Court-Mediated Disputes Between Physicians and Families Over the Medical Care of Children

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Objective: To describe the judiciary’s approach to parent-physician disputes over the care of sick children.

Data Sources: Court publications.

Study Selection: Fifty parent-physician disagreements over the care of children led to physician requests for court intervention and resulted in judicial opinions published by the court. The opinions describe 66 children from 20 states.

Data Synthesis: Physicians prevailed at the initial decision in 44 (88%) of the 50 disputes and at the final decision in 40 disputes (80%). Physicians were more likely to prevail in religion-based disputes than in other cases (27 of 30 vs 13 of 20; P<.03), but they were less likely to prevail in disputes concerning life-threatening or potentially disabling conditions (23 of 31 vs 17 of 19; P<.19). Courts acknowledged the pediatric patients’ views in only 10 of the disputes (9 of the 19 cases involving adolescents and 1 of the 31 cases involving children younger than 12 years). For most courts, the petitioning physicians provided the only source of scientific information.

Conclusions: Published court opinions create precedents for future decisions and provide insight into the consequences of seeking court intervention for the physician who encounters parental refusal of care.


FAMILIES WHO DECLINE MEDICAL care for a child put the physician in an ethical dilemma: respect for the autonomy and privacy rights of the family and the importance of familial support for any therapeutic endeavor are in conflict with the duty to provide the best available care for the pediatric patient. When negotiation fails to lead the family to accept available therapy that might forestall a serious medical problem, the physician may feel obliged to seek judicial intervention. The American Academy of Pediatrics takes the position that physicians are obliged to seek legal recourse when parental refusal places a child at clear and substantial risk.

Historically, the American judiciary has been sympathetic to calls from the medical community for intervention regarding parental refusal of care. In the setting of urgently needed care, mechanisms are in place to make a prompt and enforceable transfer of medical decision authority from parents to a designated surrogate. In most episodes involving the urgent transfer of medical custody, the legal crisis passes into history at the same time that the medical crisis is resolved; neither the family nor the physician has any further interaction with the legal system. The situation is more complicated if the dispute does not require an urgent decision or if the parents (or physician) seek judicial review of an unfavorable initial decision. Less hurried circumstances provide the legal system time to engage the formal machinery of contested hearings and trials that require both parents and physicians to justify their decisions with facts and reasoning presented in their own or others’ testimony. Depending on the status of the court and the custom within the jurisdiction, these formal proceedings and appellate reviews may conclude with a simple decision or may result in a published judicial opinion. Published opinions create legal precedents that serve as mandatory guidance for lower courts in the same jurisdiction and as elective guidance for other courts. For persons outside the legal profession, court publications provide a window on how the judiciary analyzes the issues in these disputes. This article reviews disputes between physicians and parents over the care of sick children, beginning with the first report in 1912.
Methods

Cases were identified using search algorithms within electronic databases of legal publications and review of the cited references. This article examines 65 judicial opinions from the 50 identified disputes that led to prospective requests for judicial intervention and resulted in published court opinions (Table 1).

Results

Demographics

Case characteristics are summarized in Table 2. Because there is no organized way to evaluate or even count the relevant legal decisions that are not accompanied by
published opinions, it is impossible for physicians, attorneys, or magistrates to know how representative these 50 cases are. Requests for appellate review may be particularly uncommon from parents with limited financial resources or energy, when children have received treatment that cannot be reversed, or from physicians and their institutional risk management consultants.

TRENDS ACROSS TIME

The frequency and nature of court-mediated disputes have changed during the past century, reflecting changes in pediatric medicine and in society as a whole. As shown in the Figure, beginning in the 1970s, there was a sharp increase in the number of disputes that led to published opinions. The number of children involved in disputes concerning surgery decreased: 12 of the 20 children in cases before 1970 (including 5 of the 10 children discussed in the 1967 King County opinion), 14 of 46 children in cases after King County (χ² = 3.94; P = .04) (Jehovah’s Witnesses in the State of Washington v King County Hospital, 278 F Supp 488 [WD Wash 1967]). The increase in the number of physician-parent disputes is attributable in part to the development of potentially curative interventions for sick newborns (disputes over transfusions for premature infants began in the early 1970s) and for children with malignancies (disputes over medical intervention for cancer began with Custody of a Minor in 1978) (Custody of a Minor, 375 Mass 733, 379 NE2d 1053 [1978]) (Figure).2

The increase in published disputes may also reflect societal changes favoring patient autonomy and parental surrogate autonomy,1,3-6 as well as the advent of aggressive media coverage. Custody of a Minor concerned a 2-year-old boy with acute lymphoblastic leukemia whose parents were not compliant with the initial regimen of standard therapy and were then resistant to and uncooperative with the recommended care following relapse. A series of disagreements, decided against the parents by the first reviewing magistrate(s) and confirmed by the Massachusetts Supreme Court, received extensive press attention. John Truman, the patient’s managing oncologist at Massachusetts General Hospital, Boston, Mass, describes scrapbooks full of press clippings about the case.7 The following year, a legal dispute over whether a teenager with Down syndrome and cardiac disease should undergo diagnostic catheterization attracted press attention in California (Bothman v Warren B [In re Phillip B.], 92 Cal App 3d 796, 156 Cal Rptr 48 [1978]).8 Since these 2 episodes, many parent-physician disputes have been the subject of lay press reports and public interest. Media coverage, lately supplemented by postings on the Internet, has almost certainly alerted parents to the possibility of successfully resisting unwanted medical care and may also have provided heroic models for pediatricians who believe in the importance of their recommended interventions, increasing the willingness of each side to seek appellate review and, thus, the number of disputes that result in published opinions.

PARENTAL REFUSAL OF CARE ON RELIGIOUS GROUNDS

In the majority of disputes (30 of 50 cases; 42 of 66 children), parents objected to recommended interventions on religious grounds. The relative frequency of religion-based refusals has decreased from 80% (16 of 20 children in cases before 1970) to 57% (26 of 46 children) in cases after King County (χ² = 3.32; P = .10). King County and 16 other cases (26 children) arose because physicians recommended transfusions or surgical treatment that re-
quired blood product support, and consent was refused by parents who were members of the Jehovah’s Witness faith, whose adherents believe that infusion of blood is contrary to God’s law.9,10 Two disputes concerned children with cancer whose Christian Scientist parents would not consent to chemotherapy or follow-up evaluation (Contra Costa County Department of Social Services v Ted B. [In re Eric B.], 189 Cal App 3d 966, 235 Cal Rptr 22 [1987]; Newmark v Williams, 588 A2d 1108 [Del 1991]).11 Eleven disputes (13 children) involved less widely known religious beliefs. While no US Supreme Court case addresses a religion-based parent-physician dispute, a 1944 opinion includes relevant language. Prince v Massachusetts12 upheld the conviction of Sarah Prince, who permitted her 9-year-old niece to sell Jehovah’s Witness publications in violation of state child labor laws. Justice Wiley Rutledge said, “Parents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves.”12(p444) Twenty-six of 46 cases decided since 1944, including all but 3 of the cases involving Jehovah’s Witness families (In the Interest of Kevin Clark, 185 NE2d 128 [Ohio 1962]; In the Interest of J. V., 516 So2d 1133 [Fla 1987]; and Cooper v Wiley, 128 AD2d 455, 513 NYS2d 151 [NY 1987]), cited Prince v Massachusetts for support.

DECISIONS AND OPINIONS AFTER THE ISSUE IS MOOT

Reviewing courts’ opinions published after urgently needed decisions are issued and implemented may appear contrary to the common American court custom of avoiding moot decisions. In Newmark, for example, the Delaware Supreme Court reversed the authorization for chemotherapy of a 2-year-old boy with Burkitt lymphoma whose parents were Christian Scientists. The reversal was ordered on the day following the initial intervention decision, but the supporting opinion was not published until 6 months after the child had died. In Wallace v Labrenz (411 Ill 618, 104 NE2d 769 [1952]), Morrison v State (252 SW2d 97 [Mo 1952]), and State of New Jersey v Perricone (37 NJ 463, 181 A2d 751 [1962]), the state supreme courts affirmed lower-court decisions favoring transfusions, months after the orders were no longer in effect.

The initial ruling for In the Interest of E. G. (161 Ill App 3d 765, 515 NE2d 286 [1987]) followed urgently held hearings after a 17-year-old girl and her family refused transfusions as part of the supportive care recommended by physicians for newly discovered acute non-lymphoblastic leukemia. The court authorized transfusions, discounting the family’s claim that E. G. was a mature minor and entitled to make medical decisions. Over a year later, the Illinois Supreme Court reversed that decision, finding sufficient hearing evidence to support E. G.’s eve-of-majority claim to be a mature minor (State v E. G. [In re E. G.], 549 NE2d 322 [Ill 1992]).

In a few disputes, courts authorized care that was never implemented. In Cooper, Jehovah’s Witness parents refused transfusion for their infant with thrombocytopenia and falling hematocrit. The New York Family Court declared the child neglected and authorized transfusion. The child never underwent transfusion, and the order for intervention was withdrawn. The parents were later denied permission to adopt another child because of the history of child neglect. The New York Supreme Court, reversing a lower court, expunged the prior finding of child neglect, reasoning that recovery without transfusion failed to support the physician’s claim of imminent need for transfusion. There appear to be no initial decisions against intervention followed by death or irreparable harm to the child and, then, reversal in a higher court.

In In the Matter of Christine M. (157 Misc2d 4, 595 NYS2d 377 [1992]), a 4-year-old girl, admitted to the hospital with diarrhea, had not been immunized against measles. Because of an ongoing epidemic of measles in New York, the pediatrician asked for court authorization to immunize the child despite her father’s objection. The New York Family Court found Christine M. to be a neglected child but did not authorize measles vaccination because, at the time of the court’s decision, the measles epidemic had subsided. A few courts specifically addressed the question of mootness, justifying action with the public-policy importance of children’s health care.

THE CHILD’S OPINION

Children’s physicians assign weight to their patients’ views about therapy based on the age and maturity of the patient and the gravity of their medical problems. The relevant pediatric literature is largely anecdotal and includes work by authors like Sanford Leikin and Isabel Traugott, who urge the importance of respecting the autonomy of older pediatric oncology patients, and Lainie Ross, who emphasizes the importance of family integrity. In most of the 50 disputes discussed here, courts went forward without including the patients’ opinions in their deliberations.

Patients’ views are described in 10 cases, including 5 with adolescents’ agreement with parental Jehovah’s Witness–based opposition to transfusion (E. G.; In re Long Island Jewish Medical Center, 147 Misc2d 724, 557 NYS2d 239 [1990]; O. G. v Baum, 790 SW2d 839 [Tex 1990]; Niebla v San Diego, 967 F2d 589 [1992]; and Novak v Cobb County Kennestone Hospital Authority, 849 F Supp 1559 [ND Ga 1994]); 2 in which adolescents joined their parents in opposing surgical correction of cleft palate (In the Matter of Martin Seiferth, Jr, 285 App Div 221, 137 NYS2d 35 [1954]) or postpoliomyelitis deformity (Green Appeal, 488 Pa 338, 307 A2d 387 [1972]; Green Appeal, 452 Pa 373, 307 A2d 279 [1973]); 1 in which a 12-year-old girl disagreed with her father and favored surgical correction of a congenital deformity (In re Hudson, 13 Wash2d 673, 126 P2d 765 [1942]); 1 in which a 14-year-old boy joined his mother in opposing treatment for gonorrhea (In re J. F., 64 Ohio App3d 806, 582 NE2d 1138 [1990]); and Newmark, in which a 2-year-old was said to agree with his parents’ decision to decline chemotherapy. All 5 adolescents who opposed transfusions underwent transfusion, the 14-year-old was treated for gonorrhea, the 3 children involved in disputes over nonurgent surgeries

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were not required to undergo operation, and the 2-year-old with Burkitt lymphoma was not treated.

In 3 disputes, the possibility that an adolescent was old enough to qualify as a mature minor with the right to make an independent binding decision against transfusion was addressed in the court’s opinion. In E. G. and Long Island Jewish Medical Center, judges heard testimony regarding the maturity of the 17-year-old patients and acknowledged that the patients were at the beginning of potentially long courses of therapy that might require later transfusions. The initial decisions rejected the children’s claims to mature status; as noted, the E. G. decision was later reversed. In O. G., the Texas court noted that Texas law recognizes no mature minor concept.

SCIENTIFIC BASIS FOR COURTS’ DECISIONS

Although all courts favoring the physicians’ positions find the parents neglectful, in 48 of the 50 published cases (all except In the Matter of Faridah W., 180 AD2d 451, 579 NYS2d 377 [1992] and In the Matter of the Welfare of David, Martha, and Joyce Price, 13 Wash App 437, 535 P2d 475 [1975]), both parents and physicians were portrayed as motivated by the well-being of the child. Decisions in these cases have turned on the courts’ scientific understanding of the child’s medical predicament.

In all but a handful of the cases discussed here, the applicant physicians were the only source of expert testimony at the hearings. Limited by the urgency of the situation, resource constraints, or religious beliefs, nearly every set of parents relied only on their own statements to defend their decisions against medical intervention. Magistrates were rarely aware of any medical reasoning that might have favored the parental refusal of care; they were even unaware that such reasoning would be possible. Physicians, in the dual role of unopposed expert witness and litigant, may be tempted away from a strictly even-handed presentation of the medical science.

OUTCOME

Forty-four disputes (88%) were initially decided in favor of the physicians, including 24 decided in emergency hearings (Table 3). Thirty-seven of the 44 were reviewed, with 31 ultimately affirmed and 6 reversed. Five of the 6 initial decisions favoring parental refusal of care were reviewed, with 3 affirmed and 2 ultimately decided in favor of the physicians. The likelihood that a physician would ultimately succeed in overriding parental refusal (80%) has not changed across time and was not affected by patient characteristics (age, sex, or disease). Physicians were more likely to succeed against religion-based objections than against other objections (27 [90%] of 30 vs 13 [65%] of 20; $\chi^2=4.68; P=.03$). Relative judicial disfavoring of religion-based objections is consistent with the pediatric profession’s opposition to religious interference with critical care decisions about children.10,17 Judicial lack of sympathy for religious objections may simply reflect the availability of a supportive US Supreme Court opinion.12 Non–religion-based disputes must be decided on de novo reasoning or with support from decisions with less precedent-setting impact.

Emphasis on serious illness as a condition for seeking legal intervention in both pediatric writing1,10,18-20 and the court opinions suggests physicians might be more likely to prevail when serious disease is involved. Instead, there was a trend toward more parent-favorable outcomes in cases involving life-threatening or potentially disabling conditions than in cases involving less serious illnesses (8 [26%] of 31 vs 2 [11%] of 19; $\chi^2=1.72; P=18.98$).

The patient outcome is known for only 11 of the 66 children: 7 died and 4 survived. The judicial opinions describe the good outcomes for the Cooper child, Christine M., and Eric B. (no platelet transfusion, missed measles immunization, and follow-up for retinoblastoma, respectively). Phillip B.’s good health was described in a published eulogy for the attorney whose activism led to the second court review.8

The American pediatrician who seeks court-mandated medical care for a child against the objections of parents is likely to succeed, particularly when the case description calls for immediate intervention or when parental objections are religion-based. Among all disputes leading to published legal opinions, physicians had an initial success rate of 88% and an ultimate success rate of 80%.

Benefits of a successful petition include, most importantly, access to the child and the opportunity to provide what the physician judges is the best available care. Because some parental refusals may meet the definition of child neglect that requires mandatory reporting, physicians may welcome the opportunity to share the deci-

### Table 3. Judicial Outcomes of 50 Physician-Parent Disputes

<table>
<thead>
<tr>
<th>Initial Decisions (Made in Emergency Hearing)</th>
<th>Decisions Made on Appeal: Affirmed</th>
<th>Decisions Made on Appeal or Subsequent Hearing: Reversed</th>
<th>Final Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decisions in favor of a physician’s request for intervention</td>
<td>44 (24)</td>
<td>31*</td>
<td>2†</td>
</tr>
<tr>
<td>Decisions in favor of parental refusal of treatment</td>
<td>6 (1)</td>
<td>3‡</td>
<td>6</td>
</tr>
</tbody>
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*Includes 1 case (B. N.) sent back to the hearings officer for additional consideration without reversal of the order of custody and 2 cases (D. L. E., N. C.) reversed in favor of parental refusal but decided in favor of the physicians on further appeal. Case names and dates are listed in Table 1.

†Includes the Phillip B. cases; one was decided and affirmed in favor of parental refusal of intervention but reconsidered as an adoption petition, and the other was decided and affirmed in favor of the adopting parents who supported the physician’s plan for cardiac evaluation.

‡Includes 2 cases (Green, Seiferth) reversed in favor of the physician’s request for intervention but decided in favor of the parents on further appeal.
In American jurisdictions, most decisions made in response to physicians who seek judicial intervention to enforce treatment recommendations for children against the wishes of the parents do not result in published opinions that describe the ethical, legal, and medical issues of the case. The few physician-parent disputes that do result in published judicial opinions create legal precedents that shape subsequent rulings.

Undesirable consequences of legal intervention are also observed. In several of the reported disputes, the children's medical status or other circumstances changed during the period of judicial intervention, rendering court-authorized interventions inappropriate (King County; Custody of a Minor; In the Interest of D. L. E., 200 Colo 244, 614 P2d 873 [1980]; People ex rel D. L. E., 645 P2d 271 [Colo 1982]; In re Willmann, 24 Ohio App3d 191, 493 NE2d 1380 [1986]; Cooper; and Christine M.). New or ambiguous circumstances may require one or more subsequent petitions (In the Interest of Ivey, Dib: 8-31-75, 319 So2d 53 [Fla 1975]; Custody of a Minor; and Eric B.), and there is risk of unanticipated harm (Cooper).

In disputes involving mature adolescents near the legal age for independent decision making, the historical record suggests that judges are more willing than many physicians to override the patient's preferences.

Court intervention compromises a family's privacy and integrity, may do irreparable harm to the physician's relationship with the family, and may foreclose other approaches to decision making.

Finally, at any time after petitioning for judicial intervention, the physician may find his or her practice under professional or public scrutiny, as a result of the family's decision to seek judicial intervention. By petitioning for court intervention, the physician takes an aggressive stand in favor of treatment, sometimes in the face of a doubtful prognosis. The scarcity of reasoned legal opinions and the universality of the overriding principle placing the child's health needs ahead of other interests have led many courts to use decisions from other states to support their own reasoning, creating a de facto national jurisdiction for court-mediated pediatric care disputes. Petitioning physicians should anticipate both the favorable outcomes and unfavorable consequences experienced by the physicians in the 30 disputes described in formal judicial opinions.

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What This Study Adds

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