarely, if ever, been as restrictive as COVID-19-era policies.<sup>10</sup> Further, at least one COVID-19-era study has raised concerns about patients' safety outcomes in hospitals that have the most restrictive policies.<sup>11</sup> Such a lack of data should be viewed in light of the data we do have at this point in the pandemic—that vaccines are effective and widely available, including for children five to 17 years of age; that masking and social distancing, too, are effective countermeasures; that personal protective equipment is no longer in short supply; and that most healthcare workers are acquiring COVID-19 at home or in the community, not at work.

What would it take to create a more equitable policy? Campelia and Brown's recent commentary in the *American Journal of Bioethics* suggests some questions as starting points, including considerations of inclusivity in the decision-making process, data collection and transparency, shared responsibility, and stakeholders' feedback.<sup>12</sup> With regard to visitation policies, hospitals should include patients, families, and other community stakeholders in the development and review of a policy. Development should be transparent, and evidence supporting policy decisions should be made readily available to all interested parties. Data regarding implementation and impact of a policy should be collected prospectively—not retrospectively, as in our study—and it too should be transparent and easy to access. Responsibility for policy decisions should be shared and should not be the exclusive province of health professionals. Since such policies are designed for our benefit as well as for the benefit of patients and families, such transparency and shared responsibility are essential to mitigate the obvious power imbalance and promote equity.

We recognize several limitations of this research. First, our data were taken from a single, mid-sized, tertiary-care pediatric institution during the fall of 2020, and may not be generalizable to other institutions. Second, our sample size was further limited by the fact that not every request for an exception was thoroughly documented and linked to a medical record number, which prevented a review of the electronic medical record for some requests, although we have no reason to suspect bias in the recording of medical record numbers. Third, the cross-sectional nature of this study prevented us from establishing causality between demographic, family, and medical characteristics and the granting of a request for an exception to the visitation policy.

## CONCLUSION

Crear-Perry and colleagues have called for the systematic collection of data in order to scrutinize hospital policies for evidence that they are being applied inconsistently or unjustly, and/or impacting some groups more than others.<sup>13</sup> This study is a call for change at all hospitals with restrictive visitation policies that are likely to disproportionately impact vulnerable and marginalized children and their families. It also offers a model for prospective analyses of the potential for disparities in the impact of any institutional policy, including policies regarding behavioral contracts, nonbeneficial treatment, and other practices: "equity as a built-in process outcome" in institutional policy.<sup>14</sup>

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## ***Clinical Report***

# **Paternal Rights: The Ethics of Misunderstanding the “Legal Right to a Child”**

*Ian D. Wolfe and Doug Turk*

### **ABSTRACT**

Establishment of paternal rights is an unseen and misunderstood process. Generally the establishment of maternal rights is clear, and paternal rights are thought to naturally fall to the person designated as the father. However, in practice there are some nuances that can lead to negative impacts towards partnering with parents. One of these nuances, the marital presumption, is not widely known. In the United States, the marital presumption of paternity can leave some nonmarried or spiritually or culturally married fathers finding themselves having to petition for paternity rights. This clinical report will discuss some relevant history of paternity that has influenced how paternal rights are viewed in the U.S. We provide a case example of how these nuances affect families, discuss the legal and ethical considerations, and provide guidance to clinicians who might face these complicated situations.

### **INTRODUCTION**

Imagine that your partner goes into labor and delivers before you can make it into the hospital. Say you cannot make it to the hospital until a day later. You walk into the hospital excited to see the

child you and your partner have brought into the world. You step up to the desk and inquire to where they are. The person at the desk says you are not listed as a legal guardian. Puzzled, you tell them you are the child’s father. The person then says, “I’m sorry sir, you need to contact the child’s mother to sign a release of information allowing us to let you see your child and receive updates on how your child is doing.” And then, “You have no legal right to this child.”

How would you feel? What does it even mean? How can you be the father of a child and not have any legal right to the child?

### **ESTABLISHING PATERNITY**

Legal parenthood is established differently for mothers and fathers in the United States.<sup>1</sup> Paternal rights are afforded through a marital presumption—the husband of the woman, at conception and/or at birth, is the father. Maternal rights, in nonsurrogate childbirth, are inherently presumed. This means that when a child is born to an unmarried woman, legal guardianship is granted to the mother only.

One can usually be certain of maternity; however, prior to DNA testing, biological paternity might have been uncertain. Different societies have developed different procedures and norms to assign paternity in the face of uncertainty. In the U.S., legal genetic paternity, outside of marital presumption,

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can be obtained through an acknowledgment of paternity by the father, or a legal petition for determination of paternity can be sought.<sup>2</sup>

Historically, there have been many approaches to the problem of what to do when biological maternity is known but biological paternity is not. In one example, paternity was based on establishment through paternal intention. This method of establishing paternity in cases of unmarried women dates back to the Roman Empire. In Roman times, as early as 400 BCE, children had to be accepted by the father, an intention to parent. The basic thought was that one could always be certain of who the mother of the child was, but there was not this same certainty for the father, and based on the notion of *patria potestas*—the father's will and power—the lives of children were defined by the fathers as their property; they could choose whether to accept the child.<sup>3</sup> This was an era when unwanted children were often abandoned and either adopted, enslaved, or died. With child mortality high, children often did not receive a name until they were thought to have survived childhood.<sup>4</sup>

While the issue of paternal rights might not seem like a very pressing issue, that might be because many take it for granted. It also has the potential to negatively impact how pediatric clinicians partner with families. Hospitals and clinics have to work with established societal policies, and they need to provide some control of visitors. However, new fathers may not be aware of how to establish paternity until they are halted from entering the hospital to see their child. This process is probably one of the last things you think about when you are expecting a child, and sometimes even later on in life.

### CASE EXAMPLE

A young adolescent was admitted for a significant infection that caused multiple complications that required a period of intubation and impacted her neurologic functioning, possibly long term. She was accompanied to the hospital by her father and his partner, who was not the patient's biological mother. The father explained that he and the patient's biological mother created an arrangement 10 years earlier that he would assume all responsibilities and care for their child, and she would have visitation at agreed-upon times. The biological mother was present at the hospital and began to inquire about assuming care of child, and asked about applying for various financial benefits for the child who might have had new medical needs or disabilities associated with that crisis. Dad was not only

concerned about his child's medical crisis, but also he learned that he could not stop the biological mom from assuming care for their child, as there was no legal aspect to their arrangement. Dad was concerned about how destructive this might be for his child as she recovered and was displaced from her known, supportive, family environment. Dad went to court during this hospital admission to attempt to establish paternal rights emergently and was denied. Fortunately, as the patient's recovery continued, her biological parents were able to agree that the patient would return to her dad's home, and Dad planned to pursue more definitive legal rights following his daughter's admission.

In this case, the father was the person who brought the child into the hospital, and was thus granted access by the hospital. This privilege was not necessarily policy, but was more of a practice. It was generally assumed that a parent who brought an ill child to the hospital had some connection to the child, and pragmatically this parent would be the only source of information about the child. In this case, suppose the child was brought into the hospital through emergency services, and her mother arrived first. According to many hospital admission processes, legal guardianship would have been established and updated in the child's chart. The father would have been stopped at the point of entry and likely denied access until he was granted access by the child's legal guardian, the child's mother. For many, this would seem like a procedural inconvenience, and one with good intentions, but for many fathers this would be a negative interaction that affects how they view their role in partnering with the healthcare team.

### ETHICAL AND LEGAL PARENTAL RIGHTS

When people are fathers to expected children, they assume the role of fathers, and they take their obligation and responsibility from this social norm, and, with that, they expect the societal rights and privileges that will allow them to fulfill their paternal obligations. It's a natural process that we in society grant, based on the child being genetically linked to a particular parent. We even bestow this moral status on figures in a child's life who are not genetically related, but who have assumed the role through their agency and intentions. This role contains responsibilities that are separate from the law or the social institution of marriage. The important distinction is that there is a socially constructed and legally constructed right to parental authority. Even when there are questions around legal parental

rights, there is often still a consideration of parental inclusion in medical decisions, even when the state has the final say, sometimes even when parents are at risk of losing parental rights.

In Minnesota, the state where these authors practice, a father, along with a child's mother, have up to 10 months to make a declaration of parentage under oath in front of a notary.<sup>5</sup> A "Recognition of Parentage" form can be filled out to establish a legal connection between a father and child, but this does not equate to legal custody. If recognition of parent-

ians who needed permission to visit their child. Visitor restriction policies varied between children's hospitals, but most policies restricted visitation to only two adults—often presumed to be a child's legal guardians. Some hospitals allowed those identified as caregivers to visit.<sup>8</sup>

There is a difference between a "legal" right and an "ethical" right. What is legal is not always ethical, and what is ethical is not always legal. The two domains are not synonymous. This is exactly why we continue to enact new laws and remove old ones.

***Fathers of newborn infants who have not established paternal legal rights should still be afforded the ethical right to exercise their parental duty to be involved in decision making.***

age does not happen, a father must go through the court process of paternal adjudication.<sup>6</sup> This process can be initiated by the child, the mother, or the presumed father.

Parents can lose their parental rights through criminal action, be it abuse, negligence, or abandonment. Parents can also give up their parental rights, such as in an adoption. This is ethically different than not establishing parental rights legally. Fathers of newborn infants who have not established paternal legal rights should still be afforded the ethical right to exercise their parental duty to be involved in decision making. Fathers should be included in the care of their child, particularly when there are barriers to a formal declaration of paternity that involve visiting restrictions, reduced hours of visitation, transportation, and so on. Many of these barriers were heightened during the COVID-19 pandemic.

Accommodations can be made to create open communication with the medical team by having the child's mother sign a release of information form that allows the father to receive medical updates when the mother is not present, and even to create temporary legal ties to the child by having both parents sign a Delegation of Parental Authority (DOPA), which authorizes the father to consent for routine medical treatment and educational services.<sup>7</sup>

During COVID-19 visitor restrictions, there was a need to make "exceptions" for fathers who were not identified in the medical record as legal guard-

Many things that were once legal were certainly not ethical, and never were. Likewise, many things that were once illegal were completely ethical.

**AVOIDING THE PITFALLS OF STRUCTURAL CONSTRAINTS TO ETHICAL PRACTICE**

We have an ethical obligation to affirm and honor paternal interests when they are based on a well-established intention. This is particularly important when bias and structural racism exist as undercurrents in our society and our systems. It is easy to use a lack of legal connection as we would use a termination of parental rights.

We should caution ourselves from falling into the trap of relying on a legal nuance (or artifact) for practical or convenience purposes, such as designating fathers as "difficult" and using a nonlegally established paternity status to exclude them from the bedside. Fathers who have yet to declare paternity and are recognized as the father by the mother of the child, or even by the child, are not the same as fathers who have lost or refuse legal paternity. There are many "difficult" parents who have legal parental rights. Inappropriate interactions and behavior in the hospital are just as bad when a person is a parent with legal custody or a visitor; the person's behavior guides our response, not a legal loophole.

While recognition of legal paternity and its process might be practical (or expedient) from a gov-

ernmental perspective, it does impact issues in the hospital, and we should be wary of how we employ it, as clinicians. It is important to know the nuanced difference between termination of rights and unestablished paternity. In termination of rights, a burden of proof has been satisfied that a person may not have the rights of parenthood because extending such rights would be inconsistent with the best interest of the child. In the other case, to deny the person the rights of parenthood without proof is a serious harm to both the parent and child. Our presumption should be to honor parental interests, unless we've gone through a fair process, for good reason, to terminate that right. It is our obligation, and that of society, to meet the burden of proof prior to the exclusion or termination of parental rights. We also need to be aware of the nuances of a situation to ensure that we are not inadvertently being used to unfairly block fathers from being involved in their child's life.

Clinicians can feel caught within an imperfect system—working within social and legal policies, trying to control visitors, providing adequate infection control—but often must deal with incomplete information and slow or imperfect processes. It can be easy for either parent to exploit structural or systemic advantages when they are engaged in a relational conflict, and it can be easy for clinicians to accede to those forces. Some mothers may use their rights to exclude fathers who were involved in the pregnancy or the upbringing of the child when the relationship between the parents dissolves—and fathers may be unfairly removed from this process. There are certainly fathers who should be ethically and legally excluded for valid reasons, such as for the protection of the mother and child.

Clinicians can also explicitly or implicitly misuse a lack of legal paternity. It is important help both parents acknowledge that while there may be a history or dynamics that impact their relationship, they likely have a shared investment in what is best for their child, however difficult their relationship may be. We as clinicians must also be aware that we must not use a lack of legal paternity as a way to get to a decision or situation we might want, in the same way that it is wrong to use the threat of involving child protective services (CPS) to push a parent into a certain position. When we are faced with complexity and uncertainty, in non-ideal situations, it is best to look pragmatically at how to best go forward while we satisfy our many obligations to a child and family. Understanding the nuances, the hazards, and the perspectives of those affected can help us to establish better practices when we partner with families.

## CONCLUSION

Since we work in a pluralistic society, familiarity with the nuances of legal policy may help us to avoid structural barriers to ethical practice. It may help us to avoid being inadvertently unethical. As members of healthcare institutions, we have a greater responsibility to overcome communication difficulties. We should think of the institutional power we wield and how a parent can be vulnerable and powerless against how we put our policies into practice, even when such consideration makes our job harder. Communication breakdowns happen with many families, with or without the involvement of their legal rights. Our ethical obligation is to join together with the parents and families of our patients, as caregivers, and not as agents of the state, even when this will be more difficult for us.

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## *The Family Voice*

# Transparency Conversations that Build Strong Partnerships

*Amanda Bekric*

### ABSTRACT

A mother writes about the experience of learning her daughter has a nontreatable brain tumor. She describes the impact of open communication among all of the parties involved. This transparency and communication aided the family through their journey, establishing trust between the family and team. The author describes how important this was, especially during the last six months of her daughter's life.

Our youngest child was diagnosed with diffuse intrinsic pontine glioma (DIPG), a rare non-operable and nontreatable brain tumor, at the age of one. The diagnosis came after magnetic resonance imaging (MRI) for what we thought would confirm Bell's palsy, due to signs of left-sided partial paralysis, resembling that of a stroke victim, after completing treatment for strep and scarlet fever. Upon diagnosis, we were thrust into a whirlwind of procedures, processes, and an unknown world with a very grim prognosis.

Our primary care team consisted of a very large group of healthcare professionals in the clinic, at the hospital, and at home. Our team, overall, consisted of oncology, neurology, neurosurgery, palliative care, research hospitals, social work, child life,

physical therapy, and psychology. In general, all communication went to all individuals, always. As soon as we found out our child had a brain tumor, I told our oncologist that I wanted to be involved as much as possible and that I didn't want anyone to hide anything from us. Our oncologist encouraged us to be as involved as we wanted. Our team explained to us on several occasions that we are the parents, and we know our child best. This encouraged us to always be open and honest in our questions, concerns, ideas, and even our deepest fears. Our child's needs were incredibly complex due to the type of tumor and outcomes she was facing.

The success of our large team was completely dependent on the ongoing, inclusive, and transparent communication we asked for, from the beginning. This meant learning how to ask for clarification on terminology, asking for help, and learning to voice concerns. In terms of the team, it meant asking us questions to learn about our child's character, likes, dislikes, or simply following up on how a recent trip or first day of preschool went.

Our first two years of the journey were spent in surgery, completing standard treatment and trial treatment protocols, along with therapies, and traveling across the United States regularly. Our last year of medical care was spent learning how to gain compassionate-use authorizations and off-label trials through big pharmaceutical companies, receiving palliative care regularly and treatments that had the

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**Amanda Bekric** writes about the relationship she and her family received from the members of their daughter's medical team.

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least amount of side-effects once our daughter's tumor had grown to a point that we could no longer participate in trials.

During the last six months of our daughter's life, there was one conversation that occurred that remains a vivid memory for me. I was on my way home from work. As I drove along the river, big snowflakes were falling as I peered at the orange glow from the lights that lined the street. I had a call with our daughter's oncologist. I had to tell her something I had been trying to avoid since day one of our daughter's journey. I remember the pain, sadness, guilt, and vulnerability in saying, "I know [our daughter] is dying, but I want to do everything in my power to never give up on her, and always push forward. Our team needs to remind me to pick quality over quantity, and when she passes away, I need our team to continue her legacy by donating to the best researchers. You have to make decisions for her when I cannot."

It was at that moment I was reminded that our team was centered on the care of the entire family, and we were just as much a part of the team as they were a part of our family. They were there to nurture us, guide us, have honest conversations, and hold us up when we couldn't do it ourselves. I truly believe that due to the transparency and honesty that started at the beginning of our journey, we built a strong partnership. I knew I could trust them to make moral and ethical decisions for us should we not be able to do so. Our team knew us, we knew them; there was mutual trust, a bond. They were an extension of our family.

Our child went into inpatient hospice at the end of the summer and spent roughly two and a half weeks in the hospital before passing. Between the entire team and us, every need we had was met. The love, care, support, and concern that our team brought us allows us to reflect on our decisions and have no regrets. No regrets in treatment, quality of life, end-of-life planning, or postmortem tissue donations.

Transparency and honest communication build strong relationships among collaborative groups consisting of medical professionals and families. These actions through our collaborative partnership prove to be one of the most exceptional pieces to any healthcare journey that allows all parties to benefit when it is executed properly.

# Help Me Understand—Contemplating a Novel Therapy versus Waiting and Hoping

*Beth Wakefield*

## ABSTRACT

A mother describes her experience during a hospitalization where her child was transferred to the pediatric intensive care unit. The child was not improving and the team wanted to try a novel therapy. This “Family Voice” article describes the mother’s experience in a complex situation and with seemingly different opinions from the medical team.

In the summer of 2019, our seven-year-old daughter was unexpectedly hospitalized due to a dramatic increase in bleeding and bruising. She was born with a rare chromosomal difference that caused her to be medically complex, so we were quite familiar with the hospital as well as with working with many different careproviders. This hospitalization, however, was unlike any we had previously experienced.

She had been inpatient for a week on a typical medical unit when we were told she would have to transfer to the pediatric intensive care unit (PICU) at the other campus of the hospital’s care system across town. This was a first for us, and we were quite shocked. The transfer was triggered by her new diagnosis of acquired thrombotic thrombocytopenic purpura (TTP). We were informed that this is a criti-

cal illness and needed a higher level of care. The hematologist suggested that her prognosis was good, since she was young and was doing so well in the past week. This was encouraging, but my husband and I were still quite frightened.

After a week in the PICU, undergoing daily plasmapheresis (a process in which unhealthy blood plasma is filtered out and replaced with healthy plasma or a substitute), high-dose steroids, and other typical TTP treatments, we were told by the medical team that she was not improving like they would have hoped by that point. Her platelets were next to nothing and not increasing. This was very discouraging because, despite her critical illness, she still seemed pretty close to her sweet and spunky self. They told us we would have to consider an additional, more novel treatment.

The hematologist explained that there was a new medication for TTP, just approved for use over the past year. The caveat was that it had only been approved for use in adults, and there was very little experience documented for pediatric administration. When we asked for more information, the hematologist was able to gather a couple of cases of use in older pediatric patients. Results were mixed in those cases, therefore not increasing our confidence in the medication.

We knew she couldn’t maintain with such low platelets, but we kept hoping and praying that the next day would be the day they finally started to

**Beth Wakefield** writes about her family’s experience with making a complex decision about their daughter’s care.

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bounce back. But that unfortunately did not happen. We began to feel more pressure to try the new medication.

The stress was really starting to take a toll on all of us; compounded by lack of sleep and watching our child endure daily treatments and procedures with little to no improvement, I was reaching a breaking point. I no longer cared to get myself ready for the day or eat healthy meals. I did what I needed to survive, and in this case, that meant pajamas, Diet Coke, and Cheetos. I just wanted my little girl to get well and that was my primary focus. Everything else took a back seat.

We had heard subtle variations of opinions from the hematologists—depending on who was leading her case on a given day. One hematologist would suggest that improvements can take a while and she was doing okay for someone with TTP, while another would propose we consider starting the new medication soon. Some preferred well-tested therapies, while others were interested in trying more novel treatments. We were overwhelmed by the many discussions and tried to learn more about her illness and treatment options in order to keep up. At one point, I even wondered whether the new medication had been suggested out of medical curiosity or out of medical necessity. While we did understand and appreciate that each of the careproviders had their own perspective and communication style, it complicated our understanding of the severity of her situation. We wondered if we could wait a little longer to try the new medication, or should we have already started it three days earlier. We just didn't know. As parents we were stuck between two difficult choices: to use an experimental therapy or to wait and hope. Both options presented their own stressors and dangers.

It was decided that a care conference would be best, to discuss, as a group, the options in more detail, for the team to answer our remaining questions, and, ultimately, to make a decision on how to move forward. The careproviders attending the care conference included the PICU team, a pain and palliative provider—whom we had just added to our care team for this hospitalization—and the hematologist leading her case that week. Before the meeting, I asked our social worker if there was any way possible for us to get a second hematologist from the team to attend as well. We had already heard several opinions on her case, and felt it would really help us to come to a better understanding to have an additional hematologist involved in this discussion. Despite the difficulty of that request, they were able to have two hematologists attend the care con-

ference. While they could tell us that the members of the team were on the same page, it was particularly helpful for us to see the individual perspectives come together and collectively explain why they felt we should move forward with the new medication. After a long, hard discussion, we agreed to move forward with the new treatment.

We are so grateful that we were able to work through this difficult decision with the help of our daughter's care team. That medication allowed her to finally turn a corner and quite rapidly make improvements. Because the team answered our questions, were patient with our processing, and went above and beyond typical care conference protocol to help us more fully understand the circumstances and medication, we were able to come to an agreement on a care plan that, I believe, may have saved our daughter's life.