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RESOLVING PHYSICIAN–PARENT DISPUTES INVOLVING PEDIATRIC PATIENTS

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ABSTRACT

In 2019, three-year-old Noah McAdams in Hillsborough County, Florida captured headlines when his parents stopped providing him chemotherapy for leukemia. His parents asserted they wanted alternative treatments, citing concerns about the side effects of chemotherapy. The state quickly intervened, removed Noah from his parents' custody, and ordered Noah to complete recommended treatment. Stakeholders often portray such cases in binary terms, characterizing parents as irrational for denying their child a life-saving medical treatment. Multiple articles in the literature describe similar cases: courts can intervene when (1) a child has a life-threatening medical condition, (2) there is an effective treatment, and (3) the benefits of treatment outweigh the risks.

Deeper examination of these cases, however, reveals complex considerations: uncertainty of the child's diagnosis or prognosis, how to balance potentially significant treatment benefits with very serious risks, and varied success of treatment. Agreeing to a specific treatment may mean a potential chance at saving the child's life and the certainty of exhausting available medical interventions. But treatment interventions may also subject the child to unnecessary pain, serious risks, or suffering, without sufficient assurance the child will survive. Intervening in children's medical decision-making implicates a constellation of interests, including: familial privacy, the state's duty of *parens patriae* to protect children, and courts' determination of what constitutes the child's best interest. This article advocates for a model of resolution in pediatric decision-making cases that balances competing legal interests, provides de-escalation strategies, and establishes a procedural framework to improve clinical communication.

INTRODUCTION

In the Spring of 2019, Noah McAdams, a three-year-old boy diagnosed with acute lymphoblastic leukemia, captured headlines when law enforcement removed him from his parents' custody based

on disputes relating to management of his cancer care.[1] Physicians at Johns Hopkins All Children's Hospital treated Noah with two rounds of chemotherapy.[2] When physicians contacted Noah's parents, Joshua McAdams and Taylor Bland-Ball, to schedule follow up appointments for maintenance chemotherapy, they missed their scheduled follow-up appointment.[3] Parents McAdams and Bland-Ball asserted they wanted to obtain a second opinion, explored alternative maintenance treatments, and had concerns about the side effects of ongoing chemotherapy.[4]

Clinicians at Johns Hopkins All Children's Hospital contacted Child Protective Services, who worked in conjunction with the Hillsborough County Sheriff's Office to issue an "Endangered Child Alert."[5] This series of events sparked a nationwide hunt by law enforcement to locate McAdams and Bland-Ball, and, upon discovering their location, they immediately removed Noah from the custody of his parents.[6] A court hearing on the matter confirmed temporary removal of Noah from his parents' custody, placed him

1 Tony Marrero, *Chemo or Natural Remedies? Little Noah Caught in Legal Fight over How to Treat His Leukemia*, TAMPA BAY TIMES (May 2, 2019), https://www.tampabay.com/news/publicsafety/chemo-or-natural-remedies-little-noah-caught-in-legal-fight-over-how-to-treat-his-leukemia-20190501/; Tony Marrero, *Against Parents' Wishes, Judge Orders Tampa Boy with Leukemia to Resume Chemotherapy*, TAMPA BAY TIMES (May 8, 2019), https://www.tampabay.com/news/publicsafety/against-parents-wishes-judge-rules-that-tampa-boy-with-leukemia-will-resume-chemotherapy-20190508/; Anastasia Dawson, *Judge Gives Boy in Legal Fight over Cancer Treatment to Grandparents*, TAMPA BAY TIMES (May 3, 2019), https://www.tampabay.com/news/publicsafety/judge-places-boy-with-grandparents-during-legal-fight-over-his-treatment-for-leukemia-20190502/.

2 Tony Marrero, *Chemo or Natural Remedies? Little Noah Caught in Legal Fight over How to Treat His Leukemia*, TAMPA BAY TIMES (May 2, 2019), https://www.tampabay.com/news/publicsafety/chemo-or-natural-remedies-little-noah-caught-in-legal-fight-over-how-to-treat-his-leukemia-20190501/.

3 *Id.*

4 *Id.*

5 Dawson, *supra* note 1.

6 Tony Marrero, *Against Parents' Wishes, Judge Orders Tampa Boy With Leukemia To Resume Chemotherapy*, TAMPA BAY TIMES (May 8, 2019), https://www.tampabay.com/news/publicsafety/against-parents-wishes-judge-rules-that-tampa-boy-with-leukemia-will-resume-chemotherapy-20190508/; Dawson, *supra* note 1.

with his grandparents for several months, and ordered maintenance chemotherapy.[7]

The series of events in the McAdams case and similar cases highlight opportunities for improving both the communication and resolution process for remediating conflicts in physician-parent disputes involving pediatric patients. State law defines parents' decision to forgo a successful treatment when a child has a life-threatening condition as a form of medical neglect. Unlike the traditional concept of child neglect, however, parents' decisions to decline a specific treatment in many cases is not based on lack of care but rather operating from a different set of values, principles, and goals.

In Part I, this article describes the range of cases that have led to physician-parent disputes involving pediatric patients and asserts that many cases involve a series of complex value judgments about risks and benefits of treatment, different evaluations of what constitutes a sufficient chance of treatment success, and divergent opinions on the goals of treatment. Intervening in children's medical decision-making implicates a constellation of interests including familial privacy, the state's duty of *parens patriae* to protect children, and what constitutes the child's best interest. Part II provides an overview of jurisprudence intersecting family privacy and children's medical decision-making and describes how different jurisdictions determine when the state has authority to intervene in pediatric medical decision-making cases. Part III explores how state mandatory reporting laws pertaining to medical neglect fulfill the state's important duty of *parens patriae*, how to balance this duty against familial rights to privacy, and considerations for due process during judicial intervention. Part IV summarizes approaches that courts take when determining whether ordering treatment over the parents' objection would be in the child's best

[7] Dawson, *supra* note 1; Dan Sullivan, *Parents of 4-Year Old Tampa Cancer Patient Could Be Reunited With Son*, TAMPA BAY TIMES (Dec. 9, 2019), https://www.tampabay.com/news/hillsborough/2019/12/09/parents-of-4-year-old-tampa-cancer-patient-reunited-with-son/; Meagan Flynn, *Police Took a Cancer-Stricken Toddler From His Parents. Their Supporters Call It a 'Medical Kidnapping.'*, WASH. POST (May 2, 2019), https://www.washingtonpost.com/nation/2019/05/02/police-took-cancer-stricken-toddler-his-parents-their-supporters-call-it-medical-kidnapping/.

interest. Finally, Part V articulates a series of recommendations for re-envisioning how clinicians and courts can approach conflicts by reframing parents' intentions, deescalating reactive responses, and employing dispute resolution techniques.

I. OVERVIEW OF CASES INVOLVING PHYSICIAN-PARENT DISPUTES IN PEDIATRIC CARE

Parents have a legal and ethical duty to care for their children by providing them the necessities of life, such as food, clothing, shelter, and medical care. This section outlines parents' legal duty to seek medical care for their child when the child has a life-threatening illness or condition that may cause substantial bodily harm. In many instances, however, disputes between physicians and parents do not reflect a clear binary in which parents simply refuse to obtain medical treatment for a child with a life-threatening illness but instead center around what type of treatment or course of action would promote the child's interests. This section provides an overview of why physician-parent disputes occur, highlighting cases in which parents sought medical care for their child but declined specific interventions based on divergent values, assessments, and risks.

A. Parental Duty to Seek Medical Care

People v. Pierson, one of the earliest cases involving judicial intervention over parents' declining medical treatment, established a duty for parents to seek medical treatment when their child has a life-threatening illness.[8] In *Pierson*, the court examined whether a parent who believed in Divine Healing could claim a religious defense for refusing to seek medical treatment for a "dangerously ill" child who suffered from catarrhal pneumonia and died from complications.[9] The court held that religion did not constitute a defense to provide the child with the basic necessities of life, such as food, clothing, shelter, and medical attendance when it became reasonable to see that the

8 People v. Pierson, 68 N.E. 243 (N.Y. 1903).

9 *Id.*

child's life-threatening condition required medical care.[10] *Pierson's* holding examined the reasonableness of parental conduct and imposed a duty to seek medical care when the child has a life-threatening condition and may die without medical care.

Since *People v. Pierson*, judicial intervention generally involves cases in which: (1) the child has a life-threatening disease or medical condition that will cause substantial bodily harm; (2) proposed treatment has a high chance of success; (3) there are serious risks of nontreatment; and (4) benefits of treatment outweigh the risks.[11] Close examination of these cases reveals the difficulties for determining assessments of benefit and risk, how subjective benchmarks influence a court's outcome, and implicit value judgments that favor treatment over nontreatment.

B. Types of Physician-Parent Disputes

In some instances, media and even courts oversimplify the components of the dispute, asserting parents "refused to seek medical care" for their child that would have prevented "certain death."[12] Yet many cases demonstrate multiple nuances of why parents disagree with physicians' recommendations for treatment, including religious reasons, their desire to seek a second opinion, preference for alternative treatments, divergent opinions on how to manage long-term treatment plans for children, and whether certain procedures offer sufficient benefit compared to risks.

1. Religious Objections to Certain Types of Treatment

A variety of cases involve parents whose sole objection centers around religious claims, such as parents who are Jehovah's Witnesses and do not want their child to receive a blood transfusion based on spiritual beliefs. Some cases anticipate one transfusion, such as for

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10 *Id.* at 244.

11 Lee Black, *Limiting Parents' Rights in Medical Decision Making*, 8 AM. MED. ASS'N J. ETHICS 676, 676-77, 679 (2006); Douglas Diekema, *Parental Refusals of Medical Treatment: The Harm Principle as Threshold for State Intervention*, 25 THEORETICAL MED. 243, 252 (2004).

12 Marrero, *supra* note 1; *In re* Cassandra C., 112 A.3d 158 (Conn. 2015).

infants with medical complications[13] or following an accident with blood loss.[14] Other cases examine whether the state can order ongoing blood transfusions for managing a blood condition such as anemia.[15] Courts generally authorize and order blood transfusions over parental objection, holding there is "eminent danger,"[16] "immediate danger of irreparable [injury,]"[17] or "danger of death" without transfusion.[18]

Even in cases involving religious reasons for declining blood transfusions, some cases reveal that parents do not object to treatment *per se*, but rather the specific intervention of the transfusions. In *Matter of Cabrera*, parents objected to ongoing blood transfusions every three to four weeks as a method to manage the child's sickle cell anemia.[19] Parents sought alternate medical opinions on whether the child's condition required blood transfusions and whether alternative treatments existed.[20] Another case, *In re E.G.*, involved a 17-year-old child with leukemia for whom physicians recommended both chemotherapy and blood transfusions.[21] In this case, the parents agreed to the chemotherapy, but did not agree to the blood transfusions for religious reasons.[22] Similarly, in *In re Green,* the physician recommended a spinal fusion surgery for a teen boy with poliomyelitis and scoliosis.[23] The child's mother consented to the surgery, but based on religious beliefs did not consent to blood transfusion if necessary during the surgery.[24]

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13 State v. Perricone, 181 A.2d 751 (N.J. 1962); Muhlenberg Hospital v. Patterson, 320 A.2d 518 (N.J. Super. Ct. 1974).

14 Novak v. Cobb County, 849 F.Supp. 1559 (N.D. Ga. 1994).

15 Matter of Cabrera, 552 A.2d 1114 (Pa. Super. Ct. 1989).

16 *Novak*, 849 F.Supp. at 1564.

17 *Patterson*, 320 A.2d at 519.

18 *Perricone*, 181 A.2d at 754.

19 *Matter of Cabrera*, 552 A.2d at 1116.

20 *Id*.

21 *In re* E.G., 549 N.E.2d 322 (Ill. 1989).

22 *Id.*

23 *In re* Green, 292 A.2d 387 (Pa. 1972).

24 *Id*.

Here, parents understand the necessity of medical intervention, but disagree with the choice of medical intervention based on an alternate model for assessing risk. Although blood transfusions are generally safe, they do entail medical risks, such as bacterial infection, viral infection, immune suppression, and increased risk of cancer recurrence in cancer patients.[25] For parents who hold religious beliefs against blood transfusions, the risks to the child do not stem from physical risks, but rather the spiritual consequences.[26]

2. Rapid Escalation to Override Parental Hesitation

In cases involving serious and life-threatening diagnoses, several cases demonstrate parents seek certainty of the child's diagnosis, wish to obtain a second opinion, and, particularly in cases involving pediatric oncology, alternative treatments based on risks and long-term side effects of chemotherapy.[27] Two high profile media cases, *In re Cassandra C*.[28] and the case of Parker Jensen, involved children with cancer diagnoses and parents sought a confirmatory diagnosis before beginning treatment.[29] In both cases, the physicians requested state

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25 E. Patchen Dellinger & Daniel Anaya, *Infectious and Immunologic Consequences of Blood Transfusion*, 8(2) CRITICAL CARE S18 (2014).

26 *Why Don't Jehovah's Witnesses Accept Blood Transfusions?*, JW, https://www.jw.org/en/jehovahs-witnesses/faq/jehovahs-witnesses-why-no-blood-transfusions/; *see also* Amanda Schaffer, *How Jehovah's Witnesses Are Changing Medicine*, THE NEW YORKER (Aug. 12, 2015), https://www.newyorker.com/news/news-desk/how-jehovahs-witnesses-are-changing-medicine.

27 John Pevy, *Homeopathy, Holistic Medicine, and Parental Rights: What Role Should the Government Play in Regulating Parents' Rights to Choose Appropriate Care for Their Children*, 21 U.C DAVIS J. JUV. L. & POL'Y 145, 153-54 (2017) (citing parents' desire for alternative treatments constitutes the most common reason for declining treatment); *see generally* Michele Nassin et al., *Family Refusal of Chemotherapy for Pediatric Oncology Patients: A National Survey of Oncologists*, 37(5) J. PEDIATRIC HEMATOLOGY & ONCOLOGY 351 (2015); Amy Caruso Brown & Amy Slutsky, *Refusal of Treatment of Childhood Cancer: a Systematic Review*, 140(6) PEDIATRICS (2017); Jeffrey Hord et al., *Do Parents Have a Right to Refuse Standard Treatment for Their Child with Favorable-Prognosis Cancer? Ethical and Legal Concerns*, 24(34) J. CLINICAL ONCOLOGY 5454 (2006).

28 *In re* Cassandra C., 112 A.3d 158 (Conn. 2015).

29 Jensen v. Utah, No. 2:05CV00739 PCG, 2006 WL 1702585 (2006); *see also* Bryan Hyde, *Parker Jensen and the State as Our Parent*, ST. GEORGE NEWS (Nov. 14, 2020), https://www.stgeorgeutah.com/news/archive/2012/05/14/analysis-parker-jensen-and-the-state-as-our-parent/#.X6WvUGhKhyw; Stephen Hunt, *Parker Jensen's Parents Lose Cancer*

intervention by calling state child protective services (CPS) before the parents could obtain another opinion for the child's diagnosis.[30] Notably, in *In re Cassandra C.*, the physician escalated to state intervention after relaying the child's diagnosis to the mother over the phone before meeting in person to discuss her desire for additional medical opinions or her concerns about drug toxicity.[31] The expedited timeline in some cases for pursuing state intervention based on parents' desire for a second opinion or alternative treatment indicates not merely shortcomings in physician-parent communication, but reflects a model oriented toward producing compliance that relies on invoking disease severity and leveraging state intervention as a form of coercion.[32]

3. Invoking Emergency Circumstances to Accelerate Decision-Making

Cases that involve rapid escalation highlight distinct assessments by the physician and parents of whether to proceed immediately with aggressive treatment or adopt a cautious approach of gathering additional information. Even in cases involving emergency care, the physician and parent may hold divergent opinions on the scope of care necessary to address the emergency condition. In *Mueller v. Auker*, a mother brought her infant who had a fever of 100.8 degrees Fahrenheit to the emergency department for assessment.[33] Based on the infant's fever, the mother agreed to certain tests and in-patient monitoring but declined the physician's recommendation for a spinal tap to rule out meningitis.[34] In this case, the physician estimated a five percent chance

Case Rights Battle, SALT LAKE TRIBUNE (Mar. 30, 2011), https://archive.sltrib.com/article.php?id=51525460&itype=CMSID.

30 *In re* Cassandra C., 112 A.3d at 162-63; Hyde, *supra* note 29.

31 *In re Cassandra C.*, 112 A.3d at 161-63.

32 *See also* Custody of a Minor, 379 N.E. 1053, 1065 (Mass. 1978). In support of authorizing chemotherapy for a child with leukemia, the court adopted physician testimony, holding that because "leukemia cells in the body double in number every four days, *time was of the essence*." (emphasis added).

33 Mueller v. Auker, 576 F.3d 979, 983 (9th Cir. 2009).

34 *Id.*

that the infant's fever could be caused by meningitis.[35] Despite seeking treatment for the infant's fever, the mother believed the risks of a spinal tap did not outweigh the small chance that the cause was meningitis.[36] The physician involved the hospital social worker, who immediately called CPS and the police.[37] The social worker declared that the infant was "in imminent danger" and transferred temporary custody to CPS on the spot without judicial intervention to authorize the spinal tap for the infant.[38] Though the court noted the error authorizing the procedure without judicial intervention, *Mueller v. Auker* and other cases demonstrate preference toward viewing more aggressive interventions as beneficial and invoking exigency to accelerate the decision-making process.

4. Second Opinions and Assessing Long Term Risks and Benefits of Treatment

In several cases, parents consented for their child to undergo initial treatment, but sought a second opinion during the course of treatment. For Noah McAdams, the parents agreed to the initial intervention of chemotherapy, but sought a second opinion on maintenance treatment.[39] Similarly, in *In re D.G.,* parents consented to their child undergoing surgery to remove a cancerous tumor, but sought time for alternate opinions and treatments rather than consenting to immediate radiation and chemotherapy.[40]

With treatment plans involving multiple steps, each intervention carries distinct risks and benefits about which the physician and parents may disagree. In *In re Willmann*, parents agreed to chemotherapy to treat their child's osteosarcoma for several weeks.[41] Following chemotherapy, monitoring revealed the tumor decreased in

35 *Id.*

36 *Id.*

37 *Id*. at 984.

38 Mueller v. Auker, 576 F.3d 979, 983, 985 (9th Cir. 2009).

39 *See supra* notes 1-7.

40 *In re* D.G., 970 So.2d 486 (Fla. Dist. Ct. App. 2007).

41 *In re* Willmann, 493 N.E.2d 1380,1383 (Ohio Ct. App. 1986).

size and could be surgically removed.[42] Physicians, however, asserted surgery should include both tumor removal and amputation of the child's arm and shoulder. Despite agreeing to the chemotherapy, parents declined the surgery based on the child's chance of survival with a surgery that would entail "gross mutilation."[43] Cases involving pediatric oncology patients hint at the complexity of parental decision-making for high-stake decisions involving serious risks, potential benefits, and how to weigh competing interests involved in long-term or multi-step treatment plans. As oncologist Dr. Angela Alessandri observes, although it is often portrayed as parental abuse, neglect, or incompetence, parental refusal for chemotherapy in pediatric oncology instead reflects a conflict of values and estimates of whether benefits of treatment outweigh the risks.[44]

5. Quality of Life and Shifting Goals of Treatment

Compared to physicians, parents may give more weight to the risks of multiple interventions and aggressive treatment. If the treatment would induce pain and suffering without a certain level of potential success, parents may start to shift the goals of care for their child.[45]

In *Custody of a Minor*, the court held that a child with leukemia had "substantial hope for life" with chemotherapy but would face "certain death" without chemotherapy.[46] Physicians estimated a 90 percent chance of survival after one year, and after four years, the potential for survival dropped to 50 percent.[47] While the physicians and court viewed the survival rates with optimism and the court ordered

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42 *Id*. at 1383-84.

43 *Id.* at 1387.

44 Angela Alessandri, *Parents Know Best: or Do They? Treatment Refusals in Pediatric Oncology*, 47 J. PEDIATRICS & CHILD HEALTH 628, 629 (2011); *see also* Jennifer Rosato, *Using Bioethics Discourse to Determine When Parents Should Make Healthcare Decisions for Their Children: Is Deference Justified?*, 73 TEMPLE L. REV. 1, 26-27 (2000).

45 Dominic Wilkinson & Tara Nair, *Harm Isn't All You Need: Parental Discretion and Medical Decisions for a Child,* 42(2) J. MED. ETHICS 116, 117 (2016).

46 Custody of a Minor, 379 N.E. 1053, 1056 (Mass. 1978).

47 *Id.* at 1057.

restarting chemotherapy for the child, the mother focused on the child's quality of life and uncertain potential for long-term survival. After witnessing adverse effects from chemotherapy to the child and considering his long-term survival rates, parents wanted to discontinue chemotherapy.[48] The mother stated: "We would love for [the child] to have a full and long life. But it is more important to us that his life be full instead of long."[49] Such statements suggest parents may view comfort and support measures as more desirable than exhausting medical interventions that impact the child's quality of life when long-term success falls below a certain threshold.[50]

Similarly, several cases address instances when parents initially consented to treatment for their child, but, based on side effects and adverse reactions, change their opinion during the course of treatment. In *In re S.H.*, Sarah Hershberger was an Amish ten-year-old child diagnosed with lymphoma.[51] Hershberger's parents initially agreed to chemotherapy and completed six weeks of treatment, but sought to discontinue treatment based on the side effects and concerns relating to long-term risks.[52]

These cases reflect disputes in which parents agree to the physician's treatment recommendations, but during the course of treatment change their assessment based on additional information, such as side effects or prognosis. Parents may modify their assessment for the goals of the child's treatment based on how the child responds to an ongoing treatment intervention, particularly in cases of pediatric oncology. A systematic review in *Pediatrics* found 73 cases of documented pediatric treatment refusal.[53] Notably, in 45 percent of

48 *Id*. at 1064.

49 *Id*.

50 Hannah Gerdes & John Lantos, *Differing Thresholds for Overriding Parental Refusals of Life Sustaining Treatment*, 32 HEC FORUM 13 (2020).

51 *In Re* S.H., 2013-Ohio-3708 (Ohio Ct. App. 2013); Kim Palmer, *Court Battle Over Amish Girl's Cancer Treatment Ends*, REUTERS (Oct. 9, 2015, 12:55 PM), https://www.reuters.com/article/us-usa-ohio-amish/court-battle-over-amish-girls-cancer-treatment-ends-idUSKCN0S326E20151009.

52 *Id.*

53 Brown & Slutsky, *supra* note 27.

these cases, parental refusal did not occur during initial conversations between physician, parents, and child but instead happened during the course of treatment.[54] This suggests that parents and physicians assess the ongoing benefits, risks, and goals of treatment differently than physicians once parents observe how the intervention affects their child.

6. Distinguishing Between Seeking Medical Care and Agreeing to Recommended Interventions

People v. Pierson imposed a constructive duty on parents to seek medical care when a child is suffering from a life-threatening illness. Yet even establishing this duty, these cases highlight the nuances involved in medical decision-making when considering the severity of illness, how to compare risks and benefits of treatment, the value parents place on seeking second opinions or alternatives, and how parents may assign different weights to intrusive medical interventions, risk assessment, and quality of life than physicians.[55] Importantly, the cases emphasize that dismissing parental concerns or all parental dissent as refusing to seek treatment for their child is both inaccurate and misleading.

II. DETERMINING WHETHER THE STATE HAS AUTHORITY TO INTERVENE IN FAMILIAL DECISION-MAKING

Although physicians may disagree with parents about what course of action constitutes the optimal treatment decision, the physician does not have authority to intervene and request state intervention unless certain factors are present. First, this section describes the foundation for familial privacy and parental rights to make medical decisions for their children. Second, this section sets forth the standard for determining whether the state has authority to

54 *Id*. at 6.

55 Gerdes & Lantos, *supra* note 50; Alessandri, *supra* note 44, at 629.

intervene in the family dynamic during the process of medical decision-making for children.

A. Familial Privacy

Parents are endowed with the care, custody, and control of their children, and the Supreme Court in *Pierce v. Society of Sisters* held familial privacy constitutes a constitutionally protected fundamental right.[56] Parents enjoy wide latitude in decisions relating to child rearing, education, and making medical decisions for their children.[57] Absent a finding of neglect or abuse by a court, parents are the appropriate decision-makers for their children.[58]

The Supreme Court in *Parham v. JR* clarified that "natural bonds of affection lead parents to act in the best interest of their children" and simply because the child, state official, or court may believe a specific medical intervention would benefit the child, this assessment does not transfer decision-making authority.[59] *Pierce v. Society of Sisters* sets forth the proposition that "the child is not a mere creature of the state" but rather under the care and protection of his parents.[60] The special importance and primacy of this familial relationship "militates against government intrusion."[61]

Both courts and physician ethicists such as Dr. Douglas Diekema note that most parents act in the best interest of their children; they know their child best, are best suited to weigh competing interests, and make decisions based on specific values and priorities.[62] Cursory

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56 Pierce v. Soc'y of Sisters, 45 S.Ct. 571 (1925).

57 *Id.*; Parham v. J.R., 99 S.Ct. 2493, 2504 (1979); *see also* M.N. v. S. Baptist Hosp., 648 So.2d 769, 770 (Fla. Dist. Ct. App. 1994); Newmark v. Williams, 588 A.2d 1108, 1115 (Del. 1991); Custody of a Minor, 379 N.E. 1053, 1062 (Mass. 1978); *In re* Matthew V., 68 N.Y.S.3d 796, 801 (N.Y. Fam. Ct. 2017).

58 Parham v. J.R., 99 S.Ct. 2493, 2504 (1979).

59 *Id.*

60 Pierce v. Soc'y of Sisters, 45 S.Ct. 571 (1925).

61 Newmark v. Williams, 588 A.2d 1108, 1115 (Del. 1991).

62 Diekema, *supra* note 11; Alessandri, *supra* note 44, at 628; *see generally* June Carbone, *Legal Application of the "Best Interest of the Child" Standard: Judicial Rationalization or a Measure of Institutional Competence*, 134 (2) PEDIATRICS S111 (2014); Parham v. J.R., 99 S.Ct. 2493, 2505

professional assessments from the state examining children's medical interests alone are insufficient to replace the judgment of a loving and nurturing parent, but instead must be weighed in the context of interwoven interests.[63]

Legal scholars such as Jennifer Rosato suggest that deference for parental decision-making is based on parents' proprietary interests over children and the sociological presumption that parental decisions promote children's interest rather than empirical evidence.[64] But these factors do not fully capture the interests at stake; such as the inherent rights of parents in natural law, the irreplaceable value of the family unit, and the significant principled reasons for protecting the family from undue state interference.[65] Both natural law doctrine and classical liberal tradition dating back to Aristotle, Greco-Roman law, and common law elevates the unity and security of the family relationship as a microcosm of the larger society. Legal scholar Robert John Araujo maintains the stability of the family reflects the stability of the society: undue intrusion, interference, or separation of the family can indicate a concentration of excess power in the state, signaling an unraveling of democratic principles.[66]

For families and children to flourish, they require freedom from intrusion by the state.[67] The court in *Newmark v. Williams* recognized that "preservation of the family unit is fundamental to the maintenance of a democratic society and primacy of the familial unit is the bedrock principle of law.[68] Respecting parental autonomy free

(1979); M.N. v. S. Baptist Hosp., 648 So.2d 769, 770 (Fla. Dist. Ct. App. 1994); *see generally* Newmark v. Williams, 588 A.2d 1108 (Del. 1991).

63 *See Newmark*, 588 A.2d at 1116.

64 Jennifer Rosato, *Using Bioethics Discourse to Determine When Parents Should Make Healthcare Decisions for their Children: Is Deference Justified?*, 73 TEMP. L. REV. 1, 6-8 (2000).

65 *See* John Witte Jr., *The Nature of Family, the Family of Nature: The Surprising Liberal Defense of the Traditional Family in the Enlightenment*, 64(3) EMORY L. J. 591, 597, 601, 618-619 (2015); Robert John Araujo, *Natural Law and the Rights of the Family*, 1 INT'L J. JURIS. FAM. 197, 200 (2010).

66 Robert John Araujo, *Natural Law and the Rights of the Family*, 1 INT'L J. JURIS. FAM. 197, 200 (2010)

67 *See* Diekema, *supra* note 11, at 244; M.N. v. S. Baptist Hosp., 648 So.2d 769, 770 (Fla. Dist. Ct. App. 1994).

68 Newmark v. Williams, 588 A.2d 1108, 1115 (Del. 1991).

from government interference provides continuity while promoting the psychological well-being of the child.[69] The notion of familial privacy involves reciprocal interests encompassing not only a parental right to make decisions for their children, but children's right to be secure in their family structure without state interference.[70]

Several cases overlook the significance of children's reciprocal right of security both in their family structure during initial assessment whether the state has jurisdiction to intervene and during subsequent court hearings. Some cases demonstrate a striking escalation to involve state intervention and law enforcement aimed at swiftly removing of a young child from parental custody based only on disputes relating to medical care.[71] In *Newmark v. Williams*, the treating physician called for separating a three-year-old child from his family, demanding that the court should place him in foster care for the duration of chemotherapy based on parents' medical decisions, even though the parents provided a loving and stable home.[72] Both medicine and courts must recognize that separating children from their parents, especially children of tender years for extended periods of time, constitutes by itself a traumatic intervention when the state does not have other evidence suggesting abuse or neglect.[73]

A child's interest in familial security is not limited to young children, but applies to all children. *In re Cassandra C.* involved a 17-year-old child with Hodgkins lymphoma where both the mother and child wanted a second opinion and alternative treatment rather than chemotherapy.[74] In the case of Cassandra C., the state ordered

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69 *Id.*

70 Novak v. Cobb County, 849 F.Supp. 1559, 1567 (N.D. Ga. 1994).

71 *See supra* notes 1-9.

72 *Newmark*, 588 A.2d at 1119.

73 June Carbone, *Legal Application of the "Best Interest of the Child" Standard: Judicial Rationalization or a Measure of Institutional Competence*, 134(2) PEDIATRICS S112 (2014).

74 *In re* Cassandra C., 112 A.3d 158, 160 (Conn. 2015); Elizabeth Harris, *Connecticut Teenager With Cancer Loses Court Fight to Refuse Chemotherapy*, N. Y. TIMES (Jan. 9, 2015), https://www.nytimes.com/2015/01/10/nyregion/connecticut-teenager-with-cancer-loses-court-fight-to-refuse-chemotherapy.html; Nicholas St. Fleur, *You Must Be This Old to Die*, THE ATLANTIC (Jan. 7, 2015), https://www.theatlantic.com/health/archive/2015/01/you-must-be-this-old-to-die/384303/.

temporary removal of Cassandra from her mother's custody pending an investigation.[75] Cassandra reported she only acquiesced to cooperating with treatment simply because she wanted to return home to her mother and was scared.[76] When the court classified running away from treatment and wanting to return home to her mother as evidence of immaturity, it missed the significance of psychosocial stability and familial comfort for a child's overall well-being.[77]

B. Does the State Have Authority to Intervene?

1. Conditions Required for State Intervention into Children's Medical Decisions

Acknowledging familial privacy and parental rights, the state does not have legal or ethical authority to intervene merely when the physician disagrees with the parents or even when the parents choose what the physician believes as a less than optimal course of action for their child.[78] Ethicists note that parents make suboptimal decisions that may not maximize the child's best interest, or apply a decision-making framework that reflects alternate values and priorities.[79] Physicians who seek state intervention to influence medical decision-making for pediatric patients with serious medical conditions must overcome the legal presumption of familial privacy.

Diekema identifies eight conditions that the state should meet to justify interference with parental decision-making, that includes the following factors:

1) Does parental refusal place the child at significant risk of serious harm?

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75 *In re Cassandra C.*, 112 A.3d at 160.

76 *Id.*; Cassandra Callendar, *Cassandra's Chemo Fight: 'This Is My Life And My Body'*, HARTFORD COURANT (Jan. 8, 2015), https://www.courant.com/opinion/op-ed/hc-op-cassandra-my-body-my-life-0109-20150108-story.html.

77 *In re* Cassandra C., 112 A.3d 158, 167-68 (Conn. 2015).

78 *See* Barbara Van Arsdale et al., *Consent of Parent to Medical Treatment of Child*, 70 C.J.S. § 138 (2021); Rosalind McDougall & Lauren Notini, *Overriding Parents' Medical Decisions for their Children: a Systematic Review of Normative Literature*, 40 J. MED. ETHICS 448, 450 (2014); Diekema, *supra* note 11; Wilkinson & Nair, *supra* note 45.

79 Diekema, *supra* note 11; *see also* Wilkinson & Nair, *supra* note 45.

2) Is the harm imminent and require immediate action to prevent it?
3) Is the intervention necessary to prevent this harm?
4) Does the intervention hold proven efficacy?
5) Do the benefits outweigh the burdens for the proposed intervention?
6) Are there other options that prevent serious harm to the child and are less intrusive to parental autonomy?
7) Can the state intervention be generalized to similar situations?
8) Would most parents agree the intervention is reasonable?[80]

These criteria provide a framework for understanding that the burden for state intervention must be high. Although Diekema envisions these factors as a benchmark for when a court may compel treatment to override parents, physicians should consider these questions before even seeking state intervention to consider whether the state has authority to intervene.

2. *Variations Across Jurisdictions Permitting State Intervention into Children's Medical Decisions*

Jurisdictions use different frameworks for assessing whether the state has subject matter jurisdiction and how it defines whether the child has a serious or life-threatening health condition. Courts fall along a continuum: some jurisdictions only authorize state intervention and order treatment for cases involving emergency or impending death;[81] other jurisdictions extend this authority to address a child's serious medical condition where imminent danger is foreseeable;[82] and some jurisdictions broaden state authority further by ordering medical treatment over parental objections to solve "a substantial medical problem."[83]

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80 Diekema, *supra* note 11, at 252.

81 *In re* Green, 292 A.2d 387, 389-90 (Pa. 1972).

82 Matter of Cabrera, 552 A.2d 1114,1119 (Pa. Super. Ct. 1989).

83 *In re* D.R., 20 P.3d 166,169 (Okla. Civ. App. 2001).

a. State Intervention for a Child's Life-Threatening or Emergency Condition

Some jurisdictions specify the state may intervene in cases of emergency, if the child's death is imminent, or his life is imperiled. These cases generally involve children diagnosed with cancer[84] and emergency medical conditions in which standard treatment entails a blood transfusion.[85] In *Custody of a Minor*, the court framed the decision whether to intervene and authorize chemotherapy for a child's leukemia as "certain death" without treatment versus "substantial hope for life." Courts generally authorized chemotherapy over parental objection when physicians predict it could save the child's life.[86] In *Novak v. Cobb County,* the court ordered a blood transfusion for a 16-year-old child following a car crash that required surgery.[87] The court noted that the child was in "eminent danger" based on his low blood count and at any moment his condition could deteriorate and threaten his life.[88] Other cases specify court intervention is appropriate and necessary when the physician can demonstrate with reasonable medical certainty that without the intervention the child will suffer irreparable physical harm. In *Muhlenberg Hospital v. Patterson*, the court authorized a blood transfusion over parental objection for a premature infant born with jaundice.[89] The court adopted physician testimony that without the transfusion, the infant with reasonable medical certainty was in danger of irreparable brain damage, constituting "grievous bodily injury."[90]

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84 Custody of a Minor, 379 N.E.2d 1053 (Mass. 1978); *In re* D.G., 970 So.2d 486 (Fla. Dist. Ct. App. 2007).

85 State v. Perricone, 181 A.2d 751 (N.J. 1962); Muhlenberg Hosp. v. Patterson, 320 A.2d 518 (N.J. Super. Ct. 1974); Novak v. Cobb County, 849 F.Supp. 1559 (N.D. Ga. 1994).

86 *Custody of a Minor*, 379 N.E.2d at 1056.

87 *Novak*, 849 F.Supp. at 1564.

88 *Id.*

89 *Patterson*, 320 A.2d at 519.

90 *Id.* at 519, 521.

b. State Intervention to Prevent a Serious and Imminent Medical Condition

Other jurisdictions permit state intervention and authorize medical procedures to prevent serious foreseeable danger to the child that physicians predict will occur in the future. In *Matter of Cabrera*, a child with sickle cell anemia experienced a stroke and physicians testified the child would likely suffer another stroke without maintenance blood transfusions.[91] Instead of focusing narrowly on the risks of untreated sickle cell anemia, physicians collapsed the risks of the child's present disease (sickle cell anemia) with the potential risks of a stroke (a possible future medical condition that the child did not currently have). In this case, physicians asserted if the child did not receive ongoing transfusions and also experienced a stroke this could lead to loss of intellectual functioning, physical disability, blindness, and the ability to speak.[92] The court held the child does not need to be "immediately imperiled" or "at death's door" to intervene, but that courts may intervene to minimize the likelihood of a child sustaining debilitating or fatal injury in the future.[93]

Similarly, *In re Eric B.* also held that the state can intervene to prevent serious perceived danger before it occurs, finding "the idea that the state can only act after the fact is untenable."[94] In this case, physicians recommended several treatments for a child with retinal blastoma: surgery to remove the child's eye, then chemotherapy and radiation to prevent recurrence. Parents consented to the surgery, but disagreed with chemotherapy and radiation based on their religious beliefs. The court noted a jurisdictional split of whether the state has authority to intervene after physicians already treated the immediate condition, and held the court had authority to authorize chemotherapy and radiation to prevent future recurrence in addition to ordering ongoing oversight to monitor the child for cancer recurrence.[95]

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91 Matter of Cabrera, 552 A.2d 1114, 1115-17 (Pa. Super. Ct. 1989).

92 *Id.*

93 *Id.* at 1120.

94 *In re* Eric B., 189 Cal. App.3d 996, 1003 (Cal. Ct. App. 1987).

95 *Id.* at 1002.

c. State Intervention to Solve a Substantial Medical Problem

Even if a child's life is not at stake or the child is not at risk of imminent substantial bodily harm, some jurisdictions permit state intervention to address "a substantial medical problem," particularly if the medical issue could result in future harm.[96] In *In re D.R.*, a 17-month-old child experienced frequent seizures and experienced developmental difficulties.[97] When parents stopped attending the child's recommended physical therapy and stopped giving the child medication to control the seizures, CPS intervened and the court ordered the child to take seizure medication.[98] The court combined its assessment of whether the child's condition constituted a substantial medical problem along with physician testimony that the child's medical condition could become more severe or life-threatening without treatment.[99]

In re Jensen also examined the court's authority to intervene to treat a substantial medical condition that was not currently life-threatening, but had the potential to lead to more serious medical consequences. *In re Jensen* involved a 15-month-old child with hydrocephalus. The physician recommended a series of surgeries to relieve pressure on the child's brain and asserted this could lessen the chance of mental retardation.[100] Parents declined the physician's recommendation for multiple surgeries based on their religious beliefs.[101] The court held the child was at risk of serious and irreparable brain damage without surgery, and stated the court may assess not only whether the child's life is endangered, but whether the child's *quality of life* is endangered.[102]

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96 *In re* D.R., 20 P.3d 166 (Okla. Civ. App. 2001).

97 *Id.*

98 *Id.*

99 *Id.* at 168.

100 *In re* Jensen, 633 P.2d 1302, 1303-04 (Or. Ct. App. 1981).

101 *Id.*

102 *Id.* at 1306.

d. Caution Against Broad Authorization of State Intervention for Children's Medical Decision-Making

Despite many courts finding the state has subject matter to intervene for serious and substantial medical issues, one court cautioned against involving the state unless the child's life or health is "immediately imperiled."[103] In *In re Green,* the physician recommended a spinal fusion surgery for a teen boy with poliomyelitis and scoliosis.[104] The child's mother consented to the surgery, but did not consent to blood transfusion if necessary during the surgery because of religious beliefs.[105] The court noted that, although the physician testified the operation would be beneficial to the child, there was no evidence that the child's life was in danger or that the surgery would address an emergency condition. If courts permit the state to intervene simply because the physician invokes authority labeling a procedure as beneficial and required, the court warned this would permit the possibility of courts mandating other types of intrusive and risky surgical procedures simply based on a physician declaration that the child would benefit.[106] Even if courts authorize state intervention, it may also caution against using state intervention as a dispute resolution mechanism for reasonable disagreements. *In re Matthew V.* set forth an insightful reminder for approaching questions of discretion, stating that courts should not be in the role of a surrogate decision-maker when clinicians and parents face disagreement. As long as parents are not choosing a course of treatment that has been "totally rejected by all medical authority," the court should not intervene.[107]

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[103] *In re* Green, 292 A.2d 387, 387 (Pa. 1972).

[104] *Id.* at 388.

[105] *Id.*

[106] *Id*.

[107] *In re* Matthew V., 68 N.Y.S.3d 796, 803 (NY Fam. Ct. 2017).

III. PARENS PATRIAE AND THE STATE'S DUTY TO PROTECT CHILDREN

Recognizing familial privacy, states have a co-existing duty of *parens patriae* to protect vulnerable children and intervene in cases involving allegations of abuse and neglect. This section provides an overview of federal and state law relating to child abuse and neglect. While some states specify medical neglect constitutes a form of child neglect, these definitions vary across states and raise pertinent questions about how to interpret state medical neglect laws in cases where parents seek medical care for their child, but hold divergent opinions on what constitutes an optimal treatment decision. Next, this section explains statutory duties of clinicians to report suspected cases of neglect, including alleged medical neglect, and sets forth specific considerations when applying mandatory reporting laws for pediatric treatment disputes. Finally, this section outlines the importance of due process when the state intervenes in the familial relationship for the purpose of overriding parental decision-making.

A. *Parens Patriae*

1. Limits on Parental Rights and When the State May Intervene

Parental rights are sacred and may only be invaded for compelling reasons.[108] However, the state can—and must—intervene to protect children from neglect and abuse. *Prince v. Massachusetts* set forth restraints on parental autonomy when parental decisions would jeopardize children's health and safety.[109] In *Prince v. Massachusetts*, the Court upheld the state's power to enforce child labor laws, even when the parents claimed this impinged on religious liberty for the child to sell religious booklets and pamphlets in public streets.[110] Under the doctrine of *parens patriae*, states may enact laws to further the health and safety of children, such as mandating school attendance

[108] Newmark v. Williams, 588 A.2d 1108, 1115 (Del. 1991).

[109] Prince v. Massachusetts, 321 U.S. 158 (1944).

[110] *Id.* at 166-67.

and prohibiting child labor.[111] In *Prince v. Massachusetts*, the Court stated in dicta that *parens patriae* also permits the state to further restrict parental authority: "The right to practice religion freely does not include the liberty to expose the community or child to communicable disease or the latter to ill health or death" and "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."[112]

The state has an interest in protecting vulnerable populations, such as children, from maltreatment and has an interest in preserving human life.[113] Courts have incorporated this dicta, holding the state has authority to both intervene and potentially order various types of medical treatment when it is necessary to save the child's life or treat a serious medical condition.[114] The state's interest in intervening in the familial relationship increases based on the severity of the child's illness and when the likelihood of death without treatment increases. However, courts recognize that children, just like competent adults, also hold a right to refuse life-sustaining treatment in specific circumstances in which potential for survival with treatment is low and/or treatment is burdensome and risky.[115]

2. Defining Child Abuse, Neglect, and Medical Neglect

Both federal and state law set forth definitions of what constitutes child abuse and neglect and the duty of the states to intervene on behalf of children. The Federal Child Abuse Prevention and Treatment Act defines child abuse and neglect as an "act or failure to act on the part of a parent or caretaker which results in death, serious physical or emotional harm, sexual abuse, or exploitation; an act or failure to act which presents an imminent risk of serious harm."[116] The vast

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[111] *Id*.

[112] *Id*. at 170.

[113] *Newmark*, 588 A.2d at 1116.

[114] *See* Custody of a Minor, 379 N.E.2d 1053, 1062 (Mass. 1978); *In re* Jensen, 633 P.2d 1302, 1305 (Or. Ct. App. 1981); *In re* Willmann, 493 N.E.2d 1380, 1390 (Ohio Ct. App. 1986); M.N. v. S. Baptist Hosp., 648 So. 2d 769, 770 (Fla. Dist. Ct. App. 1994).

[115] *M.N.*, 648 So. 2d at 771.

[116] Child Abuse Prevention and Treatment Act, 42 U.S.C. § 5106(g).

majority of cases triggering state intervention involve neglect (e.g., leaving children unattended, failure to feed children, parental impairment from substance abuse) or abuse (e.g., shaking, beating, biting, kicking, punching, and burning, sexual abuse).[117] These traditional concepts of child neglect or abuse entail intentional harm, reckless indifference, or callous disregard to a child's physical, social, and emotional well-being where the state not only has a duty to rapidly intervene, but in some cases quickly remove the child from parental custody pending a hearing to prevent imminent harm.[118]

In 2013, the American Academy of Pediatrics (AAP) published a policy statement, stating that parental failure to provide children with essential medical care constitutes medical neglect, and that failure to obtain recommended treatment can result in serious harm, such as death, disability, or pain.[119] Several states recognize children's right to medical treatment and classify certain types of parental failure to provide necessary medical care as a form of child neglect or provide a distinct classification for medical neglect.[120] Definitions vary in each

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[117] ADMIN. FOR CHILD. & FAMS., U.S. DEP'T HEALTH & HUM. SERVS., CHILD MALTREATMENT (2021); *Definitions of Child Abuse and Neglect*, CHILD WELFARE INFO. GATEWAY 2–3 (2019), https://www.childwelfare.gov/pubPDFs/define.pdf [hereinafter *Child Abuse and Neglect*]; *see also What is Child Abuse and Neglect?* N.Y. CHILD.'S ADMIN. & SERVS. (2020), https://www1.nyc.gov/site/acs/child-welfare/what-is-child-abuse-neglect.page.

[118] *See* Katherine Drabiak, *Toxic Breastmilk: When Substance Abuse Relapse Means Death for Baby*, HARV. L. BILL HEALTH (Nov. 15, 2018), https://blog.petrieflom.law.harvard.edu/2018/11/15/toxic-breastmilk-when-substance-abuse-relapse-means-death-for-baby/.

[119] Armand H. Matheny Antommaria & Kathryn L. Weise, *Conflicts Between Religious or Spiritual Beliefs and Pediatric Care: Informed Refusals, Exemptions, and Public Funding*, 132 AM. ACAD. PEDIATRICS 962, 962 (2013).

[120] CHILD WELFARE INFO. GATEWAY, *supra* note 116, at 2–3; *see also* FLA. STAT. ANN. § 827.03 ("'Neglect of a child' means: a caregiver's failure or omission to provide a child with the care, supervision, and services necessary to maintain the child's physical and mental health, including, but not limited to, food, nutrition, clothing, shelter, supervision, medicine, and medical services that a prudent person would consider essential for the well-being of the child . . . neglect of a child may be based on repeated conduct or on a single incident or omission that results in, or could reasonably be expected to result in, serious physical or mental injury, or a substantial risk of death, to a child."); UTAH ADMIN. CODE r.512-80-2(19) ("Medical neglect means failure or refusal to provide proper or necessary medical, dental, or mental health care or to comply with the recommendations of a medical, dental, or mental health professional necessary to the child's health, safety, or well-being."); MINN. STAT. § 260E.03

state, but generally the laws specify that parents must provide a minimum degree of care, "adequate medical treatment,"[121] or "necessary medical care."[122] States such as Utah set forth a broad definition of medical neglect, defining it as parental refusal to provide necessary medical care or failure to comply with recommendations of a health provider that would be necessary for the child's health, safety, or well-being.[123] Some states qualify necessary medical care as medical services that a reasonable or prudent person would believe are necessary for a child.[124] Other laws specify potential neglect occurs based on context in which parents fail to provide treatment for a child who has a serious or life-threatening medical condition,[125] or in which the refusal would cause the child "serious impairment" or "seriously endanger" the child.[126] Multiple states directly address religious objections to treatment, and several states specify that while religious reasons for declining treatment should not be considered neglect,[127] the state retains authority to intervene, investigate, and potentially order medical treatment for the child to prevent serious harm or death.[128]

Subdiv. 15(b) (" Nothing in this chapter shall be construed to mean that a child is neglected solely because the child's parent, guardian, or other person responsible for the child's care in good faith selects and depends upon spiritual means or prayer for treatment or care of disease or remedial care of the child in lieu of medical care."); *but see* MINN. STAT. § 260E.06 ("If the child's parent, guardian, or other person responsible for the child's care in good faith selects and depends upon spiritual means or prayer for treatment or care of disease or remedial care of the child in lieu of medical care, the parent, guardian, or caretaker or a person mandated to report pursuant to subdivision 1, has a duty to report if a lack of medical care may cause serious danger to the child's health.")

121 ALA. CODE § 26-14-1(2) (2019).

122 UTAH ADMIN. CODE r. 512-80-2(19) (2020).

123 *Id.*

124 LA. CHILD. CODE ANN. art. 603(18); COLO. REV. STAT. ANN. § 19-3-102.

125 IND. CODE ANN. § 31-34-1-1.

126 *Id.*

127 COLO. REV. STAT. § 19-3-103; IDAHO CODE ANN. § 16-1602(31)(a).

128 FLA. STAT. ANN. § 39.01(35)(f) (2020); IDAHO CODE ANN. § 16-1602 (2019).

3. Medical Neglect or Divergent Decision-Making?

These state laws provide essential guardrails to hold parents accountable and intervene when parents exhibit indifference or disregard toward their child's medical needs, particularly when the child has a serious or life-threatening condition. But the law and clinicians should distinguish circumstances in which parents fail to provide medical care from cases in which parents acknowledge the gravity of the child's medical condition and seek medical care, but decline a treatment based on divergent assessments of benefits, burdens, and values.[129] Florida, for example, attempts to distinguish these circumstances by specifying in the law that a parent who made reasonable attempts to seek necessary health services or forgoes recommended treatment that offers limited net benefit to the child compared to its risks does not constitute medical neglect.[130] Virginia similarly recognizes nuance in medical decision-making, and affords parents more discretion to balance the potential benefits and burdens of treatment.[131]

In practice, some physicians acknowledge and support parents' decisions to decline treatment based on benefits, burdens, and threshold for survival. But other physicians do not: a study in the *Journal of Pediatric Hematology and Oncology* evaluated attitudes from oncology providers whether they would support parental refusal of standard chemotherapy for a child diagnosed with cancer.[132] Physician responses varied by the child's age and anticipated rate of survival.[133] Controlling for age, the study found approximately 25 percent of providers would not support parents' decision to decline treatment in cases where the cure rate was poor.[134] These findings suggest that some physicians may view *available treatment* as "necessary medical treatment" without fully evaluating factors such

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129 Rosato, *supra* note 44, at 26-27.

130 FLA. STAT. ANN. § 39.01(47) (2020).

131 VA. CODE. ANN. § 63.2-100(2) (2020).

132 Nassin et al., *supra* note 27.

133 *Id*. at 354.

134 *Id*.

as the burdens of treatment or impact to the child's quality of life. As the court in in *Muhlenberg Hospital v. Patterson* aptly stated, not every refusal to consent to treatment constitutes evidence of parental unfitness or neglect.[135]

B. Mandatory Reporting

To protect vulnerable members of the public, including children, state laws set forth mandatory reporting requirements that govern the duties and procedures for reporting cases of suspected abuse or neglect.[136] Many state laws designate clinicians as mandatory reporters who have a duty to report to CPS when they have reasonable cause to believe that a child is being abused or neglected.[137] Approximately seven states include medical neglect as a reportable condition under the state's mandatory reporting law.[138] To encourage reporting and protect children from abuse and neglect, many state laws also specify penalties for failure to report cases of neglect and abuse.[139] Clinicians could face sanctions such as disciplinary action from the state licensing board, civil penalties, or criminal penalties if they do not fulfill their legal duty to report suspected cases of abuse or neglect.[140]

In its 2013 policy statement, AAP recommends that pediatric specialists report suspected cases of medical neglect to CPS.[141] AAP's policy statement is designed for the important purpose of increasing recognition and prompt reporting cases of suspected medical neglect to ensure children receive medical care. But interpreting policies or state laws in a manner that advocates blanket immediate reporting as a procedural requirement omits considering the complexities in

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[135] Muhlenberg Hosp. v. Patterson, 320 A.2d 518, 521 (N.J. Super. Ct. Law. Div. 1974).

[136] *See generally* Child Abuse and Neglect, supra note 116.

[137] *Id.*

[138] *Id.* at 3.

[139] Thaddeus Mason Pope, *Parental Treatment Refusals: What Your Responsibilities Are When Mom and Dad Decline Cancer Treatment for a Child*, ASCO POST (July 25, 2019), available at: https://ascopost.com/issues/july-25-2019/parental-treatment-refusals/.

[140] *Id.*

[141] Antommaria & Weise, *supra* note 119.

medical decision-making, the timing of reporting, and the importance of concerted efforts toward dispute resolution before invoking state intervention.

First, as cases of judicial intervention and Diekema's criteria suggest, what constitutes suspected medical neglect may not stem from parents refusing necessary medical care but from situations in which parents do seek treatment for their child, and agree to some, but not all, recommended interventions. State intervention may not be appropriate in cases when the condition is not life-threatening, treatment involves significant burden, or the child's chance of survival is low.[142]

Second, although immediate mandatory reporting enables the state to quickly intervene when children are at imminent risk or the child's life is endangered, not all cases meet this definition and thus require immediate action. Several cases of state intervention invoke an emergency label or declare "time is of the essence" as a strategy to bypass attempts at physician-parent discussion.[143] Instead, physicians should conceptualize clinical care interactions on a time spectrum that accounts for the severity of the medical condition and time exigencies. In certain cases, such as ongoing management of children's medical disorders or pediatric oncology cases, treatment decisions properly involve multiple conversations; time to administer and assess test results; time to process information; space to ask questions about risks, benefits and alternatives; and time to seek a second opinion.

Finally, while physicians may believe based on their professional experience that an intervention is necessary or required for a child, their conversations with parents should aim at engaging and facilitating resolution rather than attempting to compel immediate acquiescence. This framing strengthens the physician-family relationship through communicating their reason for recommending a specific treatment or intervention, promotes trust between the parents

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[142] Custody of a Minor, 379 N.E.2d 1053, 1062 (Mass. 1978).

[143] *Id.* at 1065 (stating that "time is of the essence" to intervene immediately when parents discontinued chemotherapy for child's leukemia based on risk, benefits, and survival statistics); *In re* D.G., 970 So2d 486, 489 (Fla. Dist. Ct. App. 2007) (where CPS petitioned the court for an emergency hearing to order immediate chemotherapy and radiation when the child's mother requested a second opinion following the child's surgery).

and physician, facilitates informed consent, and encourages parental compliance with treatment regimes. Clinicians should exercise their professional judgment when determining instances in which immediate reporting is required, such as life-threatening emergency circumstances, and cases in which engaged discussion may lead to consensus eliminating the need to invoke state intervention. Recognizing these complexities preserves the law's function while also promoting the state's interest in upholding the ethics and integrity of the medical profession.[144]

Once physicians make a report, social workers have a duty to investigate cases of suspected medical neglect. Both federal and state law specifies that preserving family integrity constitutes a statutory priority, and social service agencies should aim to preserve the family unit.[145] This requires delineating between investigation and recommendations relating to the child's placement of whether the child remains in the physical custody of his parents. In practice, however, in some cases of judicial intervention involving suspected medical neglect, both clinicians and CPS petition the court for immediate and short-term removal of the child from parental custody despite the investigation demonstrating parents provide the child a stable and loving home.[146] Courts that intervene and authorize treatment over parental objections can do so by appointing a guardian solely to address the child's specific medical issue while retaining the child in the home environment.[147] As the court in *Newmark v. Williams* stated, "no American court . . . . has ever authorized the state to remove a child from the loving, nurturing case of parents," because

144 *See Custody of a Minor*, 379 N.E.2d at 1066.

145 *Reasonable Efforts to Preserve or Reunify Families and Achieve Permanency for Children*, CHILD WELFARE INFORMATION GATEWAY (2020), https://www.childwelfare.gov/pubPDFs/reunify.pdf.

146 *See supra* notes 1-7; *supra* note 74; Newmark v. Williams, 588 A.2d 1108, 1118-19 (Del. 2001) (where the physician testified to his opinion that the state should remove a 3 year old child from his parents' home and place him in foster care while he received chemotherapy for lymphoma because parents disagreed with treatment recommendations).

147 *See In re* Matthew V., 68 N.Y.S. 3d 796, 797 (NY Fam. Ct. 2017); Novak v. Cobb County, 849 F. Supp. 1559, 1559 (N.D. Ga. 1994); State v. Perricone, 181 A.2d 751, 753 (N.J. 1962).

this would exceed the scope of the state's authority under *parens patriae*.[148]

C. Due Process to Intervene in Parents' Medical Decision-Making

1. Substantive and Procedural Due Process

In *Santosky v. Kramer,* the Supreme Court held that the Constitution requires due process to remove parental rights.[149] Although *Santosky v. Kramer* addressed permanent termination of parental rights, lower courts have held that states must also comport with due process when limiting or curtailing parental rights relating to children's medical decisions.[150] Substantive due process recognizes that government intrusion into the familial relationship involves important interests relating to liberty, privacy, familial integrity, and freedom from intrusion.[151] Procedural due process requires in most instances that the state provide parents notice of the hearing, ability to present evidence, and opportunity to object.[152] The state must overcome the burden of intruding into the familial relationship by presenting clear and convincing evidence of: (1) why the court has authority to intervene, and (2) why the court should override parental decisions relating to medical treatment for the child.[153]

At its core, procedural due process requires a fair procedure that recognizes the complex and serious judgments at stake. In practice, courts may test the boundaries of due process by providing what appears to be a perfunctory hearing. In *In re D.G.*, the mother had been working with physicians for several months, obtaining a diagnosis and

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[148] *Newmark*, 588 A.2d at 1119.

[149] Santosky v. Kramer, 102 S.Ct. 1388, 1414 (1982).

[150] *In re* Hamilton, 657 S.W.2d 425 (Tenn. Ct. App. 1983); *In re Matthew V.*, 68 N.Y.S.3d at 802; *Novak*, 849 F.Supp. at 1566-67; Glenn H. v. Hoskins, 419 P.3d 567, 571 (Ariz. Ct. App. 2018).

[151] *Novak*, 849 F.Supp. at 1566.; P.J. *ex rel.* Jensen v. Utah, No. 2:05CV00739 PGC, 2006 WL 1702585 *7 (D. Utah June 16, 2006).

[152] *Novak*, 849 F.Supp. at 1567-68.

[153] *Santosky*, 102 S.Ct. at 1393; *In re Matthew V.*, 68 N.Y.S.3d at 802; *In re Hamilton*, 657 S.W.2d at 427.

developing a treatment plan for D.G. The mother agreed to surgery to remove her child's tumor. Following surgery, the mother did not agree to chemotherapy or radiation and wanted time to research alternative options.[154] CPS filed a petition for dependency and an emergency motion for medical treatment.[155] The court scheduled the hearing for the same day, mere hours after it received the state's request.[156] Despite the mother's objection on appeal that there was no medical emergency to invoke an emergency hearing and she lacked time to gather evidence, the court rejected the mother's claims, holding that the child "needed prompt radiation and chemotherapy" and characterized this as an "exigenc[y]" that "demanded prompt attention."[157] In this case, expediting the hearing satisfied the letter of the law to provide a hearing, but should raise questions about what constitutes fair and just opportunity to present and respond to evidence.

2. *Exceptions to Due Process: Ex Parte Requests for Emergencies or Imminent Danger*

Many states recognize an exception to the sequencing requirements for procedural due process and permit the state to intervene to remove the child from the parents when the state believes the child is in imminent danger. In the context of suspected medical neglect, some states permit the physician to contact CPS and request an ex parte hearing to authorize medical treatment over parental objections when emergency circumstances exist as long as the state affords parents an adequate post-deprivation remedy.[158] Notably, the specific facts in these cases demonstrate significant judicial deference to clinician assessment that the child's medical condition constitutes an emergency, whether the child is in "imminent danger" without the

154 *In re* D.G., 970 So.2d 486, 487 (Fla. Dist. Ct. App. 2007).

155 *Id.*

156 *Id.*

157 *Id.* at 488, 490.

158 Novak v. Cobb Cty., 849 F.Supp. 1559, 1569 (N.D. Ga. 1994); Mueller v. Auker, 576 F.3d 979, 995 (9th Cir. 2009).

intervention,[159] or if the child requires immediate medical treatment to save his life.

In clinical care, "emergency" denotes a specific definition: "an unforeseen combination of circumstances or the resulting state that calls for immediate action," such as a "sudden bodily alteration" that requires immediate attention like a ruptured appendix or surgical shock.[160] In cases such as these, laws permitting ex parte requests are designed for the clinician to act swiftly and intervene to save the child's life. But this definition precludes multiple conditions in which physicians have time to discuss, plan, and communicate with parents or when managing the child's condition is not unforeseen or sudden. Multiple cases involving pediatric oncology patients such as *In re D.G.* underscore that a physician's professional assessment that the child should immediately begin chemotherapy or radiation does not transform the child's underlying condition into an emergency state.

Clinicians hold immense discretion when determining—and communicating to the state— whether the child is in imminent danger without a specific intervention. In *Mueller v. Auker*, for example, the mother sought medical attention, agreed to in-patient tests and monitoring for her infant's fever, but did not authorize a spinal tap for her infant based on her assessment of risk.[161] The court held determining whether the infant was in imminent danger because the mother declined the spinal tap constituted a genuine issue of material fact—reasonable people may disagree.[162] This case raises critical questions about the scope of discretion clinicians hold, viability of alternatives, and the threshold to determine when aggressive interventions constitute a strong recommendation or whether they are truly necessary to avert patient deterioration and death.

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159 *Mueller*, 576 F.3d at 991-92; *Novak*, 849 F.Supp. at 1569-70 .

160 *Emergency*, *Merriam-Webster Medical Dictionary*, available at: https://www.merriam-webster.com/dictionary/emergency#medicalDictionary.

161 *Mueller*, 576 F.3d at 983.

162 *Id.* at 994.

3. Limitations to Ex Parte Requests

Not all jurisdictions permit ex parte requests, and some courts specify that clinicians do not have authority to obtain an ex parte request unless specifically authorized by state law.[163] In *Glenn H. v. Hoskins*, physicians treated a 14-year-old child with osteosarcoma using chemotherapy.[164] Parents agreed to chemotherapy and clinicians formulated a treatment plan that would avoid the use of blood products based on the parents' religious beliefs as Jehovah's Witnesses.[165] Two months into treatment, clinicians used an "emergency hotline" without notifying the parents to request ex parte judicial authorization to administer a series of blood transfusions to the child.[166] The parents asserted the court lacked subject matter jurisdiction because the state did not first satisfy the burden of showing the child was "dependent" to trigger state intervention, nor did clinicians establish that the child's condition constituted an emergency.[167] The court agreed that the action lacked subject matter jurisdiction: the law required clinicians and CPS to first demonstrate how the state has authority to intervene and how the child met the definition of a neglected child before requesting judicial intervention to override parents and compel a specific medical treatment.[168] *Glenn H. v. Hoskins* highlights the importance of recognizing that courts may not have authority to issue ex parte requests for children's medical treatment without first establishing subject matter jurisdiction to intervene in the familial relationship.

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163 Glenn H. v. Hoskins, 419 P.3d 567, 571 (Ariz. Ct. App. 2018).

164 *Id.* at 569.

165 *Id.*

166 *Id.*

167 *Id.*

168 *Id.* at 570-71.

IV. STATE AUTHORITY TO COMPEL MEDICAL TREATMENT FOR MINORS

Once the court determines whether it has the authority to intervene, it will assess whether compelling treatment would be in the child's best interest.[169] First, this section sets forth a list of factors that clinicians, parents, and courts consider to assess whether the physician's recommended course of treatment would promote the child's best interest, such as the severity of the illness, risks and benefits of treatment, the potential for survival with and without treatment, and psychosocial considerations. Different courts adopt varying formulas that may account for only certain factors, or ascribe significant weight to other factors. Second, this section describes the range of formulas courts use when determining the child's best interest, how many courts provide significant weight to the physician's recommendations for treatment, and why many courts favor treatment over nontreatment.

A. State Interest in Compelling Medical Treatment for Minors

The state's interest in ordering treatment for the child increases with the severity of the illness and the likelihood of death without medical intervention. Several factors weigh against the court mandating treatment over parental objection, such as whether treatment is risky, toxic, or invasive,[170] when treatment itself has a low chance of success, or if treatment is not medically necessary.[171] Different jurisdictions adopt a range of formulas and weigh these factors differently in the course of determining whether mandating treatment would fall within the child's best interest. Some courts determine the child's best interest by considering (1) the severity of the illness and (2) the benefits of treatment against risks and burdens. Some also address (3) the threshold for survival and likelihood treatment will be effective. Finally, some courts adopt a

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169 *See* Diekema, *supra* note 11, at 252-54.

170 *In re* Green, 292 A.2d 387 (Pa. 1972); People *ex rel.* D.L.E., 614 P.2d 873 (Colo. 2000).

171 *In re* Samson, 317 N.Y.S.2d 641 (N.Y. Fam. Ct. 1970).

comprehensive approach that includes (4) psychosocial considerations.

1. Determining the Severity and Course of Illness

In cases where the child's condition is severe and likely to cause substantial bodily harm or result in death, the court is more likely to intervene and order treatment. Examples include instances when a child has a life-threatening condition that could be alleviated by a blood transfusion,[172] the physicians diagnosed the child with a form of cancer,[173] or the child suffers from a debilitating condition such as epilepsy so severe it results in neurological damage.[174]

Multiple cases illustrate the significance that parents attach to certainty of both diagnosis and prognosis, particularly in pediatric oncology.[175] In several instances, parents express their desire to obtain additional medical opinions and more tests to confirm the child's diagnosis or seek alternative treatments.[176] Similarly, in cases involving an uncertain diagnosis, parents may request time to observe the child's status and express that they want to wait to act once they see the child's condition change.[177] In some instances, parents may view immediate intervention as intrusive, more risky, and unwarranted.[178] Even with uncertainty in diagnosis or prognosis,[179] several courts express preference for mandating early and aggressive

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[172] *See* Novak v. Cobb Cty., 849 F.Supp. 1559 (N.D. Ga. 1994); State v. Perricone, 181 A.2d 751 (N.J. 1962); Muhlenberg Hosp. v. Patterson, 320 A.2d 518 (N.J. Super. Ct. 1974); *In re* Cabrera, 552 A.2d 1114 (Pa. Super. Ct. 1989).

[173] *See In re* Matthew V., 68 N.Y.S.3d 796, 803 (N.Y. Fam. Ct. 2017); *In re* D.G., 970 So.2d 486 (Fla. Dist. Ct. App. 2007); *In re* Willmann, 493 N.E.2d 1380 (Ohio Ct. App. 1986).

[174] *See* People *ex rel.* D.L.E., 614 P.2d 873 (Colo. 2000); *In re* D.R., 20 P.3d 166 (Okla. Civ. App. 2001).

[175] Gerdes & Lantos, *supra* note 50; Brown & Slutsky, *supra* note 27; Wilkinson & Nair, *supra* note 45, at 117.

[176] Jensen v. Utah [Not reported], 2006 WL 1702585 (D. Utah 2006); *In re* Cassandra C., 112 A.3d 158, 160 (Conn. 2015).

[177] *In re* Matthew V., 68 N.Y.S.3d 796, 803 (N.Y. Fam. Ct. 2017); Mueller v. Auker, 576 F.3d 979 (9th Cir. 2009).

[178] *In re Matthew V.*, 68 N.Y.S.3d at 803; *Mueller*, 576 F.3d.

[179] Alessandri, *supra* note 44, at 629 (conceding that disease prognostication is difficult).

intervention if the intervention has a chance at curbing the disease or preventing recurrence.[180]

2. Benefits and Risks of Treatment

a. Assessing General Benefits versus Risks

In many cases, the benefits of treatment could be significant, such as using a blood transfusion to avert death, medication to control epileptic seizures, or chemotherapy to shift a child's cancer into remission. When determining whether to compel treatment, some courts focus narrowly on medical benefit. According to Alessandri, this narrows viewing children's best interest into only medical interests because the physician, state, and court presumes that certain risks and side effects are tolerable as they confer a chance at the child's survival.[181]

Courts, however, exhibit wide variance in how they describe risks of treatment. Some courts carefully acknowledge the risks while other courts downplay or even dismiss significant risks. Risks vary not only based on the type of medical intervention, but whether it constitutes a short time limited treatment (e.g., one blood transfusion) or lengthy ongoing management (e.g., ongoing medication plan or years of chemotherapy). This dramatically modifies the perception of whether, and by what weight, the benefits may exceed the risks. As more research emerges on the serious and life-long risks associated with certain treatments such as chemotherapy, courts should carefully assess and integrate the significance of these outcomes when considering whether compelling treatment would further the child's best interest.

b. Specific Considerations for Pediatric Oncology

Despite significant potential benefit, chemotherapy treatments can also be highly painful and invasive, carry short-term side effects such as nausea, vomiting, pain, immune suppression, cognitive

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[180] *See In re* Eric B., 189 Cal. App.3d 996, 1003 (Cal. Ct. App. 1987); *In re* Hamilton, 657 S.W.2d 425, 427 (Tenn. Ct. App. 1983).

[181] Alessandri, *supra* note 44, at 629.

dysfunction, and entail long term risks.[182] As physician Dr. Amy Caruso Brown and health sciences researcher Dr. Amy Slutsky observe, characterizing chemotherapy as "poison" is not without some mechanistic validity.[183] While this can result in the child suffering for the duration of treatment, it also involves significant long-term risks, such as organ damage, including increased risk for heart disease, stroke, pulmonary damage, obesity, infertility, neurological damage, memory and learning disabilities, and increased risk of other cancers.[184] Several studies derived from the St. Jude Lifetime Cohort Study suggest that pediatric chemotherapy entails trading risks: while the child may benefit from cancer remission, chemotherapy results in chronic and serious conditions in adulthood.[185]

Pediatric chemotherapy dramatically modifies the trajectory of the child's health later in life: a study by physician Dr. Kevin Oeffinger and colleagues in the *New England Journal of Medicine* found that by age 26, 62.3 percent of pediatric cancer survivors had at least one chronic condition, such as secondary cancer, coronary artery disease, renal failure/dialysis, severe cognitive dysfunction, hearing or vision loss, or ovarian failure.[186] By age 45, these figures rise dramatically: 95.2 percent of pediatric cancer survivors had at least one chronic condition, 80 percent of which were serious, disabling, or life-threatening.[187]

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[182] *Chemotherapy*, MAYO CLINIC, https://www.mayoclinic.org/tests-procedures/chemotherapy/about/pac-20385033 (last visited Apr. 24, 2021); Gerdes & Lantos, *supra* note 50, at 2-3.

[183] Brown & Slutsky, *supra* note 27, at 2.

[184] *Cancer Survivors: Late Effects of Cancer Treatment*, MAYO CLINIC, https://www.mayoclinic.org/diseases-conditions/cancer/in-depth/cancer-survivor/art-20045524; *see also* Kevin Oeffinger et al., *Chronic Health Conditions in Adult Survivors of Childhood Cancer*, 355(15) NEW ENGLAND J. MED. 1572 (2006); Nickhill Bhakta et al., *The Cumulative Burden of Surviving Childhood Cancer: An Initial Report From the St. Jude Lifetime Cohort Study*, 390(10112) LANCET 2569 (2017); Leslie Robison & Melissa Hudson, *Survivors of Childhood and Adolescent Cancer: Life-Long Risks and Responsibilities*, 14(1) NATURE REV. CANCER 61 (2014).

[185] Bhakta et al., *supra* note 184; Robison & Hudson, *supra* note 184.

[186] Oeffinger et al., *supra* note 184, at 1577.

[187] Bhakta et al., *supra* note 184.

Finally, despite predicted benefits of treatment such as chemotherapy, treatment itself can result in the child's death. A study published in the *British Journal of Cancer* estimated that one-fourth of all pediatric cancer deaths were classified as treatment related mortality.[188] Brown and Slutsky note that while physicians may focus on the chance of the child's death *without* treatment, this minimizes considering how the child could die *from* treatment while also experiencing considerable suffering.[189]

c. Differences Between Physician's and Parent's Perspectives of Benefits versus Risks

The aforementioned studies suggest that even narrowing the focus to medical risks, parents, physicians, and the court may differ in the temporal framework when considering what course of action would be in the child's best interest, particularly in cases of pediatric oncology. While physicians and the state may focus on the child's immediate health condition, benefits related to cancer treatment, and promising statistics for remission, parents may be assessing whether the child's suffering of risks should be tolerable and integrating their considerations for the child's future health. This framework may result in the dichotomy that is present in multiple pediatric physician-parent disputes: Physicians express strong confidence that conventional treatment will be effective and must begin immediately. Parents, on the other hand, may seek certainty, opt for alternative treatments, and place confidence in low statistical chance of survival without conventional treatment, or alternatively, for children with a poor prognosis, parents may shift their focus to palliative care.

3. Threshold for Survival

When a treatment intervention holds significant benefits but also entails serious risks, physicians, parents, and the court may consider the survival threshold and anticipated likelihood of the treatment's success. Some research suggests that physicians' perception of what

[188] Brown & Slutsky, *supra* note 27.

[189] *Id*.

constitutes a threshold where courts should intervene and mandate treatment varies based on physician specialty, the child's age, and the child's specific diagnosis.[190] For younger children and when treatment offers a higher likelihood of survival, physicians are more likely to challenge parents' decisions to forgo treatment and seek state intervention to mandate conventional treatment for the child.[191] Some physicians, however, may assert that complying with treatment recommendations furthers the child's best interest even when the treatment offers little chance of success, specifically in the context of pediatric oncology. As Dr. Michele Nassin and colleagues found, after controlling for the child's age, about 25 percent of physicians would not support the parents' decision to forgo chemotherapy when the "cure rate" or potential for success is low, which is defined at a potential for zero to 33 percent success.[192] The physician's view of what threshold for success is sufficient to request compelling treatment holds significant weight in court, where physician's views generally prevail when the court determines the child's best interest.[193]

Jurisdictions that focus on the child's potential for survival with and without treatment may also adopt varying ranges for the minimum threshold where the court would mandate treatment for the child. While courts are likely to hold that mandating treatment furthers the child best interest for a high likelihood of survival (e.g., such as greater than 80 percent),[194] other cases still mandate treatment for a poor chance of survival (15 to 30 percent), even when physicians estimate potential survival without further treatment fell just below that range.[195] Thus, courts facing the same statistical rate of potential survival may differ in their classification of whether the poor or modest chance of survival with conventional treatment would be in the child's best interest.

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190 *Id*.; Gerdes & Lantos, *supra* note 50; Alessandri, *supra* note 44.

191 *Id*.

192 Nassin et al., *supra* note 27, at 354.

193 Alessandri, *supra* note 44, at 630.

194 *Id*. at 629.

195 *In re* Matthew V., 68 N.Y.S.3d 796, 804 (N.Y. Fam. Ct. 2017).

Importantly, the concepts of treatment success or cure rate may vary in definition and may also change over time during the duration of the child's illness. In *Custody of a Minor*, for example, physicians anticipated the child's success for survival in the first year of treatment would be 90 percent with treatment.[196] However, by year five, the potential for the child's survival with treatment dropped to a 50-percent chance.[197] The court's perception of survival threshold changes based on the time from diagnosis benchmark it adopts for defining survival.[198]

Despite benefits of treatment, when the potential for survival falls over time or below a certain threshold, this raises the question of how the court should balance whether mandating treatment would be in the child's best interest, particularly when treatment carries significant side effects, long-term risks, and pain for the child. If the child's chance at survival with treatment falls below a certain level, physicians and parents may diverge on what constitutes the goal of treatment. Some physicians may believe that the goal of treatment is to provide the child with a treatment plan that offers the best chance at survival while parents may believe that a lower chance of success serves as a point to revise goals of treatment and accept the child may not survive. Diekema asserts that courts should be reluctant to compel treatment or override parental decisions when the therapy poses grave risks or the treatment offers a limited chance of success.[199]

4. Psychosocial Considerations

Determining the child's best interest should also account for the consequences of state intervention and the impact of mandating treatment to the child's physical, social, and emotional well-being. Some courts carefully assess the intrusion into familial privacy, parental decision-making, and the child's interests in security, recognizing that the child exists within a family structure while other

196 Custody of a Minor, 379 N.E. 1053, 1057 (Mass. 1978).

197 *Id.*

198 *See* Robison & Hudson, *supra* note 184.

199 Diekema, *supra* note 11, at 256.

courts omit this factor. Courts that hold mandating treatment would serve the child's best interest can do so in a manner that preserves family functioning and demonstrates respect to the parents. If the underlying reason for state intervention relates only to the dispute over medical decision-making and CPS has no other evidence of parental abuse or neglect, then CPS and the court should intervene in the least intrusive manner. Isolating the child from the family unit through conflict, removing the child from parental custody,[200] or limiting parental contact with the child[201] could unintentionally cause the child anxiety, fear, and anguish.[202]

B. Formulas to Determine the Child's Bests Interest

Courts hold immense discretion when characterizing and weighing each factor, which significantly influences how the court rules what course of action would serve the child's best interest. This section articulates courts' reasoning behind cases examining whether to compel medical treatment for the child, describes how courts generally focus on potential benefits of treatment but downplay risks or presume risks should be tolerable, and explains why courts may mandate treatment even in cases where treatment offers minimal potential success.

1. Prioritize Medical Benefits, Dismiss Burdens, Without Focusing on Survival Threshold

In re Willmann provides one example of a case in which the court focused narrowly on medical benefits, overlooked burdens associated with treatment, and provided minimal attention to survival threshold in its assessment.[203] This case involved a seven-year-old child diagnosed with osteosarcoma; the parents agreed to chemotherapy and radiation as treatments but did not agree with surgical amputation

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200 *See* notes 1-7.

201 *See* notes 74-76.

202 *See* Diekema, *supra* note 11, at 247; Brown & Slutsky, *supra* note 27, at 9; Newmark v. Williams, 588 A.2d 1108 (Del. 1991).

203 *In re* Willmann, 493 N.E.2d 1380 (Ohio Ct. App. 1986).

of the child's arm and shoulder.[204] In *In re Willmann*, the court focused on the potential medical benefit of chemotherapy and surgery, characterizing the treatment plan as the child's only chance of survival.[205] Although the parents agreed to chemotherapy and radiation, they did not consent to surgical amputation, stating it would be "particularly mutilating," and asserted physicians did not provide sufficient evidence that such surgery would be successful.[206] Although both physician and parent testimony cited to estimated rate of success (about 50 to 60 percent chance of success), the court did not provide any substantive discussion related to these statistics but instead focused narrowly on potential benefit and ordered surgical amputation of the child's arm and shoulder.[207]

This formula defers to physician's discretion and prioritizes aggressive interventions that hold potential benefit when determining the child's best interest. However, this model overlooks considering whether sufficient evidence exists to support the effectiveness of the intervention, what constitutes a minimum threshold for potential survival with treatment, and how to account for serious risks of the intervention.

2. *Consider Medical Benefits, Dismiss Burdens, and Integrate Survival Threshold*

Custody of a Minor, another pediatric oncology case that involved a 20-month-old child with leukemia provides an example in which the court assessed medical benefits, characterized risks as minimal, and integrated an assessment of the child's potential survival with treatment.[208] Parents consented to chemotherapy, which involved

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[204] *Id.* at 1382-84.

[205] *Id*. at 1385.

[206] *Id*. at 1388.

[207] *Id.* at 1390. In testimony, the physicians estimated the child would have a 60 percent chance of survival with surgery and chemotherapy. *Id.* at 1384. During the parents' testimony, the parents discussed the risks and side effects, stating "for what? For a 50% chance maybe?" *Id.* at 1387. Both the physician and parents cite to different survival statistics and the record is unclear which statistic, or range of statistics, the court found more compelling.

[208] Custody of a Minor, 379 N.E.2d 1053, 1055-56 (Mass. 1978).

intravenous medication, daily oral medications, and spinal injections.[209] Several months into treatment, the treatment plan shifted to maintenance chemotherapy and a bone marrow test indicated the child was in remission.[210] During one encounter, parents discussed concerns about the medication's side effects on the child and the intrusiveness of treatment injections.[211] Parents expressed concern about the child's pain from spinal injections, stomach cramps, constipation, and testified to behavior changes in the child they attributed to treatment.[212] While parents continued to bring the child to physician appointments, they stopped giving the child oral medications at home.[213] Over the course of several days, the physician attempted to persuade parents to resume oral medications, and when unsuccessful, the physician requested state intervention.[214] Physicians testified that the survival rate after one year with treatment provided 90 percent chance of remission, a rate which dropped each year and after four years, the survival rate was about 50 percent.[215]

The court framed the facts in a binary manner, stating that the parents were denying treatment to the child, which would cause "certain death," but resuming chemotherapy provided "substantial hope for life."[216] Focusing on the benefits of chemotherapy, the court noted the only medically effective program to treat leukemia is an aggressive three-year treatment plan.[217] The court minimized the side effects and risks of chemotherapy, classifying them as "short term," "controlled," and "reversible," and concluded they did not constitute "significant" side effects.[218] When balanced against the potential

[209] *Id.* at 1057-58.

[210] *Id.*

[211] *Id.* at 1058.

[212] *Id.*

[213] Custody of a Minor, 379 N.E.2d 1053,1058 (Mass. 1978).

[214] *Id.*

[215] *Id.* at 1057.

[216] *Id.* at 1056.

[217] *Id.* at 1057.

[218] Custody of a Minor, 379 N.E.2d 1053, 1064-66 (Mass. 1978).

survival rates, the court held that "temporary pain of chemotherapy could not overcome his long term interest in leading a normal, healthy life."[219] The child's best interest, according to the court, weighed heavily toward resuming mandated chemotherapy because it would likely extend his life and provided the only hope for a cure.

3. Consider Medical Benefits, Consider Burdens, and Integrate Survival Threshold

Unlike *Custody of a Minor*, *Newmark v. Williams* acknowledged the benefits of the medical intervention, but afford more weight to side effects, risks of treatment, and potential success of survival. Unlike most cases than adopt the physician's recommendation to mandate treatment, this case stands as an outlier. In *Newmark v. Williams*, physicians diagnosed three-year-old Colin with aggressive lymphoma and recommended chemotherapy and radiation, which would have a 40 percent chance of "curing" his illness.[220] The parents declined this course of treatment based on their religious beliefs and sought spiritual healing.[221]

The court acknowledged the potential benefits of chemotherapy, but quoting *In re Quinlan*, stated that the state's interest weakens "as the degree of bodily invasion increases and the prognosis dims."[222] The court focused on describing detailed steps of chemotherapy, risks and side effects, and the invasive nature of treatment.[223] Despite the benefits, the court noted that intravenous hydration treatment created a risk of renal failure and dialysis; chemotherapy's side effects included neurological dysfunction, increased risk of infection, and bone marrow toxicity; multiple surgical biopsies carried additional risks; and the proposed radiation of Colin's groin would likely render him sterile.[224] This aggressive treatment plan, according to the court,

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[219] *Id.* at 1066.

[220] Newmark v. Williams, 588 A.2d 1108, 1111 (Del. 1991).

[221] *Id.*

[222] *Id.* at 1118.

[223] *Id.* at 1118-19.

[224] *Id.*

was more likely to fail than succeed, it was highly invasive, and the treatment itself could have caused Colin's death.[225]

According to the court, the child's best interest calculation must assess not only the state's interest in protecting potential life through *parens patriae*, but must also integrate competing interests at stake, such as the privacy of the familial relationship, the ability of parents to make medical judgments for their children, the gravity of the illness, the risks and invasiveness of treatment, and the potential for a successful outcome.[226] *Newmark v. Williams* stands as an outlier among cases of judicial intervention, and constitutes an important reminder of the limits of both medicine and law. When treatment is risky and invasive and does not meet a certain threshold of success, the court held that parents must retain the right to decline medical treatment even when the child could die.[227]

4. Consider Medical Benefits, Consider Burdens, Address Survival Threshold, and Assess Psychosocial Needs

Finally, when determining the child's best interest, some courts afford significance to considering benefits of treatment, acknowledging risks, integrating the child's potential for survival with and without treatment, and addressing the child— and family's— broader psychosocial needs. *In re Matthew V.* provides an example of how a court can adopt a comprehensive assessment of each of these elements for determining the child's best interest.[228]

In *In re Matthew V.*, physicians excised a small mass in Matthew's neck.[229] Upon biopsy, physicians determined the mass was Ewing's sarcoma and the surgery left clear margins (physicians successfully excised all presence of the tumor).[230] Several diagnostic scans revealed small nodules on his lungs that were too small to biopsy, but full body

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225 *Williams*, 588 A.2d at 1118-19.

226 *Id.* at 1117-18.

227 *Id.* at 1120.

228 *In re* Matthew V., 68 N.Y.S.3d 796 (N.Y. Fam. Ct. 2017).

229 *Id.* at 797-98.

230 *Id.* at 798.

scans came back negative, indicating the cancer had not spread to other areas of the body and had not spread to his bone marrow.[231] Physicians recommended a regimen of chemotherapy to prevent recurrence, estimating that the risk of recurrence without chemotherapy would be 95 percent.[232] Three months later, physicians performed another scan and discovered nodules in his chest, estimating it was possible (about 50 percent likely) that the nodules were pathogenic and indicated metastatic disease.[233] Physicians indicated if Matthew did have metastatic Ewing sarcoma, the chance of survival with treatment would be between 15 to 30 percent.[234] Without treatment, physicians estimated the chance of surviving Ewing's sarcoma would be 10 percent.[235]

Based on these statistics, the mother declined chemotherapy for two reasons. First, she indicated she wanted to wait to see whether Matthew fell within the 5 percent group who would not experience recurrence after surgical tumor excision.[236] Second, if the nodules in his chest were indeed metastatic cancer, she stated that the survival odds were not sufficient to counter the risks associated with chemotherapy compared to the survival odds associated with declining treatment.[237]

In the court's discussion, it focused on intervening to minimize risk of harm and that chemotherapy constituted the only accepted standard treatment to prevent recurrence to treat potential metastatic Ewing's sarcoma.[238] With cancer, the court reasoned, early intervention provides the child more benefit based on increased chance of survival.[239] The court acknowledged that chemotherapy

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231 *Id.*

232 *Id.* at 799.

233 *In re Matthew V.*, 68 N.Y.S.3d at 799.

234 *Id.*

235 *Id.*

236 *Id.* at 800.

237 *Id.* at 800, 804.

238 *In re* Matthew V., 68 N.Y.S.3d 796, 799-800 (N.Y. Fam. Ct. 2017). ("There is no other treatment that is medically proven to cure Ewing sarcoma other than systemic chemotherapy.").

239 *Id.* at 803 ("that the chance of recurrence is 95 percent; and that the chance of survival without

itself could be debilitating and fatal in rare cases, or Matthew could undergo chemotherapy and still die but maintained that it would "objectively unreasonable" not to try chemotherapy.[240] Despite a minimal difference in outcomes with and without chemotherapy if Matthew had metastatic disease, the court favored treatment over nontreatment, reflecting the proposition that courts may classify available treatment offering any benefit as necessary treatment. Finally, the court provided detailed analysis of factors to preserve the familial relationship and recognize partial parental decision-making by ordering chemotherapy but awarded the mother discretion to choose the provider, retained Matthew in his parents' custody, and directed CPS to assist the family with resources for counseling and pediatric cancer support groups.[241]

C. Impact of Judicial Intervention

When courts intervene and override parents to mandate a specific treatment for the child, it is critical to note that this does not always result in the child's survival. In Brown and Slutsky's systematic review of 73 cases, they examined whether court-mandated treatment impacted the patient's outcome, defined as survival at least one year after the parent declined treatment.[242] When the court overrode parents' decision and mandated treatment, only 33 percent of children survived.[243] Forty percent of children passed away, and 27 percent of children had unknown status.[244] Thus, even when courts intervene and mandate treatment to try to save the child's life, the child's underlying diagnosis and prognosis may still unfortunately lead to his death.

These outcomes reinforce the proposition that many cases of physician-parent disputes entail high stakes decisions fraught with uncertainties. Courts hold immense authority to ascribe varying

treatment is less than 10 percent.").

240 *Id.* at 804.

241 *Id.* at 804-05.

242 Brown & Slutsky, *supra* note 27, at 2, 6.

243 *Id.* at 9.

244 *Id.*

weight to potential benefits, either carefully acknowledge or quickly dismiss risks, and determine what suffering should be tolerable for the child's chance at survival. A court's holding to compel medical treatment can indeed save the child's life while posing minimal risks in some instances. But decisions to compel treatment in other cases may result in the child undergoing invasive and risky medical procedures that confer minimal benefit, induce significant suffering, and still result in the child's death. Courts that intervene in each pediatric decision-making disputes can exercise authority prudently, acknowledging that some cases involve difficult circumstances involving a set of imperfect trade-offs.

V. RECOMMENDATIONS

Resolving pediatric medical decision-making disputes between physicians and parents requires balancing co-existing considerations, such as preserving familial privacy and protecting parental rights, upholding the state's duty of *parens patriae* to protect children from medical neglect, and employing fair criteria to determine what course of action that would further the child's best interest. This section highlights an overlooked opportunity for de-escalation through improving communication competencies of physicians as a mechanism to guide conversations between physicians and parents. Next, this section describes specific dispute resolution techniques that physicians and clinical staff can employ. Finally, this section recognizes that some disputes may result in intractable conflict, sets forth parameters when it is appropriate for CPS to intervene, and articulates specific elements for the court to consider when reviewing pediatric medical decision-making cases.

A. Reframe Parental Intentions and Re-Envision the Physician-Parent Relationship

Each of these cases demonstrates the complexities involved in decision-making for pediatric patients and how many cases involve a series of value judgments rather than a singular simple solution. In cases of divergent opinions, physicians, social workers, and courts should avoid labeling parental choices as "refusing to obtain

appropriate treatment"[245] or "sacrific[ing] the child's best interest."[246] In many disputes, both the physician and the parents genuinely believe their assessment will most appropriately serve the child's best interest.

Moreover, in the course of seeking medical care, weighing and selecting among treatment options, parents may decline specific interventions based on their determination that the risks substantially outweigh the benefits, concluding that specific interventions are unnecessary, intrusive, or harmful. If the physician attempts to persuade or even coerce parents into acquiescing by immediately invoking state intervention as a method to preemptively override them, parents may respond in kind through panic, fear, and anxiety to what appears to be a forceful threat to their child's well-being. Characterizing parents as "hysterical and uncooperative"[247] during rapid escalation signifies not only disrespect for the parents' role as the natural guardian and protector of their child, but a profound misunderstanding of what constitutes an appropriate physician-parent dynamic.

Parents do not constitute an obstacle or barrier over which physicians must hurdle; rather, physicians have a duty to serve as fiduciaries to the child and family, provide specialized information, serve as a trusted advisor, and recognize that the parents are the child's legal decision-maker. The physician's role is to provide clinical information relating to the child's diagnosis, prognosis, treatment options, and recommendations based on his best professional judgment. The American Medical Association Code of Ethics Opinion 2.2.1 sets forth specific ethical obligations of physicians when treating pediatric patients, such as providing compassionate care, negotiating with parents to develop an individualized care plan with clear treatment goals, and reassessing treatment goals during the course of treatment when necessary.[248] Physicians must navigate how to

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[245] *In re* Cassandra C., 112 A.3d 158, 160 (Conn. 2015); Carbone, *supra* note 62, at S119 .

[246] Carbone, *supra* note 62, at S115.

[247] Mueller v. Auker, 576 F.3d 979, 992 (9th Cir. 2009).

[248] PEDIATRIC DECISION-MAKING, CODE OF MEDICAL ETHICS OPINION 2.2.1, AMERICAN MEDICAL ASSOCIATION, https://www.ama-assn.org/delivering-care/ethics/pediatric-decision-making.

provide balanced information, recommend treatment options based on their clinical experience, promote respectful communication, and defer to parental judgment except in very specific circumstances.[249]

Escalating to state intervention constitutes a last resort for only a narrow subset of cases when the child faces imminent danger, substantial injury, or death. Invoking immediate state intervention as a method to bypass parental disagreement for managing a child's ongoing condition, or alternatively labeling a child's ongoing condition as an "emergency" circumvents safeguards in the law designed to guard against overbroad state intrusion into parental decision-making. Implementing dispute resolution techniques may decrease the need for state intervention, which would enhance physician-parent communication, promote shared decision-making, and avoid embroiling the child in the midst of conflict.

B. Employ Dispute Resolution Techniques

Successful communication between the physician and parent can build on recognizing each party's essential role in promoting the child's best interest. Physicians hold not only the critical role of providing clinical expertise, but they can also set the standard for navigating potential conflicts with parents. Before escalation involving external parties, physicians must serve as the primary contact with parents and attempt conflict resolution.[250] As clinical ethics mediator Professor Edward Bergman notes, engaging in conflict resolution, managing family emotions, and addressing family member stress is not a distraction from the practice of medicine, but rather comprises a substantial component of successful practice.[251]

Several principles utilized in clinical ethics mediation can assist clinicians in conceptualizing how to approach conflict that may occur between physicians and parents. First, physicians can set the tone for

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[249] Edward Bergman, *Managing Conflict in Clinical Health Care With Diminished Reliance on Third Party Intervention: Forging and Ethical and Legal Mandate for Effective Physician-Patient Communication*, 15(2) CARDOZO J. CONFLICT RESOL. 473, 488 (2014).

[250] Bergman, *supra* note 249, at 475-76; *see generally* Florian Bruns & Andreas Frewer, *Ethics Consultation and Empathy: Finding the Balance in Clinical Settings*, 23 HEC FORUM 247 (2011).

[251] Bergman, *supra* note 249, at 482.

empathy and understanding.[252] Diplomatic conversations can encourage trust and communication, while abrasive, rushed, or technical communication devoid of emotion can foster disconnection. Second, conversations should focus on the medical problem rather than emotions about the people involved in decision-making.[253] Medical ethicists suggest that physicians guide conversations to address three specific needs:[254]

(1) *Specify the child's substantive needs*.[255] What is the specific medical problem, and how can physicians clarify the issues of the dispute? What treatment interventions are available? How does each party assess the benefits and risks? Do reasonable alternatives or compromises exist? Physicians should work with parents to clarify the goals for the child's treatment. Where is the specific source of disagreement?

(2) *Address the parents' and child's psychological needs*. During clinical ethics conflicts, family decision-makers have a need to feel heard and understood.[256] Clinicians who take the time to genuinely listen to the parents' goals and concerns for the child can build rapport, trust, and work toward compromise. If physicians understand parents' specific concerns, they may be able to clarify uncertainties, adapt interventions, or provide alternatives that would be amenable to both physician and parents. Framing conflict resolution as joint problem solving can assist in producing durable resolution in which parents endorse and uphold the agreement. Respectful communication and clinical empathy between physician and parents

252 Bruns & Frewer, *supra* note 250, at 247, 252-54.

253 Haavi Morreim, *Conflict Resolution in the Clinical Setting: A Story Beyond Bioethics Mediation*, 43 (4) J. L. MED. & ETHICS 843, 845 (2015).

254 Morreim, *supra* note 253, at 848; Lauren Edelstein et al., *Communication and Conflict Management Training for Clinical Bioethics Committees*, 21(4) HEC FORUM 341, 343 (2009); Charity Scott, *Ethics Consultations and Conflict Engagement in Healthcare*, 15 CARDOZO J. CONFLICT RESOL. 363, 381 (2014) (quoting bioethicist Nancy King).

255 *See* Morreim, *supra* note 253, at 847.

256 Bergman, *supra* note 249, at 477-78; Scott, *supra* note 254, at 381.

also supports a positive therapeutic environment for the child, rather than adding anxiety or stress.[257]

(3) *Provide the parents fair procedures*. The decision-making and conflict resolution process should abide a standard process that attempts resolution between the physician and parents first. If the physician and parents are unable to reach satisfactory agreement, the American Medical Association Code of Ethics Opinion 2.2.1 advises that physicians should seek assistance of the ethics committee.[258] Here, the medical ethics committee can support communication between physician and parents to clarify the issues described above. The medical ethics committee should work with the physician and parents to elicit the goals, values, and concerns and work toward potential solutions. If the medical ethics committee is unable to facilitate resolution, then the physician can consider whether the specific case warrants state intervention.

C. Escalate to State Intervention

1. Conditions Required for State Intervention

If the physician is unable to resolve the conflict with parents and reach satisfactory agreement, the physician must determine whether the dispute rises to meet the definition of potential medical neglect. Parents may make decisions that physicians assess are less than optimal, but when parental decisions place the child at risk of death or serious harm, states have authority to intervene in narrow specific circumstances to protect the rights of the child. For intractable conflicts, physicians can request state intervention when all of the following conditions exist:

a) The a child has an emergency condition; or a condition that is life-threatening; or a condition that will cause serious imminent harm; and

b) The proposed treatment has a high chance of success; and

c) There are serious risks of nontreatment; and

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[257] Bergman, *supra* note 249, at 490-92.

[258] *Id*.

d) Benefits of treatment outweigh the risks.[259]

Physicians can communicate to parents that they also have a duty to protect the child's interests, and explain how their professional clinical judgment supports their assessment that forgoing a specific treatment intervention places the child in imminent danger. Then, physicians can report the case to the appropriate state agency to begin investigation and the state may petition the court to intervene.

2. Best Practices for the Court

First, the court must determine whether it has the authority to intervene. Next, courts will balance protecting familial privacy while upholding the state's duty of *parens patriae* in a manner that serves the child's best interest. Courts can consider the following questions when examining cases of physician-parent treatment disputes for pediatric patients:

1) *Examine whether the court has subject matter jurisdiction*. This requires assessing the severity of the child's medical condition. Is the circumstance truly an emergency? Or, is death or serious harm imminent without intervention? The state's authority to intervene stems from *parens patriae* and the duty to protect children's life. For cases that do not constitute an emergency or do not involve treating the child's serious or life-threatening condition, the state does not have authority to intervene.

2) *Acknowledge familial privacy and the parents' interest in making decisions for the child*. Consider whether parents have questions relating to child's diagnosis or prognosis. Parents may seek second (or multiple) opinions from external providers on the child's diagnosis, prognosis, treatment alternatives, or assessments of risks and benefits. What is the exact source of the disagreement between physician and parents? In some cases, parents request treatment alternatives, or view the goals of treatment distinctly.

3) *Address the child's welfare and interests*. How effective is the treatment? By what metrics does the physician define effectiveness? What are the benefits of treatment? How invasive or risky is the

[259] Black, *supra* note 11, at 676.

treatment? What are the risks, including both short-term side effects, potential adverse reactions, and long-term effects of this specific intervention? Are there treatment alternatives? What is the child's chance of survival with and without this treatment? Courts should note that although opting for a specific treatment provides the benefit of certainty even when the child subsequently dies (e.g. "We tried everything to save the child"), interventions can also cause suffering and result in – or cause – the child's death (e.g. the child endured painful treatments but tragically still died). Courts may compel a treatment that is highly effective, low risk, and will likely treat a child's life-threatening condition, but courts should be hesitant to compel treatment in cases where the treatment is invasive, risky, or offers only a minimal chance of benefit.

4) *Integrate a threshold for success before compelling medical treatment*. Several cases involving pediatric oncology disputes in particular recognize that prolonged, intense, and risky treatment regimens should correspond to certain threshold for potential success. Treatments that promise a high likelihood for success and greater benefits than risks uphold the state's duty to intervene and protect children's life and health. But once treatment falls below a certain threshold of success, courts must carefully assess whether the potential benefits of treatment outweigh the risks before compelling treatment. Courts should acknowledge and support goals of treatment for the child that correspond to the child's potential for survival. When the child has a low potential for survival with treatment, the treatment is burdensome or risky, and the parents object to the intervention, the court should clarify that it is legally and clinically appropriate for physicians to shift care toward palliative measures and familial support.

5) *Appreciate the complexities of each case*. Courts should acknowledge that both physicians and parents generally act in furtherance of what they perceive to constitute the child's best interest. While some cases demonstrate clear and significant benefit to compelling treatment for the child (such as one emergency blood transfusion to save a child's life), many disputes involve uncertainties.

CONCLUSION

Parents have a legal and ethical duty to care for their children, which includes providing children with necessary medical care to avert substantial injury or death. In many high profile cases where parents declined treatment, their decision did not stem from failure to provide the child any medical care but rather a divergence with the physician on the child's diagnosis, prognosis, relative risks and benefits of treatment, or goals of treatment. Agreeing to a specific treatment may mean a potential chance at saving the child's life and the certainty of exhausting available medical interventions. However, although some treatment interventions offer a chance of success, they may also subject the child to unnecessary pain, serious risks, or suffering, without sufficient certainty of whether the child will survive.

Clinicians, parents, and courts can more effectively address physician-parent pediatric treatment disputes by recognizing the difficult value judgments involved in each case and acknowledging the co-existing interests at stake. Many cases involve reactive measures: striking escalation, characterizing parental decision-making as irrational, and viewing parents as an obstruction to effective clinical practice. Pediatric treatment disputes provide an opportunity to improve the physician-parent relationship, deescalate conflict, and implement a framework to resolve disagreement in a fair, diplomatic manner. State intervention should constitute a last resort for intractable conflicts involving narrow and specific circumstances: when a child has a serious or life-threatening condition, there is an effective treatment that has a high chance of success, and the treatment benefits outweigh the risks. Courts have the challenging task of balancing how to protect familial privacy, uphold the state's duty of *parens patriae*, and decide what course of medical action would further the child's best interest according to clear and just criteria, recognizing that each decision entails difficult concessions.